APPENDIX 26

Site Visit Report
Palliative Care Program Assessment

Program Name: Children’s Mercy Hospital/ PACCT Program
Date of Survey: 5/8 - 5/9/06
Location of Program: 2401 Gillham Road, Kansas City, MO  64108
Web address (if available): www.childrensmercy.org
Primary Contact: Rosemary Hubble, RN, M.Div, MA     Phone: (816) 234-3066
Name of Person Providing Information: See attached list.
Title of Person Providing Information: See attached list
Site Visit Completed by: Cheryl Naulty, Carol Marsiglia, Pam Cunningham and Karen Ann Lichtenstein

Program Description:
Children's Mercy health care system includes the state-of-the-art, 241-bed hospital at 2401 Gillham Road in Kansas City, outpatient clinics in midtown and in suburban Johnson County, Kan., and outreach clinics in outlying communities. Children and families from six states are regularly served by the hospital, which sees patients living from coast to coast and overseas.

Approximately five years ago, the hospital system identified the need for a coordinated approach to both inpatient and outpatient care delivery for children diagnosed with life-threatening illness. To respond to that need, the hospital supported the development of the Pediatric Advanced Comfort Care Team referred to as PACCT. The PACCT program is an interdisciplinary team of care providers dedicated to providing palliative care to patients and families from the time of diagnosis of a life-limiting or life-threatening illness. PACCT provides comprehensive palliative care that includes clinical services, education and research.

CMH considered application for a CHI PACC program, but chose to forego that funding opportunity due to the broad geographic area they serve crossing multiple states. In addition, CMH expressed that such a program may be too restrictive as to who could be served in the program.

The program approach is basically a consultative service based within the hospital network (inpatient and outpatient clinics at the hospital site only) to support the primary or subspecialty healthcare team to ensure that both medical and non-medical needs of the patients and families are addressed. The most intensive monitoring of the palliative care service occurs while the child is an inpatient. When children return to outpatient clinics for follow up, the palliative care team will see the child at the time of the visit. The focus of this service is to provide the best quality of life for the child that is consistent with the family’s values. The following team members are involved in the delivery of this care and the disciplines are:

- Patient and family
- Physician
- PACCT Nurse Clinician (Coordinators)
• Chaplain
• Social Worker
• Advanced Practice Nurse Case Managers
• Pain Management Specialist
• Psychologist
• Child Life Specialist
• PACCT Medical Director
• Community Hospices

The program currently serves approximately 120 children and families. However, it is reported that the referrals to the PACCT program have consistently increased over the past several years. The PACCT Program attributes that increase to efforts to promote the program through education of physicians and the addition of designated PACCT coordinators.

The designated program staff is comprised of:
• A Program/Operations Manager
• 1.8 FTE Nurse Clinician (referred to as a Care Coordinator or Care Facilitator)
• Medical Director

Other multidisciplinary team members are accessed through the existing hospital staff from other departments.

The PACCT Program falls under the hospital’s Department of Patient Care Services and is not a physician directed service. The program has an Advisory Board that includes representation from parents, social work, child life, chaplaincy, behavioral medicine, integrative pain medicine, physicians, intensive care nursing, education and administration. The Advisory Board meets on a quarterly basis and is divided into sub-committees on education/communication, research, parent support, clinical services and technology. The program emphasizes parent to parent support and recruits other parents who have been served by the program to provide that support.

PACCT collaborates with the local University to support efforts in the area of research (see Research Section) and works collaboratively with a community hospice provider called Carousel.

**Population Description**
The PACCT population is exclusively comprised of children served at CMH through the inpatient and outpatient department at the main campus site. Total consults for the PACCT program from 2002 through April 2006 reportedly total 216 children. The following categories are used to define the population served in PACCT: (definitions have been requested for categories below)
• Acute life threatening
• Life threatening
• Life limiting
• Life-style limiting
The age of children served in the PACCT program are typically 0 – 18. However, if CMH has been serving a young adult who is beyond 20 years old, the program may choose to continue to provide services within the system. Based on observation, the population understandably reflects the general population of the geographic region of the country and does not seem to represent a broad diversity of ethnic culture.

Service Delivery
- Referrals for PACCT services are initiated by medically licensed personnel and the parents must be in agreement to proceed with the process.
- The PACCT coordinator gathers patient history from records to determine if PACCT care is appropriate and to prepare for contact with the primary care physician.
- If the Primary Care Physician (PCP) is not in agreement with participation, but the PACCT staff assesses a serious need for palliative care, the PACCT Medical Director will have a discussion with the PCP. Ultimately, if the PCP does not agree to the service, the referral is ended.
- If the PCP is in agreement the referral proceeds and the Nurse Clinician meets with the family within 48 hours.
- Prior to the initial meeting with the patient, the PACCT coordinator reviews the medical record to identify any psycho-social issues, etc in preparation to meet with the family.
- In addition to the record review, the PACCT coordinator determines the composition of the team and notifies the following departments - SW, Chaplain, Psych, Child Life, Pain Management, etc. For disciplines that are necessary to meet the patient’s needs, the PACCT coordinator will ask for an assigned team member.
- An email is then sent to the team to inform them of the PACCT referral.
- At the initial meeting with the patient/family, the PACCT coordinator will explain the service, provide a brochure, answer questions, and discuss the child’s illness and what the parent understands about it.
- If the parent agrees to participate, the coordinator provides a binder with PACCT information and assessment documents, brochure, blank Comprehensive Comfort Care Tool (CCCT), DNAR parent document, grief assessment form if appropriate and provide psychiatric evaluation form for completion when appropriate.
- The CCCT may not be appropriate to discuss in the initial meeting and this discussion may occur at a much later date. In the meantime, the PACCT staff may continue follow up visits based on family response to services.
- A meeting is convened with the family and team members to discuss the CCCT and develop an action plan.
- The CCCT is fully developed and reviewed by the parents, then signed by the physician.
- The PACCT coordinator monitors the plan by visiting the family (frequency is determined by family and PACCT coordinator) while the child is an inpatient or the coordinator may identify opportunities to connect with the family when they return for outpatient clinic visits at the hospital site.
- When a death occurs, chaplaincy services are responsible for the administrative assistance in addition to any spiritual care. Administrative assistance includes coordinating the medical examiner work when appropriate, being the primary contact for organ/tissue donation, coordinating in-house autopsy when applicable and primary communication regarding funeral or service arrangements.
“After Care” is the service that addresses bereavement needs and care and completes the process. This is a separate hospital team that is outside of the PACCT program.

The PACCT nurses serve to initiate palliative care and to facilitate the discussions among the family and the interdisciplinary team. The PACCT is not involved in the daily disease management, approach to pain management, or the process of identifying and/or obtaining resources for the family. Rather the team will monitor the progress of such issues with the family through regular contact and informal discussions. The social workers are primarily responsible for obtaining resources, equipment and other services as identified in the CCCT.

The PACCT nurses along with the primary care physician provide continuity for the family. This physician may be either a general staff pediatrician or a specialist. Residents do not fill this role, but they may be involved through their various clinical rotations or the PACCT elective. There is no consistent continuity among the other disciplines, as the teams are drawn from the staff assigned to specific departments or specialties of outpatient clinics. However, there seems to be sufficient trust and communication between and among the various members of the support staff that information relevant to the continuing care of the family is passed along at the time of readmission.

Funding for Services
The CMH system is currently funding the PACCT Program through philanthropic money that supports 1.8 FTE for the Nurse Clinician positions and the Program Manager role. The Medical Director also serves as an Intensivist in the PICU and is loaned to the PACCT team for this role; therefore, no costs are attributed to the program for medical direction. Other disciplines are funded through their specific departments and basically add the PACCT responsibilities to usual daily responsibilities.

The Social Work department explores insurance benefits to access funding for medical needs. However, CMH reportedly has access to private funding that often covers items and services not funded through traditional health insurance plans.

Research Component
The PACCT program collaborates with a Research Assistant Professor from the University of Missouri-Kansas City to promote evidence based practice through qualitative research. A current initiative is underway to access R-15 funding to develop and study parental values and understand how variables have an impact on communication between healthcare teams. In addition, it is the vision of the researcher that by having a better knowledge of parental values, care can be promoted in a manner that is “ethically appropriate, culturally sensitive and consistent with the family’s stated values”. The research has proposed using a Parental Values Inventory (PVI) tool, which is an instrument that identifies, assesses and allows families to express their values. Some variables that impact values are reported as: spirituality, coping styles, communication preferences, caregiver control desires and quality of life. Initial funding efforts for researching these issues have been denied but will be pursued further upon collection of additional data.

