

APPENDIX 27

SITE VISIT REPORT/PALLIATIVE CARE PROGRAM ASSESSMENT SUMMARY

This report is a summary of the five site visits made to various pediatric palliative care programs around the country which were made from May – December 2006. The strengths of each program in terms of what constitutes a good pediatric palliative care program will be outlined under the following headings, Program Description, Population Description, Service Delivery, Funding for Services, Research Component, Education Component, Strategies Used for Implementation, Current Challenges for the Program, and Possible Application to the Military Environment. A final narrative summary and conclusions will follow.

The six sites visited were as follows:

- Children’s Mercy Hospital PACCT Program
- Children’s Hospital Denver/ Butterfly Program
- Harriett Lane Compassionate Care/Johns Hopkins Children’s Center
- St. Mary’s Healthcare System for Children/ Bayside, NY
- The Omega Life Program
- Seattle Children’s Palliative Care Consulting Service

Program Description

Children’s Mercy	Children’s Denver	Harriet Lane	St. Mary’s	Omega Life	Seattle Children’s
<ul style="list-style-type: none"> • Pediatric Advanced Comfort Care Team developed 5 years ago to address needs of children with life-limiting illnesses • Provides comprehensive palliative care that includes clinical care, education and research • Consultative service based within the hospital network only (no homecare) (inpt/outpt) • Team members include MD, PACCT Nurse Clinician, Chaplain, Social Worker, Advanced Practice Nurse 	<ul style="list-style-type: none"> • Partnership between the hospital and Centura Health at Home (hospice and home care) • Initially designed to accept outpts with life-limiting conditions and a prognosis of less than 12 months; accepted first patient 6/99 • Program supports concurrent curative and palliative care • Centura Health at Home provides the emotional support on an outpt basis • Developed an inpatient 	<ul style="list-style-type: none"> • Main focus is to provide education and support for the inpt and outpt staff • Program started 6 years ago • Decision to work primarily with the staff to provide emotional support for the team and allow for a reconnection for “meaning” with respect to what they are doing • Program provides consultation on pain and symptom management, psych and spiritual 	<ul style="list-style-type: none"> • Hospital was founded in 1870 and specializes in post acute care for children with special needs • Palliative care program developed by “champion” Dr. Bert Grebin over 25 years ago • Palliative care unit opened in 1984; program has expanded since • Scatter bed system in 1986 • Various programs added over the years such as pastoral care, social work, bereavement, parent support groups, 	<ul style="list-style-type: none"> • Palliative care program available to individuals receiving services through Johns Hopkins Health Plan • Provides palliative care through case management model • Case managers address access to relevant providers, pain and symptom management, and access to services that provide spiritual and emotional well being • Developed in 2002 and offered to individuals with the 	<ul style="list-style-type: none"> • Palliative care program • No Medicaid Waiver • Program has been in existence for over 6 years • Program is affiliated with the hospital

