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**Abstract**

The goal of this program is to develop and recommend a model of care that enhances the quality of life for DOD children with life-threatening conditions and their families. Our strategy is to maximize current benefits and coordinate medical care with existing community resources and services, tailored to support the family's specified needs and requirements. The first year of work focused on a feasibility study to gather data on the intent, interpretation and implementation of the benefit; status of service delivery; available resources through the Military Health System, contract providers, community and other government agencies; and to conduct an assessment of needs of families. A distinct research protocol was designed to use individual interviews and focus groups to determine family and provider needs. The benefits likely to be used by military families and their children were analyzed. A data assessment collection tool has been designed to capture descriptors regarding community resources. The plan is to web enable the database in order to provide maximum availability and accessibility to the various potential users. An existing education curriculum for providers, Initiative for Pediatric Palliative Care, developed by the Education Development Center, was selected as one that best aligns with the CHI PACC® model.

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EXECUTIVE SUMMARY

This project is designed as a feasibility study to explore the capability of providing pediatric palliative care within the Military Health System (MHS). The ultimate goal is to make recommendations for a program of pediatric palliative care that would integrate palliative care interventions with therapeutic approaches to disease management from the time of diagnosis and provide a smooth transition to hospice care, when the child and family is ready to make that choice (a Children’s Hospice International Program of All-inclusive Care for Children and their families (CHI PACC®) model). The overall approach is to optimize currently available healthcare benefits as well as military and community resources in a manner that responds to the individualized needs of children with life-threatening conditions who are beneficiaries of the MHS.

Palliative care refers to patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care provided across the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice. The current CHAMPUS/TRICARE authorized benefit for hospice is based on a Medicare model for adults, and the requirements for these services severely restrict pediatric access and do not provide appropriate pediatric care.

The project team researched the following areas related to the delivery of pediatric palliative care in the MHS:

- Assessment of needs of children, families and healthcare providers in the MHS
- Analysis of the benefit and the current status of service delivery
- Determination of eligibility criteria and an estimate of the numbers of children who would benefit from palliative/hospice care and the costs to serve them
- Description of availability and accessibility of community resources
- Exploration of case management and care coordination
- Documentation of formal and informal education curricula and strategies
- Investigation of current approaches to pediatric palliative care through site visits to existing programs
- Application of the standards of effective quality management systems

The published literature describes four types of children with life-threatening conditions based on trajectories of dying: those with incurable disease (some chromosome disorders), manageable disease (cystic fibrosis), possibly curable disease (childhood cancers), or those with significant co-morbidities that are often associated with hospitalization and death (child with a tracheostomy). A count based on diagnostic codes chosen for each type of condition was executed through data searches of the MHS administrative database for FY 2001 through FY 2002 and revealed 3,871 children who would be eligible for palliative care services. This number of children was verified by the prevalence rate of life-threatening conditions in a comparable population.
Analysis of the benefit showed the key services necessary for the provision of a comprehensive program of pediatric palliative care, not available through the current CHAMPUS/TRICARE benefit, are care coordination, respite care, flexible home health care, bereavement counseling, and the ability to provide hospice care to enhance quality-of-life concurrently with life-sustaining treatment.

The gap analysis collated and synthesized the findings of this feasibility study by bringing together the needs of families and providers, the MHS benefit, and the availability and limitations of resources and services in order to determine the existing gaps. The identified gaps are the following:

- Processes are needed to improve families’ access to needed services within the MHS.
- Comprehensive care coordination and continuity of care is vital for children with life-threatening conditions and their families but are inconsistently available.
- While the TRICARE benefit provides for care that addresses a child’s medical needs, the complexity and duration of care needed by children with life-threatening conditions creates challenges that require extra coordination.
- A Medical Home, as recommended by the American Academy of Pediatrics, is generally not available to children with special needs in pediatrics or family medicine clinics in the MHS.
- Administrative challenges frequently create barriers to access of care and services for children and families.
- Families and providers are not trained or equipped to advocate for these children, and there is no specific resource to assist in filling this role for individual patients and families.
- Many providers remain untrained in effective communication techniques for discussing palliative and end-of-life care and in the medical options available for palliative care.
- Many of these children and families have various unmet needs for both emotional and social support.
- There are limited knowledge and resources available to families for either advice or support financially, a frequent need during relocation of the family to a medical center.
- Not all professional clinical and pastoral counselors are qualified to provide counseling for parents under the extreme stress of the initial diagnosis of a life-threatening condition.
- End-of-life care for children is inconsistent, rarely planned with a child and family, and, when done without sensitivity, can increase child and family suffering.
- Both providers and families lack sufficient knowledge about pediatric palliative care and how to identify and provide the support and services necessary for a comprehensive approach to care.
- Military issues such as transfers and deployments create unique problems and added stress for these families. Additional care coordination and services are needed to support families before, during, and after deployments.
This study concluded that it is not feasible to implement pediatric palliative care as a model based on CHI PACC® within the MHS. However, it is feasible to implement the principles of pediatric palliative care within the MHS as set out by the CHI PACC® core standards, the Institute of Medicine, and the National Quality Forum. Military treatment facility commanders have the administrative flexibility to provide palliative care and care coordination to children with life-threatening conditions in their catchment area, using a variety of program designs as best fits their population. Services can be provided by the direct care system and by medical resources in the community using CHAMPUS/TRICARE. Non-medical community resources are also important to families, but require additional coordination to facilitate access.

Program models vary across the nation in their structure, staffing, and service delivery model. Models differ according to the needs of the children and families they serve as well as factors such as the availability and qualifications of staff, budget constraints, and the population density of children with life-threatening conditions. The key aspects of palliative care are: education of all who provide care and services to children with life-threatening conditions and their families and care coordination across all aspects of care throughout the entire course of the child’s illness and in all settings of care.

It is recommended that:

1. Education and information appropriate to the provision of pediatric palliative care and access to necessary resources and services be made available to all healthcare providers and families of children with life-threatening conditions.
2. Care coordination be made available to facilitate communication, promote continuity during transitions, and assist in identifying and obtaining necessary resources and services for all children with life-threatening conditions and their families.
3. TRICARE Management Activity establish an interdisciplinary process team on palliative and end-of-life care for children and adults to review options, make guidance available, and address challenges within the MHS.
STATE THE PROBLEM

Recent advances in medicine have greatly reduced infant and child mortality. Providers caring for children with life-threatening conditions are usually committed to pursuing all curative and life-prolonging options until death is close and inevitable. Effective, compassionate, reliable palliative and end-of-life care has not been a priority and most providers lack the knowledge and experience on how to advise families and approach end-of-life decision-making. Even when a child is gravely ill, parents want to feel they did everything possible. In addition, families and providers are bound by the limitations of what the health care system can and will provide.