Education Component
Education is addressed at various levels within the system of care at CMH and specific initiatives are listed below. The PACCT program emphasizes a strong connection between the educational efforts they are making and the buy in factor of staff to the palliative care philosophy at their facility. IPPC training is a tool used for educating providers at CMH. In order to generate energy around palliative care, the facility used a master facilitator such as David Browning from IPPC to introduce the palliative care concept within the institution, and then the PACCT staff conducts IPPC training in a train the trainer model.

The levels of education seem to address the general education of staff related to what palliative care means as well as education specific to the PACCT program and individual opportunities for modeling the palliative care approach as it applies to specific children and families.

PACCT Education initiatives targeted to families are:
- DNAR Care Card
- *Shelter from the Storm* written by Joanne Hilden and Daniel Tobin
- PACCT Brochure describing program services

PACCT Education Initiatives for hospital staff include:
- Department updates for nurses, social work and child life
- Grand Rounds/ Special Events (e.g. David Browning)
- One-on-One with PACCT Clinicians
- Small group lectures
- IPPC curriculum
- Resident/Fellow Program elective (objectives and outline for training are available upon request for mCare project team)
- Child Life Internships
- Nursing Student rotations
- Nursing Orientation
- Journal Club

PACCT Educational Initiatives presentation topics include:
- Basics of palliative care
- Introduction to PACCT
- Loss Exercise
- Ethic of Pediatric Palliative Care
- Caring for Dying Children and Supporting Families
- History of Palliative Care – Palliative care vs. hospice
- Death and dying
- Nutrition and Hydration
- Children and Grief
- Language and the Power of Grief
- Ethics of Self Care

If CMH staff request individual training for their hospital specific unit, the nurse clinicians from the program provide the specified training. The nurse clinicians emphasized that a majority of
the education is provided at an individual level and that “modeling” palliative care practice is a primary strategy for educating coworkers.

**Strategies Used for Implementation**

- Gain support from key senior administrators to include the CEO and the senior Vice President of the clinical service product line.
- Initiate services in departments of the hospital that had a greater need for education rather than those that already support the philosophy (for example, CMH does not include heme/oncology in their efforts because that department already has a strong base in the philosophy of palliative care)
- Meet with other disciplines (i.e. SW, child life, etc.) to gain support prior to implementing the palliative care program
- Use a master facilitator such as David Browning from IPPC to introduce the palliative care concept within the institution, and then conduct IPPC training in a train the trainer model. This strategy generates energy around the effort
- Base the palliative care model in an arena where children are frequently seen (i.e. Many children are seen in the outpatient clinics and this presents an opportunity to make regular contact with the families to review and modify the CCCT)
- The Nurse clinician is key to the overall success of the program. Suggest hiring for that role based on “the right person” for the job as opposed to focusing a specific certification or educational requirement.
- Identify specific diagnoses that would generate an automatic PACCT referral
- Use champions to promote the program across departments, but target staff who have a sincere commitment to supporting the philosophy of palliative care.
- Use physician champions who are critical to buy in
- Don’t push the issue of palliative care on a department or staff that demonstrates resistance to the concept.
- A palliative care program may reduce referrals to the hospital Ethics Committee and in the event a situation gets to the ethics committee, a PACCT consult is typically made
- Implement program in “baby steps” and “small bites”
- Be persistent in efforts to infuse the principles of palliative care, but balance the effort so not to force the issue
- In the initial phase of program development, CMH used a task force, but once the program was underway, they moved the task force into an advisory committee model.

**Strengths of PACCT Program**

A primary factor at CMH that supports success of the PACCT Program is the supportive, family centered culture that exists within the facility. Since the hospital system exclusively serves the pediatric population, many of the philosophical practices already in place to support children and families naturally exist and therefore the promotion of palliative care is not foreign to the existing culture.

The staff at CMH attributes much of the success of the program to a key nurse clinician who brings “the right stuff” to the position. There was not an emphasis placed on credentials or certifications for that role (except that it be an RN) but rather to find the right person who could promote the program in a subtle, consistent manner throughout the hospital system. The role of
the primary nurse clinician is to be a neutral “care facilitator” who monitors the CCCT document and is a consistent resource for child and family communication among the entire health care team. The PACCT staff felt that an RN would better serve as an advocate for the patient and family in relating to the physician staff.

Parents indicate that the “web of support” is one of the single most valuable resources provided by the program.

**Current Challenges for the Program**
- Quantifying outcomes that add credibility to the PACCT initiative to maintain support of hospital administrators
- Expanding the “buy in” factor to all physicians and staff at CMH
- Locating alternatives to philanthropic money for funding nurse clinicians which has a time limit of approximately 1 -2 years
- Dealing with territorial issues within the facility (i.e. the overlap between SW and palliative care clinician)
- Avoiding the presumption that when palliative care staff are involved it means death. This factor is down played by a focus on the role of the clinicians and the supportive nature of the program rather than the final clinical outcome
- Dealing with the fact that Information technology plan for PACCT program is not part of the main clinical documentation system; however some elements link the programs.

**Possible Application to the Military Environment**
- Program implementation occurred in a hospital based system and gradually expanded, therefore some of the implementation strategies listed above may apply in the military environment.
- Some of the components that exist in the CMH program would also exist in a MTF.
- The only new positions are the 2 PACCT RNs.
- Strong reliance on existing staff within the hospital to provide the direct care allows for tailoring care and services specifically to meet the needs of each child and family and provides for relative autonomy for each interdisciplinary team. PACCT RNs are primarily facilitators.
- Emphasis on developing partnerships among existing resources, both in the hospital as well as in the community.
- Care coordination focused on issues and assigned responsibilities identified in the CCCT.

**Documents available for review by mCare team from PACCT visit:**
- PACCT brochure
- Pediatric Palliative Care Residency/ Fellowship Elective (program objectives, outline and evaluation form)
- PACCT Powerpoint Presentation of program
- Child Life brochure
- 2004 PACCT Annual Report
- Discharge Planning Tips ( used by as an educational and reference tool)
- PACCT Clinical Services Process diagrams
• Comfort Care Communication Tool (sample)
• Contact list and business cards for PACCT and CMH staff

Site Visit Report
Palliative Care Program Assessment

Program Name: Seattle Children’s Palliative Care Consulting Service  
Date of Survey: 5/25/06  
Location of Program: Seattle Children’s Hospital  
Web address: http://www.seattlechildrens.org/our_services/clinical_services/palliative_care.asp
Primary Contact: Scott McKinstry  
Phone: 206-987-4751
Name of person providing information: Ross Hays MD, Scott McKinstry, Leslie Adams, Michelle Frost RN, Mark Power BCC
Title of person providing information: Medical Director, Program Coordinator, Social Worker, RN, Chaplain (all act as Palliative Care Consultants)

<table>
<thead>
<tr>
<th>Program Description</th>
<th>Program Affiliation:</th>
</tr>
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<tbody>
<tr>
<td>Type of Program: (Mark all that apply.)</td>
<td>Hospital</td>
</tr>
<tr>
<td>Hospice</td>
<td>Community Based Entity</td>
</tr>
<tr>
<td>X Palliative Care</td>
<td>Provider Group (describe)</td>
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<tr>
<td>Associated with a Medicaid Waiver</td>
<td>Hospice component</td>
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<tr>
<td>Not a formal program, but Palliative Care Services are provided as part of a specialty clinic (identify type of clinic)</td>
<td>Other</td>
</tr>
<tr>
<td>X Other (describe) Consulting Service</td>
<td></td>
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</tbody>
</table>

Program has been in existence:
| X 6 – 10 years |
| 11 years or more |

Additional Comments:
<table>
<thead>
<tr>
<th>Population Served</th>
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<tbody>
<tr>
<td><strong>Age of population:</strong> (mark all that apply)</td>
</tr>
<tr>
<td>X Pediatric (0 – 18 years)</td>
</tr>
<tr>
<td>❑ Adult (18 years and older)</td>
</tr>
<tr>
<td>❑ Other (specify)</td>
</tr>
</tbody>
</table>

| Geographic location of population: (mark all that apply) |
| ❑ Rural |
| ❑ Urban |
| ❑ Suburban |
| X Statewide (specify) |

Provide services for patients all over the State of Washington and from other states in the Pacific Northwest.

| Eligibility criteria for program: (mark all that apply) |
| ❑ Age |
| ❑ Financial |
| ❑ Medical (specify) |

| ❑ Recent diagnosis of life threatening condition |
| ❑ < than 6 month life expectancy |
| X Other criteria (specify) |