<p>Case Managers, Pain Management Specialist, Psychologist, Child Life Specialist, PACCT Medical Director, Community Hospices</p> <ul style="list-style-type: none"> • Currently servicing 120 pts and families • Part of Patient Care Services and not physician directed • Advisory Board comprised from various departments in the hospital and meets quarterly • Currently not pursuing a CHI-PACC waiver due to geographic catchment area and possible restrictions on who could be served 	<p>consultative service in January 2002 following receipt of CHI-PACC grant</p> <ul style="list-style-type: none"> • Team members include a Medical Director, Inpt Coordinator (PNP), 2 inpt chaplains, Outpt Coordinator (LCSW), Outpt Chaplain, Outpt Social Worker, Bereavement Counselor, Centura Home Care Coordinator • Access to Pain Management Services, Child Life Specialists, Volunteers • Outpt program works with multiple home care agencies including Centura • Steering 	<p>support, advance care planning, and bereavement counseling</p> <ul style="list-style-type: none"> • Program supports concurrent curative and palliative care • Members of program facilitate Patient Care Conferences (no parents present) and discuss all aspects of care (medical, spiritual, psychosocial) • Team is comprised of 4 members: program director (RN), medical director, family care coordinator (LCSW), and bereavement coordinator (MDiv) 	<p>creative therapies such art music and pet therapies, and complementary therapy</p> <ul style="list-style-type: none"> • Developed Palliative Care Pathway in 2002 which is a care map for providing palliative care • Estimated that 20% of St. Mary's daily population of 3200 pts might benefit from palliative care approach • Core team includes administrator, physicians, manager, director of complementary therapy, deacon/pastoral care, social workers • Program does not enroll pts from time of diagnosis 	<p>diagnosis of cancer</p> <ul style="list-style-type: none"> • Currently serves 85 individuals • Team comprised of 2 registered RNS and one case management assistant • Team facilitates communication and services through home visits, telephone communication , and attendance at pt care meetings 	
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	<p>Committee meets quarterly</p> <ul style="list-style-type: none"> • Enrolled over 250 pts into program since inception • State Medicaid office has submitted 1915c waiver embracing the CHI-PACC model of care (resubmitted October 2006) 		<ul style="list-style-type: none"> • Program has not submitted Medicaid waiver embracing CHI-PACC standards of care although New York State working on such a waiver 		
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Population Description

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • Population exclusively comprised of children through inpt and outpt department at main campus site • Categories used to define population include acute life threatening, life limiting, threatening, life limiting, and life style limiting • Population reflects general population of the geographic region and does not seem to represent broad diversity of culture • No home care population 	<ul style="list-style-type: none"> • Inpatient population includes not only pts from Denver metro area but also catchment area for hospital which includes Colorado outside Denver metro area, Wyoming, Montana, and parts of Kansas, Nebraska, South Dakota, and New Mexico • Outpt/home care population comprised of pts living in the Denver metro area; 98% are Medicaid eligible • 60% of pt population has non-oncologic diagnosis 	<ul style="list-style-type: none"> • Program accepts requests for patient care conferences from within the facility • “High density” areas that make referrals include PICU, NICU, Oncology, and ED • No home care program 	<ul style="list-style-type: none"> • Population of program comes from pts requiring post acute care due to a variety of chronic conditions such as complications of prematurity, HIV/AIDS, genetic / metabolic disorders, and traumatic brain injury • Any child who is part of the Healthcare System eligible to receive services • Established outpatient program 	<ul style="list-style-type: none"> • Exclusively serves adults 18 years and older with diagnosis of cancer • Eligible pts are those recently diagnosed, preparing to begin treatment, currently in treatment, those who have completed treatment but continue with signs and symptoms, and those at high risk for recurrence 	<ul style="list-style-type: none"> • Population served is only pediatrics • Population comes from inpatient service following referral from a physician • Program does 150 consults per year • Program services pts from all over WA and from other states in Pacific Northwest • Program does provide services to military families

Service Delivery

Children's Mercy	Children's Denver	Harriett Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • Referrals to program come from medically licensed personnel and parents must be in agreement • Nurse clinician meets with family within 48 hours of referral after reviewing record to prepare for meeting • PACCT coordinator determines composition of team and notifies various departments such as social work, chaplain, psych, pain management and child life to ask for assigned team 	<ul style="list-style-type: none"> • Referrals initially made by RN, MD, or family themselves • Attending MD must agree to proceed with referral • Initial consult done by inpt or outpt coordinator or medical director • Signed consent obtained from parents to participate in the program • Inpt coordinator responsible for identifying families concerns, discuss pain/symptom management, discuss DNR, and work with 	<ul style="list-style-type: none"> • Request for Patient Care Conference made by member of primary inpt care team • Member of HLCC Team acts as facilitator at meeting; parents not invited • Goals of pt care (medical, psychosocial, spiritual) discussed at conference • Primary MD, assigned social worker, and case manager invited to conference and can help facilitate outpt services • Documentation tool completed for each conference; this is not a specific care plan but an 	<ul style="list-style-type: none"> • Referrals come from the inpatient medical service • Core team consists of an administrator, 2 physicians, program manager, nurse director for complementary care, deacon, and 2 social workers • Additional interdisciplinary collaboration with nutrition, therapeutic rec, rehab, pharmacy, and inpatient nursing units • Program has 	<ul style="list-style-type: none"> • Referrals made through the general referral processes within the health system and include high cost users, request from family, physician or other entity • Case manager contacts the pt by phone and then arranges for a visit • Following the assessment, a care plan is developed • Services as outlined by the plan coordinated 	<ul style="list-style-type: none"> • Program provides care coordination, indirect medical care • Referring MD makes referral to team and a consultant assigned to the case based on availability • Consultant meets with providers and program coordinator schedules care conference with family and health care providers • Care conference lasts about an hour during which time consultant facilitates communication and