The goal of this project was to conduct a feasibility study to explore how pediatric palliative care has been implemented in the medical community, particularly through the use of Medicaid waivers and the application of the principles promoted under the Children’s Hospice International Program of All Inclusive Care for Children (CHI PACC®) goals and standards; to identify and analyze issues relevant to providing pediatric palliative care within the Department of Defense (DoD) Military Health System (MHS); and to make recommendations and provide strategies for implementation of such a program that would enhance the quality of life for these children with life-threatening conditions and their families.
Definitions

Care Coordination
Care coordination is “a collaborative process of assessment, planning, facilitation, and advocacy for options and services to meet an individual’s health needs through communication and available resources to promote quality, cost-effective outcomes.”1 In this report, care coordination also addresses the needs of the family, is proactive (especially in obtaining palliative care and integrating palliative care with disease-directed care), and ensures that the family obtains the support they need while planning for the peaceful and meaningful death of their child and that the family receives needed bereavement support following the death of the child.

Care coordination is a component of medical management, which also includes utilization management, case management, and disease management, as directed by the TRICARE Management Activity Department of Defense Instruction (DoDI 6025.20) and in the Medical Management Guide.2 The DoD TRICARE Management Activity defines care coordination as clinical case management or individually-based case management when provided by a clinical case manager rather than another member of the health care team, and recommends clinical case management be available across the entire health care continuum.3

CHAMPUS
Title 10, USC, which defines the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS), is now known as TRICARE. It outlines the health care benefits to which uniformed service members and their dependents are entitled.

Disease-Directed Care
Disease-directed care is medical care that is intended to cure or slow the progression of a medical condition.

Exceptional Family Member Program (EFMP)
The Exceptional Family Member Program (EFMP) is a military personnel function used during the assignment process to identify active duty service personnel whose family members have special needs. The purpose of early identification is to coordinate the assignment of the active duty service member with the medical needs of their dependents. The program serves to ensure the availability of necessary medical services upon change of duty stations.

Life-Threatening Condition (LTC)
A life-threatening condition (LTC) is a medical condition that has a substantial likelihood of leading to the death of an individual before the age of 24 yrs. This term includes children born

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2 DoD TRICARE Management Activity, Medical Management Guide; January 2006.
with lethal conditions as well as those who develop a life-threatening illness. As used in this report, it does not include children who die soon after birth, an injury, or a sudden illness.

Military Health System (MHS)
The MHS provides medical care for active duty and retired service members and their dependents. The direct care component includes 70 hospitals and 411 medical clinics in the U.S. and throughout the world. Medically necessary care is also purchased from the civilian sector as described in CHAMPUS and implemented by TRICARE.

Military Treatment Facility (MTF)
A military treatment facility is any clinic, hospital or regional medical center within the Military Health System that delivers direct health care to military beneficiaries.

Palliative Care
Palliative care, as defined by the Centers for Medicare and Medicaid Services in its proposed Hospice Conditions of Participation and as adapted from the World Health Organization, refers to patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice.

Quality of Life
Quality of life is satisfaction and pleasure derived from living. Quality of life is affected by one’s physical, interpersonal and social setting. Each person and family may view quality of life differently, depending on their circumstances and values. Factors that affect their own ability to derive satisfaction and pleasure from living determine each child and family’s quality of life.

TRICARE
TRICARE is the managed health care program that is established by the Secretary of Defense under authority of chapter 55 of title 10, United States Code, principally section 1097 of such title, and includes the competitive selection of contractors to financially underwrite the delivery of health care services under the Civilian Health and Medical Program of the Uniformed Services. TRICARE uses military health care as the main delivery system augmented by a civilian network of providers and facilities. TRICARE contractors oversee the purchase of care from the civilian sector, ensure that it is medically necessary and appropriate, and adjudicate payment of the provider and/or reimbursement of the service member.
BACKGROUND:
Summary of the Issues from the Literature

For many reasons, current approaches to care for children with life-threatening conditions leave children, families, and health care providers with unmet needs and unresolved quandaries. Children account for a relatively small percentage of all deaths in this country because of their general good health. The causes of death in children are substantially different from the causes of death in adults and vary considerably with age. Many children are born with rarely seen medical conditions, which create uncertainty in diagnosis, prognosis, and medical management. Therefore, limited knowledge and experience leave parents and health care providers unsure about how to provide care for these children. Even for common medical problems, children’s general physiologic resiliency complicates predictions about survival and other outcomes.

“Palliative care seeks to prevent or relieve the physical and emotional distress produced by a life-threatening medical condition or its treatment, to help patients with such conditions and their families live as normally as possible, and to provide them with timely and accurate information and support in decision-making. Such care and assistance is not limited to people thought to be dying and can be provided concurrently with curative or life-prolonging treatments. End-of-life care focuses on preparing for an anticipated death……….and managing the end stage of a fatal medical condition…………Together palliative and end-of-life care also promote clear, culturally sensitive communication that assists patients and families in understanding the diagnosis, prognosis, and treatment options, including their potential benefits and burdens. 5”

Current insurance models for end-of-life care are based on a Medicare model for adults, and the requirements for these services severely restrict pediatric access. Due to third-party reimbursement and state licensing requirements, hospice programs generally must limit their populations to individuals expected to be within six months of death who have elected to forego curative care and treatment. Few parents or physicians are willing to make such predictions or to forego curative care for children. As a result, this stipulation restricts the availability of hospice services to children, given the numerous therapeutic options that are often available, as well as the unpredictability of the length of survival of this population. Parents, physicians, and other health care providers move from treatment and curative therapy to palliative care much more hesitantly with children than adults. There are few hospice programs dedicated specifically to hospice care for children and most programs are unable to address the unique needs of children and their families. Palliative care for children requires an integrated interdisciplinary approach among the child, the family, and all providers of care and services that spans the spectrum of all the physical, emotional, psychosocial, and spiritual needs of children and families.