Hospitalized with a referral from physician

| Total number currently served in program: |
| 150 consults per year |

| Have you provided services to military families? | Y |

| If yes, what are the challenges? |
| ❑ Getting services paid for by TRICARE |
| ❑ Working with families who may be moving |
| ❑ Communication with receiving MTF |

| Additional Comments: |
### Services Provided by Program

<table>
<thead>
<tr>
<th>Identify key services provided by your program to support palliative care: (Mark all that apply)</th>
<th>How are services funded within your program? (Mark all that apply)</th>
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<tbody>
<tr>
<td>X Care Coordination (some)</td>
<td>❑ Medicare (if eligible)</td>
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<tr>
<td>❑ Respite</td>
<td>❑ Medicaid Waiver</td>
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<tr>
<td>X Medical Care (indirectly)</td>
<td>❑ Medicaid (fee for service or managed care program)</td>
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<tr>
<td>❑ Clinical Treatments</td>
<td>❑ Other government (e.g. Tricare, VA, etc.)</td>
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<tr>
<td>❑ Counseling services</td>
<td>❑ Private Insurance</td>
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<tr>
<td>❑ Bereavement services</td>
<td>❑ Self Pay</td>
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<tr>
<td>❑ Pain Management</td>
<td>❑ Services are provided in kind</td>
</tr>
<tr>
<td>❑ Support at time of diagnosis</td>
<td>❑ Costs are absorbed by an umbrella program</td>
</tr>
<tr>
<td>X Other services (specify)</td>
<td>❑ Other (specify)</td>
</tr>
<tr>
<td>• Facilitate communication using Decision Making Tool</td>
<td>• Paid for by hospital administration fund</td>
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<tr>
<td><strong>Care Coordination</strong></td>
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<td>-----------------------</td>
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<tr>
<td><strong>Is care coordination included in your program?</strong></td>
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<tr>
<td><strong>If no:</strong></td>
<td></td>
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<tr>
<td>Is it provided informally or by another external entity?</td>
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<tr>
<td><strong>If yes:</strong></td>
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<tr>
<td>What are the qualifications for your care coordinators?</td>
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<tr>
<td>What activities do the care coordinators perform?</td>
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<tr>
<td>What is the average caseload for a care coordinator?</td>
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<tr>
<td>Do you use an acuity system to determine intensity of care coordination services? (If yes, how does that work?)</td>
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<tr>
<td>What are the criteria to qualify for care coordination services?</td>
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<tr>
<td>How do you measure effectiveness of care coordination?</td>
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</table>

They facilitate care conferences in the hospital to help develop a care plan and they follow up with individuals to implement the care plan.
<table>
<thead>
<tr>
<th><strong>How are access to care issues addressed within your program?</strong></th>
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<tbody>
<tr>
<td>They accept nearly all referrals.</td>
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<tr>
<td><strong>How are issues related to communication with providers and relationships addressed within your program?</strong></td>
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<tr>
<td>The Decision Making Tool (DMT) is the cornerstone of what they do. See attached tool and description.</td>
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</table>
### How are issues related to emotional toll on parents and family addressed within your program?

The group addresses the emotional toll on parents and family by facilitating communication and helping to build an understanding between families and health care providers and by developing a plan that incorporates the family’s values and preferences.
**How does your program incorporate families in the decision making processes?**

When there is a communication challenge:

- The physician makes a referral to the palliative care team.
- A consultant is assigned to the case by availability.
- The consultant meets with the family to see if the family wants the consultant involved.
- The consultant then meets with the providers.
- The program coordinator schedules a care conference with the family and health care providers.
- The consultant facilitates communication and shared decision making by holding a care conference for about an hour with groups up to 27 people. The key role of the consultant during the conference is to ask clarifying questions.
- After the care conference, the consultant completes the tool with what was discussed at the meeting. Writing about the meeting discussion and action plan on the Decision Making Tool takes about two hours.
- The consultant then follows up with everyone who is listed on the action plan.
- The completed DMT goes into the front of the patients chart and the parents are provided a copy to take with them. They have found a way to include the DMT in the electronic medical record, although it is not as prominent there as when they place it in the front of a paper chart.
- The DMT becomes a tool for continuity of care.
- The DMT is used most effectively when the conference facilitator comes from outside the team of healthcare professionals that provides care for the child.
<table>
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<tr>
<th>Community Resources</th>
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**How does your program assist families to access other community programs and services?**

They assist indirectly by helping to implement the action plan, primarily by following up with health care providers to make sure that each team member completes the steps designated in the plan.
### Education and Training

Describe any education and training related activities that support your programs.

- Consultants educate providers through care conferences
- They educate residents through presentations on palliative care and communication
- 4th year medical students can do an elective with the palliative care consultants
## Outcomes

Has your program been successful at demonstrating positive outcomes?

If yes:

<table>
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<tr>
<th>Types of Outcomes</th>
<th>How are the outcomes measured?</th>
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### Additional comments:

### Applications to MHS:
- The tool can be used with care coordination and can be tried at one MTF
- A goal could be to have one or more people at each MTF to facilitate the DMT
- Need a physician champion
- The person is more important than his or her discipline
- Relationship and communication is at the core of what the palliative care consultants do

### Buy-in:
- They provide a service that people in the hospital find valuable. Physicians (usually) request palliative care consults when they want help communicating, understanding families’ priorities and developing a plan.
They had a needs assessment done in the mid-1990’s, followed by a grant-funded demonstration project in which they developed the Decision Making Tool. After the grant, the administration provided $200,000 to fund the Palliative Care Consulting Service, considering it important value added to care at the hospital and a way to humanize technological processes. The now have 2.9 FTE plus .5 time of the medical director. They are collecting donations to establish an endowment for ongoing work.

**Recommended Resources:**
- They consider the palliative care guidelines from Canada to be the best. They recommend the work of Jerri Fregger at the children’s Hospital in Nova Scotia (IWK).
- They think palliative care will become a JCAHO requirement sometime in the next 10 years.

**Considerations for Getting Started:**
- Find a physician champion.
- Start in the ICU.
- Use the term “palliative care consultant.”
- Identify “trip wires” for calling the palliative care team, such as 8 days or longer in the PICU, a certain number of days on a ventilator, a cancer relapse, a tracheostomy and ventilator.

They think that TRICARE needs a palliative care benefit, with nursing or social work visits, different from the hospice benefit. They gave us the Washington State palliative care benefit as a sample.

**Name of surveyor:** Jan Hanson and Jason Cervenka
Site Visit Report
Palliative Care Program Assessment

Program Name: Children’s Hospital Denver/Butterfly Program
Date of Survey: 6/6 - 6/7/06
Location of Program: 1056 East 19th Avenue, Denver, CO 80218
Web address: http://www.thechildrenshospital.org/public/info/index.cfm
Primary Contact: Brian Greffe MD  Phone:
Name of person providing information: See attached list.
Title of person providing information: See attached list

Program Description:
The Children’s Hospital is a private, not-for-profit pediatric health-care network located in Denver, Colorado that is wholly dedicated to caring for children. It has been ranked one of the best children’s hospitals in America by U.S. News & World Report for more than a decade. With 1,130 pediatric specialists and more than 2,300 full-time employees, Children’s is home to a number of nationally and internationally recognized medical programs.

In 1999, the Butterfly Program was developed with some grant support for children who have life limiting illness. The program was designed as a consultative service to provide palliative care to children throughout the hospital system to include inpatient and outpatient departments. The Butterfly Program worked in conjunction with a Home Health Program owned and operated by the hospital system and a community based Hospice Program through Centura Health. It is best described as “a collaborative effort between the Children’s Hospital and Porter Hospice of Centura Health.” The initiative started under the leadership of Dr. Brian Greffe and utilized a nurse practitioner as well as other services available in the hospital system such as chaplain and social worker. The Home Health Program was subsequently closed and those services were then provided through an external agency.

This program is currently pursuing a CMS home and community based waiver consistent with other CHI/PACC programs. Approval for this program is pending. It is anticipated that 200 children across the state of Colorado may be served in that waiver; however, only a subset of those 200 will be in the Butterfly Program.

The Butterfly Program is basically a consultative service that provides support and comfort to families with children ranging from infants to young adults who have a potentially life-limiting illness. Under the supervision of the patient’s physician, intermittent services are provided by an interdisciplinary team that includes:
- Physicians
- Butterfly Program Medical Director
- Pediatric Registered Nurses
- Social Workers
- Spiritual Care Providers
- Trained Volunteers
- Bereavement Counselors
- Pharmacists
- Physical and Occupational Therapists
- Dietitians
- Home Health Aides

The program currently serves approximately 45 children and young adults and receives approximately 3 – 4 referrals per month. The average length of time in the program is reported to be approximately 93 days. The range for program participation is approximately 3 months to 3 years. Some Butterfly participants may be identified as inactive during the course of their illness based on the individual needs of the child and family.