<p>members; the teams are drawn from staff assigned to specific departments or specialties of outpt clinics therefore there is no consistent continuity</p> <ul style="list-style-type: none"> • If parent agrees to participate, PACCT information, brochure, blank Comprehensive Comfort Care Tool (CCCT), DNAR parent document given to family; additional forms if appropriate include grief form and psychiatric evaluation form • Meeting later convened with family and team members to discuss CCCT and develop an 	<p>inpt primary care team on any relevant issues</p> <ul style="list-style-type: none"> • Written Palliative Care Plan is developed either by inpt or outpt coordinator • If pt transitions to outpt program, the outpt coordinator meets with family to discuss resource needs, counseling issues, and continue discussion regarding advance directives • Chaplain from either inpt or outpt team meets with child depending on location • Inpt coordinator or medical 	<p>outline of goals</p> <ul style="list-style-type: none"> • Second conference arranged with family to discuss these goals; members of HLCC not automatically present at this conference but are invited on a case by case basis • No formal outpt pediatric palliative care team • Well established home care program which may eventually build in a peds palliative care component • Patients needing outpt hospice referred to Community Hospice of Maryland; two MDS from Hopkins act as directors of pediatric team • HLCC Team available for 	<p>defined 3 levels of care with reflect the severity of the illness and life expectancy</p> <ul style="list-style-type: none"> • Referrals take place with progression of life limiting illness and not a time of diagnosis • Palliative care is provided based on set of interventions known as the Palliative Care Pathway which outlines care components, outcomes, and outcome measures • Formal and informal palliative care rounds occur in the 	<p>by case manager who makes appropriate referrals</p> <ul style="list-style-type: none"> • Case manager facilitates communication with pt, family, and others involved with the care • Case manager assists family in accessing appropriate services at time of death and afterwards 	<p>shared decision making</p> <ul style="list-style-type: none"> • Following the conference the consultant completes the Decision Making Tool (DMT) which usually takes up to two hours to complete; tool contains information on meeting discussion and action plan • Consultant follows up with all who are listed on the action plan • Completed DMT goes into the front of the patient's chart and parents also given a copy; there is an option of placing the document in the EMR • DMT becomes tool for
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<p>action plan</p> <ul style="list-style-type: none"> • CCCT reviewed by parents and signed by MD • PACCT coordinator monitors family as needed either in the inpt setting or in the outpt clinics • Chaplaincy services responsible for administrative assistance and spiritual care when death occurs • Bereavement provided by “After Care” program which is a separate hospital team and is outside the PACCT program 	<p>director round on inpts as needed</p> <ul style="list-style-type: none"> • General hospital interdisciplinary services available as needed including Child Life • If child is outpt, outpt coordinator or other social worker and chaplain regularly meets with pt and family • Primary care MD remains involved when pt is outpt and can access medical director or inpt coordinator regarding pain/symptom management questions • Home care for outpts provided by independent agencies or Centura Health 	<p>debriefings following death of pt</p> <ul style="list-style-type: none"> • Additional programs include Annual Tribute Service, bereavement groups for parents and sibs, support group for grandparents, and quarterly staff memorial services • Will consider expanding into more of a clinical service in the future if funding allows 	<p>facility</p> <ul style="list-style-type: none"> • AM Rounds occur each am among core team members • Peaceful Dying Plan completed when patient is terminally ill and reflects both parents’ and patient’s wishes • Doula Program made up of volunteers who assists patients and families during the dying process (“dying coach”) • Booklet, “Gentle Transitions” is for families and discusses the physical, emotional, and spiritual aspects of approaching 		<p>continuity of care</p> <ul style="list-style-type: none"> • DMT used most effectively when the conference facilitator comes from outside the team of healthcare professionals that provide care for the child • Program accepts nearly all referrals
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	<ul style="list-style-type: none"> • Death at Home Procedure developed if child is to die at home • Families may access the “Cocoon” if child is to die in the hospital; Cocoon transforms hospital room into more home like environment and contains sheets, blankets, pillows, soft lighting, video camera, coffee pot, CD player • Families offered booklet that explains system by system, the dying process • Bereavement is provided by either Centura bereavement coordinator as well as Bereavement Program/Grief 		<p>death</p> <ul style="list-style-type: none"> • Social worker visits family 2 weeks after death to give family memory box and siblings a sibling bag • Ethics committee available as recommending body that helps with care dilemmas • Home care component to the program which involves nursing, social work, and chaplain 		
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	<p>Groups offered by the hospital</p> <ul style="list-style-type: none">• Additional programs include annual memorial service and Creative Memories Workshop which helps families start scrapbook album				
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Funding For Services