Children with life-threatening conditions (LTC) who are entitled to services from the Military Health System (MHS) - do not receive care in the comprehensive pediatric palliative care and


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hospice model called for by the Institute of Medicine, Medicaid, the Children’s Hospice International, and the National Quality Forum. This model is rapidly becoming the standard-of-care for dying children. Children with LTC include those who have irreversible progressive conditions in which treatment is exclusively palliative from diagnosis to death; conditions requiring long periods of intensive treatment aimed at prolonging and improving quality of life; conditions for which curative treatment is possible but may fail; and conditions with severe, non-progressive disability causing extreme vulnerability to health complications and death. The Institute of Medicine recommends “insurers should restructure hospice benefits for children to … eliminate eligibility restrictions related to life expectancy, substitute criteria based on diagnosis and severity of illness, and drop rules requiring children to forgo curative or life-prolonging care [and] reimburse bereavement services for parents and surviving siblings of children who die.” These key features of a pediatric palliative care and hospice program are not available to most children with life-threatening conditions in the MHS.

Children’s Hospice International-Program for All-inclusive Care for Children (CHI-PACC)

The mission of Children’s Hospice International (CHI) is as follows
- To create public awareness of the needs of children with life-threatening conditions and their families, and of what children’s hospice care can do to meet those needs
- To promote the establishment of CHI’s Program for All Inclusive Care for Children and Their Families (CHI-PACC), which provides an increased array of integrated medical, social, and spiritual services to children with life-threatening conditions and their families from the point of diagnosis to the provision of bereavement counseling for family members if cure is not obtained, on both national and international levels
- To include palliative care and hospice perspectives in all areas of pediatric care and education
- To include hospice children in existing and developing hospice and home care programs
- To create and maintain a sustaining resource base

Children’s Hospice International (CHI) created their Program for All-Inclusive Care for Children and Their Families (PACC) model, during a two-year period from 11/97-11/99. The CHI’s Demonstration Task Force who created the model was comprised of leaders from pediatrics, hospice and palliative care, home care, and related national organizations. The model promotes a philosophy that seeks to expand access to curative and palliative services beyond the scope of the traditional hospice benefit. Children with life-threatening illnesses and their families would have

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access to this approach to care from the time of diagnosis through cure or, if cure is not attained, through end-of-life care to include bereavement. This model of pediatric palliative care (PPC) is in accordance with the recommendations made by the 2003 Institute of Medicine report on PPC as well with the American Academy of Pediatrics paper from 2000 which also recommends that PPC commence at the time of diagnosis of a life-threatening condition. Furthermore, it follows the guidelines from the National Quality Forum (NQF) published in 2004, which provide an extensive outline for the delivery of palliative care.

The CHI PACC® model consists of four core standards, each of which contains 16 categories related to practice guidelines that are required to be in place in order for a program to be recognized as a CHI PACC® program. See Appendix 1: CHI PACC® Standards of Care and Practice Guidelines. The four core standards are the following:

- Comprehensive care delivered by an interdisciplinary team
- Simultaneous curative and palliative care
- Care from point of diagnosis with single entry into system
- Ample and flexible funding.

The CHI PACC® model stresses family-centered care and creation of an interdisciplinary team. The guidelines propose development of a broad range of services that provide for medical, nursing, psychological, and spiritual care for eligible patients and families. While hope for cure is important, the CHI PACC® model includes structured and adequate bereavement services in the event of the death of the child. Ethical considerations, volunteer services, plans for management and operations, and a plan for governance and administration comprise part of the guidelines as well.

CHI PACC® seeks to ensure that funding will follow the child/family into the most appropriate treatment setting. CHI has worked very closely with the Centers for Medicare and Medicaid (CMS) to promote that each state apply for a Medicaid waiver to cover CHI PACC® services. These waivers must be shown to be cost neutral or have cost savings for Medicaid prior to their implementation.

The CHI PACC® program is based on the concept of 1915(b) and 1915 (c) federal waivers. The Social Security Act authorizes multiple waiver and demonstration authorities to allow states flexibility in operating Medicaid programs. Within the parameters of broad Federal guidelines, states have the flexibility to develop Home and Community Based Service (HCBS) waiver programs designed to meet the specific needs of targeted populations, such as children with life-threatening conditions. Under the 1915 (b), states can implement managed care delivery systems, or otherwise limit individuals' choice of provider. The 1915 (c) allows states to waive traditional Medicaid provisions in order to allow long-term care services to be delivered in community settings. This program is the Medicaid alternative to providing comprehensive long-term services in institutional settings. For CHI PACC® programs, the cost of hospital or institutional care is compared to the cost of community care. In addition, key services such as care coordination and bereavement are incorporated in the programs as they are not traditionally
available under other Medicaid programs. Federal requirements for states choosing to implement an HCBS waiver program include:\footnote{12}

- Demonstrating that providing waiver services to a target population is no more costly than the cost of services these individuals would receive in an institution.
- Ensuring that measures will be taken to protect the health and welfare of consumers.
- Providing adequate and reasonable provider standards to meet the needs of the target population.
- Ensuring that services are provided in accordance with a plan of care.

This is a major issue when considering the feasibility of implementing a CHI PACC\textsuperscript{®} Program in the military system. Based on the nature of the military demographics, and the fact that the military system has national and international reach, there is no mechanism for the system to apply for a waiver as the system is beyond the boundaries of a particular state. In addition, the CHAMPUS authorization for military health care is determined by law and does not allow for deviation from or flexibility of the authorized benefit.

As of 2007, there have only been two waivers submitted to CMS that have come from CHI PACC\textsuperscript{®} Demonstration Projects. Florida Medicaid was approved for a 1915 (b) Managed Care Waiver in mid 2005. This waiver includes the comprehensive services as listed above with the exception of bereavement. It has 900 slots for eligible children. Colorado Medicaid was approved in January 2007 for a 1915 (c) Home and Community Based Waiver which covers all CHI PACC\textsuperscript{®} suggested services including bereavement and has slots for 200 eligible children. The New York CHI PACC\textsuperscript{®} Demonstration Project hopes to include the CHI PACC\textsuperscript{®} model as part of a larger 1115 Medicaid waiver. Finally, CHI is working closely with the state of California to help with submission of a 1915 (c) waiver by the end of 2007. The success in obtaining the waivers clearly signals that the CHI PACC\textsuperscript{®} model is becoming a standard of care with respect to pediatric palliative care. As more states move to approve Medicaid waivers based on the CHI PACC\textsuperscript{®} model of PPC, it would be anticipated that private insurance companies and other entities that provide health care, such as the Department of Defense, would also move to establish similar models of care, that would prove to be cost neutral or demonstrate cost savings once implemented.