The staff designated from Childrens Hospital to the Butterfly Program are:
Medical Director 0.5 FTE
Nurse Practitioner or Inpatient Coordinator .25 FTE (other portion of time is spent on Bone Marrow Transplant Unit)
Spiritual Care Providers 2- 0.5 FTE

Centura Health, a community based provider designates the following staff to the Butterfly Program:
Outpatient Coordinator / Social Worker 0.5
Administrative support 0.45 FTE
Outpatient Chaplain 0.2 FTE

Fund raising efforts

The Program has a Steering Committee that meets quarterly. Some topics addressed the steering committee include current and future fundraising efforts, Medicaid Waiver Updates, CHI Grant and updates, Provider issues, Volunteer Training, policies and procedures development, clinical staff recruitment for the program and other items of concern to the Program.

Population Description
Although the inpatient population is described as including children in the Colorado area, it may serve children across seven states including Wyoming, Nebraska and Montana. However, the community based portion of the Butterfly Program, provided primarily through Centura Health System Services are only provided within the state of Colorado. Centura Health indicates that 98% of the families they see would be Medicaid eligible. A child can participate in the Butterfly Program if they have a 12 month prognosis and they may access curative therapies. It is not required that child have a DNR status to participate in the program.

Dr. Greffe reports that approximately 40% of the program population are followed by oncology with the remaining 60% having other life limiting conditions.

Service Delivery
The following steps address the basic process for the delivery of services in the Butterfly Program:
- A referral is made by a nurse, family or other staff to the Program
- An agreement from the attending physician is obtained to proceed with the referral
• An initial consult is made by Dr. Greffe or the Inpatient or Outpatient Clinical Coordinator
• The Inpatient Coordinator is a nurse practitioner. This person’s role is to explain the program and begin to identify the family’s concerns, identify specific needs of the child and family, coordinate with the outpatient team if appropriate, discuss DNR, pain management and symptom control. The inpatient coordinator will also enlist the support of the hospital social work team and the nursing staff to address the child’s needs. If and when the child transitions out of the hospital facility, the outpatient coordinator who is a licensed clinical social worker from Centura Health will provide similar activities to address the child and family needs. In addition, the outpatient coordinator may address resource needs, counseling issues, and continue discussion related to advance directives.
• Consent to participate in the program is obtained from the parents
• A Palliative Care Plan and progress notes are initiated
• A Family Conference may be convened and the Palliative Care Plan is completed
• The Plan is distributed to the Primary Physician, the Parent and the a copy is placed on the patient’s chart
• A chaplain will automatically see families who are participating in the program
• If the child is inpatient, the inpatient coordinator from Children’s Hospital will follow during the child’s hospital stay
• General hospital interdisciplinary resources are available as needed and would be incorporated into the child’s plan as appropriate (includes chaplain or other spiritual care providers, subspecialty physicians, pain management team, pediatric nurses, social workers, child life specialists, trained volunteers, pharmacists, physical and occupational therapists, dieticians and home health aides)
• Ethics consults are arranged when indicated
• If the child is outpatient, the Centura Health outpatient coordinator will be the primary monitor to follow the child
• Home health services are delivered by an independent nursing agency provider or Centura Health
• The outpatient coordinator addresses the ongoing needs of the child and family, such as resource issues, education, emotional support needs, sibling issues, etc.
• Medical care is provided through the primary care physician (also sign for homecare orders) or can be accessed through the special needs clinic
• The Butterfly Program coordinators and medical director are available to the family as an on call basis
• If and when a child enters a formal hospice program, the palliative care team typically transitions out of the process.

In addition to the process steps listed above, the Butterfly Program has access to pain management services and child life staff who are currently available in the hospital facility. Although pain and symptom management are often handled by the primary care physician or the medical director or inpatient coordinator, this team is available to provide consultation regarding pain management solutions. In addition, they may offer some complementary therapies such as aroma therapy, massage therapy or Reichi therapy to the pain management treatment plan.
Child Life services are also available to children who are inpatient as well as to their parents and siblings. Child life specialists play an integral role in promoting communication with the child and family especially during the delivery of difficult information and decision making. Music therapy is another adjunct to the program that can be supplemented as indicated by the child and family needs.

At the time of a child’s death, there are options the family can choose if the death is anticipated. In the event the child remains hospitalized during the dying process, the family is offered the use of the “Cocoon”. The “Cocoon is reportedly used approximately 1 – 2 times per month and is an effort to transform the typical hospital room into a more home like atmosphere. Ideally, the room is set up when the child arrives. Children may be moved from a NICU or PICU type setting to the Cocoon environment. The environment includes soft lamp lighting, a butterfly blanket and pillow and beanie baby on the bed. The sheets are soft and colored. They may place a ceramic heart box that has a battery operated votive set inside that “burns” continuously.

There is a CD player with some soft music. The family has access to a basket filled with decaf/reg coffee bags, herbal tea, hot chocolate, etc. In addition are crackers, granola bars, etc. The family also has access to some basic toiletries to use during this time. A disposable camera is available to the family in addition to TV/ VCR and movies. The families are encouraged to use the items. During this time families are offered the option to create a hand or footprint of the child as well as the use of a professional photographer at no additional cost to the family. Spiritual care providers from the hospital play an integral role during this time. Families may choose to have their personal spiritual contact or are offered services from the hospital.

When it is anticipated that a child will die at home, The Butterfly Program develops a specific procedure in conjunction with the family to provide guidance and specific steps that can be carried out at the time of death. These steps address such things as verification of absence of vital signs, notification of nurse managers, funeral home, attending physician, Butterfly social worker, Chaplain and coroner. If additional support is needed, the Butterfly Program Medical Directors and the Inpatient Coordinator (nurse practitioner) can be paged for advice regarding end of life care. See Death at Home Procedure attached.

In addition to those options listed above, Children’s Hospital has a Bereavement Program. This program works strictly with aftercare issues. There is an average 20 deaths per month reported system wide, however only a small subset are Butterfly Program patients. This program started from recommendations from the Chaplain and was initially structured as a Bereavement Council made up of interested staff, parents and community interest groups such as local funeral director. At that time, there was grant funding available for several months for a “bereavement counselor.” The program has since evolved as a service for the hospital. Participation in any of the activities are optional and is presented as possible resource for the family should they choose to participate. The bereavement service currently provides the following activities to support families following the death of a child:

- Initial condolence card with a personal note
- Annual memorial service
- 2 – 9 week Grief Groups (generally attended by 10 -12 parents)
This group is facilitated by an experienced person who is skilled in facilitation of family groups. Generally this is the bereavement counselor, the chaplain or a social worker.

- Lending Library which is a cart of books and literature that families may borrow and the literature is designed for all ages
- Holiday Card signed by bereavement council members and that also informs the families of events.
- Creative Memories Workshop is a Saturday workshop where families receive a starter pack for developing scrapbook type photo albums.
- Offering the bereavement coordinator as a resource person for families. The nature of this resource is not to act as a direct counselor for the family, but rather as a resource to link families with other services that may be indicated following the death of a child.
- Evening in the Fall Event attended by families who have lost a child. Here, the staff typically coordinates a national speaker and offer sibling and baby sitting support for families.

**Funding for Services**
According to the Director of Medical and Legal Affairs for Children’s Hospital, the Butterfly Program operates at a fiscal loss to the organization. At the end of the fiscal year the loss is split with Centura Health System. The hospital system has been willing to accept this loss and continue to support the program because they feel that it is a valuable service to families and express their commitment to providing optimal care. In the event that Colorado is successful in getting the home and community based waiver, Children’s is hopeful that some of the services they are currently providing at no cost to the patient, will become reimbursable for a subset of the population.

There is a designated “fund raising” staff member at Centura Health. This person participates in community activities and other fund raising events and reports to the Butterfly Steering Committee. Donations are used to offset the overall fiscal shortfall. For the year 2005, total funds raised are reported to be $92,755. 2005 Butterfly Program Expenses are reported to be $180,747. Total reported deficit is $87,992.

**Research Component**
There was no specific research discussed related to the Butterfly Program.

**Education Component**
Although there was no formal education plan in place to support the Butterfly Program, the medical director indicates that the program was initially promoted through education regarding palliative care provided at ongoing physician faculty meetings. The inpatient coordinator (nurse practitioner) focuses her educational efforts on the hospital nursing staff by offering End of Life Nursing Education Curriculum (ELNEC) in the fall each year. It is reported that last year there were at least 100 participants involved in the training.