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • Philanthropic funds are used for a 1.8 FTE which includes the nurse clinician position and the program manager position • Physician is “on loan” from PICU so no costs incurred • Other disciplines are funded by their own departments • Social work explores insurance benefits to access funding for medical needs • Hospital also has access to private funding to cover items and services not covered by 	<ul style="list-style-type: none"> • Costs for the outpatient emotional support are split between the hospital and Centura; program therefore operates at a fiscal loss to the organizations • Approval of Medicaid waiver (1915c) may help cover some of those costs in the future • Hospital recently has agreed to fund inpatient coordinator time, chaplain time, and secretarial support that had been 	<ul style="list-style-type: none"> • No charges submitted for consultative services • All four members of team are salaried employees of Johns Hopkins • Bereavement coordinator salary covered by Nursing Administration • Program will look into obtaining philanthropic dollars as the program expands 	<ul style="list-style-type: none"> • Majority of basic services funded by Medicaid and managed care entities • Exceptional services (complementary services and manager position) in the program funded by philanthropic funds • Patients participating in the Long Term Home Health Program may be eligible for Katie Beckett Waiver 	<ul style="list-style-type: none"> • Case management services provided by the Health Care Plan • No additional costs to individual • Unclear if there are cost savings with this program 	<ul style="list-style-type: none"> • Services are funded by hospital administration fund

insurance	<p>covered by grant funding</p> <ul style="list-style-type: none"> • Hospital has also agreed to fund a small percentage of medical director's salary for time spent on the program • Centura staff member dedicated to fund raising the organization, including The Butterfly Program and works with grant writer to secure funding via local granting agencies 				
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Research Component

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • Collaboration with researcher from University of Missouri-Kansas City to promote evidence based practice through qualitative research • Consideration of submission of an R-15 grant to develop a project to study parental values and understand how variables have an impact on communication between healthcare teams; will use Parental Values Inventory tool • Initial funding efforts have been unsuccessful but will be pursued again in the future 	<ul style="list-style-type: none"> • No current research efforts in place • Program does send out a parent satisfaction survey and this could be a possible tool for research in the future • Medical Director has contacted palliative care director of adult program regarding collaboration in the future once Children's moves to its new campus • Demographic data being collected 	<ul style="list-style-type: none"> • HLCC member of IPPC (Initiative for Pediatric Palliative Care) and has collaborated on a number of projects with this organization such as 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 	<ul style="list-style-type: none"> • No formal research component • Plan in the future to evaluate Family Centered Care Program via satisfaction survey; began administering the survey in February 2006 • Focus groups sponsored for caregivers to obtain qualitative data regarding caregiver need • Program surveyed inpatient unit nurses in 2004 to get feedback on views on palliative care within the institution • Demographic data being collected 	<ul style="list-style-type: none"> • No specific research identified with the program 	<ul style="list-style-type: none"> • None cited