**National Consensus Project (NCP) /National Quality Forum (NQF)\footnote{13}**

In December 2001, development of palliative care consensus guidelines was discussed during a national leadership conference coordinated by the Center to Advance Palliative Care. Under the direction of a 20-member steering committee, nearly 100 nationally recognized palliative care experts reviewed and contributed to the development of the guidelines. In addition, over 1000 organizations, representing significant national constituencies, were invited to review and endorse the guidelines. The Clinical Practice Guidelines, published in 2004, were designed to

\footnote{12} Centers for Medicare and Medicaid web site, \url{http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/}, last accessed May 1, 2007.
promote care of consistent and high quality and also to guide the development and structure of new and existing palliative care services.

The NCP agreed upon the following key elements of palliative care:
- Patient population – to include patients of all ages experiencing a debilitating chronic or life-threatening illness, condition, or injury
- Patient- and family-centered care
- Timing of palliative care – to ideally begin at the time of diagnosis through cure, or until death, and into the family’s bereavement period
- Comprehensive care – to alleviate physical, psychological, social, and spiritual distress
- Interdisciplinary team
- Attention to relief of suffering
- Communication skills
- Skill in care of the dying and the bereaved
- Continuity of care across settings – to include hospital, emergency department, nursing home, home care, assisted living facilities, outpatient, and nontraditional environments such as schools
- Equitable access – to include access to palliative care across all ages and patients populations, all diagnostic categories, all healthcare settings, and regardless of race, ethnicity, sexual preference, or ability to pay.

Eight different domains were subsequently identified by the NCP and provide the framework for the Clinical Practice Guidelines. They are as follows:
1. Structure and processes of care
2. Physical aspects of care
3. Psychological and psychiatric aspects of care
4. Social aspects of care
5. Spiritual, religious and existential aspects of care
6. Cultural aspects of care
7. Care of the imminently dying patient
8. Ethical and legal aspects of care.

**Institute of Medicine (IOM) Report on Pediatric Palliative Care**

In 2003, the IOM published its report, “When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families”. The working principles in this document regarding pediatric palliative, end-of-life, and bereavement care include appropriate family-centered care for children with life-threatening medical conditions and their families designed to fit each child’s physical, cognitive, emotional, and spiritual level of development from the time of diagnosis through death and bereavement, special responsibility on the part of professionals caring for these children to educate themselves and others about the identification, management,

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and discussion of the last phase of a child’s fatal medical problem, change at both the organizational and individual levels to provide consistently excellent palliative, end-of-life, and bereavement care for children and their families, and more and better research to increase understanding of clinical, cultural, organizational, and other practices or perspectives to improve palliative, end-of-life, and bereavement care for children and families.

**Comparison of CHI-PACC® and National Quality Forum (NQF)**

Both the CHI PACC® model of care and the Clinical Practice Guidelines as outlined in the NQF represent very comprehensive approaches to palliative care. Both approaches stress the need for an interdisciplinary team that can provide care in four domains – physical, psychological, social, and spiritual. Despite CHI PACC® focusing on only children with life-threatening illnesses, both models virtually discuss the same concepts with respect to an ideal palliative care model. Most importantly, both stress the need for palliative care to begin at the time of diagnosis of a life-threatening illness, a concept which is clearly only beginning to be practiced in health care today.

There are however some subtle differences between the two models. CHI PACC® explores the concept of a single point of entry into a comprehensive system of palliative care for children with life-threatening illnesses and their families. This concept would clearly ease the burden on primary caregivers and families in terms of having to contact each individual “domain” separately in order to arrive at a comprehensive care team.

The CHI PACC® model discusses the concept of funding which will follow the child and family throughout the health care system. This is clearly based on the premise that the CHI PACC® will ultimately be presented to a state Medicaid agency so that an appropriate waiver can be drafted to move this model forward. With respect to the MHS, this is not applicable. NQF does not discuss any funding issues per se. In addition, the CHI-PACC® model discusses governance and administration as related to a CHI-PACC® program; these issues are not addressed in the NQF Guidelines.

An important clinical difference between the two models is the emphasis in the NQF guidelines on care of the imminently dying patient. Specific and important end-of-life care issues are outlined in this domain. While ethical considerations are discussed in both models, common ethical concerns encountered in palliative care are listed specifically and in more detail in the NQF guidelines.

Because of its pediatric focus, the CHI-PACC® model includes a very important aspect of care under its category, continuity of care. This concept relates to transitioning a child/adolescent, who reaches adulthood, into the adult system of medical care, allowing for continuity of medical care to continue. This is an extremely important concept given that many children with life-threatening illnesses that were once fatal in childhood are now living into adulthood. Transitioning these patients to adult care providers ensures that they will receive the care they need by providers, who are knowledgeable about adult onset diseases and health care issues.
Curative therapies concurrent with palliative care is a hallmark of the CHI-PACC® model of care and is representative of the patient population enrolled in such a program. This concept is discussed in greater detail than in the NQF Guidelines.

Finally, both the NQF and CHI-PACC® approaches to palliative care stress the importance of a commitment to research that is aimed at quality improvement within the program. The CHI-PACC® model also emphasizes research activities that have scientific value or meeting reporting requirements.

Despite the subtle differences outlined above, both approaches to palliative care are solid and, for most part, interchangeable. They are both complete with respect to those services which should be in place in order to provide a complete program of palliative care. Even if all components are not in place, implementation of any aspect of this model would enhance the care, services and quality of life for these children and their families. The CHI PACC® Standards are specifically designed for children, but the NQF Guidelines are more comprehensive and were developed by a nationally recognized panel of experts. Together the CHI PACC Standards and NQF Guidelines establish the standard for how Pediatric Palliative Care (PPC) should be approached and implemented.

**Challenges of Integrating of the CHI PACC® Model of Care into the Military Health System (MHS)**

The MHS, while providing excellent medical care for patients and families, is often complex and difficult to navigate for health care providers, patients, and families. Services at each of the many military treatment facilities vary with respect to availability and access. Incorporating PPC into any institution necessitates a change in culture with respect to how care is provided and when it is provided. This challenge becomes even more pronounced when attempting to initiate pediatric-oriented services into facilities that primarily serve adults. New services may need to be established or existing services made more creative when initiating a PPC program. The discussion below explores the challenges of implementation of a CHI PACC® program into military treatment facilities, addressing each of the core standards.