Other opportunities for education are:
- Physician Rounds, especially with new residents
- Good Grief at Noon is a one hour monthly educational session sponsored by the Bereavement Council and open to all Children’s Hospital staff at no
charge. These sessions include various topics related to managing and understanding grief. Nurses who attend can receive 1 CEU per session.

- Palliative care conferences with community physicians
- Education targeted to specific units of the hospital based on their interest or need
- Individual or unit based debriefing and education provided by the Chaplain

Although the Butterfly Program staff has heard of the IPPC trainings, they were not the primary trainings used at this organization.

**Strategies Used for Implementation**

- Gain support from hospital administrators. In this situation, when the hospital owned home health service was ended, the hospital looked to a partnership with a community entity such as Centura Health to share the cost and operation of the program. The Hospital chose to continue to support the program based on it being a valued service to offer to children and families served by the hospital system.
- Incorporate the palliative care philosophy into areas such as the Bone Marrow Transplant unit that were currently providing similar support to families.
- Address “turf issues” as they experienced them with entities of the hospital such as social workers, physicians and others who had a sense that their departments were already addressing such needs of the families.
- Utilize current staff within the facility and partner with a community entity to address the more global community based needs of a child and family.
- Use a designated fund raiser to support some of the cost of operations.
- Implement the program on incremental levels; start small.
- Utilize a nurse practitioner who can assume some of the workload from the medical director.
- Target staff who have a sincere commitment to supporting the philosophy of palliative care.
- Use a physician champion viewed as key to the buy in factor
- Never replace an interdisciplinary team that is already in place, but utilize these teams to facilitate or participate in meetings that support a palliative care effort and to offer additional supports

**Strengths of Butterfly Program**

- The Medical Director is passionate about promoting palliative care and is well respected within the hospital system.
- A nurse practitioner as a coordinator who can address some of the medical issues that arise during the course of palliative care
- Having both in and out patient services - provides better continuity and follow through
- The out patient coordinator assumes a dual role of counseling and care coordination
- The long distance component, outside of usual patient catchment area provides training and the identification of and coordination with services when discharging patients to that area
- There is a strong spiritual component
• Wrap around bereavement services are combined with The Butterfly Program and whatever else the hospital already provides
• Excellent training materials have been developed by families

Current Challenges for the Program
• Quantifying outcomes that add credibility to the program; expanding the “buy in” factor to all physicians and staff at Children’s Hospital
• Raising enough funds to cover program cost, although at this point, there seems to be full financial and philosophical support from the hospital administration despite a program deficit
• Dealing with territorial issues within the facility (i.e. the overlap between SW and palliative care clinician)
• Management of data specific to the Butterfly Program
• Ensuring adequate input into state Medicaid office in the development of specific policies for the waiver, once it is approved. Without this, the program might not be able to offer all current services for reimbursement.

Possible Application to the Military Environment
• Build on existing resources
• Focus on a consultative service, not one that assumes direct care
• Although partnership with a specific home health/hospice agency is unlikely, consider what services might be provided on an out patient basis
• Use of outreach to agencies, training and coordination of services at a minimum for the outpatient arena
• Understand that there are multiple bereavement strategies that do not necessarily mandate a formal behavioral health referral

Documents available for review by mCare team from the Butterfly Program in Denver
• Butterfly Program Palliative Care Plan
• Butterfly Program Steering Committee Agenda with attachments Initiating Contact Form
• The Butterfly Report – a progress report on the Butterfly Program for 2006
• The Butterfly Program trifold brochure
• Cocoon Cabinet Inventory list
• List of contents for Child Grief Packet
• The Colors of Healing; A Family Centered Bereavement Program
• Condolence Card sent by Bereavement Program
• Let the Healing Begin brochure developed for the Centura Bereavement Center at High Street
• Helping Your Child When Death is Near booklet
• A Dad’s Journey Through Grief CD
• Grieving and Hope CD
• The Butterfly Program CD
• Good Grief at Noon 2006 schedule and topic list
Site Visit Report
Palliative Care Program Assessment

Program Name: St. Mary’s Healthcare System for Children
Date of Survey: November 1st and 2nd, 2006
Location of Program: Bayside, New York
Web Address: www.stmaryskids.org
Primary Contact: Eileen Chisari, RN, Administrator, Director of Palliative Care Program
Names of Individuals Providing Information: Eileen Chisari, Doreen Sikoscow, Alice Olwell, RN, Edwin Simpser, MD, Yolanda Chiarello, LCSW, Deacon Mike Maroutsis
Surveyors: Cheryl Naulty, MD, Ann Armstrong-Dailey

Program Description:
St. Mary’s Hospital for Children was the first children’s hospital in New York City and was founded in 1870 by the Sisters of the Community of St. Mary’s. The hospital system specializes in post acute care for children with special needs. St. Mary’s Health Care System is comprised of two inpatient facilities, St. Mary’s Hospital for Children which is a 97 bed facility, and St. Mary’s Rehabilitation Center for Children, a 44 bed facility. In addition, there are numerous community based programs such as the Long Term Home Health Care Program, The Institute for Child Development, Early Intervention, and the Care at Home Program. Over 4000 children per week living in the 5 boroughs and surround counties are seen in the outpatient programs. The program is affiliated with the Children’s Hospital of New York (Columbia University). Children eligible for care at St. Mary’s are those 0-18 years with special needs who are afflicted with conditions such as cerebral palsy, mental retardation, congenital anomalies, complications of prematurity, and metabolic disorders. Approximately 33% of patients admitted to St. Mary’s have tracheostomies; there are not ventilator beds in the facility. The average length of stay for a child at the facility is approximately 3 months.

St. Mary’s developed the first pediatric palliative care (PPC) program in the United States over 25 years ago as a result of the efforts of its founder, Dr. Bert Grebin. Dr. Grebin explored the concept of PPC with the New York State Department of Health in 1979 and in 1983 the home care program was launched providing end of life (EOL) care to terminally ill children. Subsequently a 10 bed palliative care unit was opened in 1984 at St. Mary’s and over the next 10 years critical palliative care elements were added such as pastoral care, volunteers, social work, bereavement, and support groups. Based on feedback from staff and families, the inpatient PPC program shifted from a designated inpatient unit to a scatter bed system in 1996. Additional elements such as music, art, and pet therapies were added between 1994 and 2001 and the Complementary Care Program was initiated in 2000. In 1986 the PPC Program also began providing intermittent treatment services to terminally ill children in St. Mary’s Medical Day Care serving up to 35 children in the after school program and 25 children in the Saturday program at any given time.

In 2002, the program developed a Palliative Care Pathway which is a “care map” for providing PPC. The program has continued to grow and in 2003 additional staff dedicated to PPC was recruited with the help of philanthropic dollars. Quality improvement initiatives and advanced care directives were developed in 2004. In 2005 the program launched an initiative regarding the
appropriate use of morphine and also adopted the family centered care model. Treatment vs. non-treatment options and terminology for a natural death also was explored in 2005.

It is estimated that approximately 20% of St. Mary’s daily population (3200 patients) might benefit from PPC due to progression of their life-limiting illness.

Population Description
As outlined above, St. Mary’s Healthcare System for Children focuses on post-acute medical care and/or rehabilitative therapy for children with a wide range medical needs. The Healthcare System focuses on healthcare needs of children with chronic illnesses (see below) which differs from the population of a typical children’s hospital providing tertiary care. The PPC Program is but one of many programs and services offered by the Healthcare System. The following are the more common diagnoses treated – asthma, complications of prematurity, congenital heart disorders, feeding disorders, genetic disorders, HIV/AIDS, post-acute burn treatment, post-surgical rehabilitation, pre and post transplant care, shaken baby syndrome, sickle cell disease, spina bifida, and traumatic brain injury and coma recovery. Any child who is part of the Healthcare System is eligible to receive palliative care services.

Approximately 110 children per year are actively enrolled in the PPC Program. This includes children receiving palliative care services through both the inpatient and community programs.

Service Delivery
Referrals to the program can be made by anyone from the interdisciplinary or Morning Report Team (medicine, nursing, nutrition, social work, rehabilitation, therapeutic activities, pastoral and complementary care). Additionally, inpatient admission referrals may identify the need for palliative care services triggering further team discussion, which may ultimately result in the provision of palliative care services. Access to the palliative care team can be achieved through, and not limited to, phone, e-mail, Morning Report, the interdisciplinary care plan process, palliative care rounds, and consult order.