		<p>a pediatric palliative care program, measurement of the impact of initiating a pediatric palliative care program, and survey research regarding health care professional knowledge and attitudes about caring for children with life-threatening conditions</p> <ul style="list-style-type: none"> • Additional areas of research include evaluation of relationship of trust to the experience of caregiver suffering in the PICU, exploration of the concept of hope in providing pediatric palliative care, translating “values history” 			
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		advance directives for use in pediatrics, development of a “pathway” for integrating basic and advanced components of palliative care throughout the Children’s Center, and integration of palliative care with antiretroviral therapy for children and families in the US and internationally			
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Education Component

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • IPPC training is tool used for educating providers at the hospital; use of train the trainer model • David Browning acted as facilitator to introduce palliative care concept within the institution • PACCT education initiatives targeted to families include DNAR Care Card, "Shelter from the Storm" book, PACCT brochure describing program services 	<ul style="list-style-type: none"> • Medical director and inpt coordinator offer conferences to both MDs and RNs • Inpatient coordinator has helped arrange for ELNEC (End of Life Nursing Education Curriculum) to be offered over the past 2 years • Additional opportunities for education include beside teaching at both the physician and nursing level, Good Grief at Noon (ed-ucational session) 	<ul style="list-style-type: none"> • Team participates in noon conferences for residents and medical students which are offered 6 times per year during which a variety of palliative care topics are discusses • Palliative care rounds held monthly on high density units (PICU, NICU Oncology) • Palliative Care Network open to anyone with an interest in pediatric palliative care; 	<ul style="list-style-type: none"> • Development of the Palliative Care Pathway with subsequent staff education about the Pathway • Results of staff survey regarding pediatric palliative care issues in 2004 allowed for development of educational objectives in 2005 • Caring Connection curriculum on end of life care developed in 2006 • Compassionate Partnership, 3 hour training session on palliative/end of life care, developed in 2006 • Peaceful Dying Plan developed 	<ul style="list-style-type: none"> • Participation in the Harvard Palliative Care Education and Practice Program • Informal education of staff as needed 	<ul style="list-style-type: none"> • Consultants educate providers through care conferences • Presentations on palliative care and communication given to residents • 4th year medical students can do an elective with the palliative care consultants

<ul style="list-style-type: none"> • PACCT education initiatives for staff include department updates for nurses, social work, and child life, Grand Rounds/Special Events, One-on-One with PACCT clinicians, small group lectures, IPPC curriculum, resident/fellow program elective, child life internships, nursing student rotations, nursing orientation, Journal Club • Variety of presentation topics presented as part of PACCT Educational 	<p>sponsored by The Bereavement Council offered on a monthly basis), education targeted to specific units based on their interest and need, and debriefing sessions offered by the chaplain on an as needed basis</p> <ul style="list-style-type: none"> • Program has developed an Outreach Program to educate hospice programs in CO outside the Denver metro area and in WY and MT focusing on topics in pediatric palliative care 	<p>educational sessions held quarterly</p> <ul style="list-style-type: none"> • Regional IPPC training done in March 2006 • Maryland Pediatric Palliative Care Summit held in 2004 to discuss current resources, gaps in services, and strategies for improving pediatric palliative care 	<p>in 2006</p> <ul style="list-style-type: none"> • Program sponsored Pain Awareness Month in September 2006 		
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<p>Initiatives</p> <ul style="list-style-type: none">• Individual training on hospital unit provided by nurse clinicians associated with program• Modeling palliative care practice is primary strategy for educating coworkers					
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Strategies Used for Implementation