**Challenge 1 – Development of Comprehensive Care, Interdisciplinary Team**

An interdisciplinary team with the ability to address the medical, nursing, psychosocial, and spiritual needs of a patient and family is key to a successful PPC program. Individuals must be identified who can assess the needs and resources appropriate to the provision of PPC in each military treatment facility. The individuals must have the explicit support of the commander and be willing to effect a change in the cultural thinking towards palliative care of the staff within the institution, particularly if PPC is going to be implemented at the time of diagnosis. Communication between parents of children with life-threatening conditions and their health care providers is a very sensitive area and is sometimes difficult. Therefore, it would be imperative that the individuals providing care have expertise in palliative care or the willingness to learn. The challenge is to ensure a commitment within the MHS and the specific military treatment
facility for providing PPC and to identify providers, knowledgeable in pediatric palliative care, who are will
ing to assume a leadership role in implementing these concepts.

A comprehensive, multidisciplinary approach to care is necessary in order to address all the needs of the patient and family. This is done through a multidisciplinary team of providers, often representing a spectrum of professional disciplines. The challenge is the identification of the appropriate individuals in a single military treatment facility, who are willing to work as a team to identify, access, and coordinate the needed services. Meeting this standard may be particularly challenging given the varied resources available and the current deployment cycles of health care providers.

Challenge 2 – Providing Curative and Palliative Care Simultaneously

Providing curative care along with palliative care services usually means changing the culture and philosophy of an institution. In many arenas, palliative care is seen as synonymous with hospice care rather than the supportive type of care it actually represents. The medical components of palliative care (pain and symptom management) are more readily available in the MHS through the direct and purchased care system if authorized as medically necessary care. Resources for social, emotional, and spiritual needs are more limited and access for counseling or treatment often requires a specific mental health diagnosis. The main challenge is integrating the concept of PPC within the institution through the education of providers, staff and families. An additional challenge is the provision of psychosocial services and spiritual support in all settings of care without the need for mental health labels and offered by providers who have specific expertise in caring for children with life-threatening conditions.

Challenge 3 – Provision of Care from Point of Diagnosis with Single Entry into System

This core principle encompasses the concept of availability of interdisciplinary services not only in the hospital setting but also through community services, home care, respite care, and traditional hospice. For the child, who continues to survive into adulthood, continuity of care to assist with the transition from pediatric to adult health care providers, is a critical factor. A care coordinator is critical to the development of a complete plan of care, to the identification of and access to the services necessary to implement the plan, and to the facilitation of continuity across all setting of care. Case management and care coordination become even more important with military reassignments and deployments. Transitions and the variability of resources and services from one region to another offer unique challenges to ensuring continuity of care. The challenge is the guarantee of a seamless coordination of services across all settings and throughout all transitions.

Research and program evaluation also fall under this core principle. Program evaluation is important in order to assess the quality of the processes and services and to measure patient and family satisfaction. The challenge is the development of the appropriate assessment tools for the program and the accomplishment of on-going evaluation and change.
Challenge 4 – Provision for Ample and Flexible Funding

The CHI PACC® model was designed around utilizing the concept of a Medicaid waiver program, which would allow a CHI PACC® program to exist in that state under the auspices of the state Medicaid services. The waiver then authorizes Medicaid funds to be available to provide a more flexible benefit to care for eligible patients and their families as long as cost savings can be demonstrated. Most military families do not meet eligibility requirements for disability programs under the Social Security and Supplemental Security Income programs. Therefore, enrolling these children into a Medicaid waiver following the CHI PACC® model of care is not feasible. The challenge is to provide the comprehensive services necessary for PPC within the bounds of the military benefit as established by Congress and to supplement the medical care with identification and access to resources and services within both the military and civilian communities. An additional challenge is to identify funding for those services not covered by the benefit.
METHODS

This project is designed as a feasibility study to explore the ability to provide PPC within the MHS. The goal is to make recommendations for a program of pediatric palliative care that would integrate palliative care interventions with therapeutic approaches to disease management from the time of diagnosis and provide a smooth transition to hospice care, when the child and family is ready to make that choice. The overall strategy is to understand and maximize the utilization of the current benefit and to coordinate the medical care with existing military and community resources and services tailored to support the child’s and family’s specified needs.

It is first necessary to identify the medical and non-medical care, resources and services that are currently available to families of children with life-threatening conditions, and to determine which of the required resources and services were not available, in order to focus on unmet needs. In order to gain knowledge of what is already available, what should be available, based on community standards and experience of providers and families within the MHS, and what might be proposed to meet unmet needs, the project team researched the following areas relevant to understanding the applicability of pediatric palliative care to the MHS:

- Assessment of needs as perceived by families and health care providers in the MHS
- Analysis of the benefit and the current status of service delivery as it relates to the goals and principles of PPC
- Determination of eligibility criteria and an estimate of the population among existing beneficiaries
- Availability and accessibility of resources through the MHS, TRICARE managed care support contract providers and services, and resources through the military and civilian community and other federal, state and local government agencies.
- Exploration of case management and care coordination principles as they apply to the implementation of PPC
- Documentation of formal and informal education curricula and strategies for the education for both providers and families
- Utilization of site visits to existing programs to understand current approaches to implementing PPC
- Application of the standards of effective quality management systems to PPC in a military setting

These data are used to ascertain whether it is feasible to provide the key aspects of a pediatric palliative care plan within the MHS, as outlined by the core CHI PACC® principles, namely identification of committed individuals to form an interdisciplinary team, development of a comprehensive plan of care, provision of curative and palliative care simultaneously, provision of care from point of diagnosis with single entry into the system, and provision for ample and flexible funding.
FINDINGS:
Needs Assessments – Methods and Results

The medical literature provides some insight about needs of children with life-threatening conditions and their families. The American Academy of Pediatrics has issues recommendations about palliative care for children based on the work of the Committee on Bioethics and the Committee on Hospital Care. An essay in the Journal of the American Medical Association called for improvements in palliative and hospice care for children. A few pediatric palliative care programs have described their approaches to care. These efforts report recommendations based on the clinical experience of healthcare providers.

Some studies and formal assessments of the needs of children with life-threatening conditions and their families have also been reported. In 2004, Children’s Hospice International provided a summary of the needs assessment efforts of CHI-PACC® programs. (See Appendix 2 CHI PACC® Needs Assessments for the DOD mCare Project). At that time, Utah and Kentucky had completed focus groups and interviews with parents of 40 and 23 children who had died of a life-threatening condition. Comments from the focus groups and interviews were summarized, but there was not a formal analysis of the data. Virginia and Florida had done limited needs assessments but no information was available about their methods or results. New York did a systematic survey of healthcare providers in that state and identified priorities for care and service from healthcare providers’ perspectives. The priorities were pain, decision making, dignity and respect, family-oriented care, spirituality, and psychosocial issues.