The PPC Program works with the inpatient primary care team as well as the family of the child. The team functions by combining a consultative approach as well as assuming primary care; they are available to do either. In the event the team does not assume primary care, they still remain very actively involved and remains connected adjunctively in order to continue to be part of the decision making process. There is an outpatient/home care component as well to the program. The model of care delivered is based on a family centered care approach and is integrated into the existing programs in the Healthcare System.

The core team consists of an administrator, 2 physicians, a program manager, a nurse director for complementary care, a deacon (pastoral care), and 2 social workers. In addition, the palliative care program may seek consultation from Psychology/Behavioral Health as needed. There is also interdisciplinary collaboration with pediatric medicine services, social work, nutrition, therapeutic activities, rehabilitation, pharmacy, and unit-based nursing.

The goal of the palliative care program is deliver care “upstream” based on 3 levels illness severity as follows:
• Level I – chronic illness with progression of symptoms and loss of function and/or physical decline
• Level II – life-limiting or terminal illness; anticipated death within 6 months
• Level III – end of life care with death anticipated within 2 weeks

Referral to the program usually occurs with progression of the illness and not at the time of diagnosis. The program provides inpatient palliative care based on a set of interventions known as the Palliative Care Pathway. The Pathway outlines care components, outcomes and outcome measure for the following disciplines - medical, nursing, social work/mental health, nutrition, therapeutic, rehabilitative, complementary care, and pastoral/spiritual care. A separate Palliative Care Pathway also exists for the home care component of the program.

There are both formal and informal palliative care rounds which are patient oriented. The entire palliative care team attends these rounds but they are also open to all the unit staff. There is an AM Report each morning by the palliative care team. Children who are in Level III are discussed daily. The team keeps the families of children in Level III involved in daily decision making.

Some of the unique program components include:

• Focus on Communication with Families
  o Advance care planning
  o Education of families about issues related to death and dying
• Attention to Creating Rituals
  o Crafting a peaceful dying plan
  o Displaying a candle on the unit when a child dies
  o Laying a hand-crafted quilt on the bed of a child who has died
  o Annual tree-planting ceremony and memorial service

The Peaceful Dying Plan constitutes a cornerstone in the delivery of end of life care. It seeks to ensure that the patient’s final days are comfortable and peaceful and reflects both the patient’s and family’s wishes. The Peaceful Dying Plan becomes part of the medical record and includes demographics, information regarding funeral arrangements, pre and post death rituals (special washing, dressing, handling), and special instructions before and/or after death (special dress, music to be played, special toy, staff person to be notified).

Another unique aspect of the palliative care program is the Doula Program which is made up of volunteers who assist patients and their families during the dying process. The volunteer is assigned only a single patient and family at a time. The patient is receiving either Level I or Level II care. The staff nurses make referrals to the Doula Program. The palliative care program asks for a one and half year commitment from those individuals wishing to become doulas.

The palliative care program has developed a booklet, “Gentle Transitions” for families. This booklet discusses the physical signs and symptoms of approaching death as well as the emotional and spiritual signs of approaching death.
Two weeks following the death of a patient, the social worker makes a home visit and the family is given a box with different memories, a “My Gift to You” keepsake. The patient, family, and staff all contribute to what goes into the box. A blanket is also given the family at this time and the siblings are given a “Sibling Bag” which contains stuffed animals, books, and chimes. The social worker may make home visits for up to 2-3 months post-death and then may consider a referral for additional bereavement counseling if needed.

The home care entity of the program is also very active and consists of medicine, nursing, rehabilitation, and social work. Nutrition and complementary care services are also available on an outpatient basis. Referrals to the home care program can be made by acute care facilities and/or the inpatient palliative care team. The outpatient team is instrumental in helping the patients and families navigate the health care system.

An internal Ethics Committee was formed in 2001 and acts as a recommending body. The committee assists in helping with decisions when dilemmas over care arise such as withdrawal of feeds for example. The committee was also involved in making the final policy with regards to advanced directives.

**Funding for Services**

The majority of basic services is funded by Medicaid and managed care entities. The inpatient program receives a fixed daily rate, which is not a hospice rate, for the inpatient component of the program. New York State has a history of a very strong Medicaid program for home care as well. Exceptional services (complementary therapy, manager position) are funded through philanthropy. With respect to the Long Term Home Health Program, patients may be eligible for the Katie Beckett Waiver program. Palliative care services are the added on.

**Research Component**

There is no formal research component to the program as of yet. The palliative care team however is planning to evaluate their Family Centered Care Program via a satisfaction survey. The team began using the survey in February 2006. It is administered in the home following the death of the child. There are 13 items that use the Likert scale as well as the opportunity for open-ended comments. The team is planning to publish their findings from this survey.

The Palliative Care Program has also sponsored focus groups of caregivers in order to obtain qualitative data regarding need. The groups were comprised of parents and caregivers and discussed a variety of palliative care topics. The outcome of these focus groups was that families wanted both support groups as well as informal networks.

In 2004, the program surveyed the nursing staff to get feedback on their views on palliative care. The survey requested what staff felt they needed clarification on regarding the program, what difficulties the staff has had in caring for dying children and their families, what staff would help them better take care of children receiving palliative care and their families. The information obtained from this survey allowed the team to develop their educational initiatives for 2005.

The team will also continue to collect good demographic data including when patients become part of the palliative care team.
Education Component
There have been several educational initiatives that the team has put forth over the past several years and they are as follows:

- Development of the Palliative Care Pathway in 2002 and subsequent in house education of staff on the Pathway.
- Survey given to nursing staff in 2004 regarding their thoughts on the palliative care program and how they felt about taking care of dying children and their families. Results of this survey allowed the team to plan their 2005 educational initiatives.
- In 2006, the Caring Connection curriculum on end of life care was developed and was based on the staff’s own experiences which allowed better staff buy-in of the program.
- The Compassionate Partnership training session was also developed in 2006. This is a 3 hour session on palliative/EOL care which is interactive and involves role playing as well as sharing of personal experiences.
- The Peaceful Dying Plan was developed in 2006.
- Self care component is available to staff.
- The program recently sponsored a Pain Awareness Month in September 2006.
- Pain scales for children are located on the nurses’ badges and there is a pain flow sheet to help in assessing and treating a child’s pain.
- The program wants to focus education of physicians on delivery of bad news.

Strategies Used for Implementation
- The program has greatly benefited from the vision and leadership of Dr. Bert Grebin who developed the Home Care Program for end of life care for children. He has been a champion for children who are dying.
- New York Community Trust remains a benefactor of the program.
- The Board and CEO/President remain very supportive of the program.
- The Palliative Care Program is dedicated to staff education which has allowed staff to feel more comfortable taking care of dying children and their families.
- St. Mary’s Healthcare System for Children treats a population that has chronic medical issues many of whom have been diagnosed with a life-limiting condition. This has made the palliative care program a natural fit with the rest of the programs the Healthcare System has to offer.
- The program has a dedicated staff that is always ready to learn from each patient and use previous experiences to improve care for future patients.
- The program has a long history with the Healthcare System (22 years) and is an integral part of the services provided.

Strengths of the St. Mary’s Palliative Care Program
- Support of the President and CEO of the organization
- Physician champion who founded the program
- Dedicated staff who understand that there is always room for improvement
- Development of tools such as Palliative Care Pathway and Peaceful Dying plan that allow for better care of patients and their families.
• Full time pain management coordinator who also oversees Complementary Therapy Program to assist in pain management.
• Long history with respect to the delivery of pediatric palliative care.
• Chaplain successful in interacting with 98% of families providing a pathway for rituals.
• Behavioral Health Program actively involved with the palliative care team
• Strong staff educational component
• Palliative care social worker assists and educates other social workers in the facility regarding palliative care issues
• Well established home care programs allowing transition back to home
• Doula Program

Outcomes
The palliative care team has well defined outcome measurements for all three levels of care in the following disciplines – medical, nursing, social work, nutrition, spiritual/pastoral, rehab, and complementary care. There is an interdisciplinary chart review to see if these outcomes have been met for each patient. The team also looks information from caregiver focus groups and family satisfaction survey to measure outcomes. The team also reviews its program each year in detail to determine how to improve the program in the future.