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • Gain support from key senior administrators such as CEO and senior VP of clinical service product line • Initiate services in areas of the hospital with greatest need rather than in those that already support palliative care philosophy • Identify physician champions and champions with other departments • Meet with other disciplines prior to starting program to gain support • Use master 	<ul style="list-style-type: none"> • Gain support from hospital administrators • Address "turf" issues and stress that services offered by program not meant to replace but supplement ongoing care • Partnership with established hospice program in the community allows for better access to services particularly in the outpt arena • Dedicated fundraiser for program • Buy in of hospital foundation in order to help with fundraising • Implement 	<ul style="list-style-type: none"> • Strong support of program from Chairman of Pediatrics and Director of Nursing • Team meets yearly with Chairman of Pediatrics to discuss objectives • Strong support of Director of Social Work which helps with turf issues • Continued efforts of team has sparked interest in more units to look at implementation of palliative care 	<ul style="list-style-type: none"> • Continued strong support of founder of program • Board of facility and CEO/President supportive of program • Ongoing support of benefactor over many years • Staff education has allowed staff to feel more comfortable taking care of dying children and their families • Patient population of Healthcare System lends itself to incorporating palliative care concepts more readily • Program staff builds on its 	<ul style="list-style-type: none"> • Identification of champions within the organization with previous expertise and interest in palliative care • Build on personal experiences with palliative/end of life care of key organizational players • Participation of champion in Harvard Education Program may act as catalyst for change • Incorporate program under auspices of disease management • Provide ongoing education to staff • Utilize "Five Wishes" booklet to promote communication 	<ul style="list-style-type: none"> • Provision of a service that people in hospital find valuable • MDs request palliative care consult when they need help communicating, understanding families' priorities and developing a plan • Needs assessment done in mid 1990s, followed by grant funded demonstration project in which they created DMT • Following grant, the administration provided \$200,000 to fund the

<p>facilitator to introduce palliative care concepts within the institution</p> <ul style="list-style-type: none"> • Identify a well qualified and passionate coordinator for the program • Identify specific diagnoses that generate an automatic PACCT consult • Do not push palliative care on departments resistant to the concepts • “Small steps” in moving program along • Formation of an advisory committee as program begins to grow 	<p>program on incremental levels</p> <ul style="list-style-type: none"> • Employ nurse practitioner to assist with consultations • Target staff with commitment to palliative care who can be champions within the institution • Market program to subspecialties within the hospital via participation/ presentations at departmental meetings 		<p>experiences in order to improve care for future patients/families</p>	<p>and decision making for advanced directives (My Wishes booklet available for children)</p>	<p>Palliative Care Consult Service as it felt as an important value added to care and a way to humanize technological processes</p> <ul style="list-style-type: none"> • Currently 2.9 FTE and 0.5FTE for medical director • Currently collecting donations to establish and endowment for ongoing work
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Strengths of Program

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • Supportive, family centered culture within the institution allows program to thrive • Nurse clinician promotes program in a subtle consistent manner and is seen as a neutral care facilitator; seen as right person for the role as coordinator • Parents indicate "web of support" most valuable resource provided by program 	<ul style="list-style-type: none"> • Medical director and inpatient coordinator demonstrate passion for palliative care and are well respected within the hospital • Having both inpatient and outpatient teams allows for better continuity of care • Outreach Program seminars has allowed for creation of a network which facilitates pts returning to their community • Strong spiritual component • Bereavement services offered by both the program and the hospital 	<ul style="list-style-type: none"> • Committed team members who bring different strengths to the program • Strong backing of program from Chairman of Pediatrics and Director of Nursing • Participation of team in variety of conferences and educational activities which promote pediatric palliative care within the institution • Creation of a network consisting of 100 interested individuals from within the institution • Improvement in communication and decision making on the inpatient unit due 	<ul style="list-style-type: none"> • Support of President and CEO of organization • Long, well established history of delivering pediatric palliative care • Physician champion who founded program • Dedicated staff consistently seeking to better their care • Development of tools such as Palliative Care Pathway and Peaceful Dying Plan • Full time pain management coordinator who also oversees complementary care • Strong spiritual component • Strong commitment to 		

		to program's involvement	education <ul style="list-style-type: none">• Doula Program (individuals assisting families and patients during dying process)		
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Current Challenges