Other published research reports needs described by bereaved parents. This literature describes need for pain and symptom management for children with cancer, concerns about communication between healthcare providers and parents, difficulties with policies and procedures, needs of siblings and a need for bereavement care; parents’ perspectives on decision-

making and improving quality of life in the pediatric intensive care unit;\textsuperscript{23,24} and the importance of continuity of care.\textsuperscript{25} Two programs assessed needs more comprehensively from the perspectives of both healthcare providers and parents of bereaved children.\textsuperscript{26,27} Three other studies investigated particular aspects of pediatric palliative care: acceptance of support by parents of children with profound disabilities,\textsuperscript{28} spiritual care for hospitalized children and their families,\textsuperscript{29} and preparation for the end-of-life.\textsuperscript{30}

No reported studies have systematically and comprehensively investigated the needs of children with life-threatening conditions who receive care in the same large healthcare system, including the perspectives of a representative sample of both parents and healthcare providers, and no previous studies have investigated the needs of children with life-threatening conditions in military families. In addition, most of the needs assessments that have investigated parents’ perspectives on care needs have included primarily bereaved parents, with few parents of children living with life-threatening conditions. The study reported here addresses these gaps.

Researchers from the Uniformed Services University conducted a needs assessment of children with life-threatening conditions and their families who are MHS beneficiaries, using data gathered from parents and health care providers at 6 military medical centers (the National Naval Medical Center, Walter Reed Army Medical Center and Malcolm Grow Air Force Base in the National Capital Area; the Madigan Army Medical Center; the Naval Medical Center, San Diego; and the Medical Center at Wright Patterson Air Force Base). The inclusion of these sites provided representative information reflecting the military population, as the sites represent major medical centers of the Army, Navy and Air Force in diverse geographic locations.

At each of the sites, the following data collection strategies were employed to gather information about the needs of children and families, the services available to address those needs, and access and barriers to available services:

Focus groups and interviews with parents of children with life-threatening conditions (both newly diagnosed and advanced) and parents of children who have died in the previous two years from a life-threatening condition.

Focus groups and interviews with pediatricians, pediatric residents, family medicine physicians and residents, care coordinators, case managers, social workers and other health care providers that provide care for children with life-threatening conditions.

Informal observations and conversations with individuals in the medical centers, with field notes about available care and services and collection of brochures about available services.

Appendix 3 contains a schematic diagram of care for children with life-threatening conditions and their families. The diagram includes curative care, palliative care during all phases of disease, and a full array of support services from the time of diagnosis through the time of bereavement. This tentative model was adapted from Feudtner et al.\textsuperscript{31} and Hutton et al.\textsuperscript{32} and modified after initial discussions with parents to include support services at all points on the continuum of care. The modified model guided interviews and focus group discussions with families and health care providers in the case studies, as described below.

**Institutional Review Board Review and Approval**

The needs assessment protocol was reviewed and approved by the Institutional Review Boards (IRBs) at the following sites:

1. Uniformed Services University of the Health Sciences (USUHS)
2. Malcolm Grow Air Force Medical Center (MGMC)
3. Walter Reed Army Medical Center (WRAMC)
4. National Naval Medical Center (NNMC)
5. Keesler Air Force Base Medical Center (Note: This site was not available for the study after Hurricane Katrina)
6. Madigan Army Medical Center (AMC)
7. Naval Medical Center (NMC), San Diego
8. Wright Patterson Air Force Base Medical Center (AFMC)

In addition, the protocol was reviewed by the Health Services Research Review Board (HSRRB) at Ft. Detrick, which agreed to assign oversight of the protocol to the Uniformed Services University. See Appendix 4: Research Protocol

**Sampling strategy and research participants**

Parents and health care providers were invited to participate in interviews or focus groups using IRB-approved recruitment flyers and verbal invitations at the study sites. Participants were recruited and interviewed in the National Capital Area until the themes in their responses began

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to repeat, which indicated that the sample adequately represented the group in this geographic area. Subsequently, parents and health care providers were recruited and interviewed at Madigan AMC, NMC San Diego, and Wright Patterson AFMC. Although the same major themes were described in the focus groups and interviews at all the sites, differences within the themes were evident outside the National Capital Area. The Army, Navy and Air Force bases surrounding Madigan AMC, NMC San Diego, and Wright Patterson AFMC included actively deploying populations of military service members, and the support needs and stresses were different among these families and health care providers.

Criteria for parents to participate in the study included the following:
- Having a child with a life-threatening illness (as interpreted by the parent) or a child who had died from a life-threatening illness within the prior two years.
- Being available for a focus group, interview, survey and/or review of written materials for this study.

Criteria for health care providers to participate in the study included the following:
- Providing health care or care coordination for children with life-threatening illnesses and their families within the MHS (i.e., residents, staff physicians and other health care providers in pediatrics or family medicine).
- Being available for a focus group, interview or survey for this study.

In consultation with the study team for the Children’s Hospice project, the description of children with life-threatening conditions referenced by Himelstein et al. was chosen to define the group of children for the study. The children of parents who participated represented all four categories in the Himelstein description. Several parents who participated had experienced the death of a child. Families represented the Army, Navy, Air Force, and Marine Corps. Health care providers included staff pediatricians, pediatric residents, staff family medicine physicians, family medicine residents, social workers, case managers, care coordinators and nurses. Tables with demographic information about the research participants appear in Appendix 5. A summary table of participants appears below:

<table>
<thead>
<tr>
<th>Health Care Provider Participants</th>
<th>Parent Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Capital Area Total</td>
<td>31</td>
</tr>
<tr>
<td>USUHS</td>
<td>6</td>
</tr>
<tr>
<td>WRAMC</td>
<td>8</td>
</tr>
<tr>
<td>NNMC</td>
<td>6</td>
</tr>
<tr>
<td>MGMC</td>
<td>11</td>
</tr>
<tr>
<td>Madigan AMC</td>
<td>28</td>
</tr>
<tr>
<td>San Diego NMC</td>
<td>24</td>
</tr>
<tr>
<td>Wright Patterson AFMC</td>
<td>17</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>
Advisory group of parents in the National Capital Area

An advisory group of research collaborators was developed by contacting parents of children who have had, currently are ill with, or have died from a chronic life-threatening illness. This group of parents, initially invited to participate from a group previously assembled under another project, reviewed focus group and interview plans, provided information regarding adaptation of a quality of life survey for caregivers, and assisted with interpretation of data analysis. This group helped researchers develop an understanding of parents’ experiences and provided insight about whether themes that emerged during data analysis accurately reflected their experiences.  