Current Challenges for the Program
The current challenges for the program include the following:

• The program has been able provide its extensive range of services mainly within the confines of an inpatient setting
• No physician formally trained in pediatric palliative care on team
• Physicians in community or in other acute care facilities may or may not be champions of pediatric palliative care and may disregard or change palliative care plan formulated by the team
• Physicians in the acute care facilities may treat in a “salvage mode” approach as they do not want to “give up” on the patient; this may be confusing and stressful for families whose children are then admitted to the chronic care facility and palliative care is offered; this is seen as a systemic problem
• Staff needs to maintain their own perspective in the face of a care provider who may not agree with the need for palliative care; this individual may have been caring for the patient for a long time and may see palliative care as “giving up”
• Address anticipatory grief in parents when child gets admitted; emotionally charged issue for both family and staff

Possible Application to the Military Environment
• Incorporate standards (both interventions and outcomes) from St. Mary’s home based service model
• Incorporate level of care concept at those facilities with resources to do inpatient pediatric palliative care
• Incorporate inpatient program interventions, outcome, and outcome measures for the various disciplines (medical, nursing, social work, nutrition, spiritual/pastoral, rehab, and complementary therapy) as they relate to each military facility
• Decide on set of core standards that would constitute a program and determine what resources are available and how they should be allocated
• Consider revisiting contracts with managed care partners in order for additional services to be made available in the home based on home based service model

Documents Reviewed from the St. Mary’s Palliative Care Program
• Home Care Interventions
• Inpatient Programs Interventions
• Palliative Care Staff Survey and results
• Peaceful Dying Plan
• Levels of Care
• Family Satisfaction Survey
• PowerPoint Presentation on Palliative Care Program

Dedicated Core Team

Eileen Chisari, R.N. – Administrator/Director of Palliative Care Program
Edwin Simpser, M.D. and Audrey Berman, M.D. – Medicine
Doreen Sikoscow – Manager
Alice Orwell, R.N. – Directory of Complementary Care
Deacon Mike Maroutsis – Pastoral Care
Yolanda Ciarello, LCSW and Danielle Toto, LCSW – Social Work
Site Visit Report
Palliative Care Program Assessment

Program Name: Harriett Lane Compassionate Care (Johns Hopkins Children’s Center)
Date of Survey: September 20th, 2006
Location of Program: Johns Hopkins Children’s Center, 600 N. Wolfe St., Baltimore, MD 21287
Web Address: http://www.hopkinschildrens.org/pages/clinical/hlcc_who.cfm
Primary Contact: Cynda Rushton, R.N., D.N.Sc., F.A.A.N.
Names of Individuals Providing Information: Cynda Rushton, R.N., D.N.Sc., Nancy Hutton, M.D., Elizabeth Reder, M.A.
Surveyors: Brian Greffe, M.D., Cheryl Naulty, M.D., Ann Armstrong-Dailey

Program Description:
The Harriett Lane Compassionate Care (HLCC) Program is affiliated with the Johns Hopkins Children’s Center. The Children’s Center is located on the campus of the Johns Hopkins Medical Institutions located in Baltimore, Maryland.

HLCC has been in existence for approximately 6 years. The program provides palliative care to children with life-limiting conditions and their families. The goal of the program is to achieve the best possible quality of life for the child and family, and when death is inevitable, to support the child and family through the dying process and beyond. The program provides the following services: pain and symptom management, psychosocial and spiritual support, advance care planning, and bereavement counseling. The program supports concurrent curative care along with palliative care.

The main focus of the program is to provide education and support for the inpatient and outpatient staff. HLCC is not a clinical service at the present time. At its inception, the decision was made to work firstly with staff by helping them acquire skills which would enable them to do pediatric palliative care effectively. The Program also focused on providing emotional support to the primary care team and allowed for a reconnection for “meaning” with respect to what they were doing. The Team began with small, incremental changes, targeting those areas that expressed the most “angst” regarding patient issues.

Members of the HLCC Program help facilitate Patient Care Conferences when consulted. The family of the patient is not present for this conference. The goal of these conferences is to help clarify patient care issues. All dimensions of patient care are discussed – medical, psychosocial, and spiritual. Once the goals of care have been determined, they are presented to the family in a conference format at a later date. The HLCC team may be asked to participate in this conference as an invited guest. A positive outcome of this approach has been the decrease need for formal ethics consultations.

There are four members of the HLCC team and include a program director, medical director, family care coordinator, and bereavement coordinator. (See Appendix I)

26-36
Population Description
The HLCC Program accepts requests for patient care conferences from within the Johns Hopkins Children’s Center facility. There are clearly “high density” areas that request patient care conferences from the HLCC team and include PICU, NICU, Oncology, and Emergency Department.

Service Delivery
Involvement of the HLCC Team occurs via the following steps:

- Request for a Patient Care Conference is made by a member of the primary inpatient care team.
- A member of the HLCC Team acts as facilitator for this meeting which does not involve the family.
- The main objective of this care conference is to clarify the goals of the patients care from medical, psychosocial, and spiritual standpoints and primarily serves the health care professionals involved with the patient’s care.
- The HLCC Team cultivates a model of patient care which stresses that everyone on the primary care team has the responsibility to do the best that they can in caring for the patient and family.
- The primary care physician for the patient is invited to this meeting as are the assigned social worker and case manager. These latter individuals can work with the individual insurance companies to identify appropriate and available outpatient services if so needed.
- A documentation tool is completed for each Patient Care Conference. This is not a specific care plan but does outline the goals of care for that patient.
- A second conference is subsequently arranged with the patient’s family to review the goals of care established in the Patient Care Conference. The HLCC Team is not automatically present at this conference but may be invited on a case by case basis.
- Ethics consults are arranged as indicated.
- There is currently no outpatient pediatric palliative care team in place. Johns Hopkins Medical Institutions does have a formal pediatric home care, Pediatrix at Home. This organization has recently hired Sue Huff, R.N., an individual with a great deal of pediatric palliative care experience, to manage the this program. Her goal for the future is to build a pediatric palliative care component into the program.
- Patients who needs outpatient hospice care and who are living in the appropriate catchment area are referred to Community Hospice of Maryland. This hospice program has both pediatric and adult teams. Two physicians based as the Children’s Center, Nancy Hutton, M.D. (a pediatrician and member of the HLCC Team) and Ken Cohen, M.D. (a pediatric oncologist), serve as co-medical directors for the pediatric team. Pediatric patients are able to remain in the program longer than 6 months if necessary.
- The HLCC Program makes itself available for staff debriefings following the death of a patient particularly if the death was sudden or the patient was followed over a long period of time at the institution. The institution has approximately 125 deaths per year; 40 debriefings were held in the last calendar year.
In addition to the above services, the HLCC bereavement coordinator is responsible for the Annual Tribute Service dedicated to those patients who have died. Families along with pediatric staff are invited every year even if has been several years since a particular patient has died. A “photo board” PowerPoint presentation is done in memory of the deceased patients. Families are also encouraged to sign quilt. There are also bereavement groups available to both siblings and parents. The sibling group takes place at the Dougy Center and is open-ended. The parent group is held from September to May and is topic based; 8-12 parents typically attend. There is also a support group for grandparents as well as an opportunity for the family to participate in an Outward Bound program. Families are formally followed for 2 years and are offered telephone supportive sessions as well as referrals to counselors within their community. Quarterly Staff Memorial Services are also held for the staff of the Children’s Center.

Funding for Services
At the present time, the HLCC Program does not submit a bill for its consultative services. All four members of the program are salaried employees of Johns Hopkins. Both the Chairman of Pediatrics and the Director of Nursing have been very supportive of the program. The bereavement coordinator’s salary is covered under Nursing Administration. The HLCC Program meets yearly with the Chairman of Pediatrics to discuss program objectives and future projects. As the program expands, there will be the need to look for philanthropic funding to cover expenses.

Research Component
As the Johns Hopkins Children’s Center is a member of the Initiative for Pediatric Palliative Care (IPPC), the members of the HLCC Team have participated in a number of projects in conjunction with IPPC including:

- Evaluation of the effectiveness of patient care conferences, palliative care rounds and debriefing sessions on health care professional confidence and competence in providing palliative and end of life care.
- Mechanisms of institutional change related to integration of a Pediatric Palliative Care Program
- Measuring the Impact of Initiating a Pediatric Palliative Care Program (presented at AAHPM/HPNA Meeting in January, 2005)
- Survey research regarding health care professional knowledge and attitudes about caring for children with life-threatening conditions

Additional areas of research include:

- Relationship of trust to the experience of caregiver suffering in the pediatric intensive care unit (PICU)
- Exploring the concept of hope in providing pediatric palliative care
- Translating “values history” advance directives for use in pediatrics
- Development of a “pathway” for integrating basic and advanced components of palliative care throughout the Children’s Center
- Integration of palliative care with antiretroviral therapy for children and families in the U.S. and internationally
The HLCC Team also has multiple academic publications which can be found on its website.