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • Quantifying outcomes that add credibility to the PACCT initiative in order to maintain support of hospital administrators • Expanding "buy in" to all MDs and staff at hospital • Seeking alternatives to philanthropic dollars to fund nurse clinicians • Dealing with territorial issues among staff • Education of staff that providing palliative care is not synonymous with end of life care • Information technology 	<ul style="list-style-type: none"> • Quantifying outcomes that add credibility to the program • Expanding "buy in" factor to all physicians and staff at the hospital • Continue fund raising efforts and grant applications to offset deficit that organizational partners must absorb • Dealing with territorial issues among staff • Data management specific to The Butterfly Program • Ensuring adequate input on 1915c waiver initiatives, if waiver 	<ul style="list-style-type: none"> • Program currently consultative only; clinical services in the future depending on funding • No formal care coordination and no formal outpatient coordinators • Limited contact with primary care MDs in community • Gap in mental health services from inpatient to outpatient setting • Limited chaplain services • No outpatient component to program which would allow seamless continuity of 	<ul style="list-style-type: none"> • No physician formally trained in palliative care on team • Physicians in community may or may not be champions of palliative care resulting in care plans being changed once pt is discharged • Primary care providers may see initiation of palliative care services as giving up • Addressing anticipatory grief in parents when child is admitted which is emotionally charged issue for parents and staff 	<ul style="list-style-type: none"> • Quantifying outcomes 	<ul style="list-style-type: none"> • Challenges as they relate to military include getting services paid for by TRICARE, working with families who are moving, communication with receiving MTF

plan for PACCT program not part of main clinical documentation system	approved, in order that current services offered are reimbursed	care <ul style="list-style-type: none">• Disconnect between HLCC and adult palliative care program			
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Program Elements with Potential Applications to the Military Environment

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • Implementation in hospital setting with gradual expansion • Some components of program also exist in military health care system • Strong reliance on existing staff to provide direct patient care which allows tailoring of services and care to meet specific needs of pt and family; PACCT RNs function as facilitators • Development of partnerships among existing resources both in hospital and community • Comprehensive Comfort Care Tool focuses care coordination 	<ul style="list-style-type: none"> • Build on existing resources • Focus on consultative service not one that provides direct pt care • Identify resources (such as home care) that would be available on an outpt basis • Consider outreach team to educate and train outpatient agencies with respect to care coordination • Understand that there are multiple bereavement strategies that may be used with families which may preclude a formal referral 	<ul style="list-style-type: none"> • Build on existing resources • Redefine job descriptions of existing personnel to include appropriate palliative care responsibilities • Consider holding regional IPPC retreat for interested individuals from all three branches of the military • Consider first introducing pediatric palliative care to "high density" units with the military health facilities (NICU, PICU, 	<ul style="list-style-type: none"> • Incorporate standards (interventions and outcomes) from St. Mary's inpatient and home based service models • Incorporate level of care concept as an approach to pediatric palliative care • Decide on set of core standards that would constitute a program and determine what resources are available and how they should be allocated 	<ul style="list-style-type: none"> • Incorporate My Wishes as a resource for children with life limiting conditions through Military OneSource • Utilize Harvard Education model as catalyst for changing culture and achieving enduring change • Cost containment through case management services could serve as marketing tool for this type of model • Military families participating in US Family Program through Johns 	<ul style="list-style-type: none"> • DMT could be used for care coordination and can be tried at one MTF • Identify an MD champion who from any sub-specialty but who has a passion for PC

		Oncology, ED) which could pave the way for further expansion		Hopkins Health System and who meet criteria for case management and palliative care could use Omega Life Program services	
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SUMMMARY/RECOMMENDATIONS