Focus group and interview topic guides for the advisory group appear in Appendix 6. Four focus groups meetings with this advisory group were also taped, transcribed and included in the analysis.

Focus group and interview plans

The following surveys informed the development of questions and data collection strategies for focus groups and interviews, with guidance from the advisory group:

- The End-of-Life Survey developed by the Foundation for Accountability (FACCT) (integrated in questions for focus groups and interviews, with guidance from the advisory group of parents).
- The Quality of Life of Caregivers of Children with Special Health Care Needs survey developed by Dr. Randall and Dr. Hanson (integrated in questions for focus groups and interviews, with guidance from the advisory group of parents).
- The Medical Home Assessment Questionnaires and the Medical Home Index (family and provider versions), which are available from the American Academy of Pediatrics website.

In consultation with the advisory group, the researchers developed a set of interview and focus group questions for parents and a second set of interview and focus group questions for health care providers. These questions, along with the interview and focus group topic guides, provided a framework for one-to-one interviews and focus group discussions at all four study sites, and can be seen in Appendix 7.

Parent focus groups and interviews

Parent focus groups and interviews addressed the following broad topics: (1) how parents define the needs of children and families when a child has a life-threatening illness; (2) the experience of children and families with the MHS (direct care system and TRICARE) in meeting those needs.  

needs; (3) the experience of children and families in finding and using services in their communities (both military and civilian communities); (4) education and information necessary to enable them to find and access the health care and services that they need; and (5) the degree to which the children’s care has been coordinated and what the mechanisms of coordination have been. In order to allow unanticipated themes to emerge, questions were open-ended. Focus groups and interviews were audiotaped and transcribed. In order to make study participation accessible to as many parents as possible, researchers traveled to parents’ homes to conduct one-to-one interviews. In addition, researchers conducted interviews and focus groups with parents at the Uniformed Services University, Madigan AMC, San Diego NMC and Wright Patterson AFMC.

**Health care provider focus groups and interviews**

Health care provider interviews and focus groups were conducted to discuss three broad topics: (1) how residents, pediatricians, family medicine physicians, and other health care providers define the needs of the children with life-threatening conditions and their families for whom they provide care; (2) participants’ experiences with the MHS (direct care system and TRICARE) in meeting those needs; and (3) education and information necessary to help them provide comprehensive care in a Medical Home model for children with life-threatening illnesses and their families. Interns/residents and staff physicians participated in separate focus groups. Focus groups and interviews were audiotaped and transcribed. Health care providers were interviewed at the Uniformed Services University, Walter Reed AMC, the National Naval Medical Center, Madigan AMC, NMC San Diego and Wright Patterson AFMC.

**Data Analysis**

Interview and focus group audiotapes from all four sites were transcribed, analyzed using the constant comparative method of qualitative data analysis, and coded using HyperResearch™ software. Two researchers read most of the transcripts from two sites, developed preliminary themes, and agreed on a set of themes to use for coding. These two researchers then read and coded all transcripts from these two sites. A research assistant learned the coding scheme and entered all coded comments in the HyperResearch™ software, noting any disagreements in coding by the two primary researchers. All disagreements were discussed until agreement was reached.

The overall approach to data analysis is described by Pope and Ziebland and in volumes 5 of The Ethnographer’s Toolkit, *Analyzing and Interpreting Ethnographic Data*. The constant comparative method is described in *The Discovery of Grounded Theory* by Glaser and Strauss.

**Report of parent focus groups and interviews**
This report focuses on these four facets of the needs assessment from parents’ perspectives:

- Child and family needs as described by parents.
- Resources families use in the MHS and community.
- Resources needed but not accessible, available or adequate and the barriers families experience when trying to obtain these resources.
- Families’ needs for information and education regarding these needs, resources and gaps in services.

**Report of health care provider focus groups and interviews**
This report focuses on these four facets of the needs assessment from health care providers’ perspectives:

- How residents, pediatricians (both general pediatricians and subspecialists), family medicine physicians and other health care providers define the needs of the children and families for whom they provide care.
- Their experiences with the MHS (direct care and TRICARE benefit) and community services in meeting those needs.
- How residents, pediatricians, family medicine physicians and other health care providers describe gaps in needed care and services.
- Education necessary to help physicians and other health care providers provide care in a Medical Home model for children with life-threatening illnesses and their families.

**Results**
The researchers have completed initial reports for two study sites, the National Capital Area and Madigan AMC. Interviews and focus groups have also been completed and transcribed for Wright-Patterson AFMC and NMC San Diego. Data gathered at all 4 sites that describe experiences overseas and at small bases have also been analyzed. Results reported here represent an integrated set of themes that summarize findings across sites. Each report describes the needs of children and families, the resources used and the resources needed but not accessible, available or adequate, incorporating the perspectives of both families and health care providers.

The data have been organized according to the themes that emerged from the qualitative analysis. A separate gap analysis (see pages 72-103) has been completed based on the themes that resulted from the needs assessment. The gap analysis delineates gaps in services and support, with program and policy recommendations for the MHS to address these gaps. The themes also summarize relevant needs of families, physicians and other health care providers for education and information about care and services and how to access them.
THEME GROUP 1: SYSTEMS

1. Access to Care and Services

1a. Available resources

Children with life-threatening conditions in the MHS receive a wide array of health care, including pediatrics, subspecialty care, surgeries, treatment procedures, diagnostic procedures, medications, rehabilitation hospitals, hospitalizations, equipment, speech/occupational/physical/feeding/water therapy and nursing. They receive care in military treatment facilities, Children’s Hospitals, other major medical centers, emergency rooms, urgent care centers and outpatient settings. There is generally a low dollar cost to families for care covered by TRICARE if the children are enrolled in TRICARE Prime. Some families benefit from the catastrophic cap (an annual maximum for cost-shares and co-pays). Some parents have entered or remained in the military to obtain or retain health care coverage for their children. They may drive some distance to military treatment facility or civilian care facilities, or may be air-lifted or compassionately re-assigned to get the care their children need. Parents described care received while stationed at different bases in the United States and overseas. They described getting access to all needed physician visits, hospitalizations and related procedures, and medication, although they sometimes had to work around the barriers described below. They also described access to physical therapy, occupational therapy, speech therapy, and equipment, but with some limitations and delays also addressed in theme 1b-barriers. The ECHO program in TRICARE provides up to 40 hours per week of respite care for some children. Some military treatment facilities have well-developed special services, such as a Developmental Clinic, Cystic Fibrosis Clinic or Hematology/Oncology Service. Military physicians work hard to help families access health care, learn the TRICARE system, fax and re-fax forms, and give parents back-up phone numbers and pager numbers to improve access.