**Education Component**
The HLCC Team participates in a number of formal and informal educational sessions which include:

- Noon conferences for residents and medical students during which 6 topics in pediatric palliative care are covered during the year
- Palliative Care Rounds held monthly on the high density units (NICU, PICU, Oncology)
- Palliative Care Network which is open to anyone in the institution with an interest in pediatric palliative care. There are currently 96 members and the group meets quarterly. There is an education component as well as discussions regarding patient care on the inpatient units.
- The Network also meets yearly off site to participate in an intensive training day which consists of community/team building activities. Education topics for the quarterly meeting are discussed. The November 2006 meeting will have for its topic conflict resolution.
- A regional retreat for IPPC training was held in March, 2006. From the Children’s Center, the PICU, NICU, Oncology, and Emergency Department programs each sent a team (M.D., R.N., M.S.W. and bereaved parent).
- The HLCC Team sponsored the Maryland Pediatric Palliative Care Summit on October 13, 2004. Forty professionals (health care professionals, educators, policy makers, administrators) and parents attended to discuss current resources, identify gaps in services and resources, and explore strategies for improving pediatric palliative care.

**Strategies Used for Implementation**

- The HLCC Team has strong support from both the Chairman of Pediatrics as well as the Director of Nursing.
- Historically, the Chairman of Pediatrics was approached by a hospice nurse who was dissatisfied by the lack of pediatric palliative care services available to patients of the Children’s Center. The chairman has continued with his support since the HLCC’s inception. The Team meets with the chairman on a yearly basis to review objectives.
- There are few “turf” issues with respect to social work. Some of the social workers are not comfortable with the philosophy of pediatric palliative care. There is a new director for the Department of Social Work who has a strong mental health background who appears to be very supportive of the program.
- Most likely due to continued efforts of the HLCC Team and the Network, more units have been interested in exploring implementation of palliative care into their units.

**Strengths of the HLCC Program**

- The Team is made up of 4 very committed individuals who bring different strengths to the program.
- The HLCC Program has strong backing from the Chairman of Pediatrics and Director of Nursing.
- The Program participates in a variety of conferences and educational activities to further promote pediatric palliative care within the institution.
The HLCC Team has brought together almost 100 individuals from within the institution as part of the HLCC Network.
The Team feels that their work has improved communication and decision making on the inpatient unit.

Outcomes
- The Program is looking at a quality improvement evaluation related to its participation in IPPC.
- Feedback has been obtained from provider's pre and post intervention; no feedback obtained yet from families.

Current Challenges for the Program
- The program remains consultative only at the present time with clinical services to be added in the future if funding permits.
- There is no formal care coordination. The RN case managers function more in the capacity as discharge planners. There are also no formal outpatient coordinators; this is left to the primary or specialty physician.
- There is limited contact with the primary care physicians in the community although they are invited to the Patient Care Conferences.
- There is a gap in mental health services for patients and families in terms of providing continuity of care from inpatient to outpatient.
- There is a limited chaplain service with only 1 full time chaplain and 2 half time chaplains.
- There is no outpatient component to the program at the present time which would allow for seamless continuity of care.
- Lack of funding may become an obstacle in the future should the Team want to expand its services.
- There is currently a disconnect between the HLCC Program and the adult palliative care program. The adult program does have a full time nurse who does the palliative care consults.

Possible Application to the Military Environment
- Build on existing resources
- Redefine position descriptions of existing personnel to include appropriate palliative care responsibilities
- Consider holding a regional IPPC retreat for individuals interested in peds palliative care from all three branches of the military
- Consider introducing pediatric palliative care to “high density” units in military health care institutions which would then pave the way for further expansion within the institutions.

Documents Reviewed from the HLCC Team
- All documents found on the Team’s website
HLCC Team

Program Director
Cynda Rushton, R.N., D.N.Sc., F.A.A.N.

Medical Director
Nancy Hutton, M.D.

Family Care Coordinator
Barbara Hall, R.N.

Bereavement Coordinator
Elizabeth Reder, M.A.
Program Name: The Omega Life Program
Date of Survey: 12/07/06
Location of Program: Baltimore Maryland
Web address (if available): 
Primary Contact: Leslie Piet RN, MA, CCM Phone: (410) 762-5278
Name of person providing information: Leslie Piet
Title of person providing information: Program Developer and Case Manager

Program Description:
The Omega Life Program is palliative care program available to individuals who are receiving services through the Johns Hopkins Health Plan. The Johns Hopkins Health Plan includes but is not limited to Priority Partners, US Family and the Employee Health Programs.

The Omega Program is designed to provide palliative care services through a case management model. Individuals who are eligible for the program receive a case manager to assist in the coordination of services through individualized assessment and development of a plan of care. Case managers address access to relevant providers, pain and symptom management and access to services that promote spiritual and emotional well being. The case management services are designed to address end of life issues when appropriate.

The Program was initiated in 2002 by a case manager who had extensive experience in the hospice setting. The case manager attended the Harvard Palliative Care Education and Practice Program and then promoted interest within the Johns Hopkins Healthcare Plan to develop such a palliative care program. The program was developed and accepted as a service to be offered to individuals within their health system who have a diagnosis of cancer.

The program is currently serving approximately 85 individuals over the age of 18. The palliative case management team is comprised of 2 registered nurses and one case management assistant. The case management team facilitates communication and services through home visits, telephone communication and attendance at patient care meetings. The program promotes a multidisciplinary approach with the ultimate goal of addressing concerns and goals that are important to the patient.

Population Description
The population served in The Omega Life Program exclusively adults 18 years and older who have a diagnosis of cancer. This includes individuals who:

- Have recently been diagnosed
- Are preparing to begin treatment
- Are currently in treatment
- Have completed treatment but continue with signs or symptoms
- Are at high risk for recurrence
Service Delivery
- Referrals for The Omega Life Program are identified through the general referral processes within the health system. These processes include but are not limited to high cost users, request from family, physician or other entity.
- The case manager contacts the individual via phone, then schedules a face to face visit
- An assessment is completed and followed up by the development of a plan of care.
- Services identified on the plan are coordinated by the case manager and appropriate referrals and linkages are made.
- Communication is facilitated by the case manager with the individual, the family and any other entities involved in the care.
- The case manager assists the family in accessing services appropriate at the time of death and beyond

Funding for Services
The case management services are provided by the Health Care Plan and there is no additional cost to the individual. Although case management services typically promote an overall cost savings, it was unclear as to the specific dollars saved with this population.

Research Component
Although the principles of this palliative care program are reportedly based on existing literature and research, there is no specific research identified that is part of this program.

Education Component
The educational program cited by this program developer as the motivation for development of a palliative care program is the Harvard Palliative Care Education and Practice Program. This program in Palliative Care Education and Practice “offers intensive learning experiences for physician and nurse educator who wish to become expert in the clinical practice and teaching of comprehensive, interdisciplinary palliative care, as well as to gain expertise in leading and managing improvement in palliative care education and practice at their own institutions.” It is an intensive two session (Spring and Fall) Course for Medical and Nursing Educators.1

Additionally, education is informally provided via presentations or one to one communication to staff and other providers within the health system. In addition, see the Johns Hopkins Palliative Care Program Site Visit Report for related education to other members of the Hopkins system.

Strategies Used for Implementation
- Identify champions within the organization who have previous expertise and interest in the area of palliative and or hospice care.
- Gain momentum for cultural change by utilizing personal stories or connecting with key organizational players who have experienced end of life issues with family members or close friends. These individuals often recognize the importance and need for palliative care.

1 Center for Palliative Care at Harvard Medical School, http://www.hms.harvard.edu/cki/pallcare/pcep.htm
- Have at least one champion participate in the Harvard Education Program as a catalyst for change
- Incorporate program under the auspices of disease management (i.e. Cancer diagnosis)
- Provide ongoing education to staff and providers to continue forward momentum and growth
- Utilize booklet Five Wishes to promote communication and decision making for advanced directives (there is a pediatric version entitled My Wishes)

**Current Challenges for the Program**
- Quantifying outcomes
  There was limited discussion regarding this topic during the interview.

**Possible Application to the Military Environment**
- Program implementation occurred as part of the current case management system which is currently system wide in the military (i.e. TMA)
- Incorporate the publication My Wishes as a resource for children with LTC through Military OneSource
- Utilize Harvard Education model as a catalyst for changing culture and achieving enduring change
- Cost containment through case management services could be used as a tool to market this type of model
- Military families participating in US Family program through Johns Hopkins Health System and who meet the criteria for case management and palliative care could utilize the Omega Life Program services

**Documents available for review by mCare team from Omega Life Program:**
- Palliative Care Case Management trifold brochure
- Five Wishes pamphlet
- My Wishes pamphlet