The site visits made as part of the Department of Defense's mCARE initiative indicate the many ways an organization can approach launching a pediatric palliative care program. All of the programs visited have had extensive experience (4-25 years) in providing palliative care. All of the programs embrace the basic concepts of palliative care that address the physical, emotional, psychosocial, and spiritual well being of the patient and family. The success and obstacles that each of these programs has experience during the growth of their palliative care program should help guide the Department of Defense in strategizing how to incorporate pediatric palliative care into the military healthcare system. There are several important components that the military health care system must address with respect to programmatic development. Several of these components are listed below along with possible strategies the Department of Defense could use for successful implementation of pediatric palliative care into its military healthcare facilities. The strategies listed are based on information obtained at each site visit.

Program Champion

- Identification of a program champion willing to get the program off the ground; this individual clearly does not have to be a physician but could also be an advance practice nurse
- Buy in from the administration of the facility is key to the initial and future success of any program and in the case of the military it would be important to have the support of the facility commander and other key individuals in positions of authority; this is well illustrated in Dr. Carlos Parrado's presentation during the Expert Panel meeting
- Encourage program champion to attend an educational program such as IPPC, EPEC, ELNEC, or the Harvard Education Program on Palliative Care to gain state of the art palliative care knowledge; this could ideally be done prior to the program implementation

Implementation Strategies

- Survey each potential facility to identify the perceived need for pediatric palliative care and the individuals interested in delivering this type of care
- Attempt to identify "turf" issues early to avoid confrontation when the program is implemented and consider the approach of offering support as a consultative team to the existing primary care team
- Consider starting small and building the program gradually; consider targeting high density areas (PICU, NICU, ED, Oncology) where individuals are probably more receptive to the concept of pediatric palliative care

- Depending on the size of the military healthcare facility, consider one on one marketing with each appropriate department within the facility
- In determining what services would be offered, consider developing a set of care components for the different disciplines involved (medicine, nursing, social work, spiritual care, child life, etc) along with expected outcomes and outcome measures (see St. Mary's model)
- Adopting level of care model (St. Mary's) may be useful to help identify and allocate resources needed

Personnel

- Identification of services already in place at a facility will dictate what personnel will make up the team
- Program champion may need to wear many hats and may need to be skilled in care coordination/case management in the case of smaller facilities
- Use resources that are already in place particularly if new staff can not be added due to budget constraints; this is well illustrated with the Children's Mercy program as the nurse clinician recruits a team from existing personnel in each department
- Another option to address the personnel issue is to redefine existing job descriptions to include responsibilities for palliative care

Service Delivery

- Decide on a core set of standards that would constitute a program that could be used across the board at each facility
- Program at each facility should expect to be able to offer support in all 4 areas of palliative care – physical, psychosocial, spiritual, and emotional on a consultative basis even if different models are used in delivery of service
- Bereavement services (either inpatient or outpatient) should be identified
- Determine who is able to make referrals (MD/RN/MSW)
- Consider whether a signed consent for services is appropriate
- Program should consider a documentation tool to develop a written palliative care plan that can be updated as patient's condition changes; this tool could follow patient back into community/ home care setting
- Identify home care services and other outpatient resources available in the area
- At the very least it would be important to develop a database at each facility offering pediatric palliative care which would contain demographic data, time allocation for each team member, costs

Education

- Program champions from all three branches of the military could be brought together for an IPPC retreat
- Develop educational initiatives for staff (MDs, RNs, MSWs) when feasible
- Participation in Pediatric and Nursing Grand Rounds
- Make available some basic information to parents such as general information on the program and pediatric palliative/end of life care, booklet that explains dying process, grief packets containing resources available within the facility or community; these items can be adapted from materials that have already been developed by pediatric palliative care programs in the civilian sector

Research

- Typically not a priority when beginning a new program however family satisfaction surveys and outcome measures for various components of the program could nonetheless be collected and analyzed at some future date