1b. Barriers to access in the MHS (TRICARE and Military Treatment Facilities)

Both parents and health care providers encounter barriers when trying to access care and services for children. Physicians spend a great deal of time completing paperwork, writing letters, and helping with appeals. Physicians may have somewhat less time for clinical care because of limited ancillary staff at military treatment facilities. Low reimbursement rates for care paid by TRICARE make it difficult to find providers in the civilian network. Sometimes it appears that the TRICARE contractor may try to shift costs to other payers (Medicaid, schools) and the other payers may in turn try to shift costs to TRICARE. Some areas have experienced many denials for physical therapy, occupational therapy, speech therapy, oral motor therapy, and equipment.

Other services that are hard to access include anesthesia for pediatric procedures (lack of providers at Military treatment facilities), social work, child life, intensivists, any
equipment (e.g. orthotics, wheelchairs) and help with travel expenses when children are referred to distant civilian facilities. At the military treatment facility, access is often difficult for families because of long waits, no day care for other children, or limited parking. Limitations related to staffing resources at military treatment facilities include the following: very limited child life and nutrition services, physicians who are too busy to focus on pediatric palliative care, deployment of physicians, no good system for continuity of physician care, no personnel to track children for follow-up, few general pediatricians available to follow medically complex children, few pediatric case managers, few social workers, an overload in follow-up clinics, the loss of a nurse advice line with a new TRICARE contract, limited acute pediatric appointments, and little physical therapy, occupational therapy and speech therapy at military treatment facilities.

When using military treatment facilities, barriers to care include needing repeated referrals, no same-day appointments, scheduling challenges, driving long distances to get to a large hospital, limited parking, not having a general pediatrician, long pharmacy lines, medications not in pharmacy formularies, no new prescriptions filled at the drive-through pharmacy, poor maintenance at the large military treatment facilities, inflexible front-desk staff and poor coordination between facilities. Whether at a military treatment facility or a civilian facility, civilian providers don’t understand military culture or regulations. When services are not available at a military treatment facility, parents encounter excessive “red tape” with TRICARE contractors. Again, they need repeated referrals, services are sometimes denied several times, there are months-long waits for equipment, getting authorizations requires repeat phone calls, the contractor does not return phone calls, rules and processes change with no communication, administrative staff are poorly informed and there are inconsistencies in what is approved. Retirees do not have ECHO coverage. Even when therapy, home nursing and equipment are authorized, parents cannot always find providers in the TRICARE network, or the service is far from their home, or home care is not available. There is little help navigating the system. The military treatment facilities seems understaffed and underfunded, especially to parents who have experienced care at Children’s Hospitals. Parents with a spouse deployed have no one to help them navigate the system, and little or no help caring for children. Parents with several children sometimes have a hard time getting them to all appointments.

1c. Other payers and community resources

Some families qualify for Social Security Income (SSI), Medicaid and Division of Developmental Disabilities/Developmental Disabilities Administration services on the basis of low income, but rules for eligibility determination vary by county and state. Medicaid is available to children with SSI, and qualification for SSI changes with moves between states, availability of base housing, military promotions and payment of child support. When a family does not qualify on the basis of income, there are income waiver programs that enable families to access Medicaid-provided services, but there are limited slots and long waiting lists. When families qualify, Medicaid may cover TRICARE co-
pays, diapers and related supplies, formula, personal care hours, respite care or home nursing. Sometimes families are later asked to repay costs of services provided if eligibility has changed. The TRICARE contractor may require a written denial from Medicaid before providing some services (e.g. physical therapy, occupational therapy, speech therapy), even for families with higher incomes.

Schools and early intervention programs also provide some therapy and equipment. Home nursing of any kind is extremely limited, even for occasional visits. Care coordinators may help families negotiate complicated applications for service and payment from community, state, and federal sources. Some families have purchased supplemental insurance, which covers co-payments and deductibles not paid by TRICARE. The Women, Infants, and Children WIC program covers formula up to a certain age for financially eligible families. Some families have experienced tension about who should pay for some services – schools call them health care and TRICARE calls them educational. In some cases service may be delayed or denied. No parents reported difficult with TRICARE paying for early intervention services. As with TRICARE, some services that are covered by Medicaid or a community program lack available providers at the rates paid. Community programs that provide some funds include county Developmental Disabilities Administration and private organizations (the ARC, United Cerebral Palsy, Easter Seals, Quantus Foundation, Muscular Dystrophy Association). When a child turns 18, he/she is eligible for Supplemental Social Security Income if he/she meets disability criteria. If the child will be dependent life-long, military members can apply for life-long TRICARE for that child. If a child dies, some expenses may be covered through the military (transportation of the body to a funeral home, burial in a government cemetery).

Services in communities include early intervention, schools, emergency care registries, limited visiting nurses, and community libraries for families with children with special health care needs, county social workers, 911 services, a care coordination center, and therapeutic horseback riding.

2. Care Coordination

2a. Needed care coordination

“During an already chaotic and stressful time, families are providing the large majority of the care coordination. It is exhausting and the process is exhausting.”

Children with life-threatening conditions need many health care and community resources, as do their families. Parents provide most of the care coordination to locate and utilize these resources, especially when services are not available on base. They need help coordinating information and records about their child’s medical history (especially when on leave and during moves; see theme 2c – transitions), help finding child care and respite care (especially when one parent is deployed and especially for children with
special needs), help negotiating systems, and help finding needed resources in the military and civilian communities. They need help negotiating TRICARE, Medicaid, SSI, the Exceptional Family Member Program (EFMP) and state services. In TRICARE, referrals and faxes get lost in the system. There are few care coordinators and case managers apparently fewer since the change in TRICARE contractors—and many of these children have been dropped from case management. Parents spend hours and hours on the phone; they get tired, frustrated, and overwhelmed and don’t have the time, energy or knowledge of resources necessary to find everything their children need. They need help with denials, appeals and authorizations, and need help coordinating large numbers of follow-up appointments even keeping track of dates for prescription renewals and new appointments. They don’t know the system and they don’t know the resources available until someone helps them.

Some care coordination is available and tremendously appreciated (see theme 2b—available care coordination), but much more is needed. More local care coordinators are needed and an MHS-wide network of care coordinators is needed to communicate across the MHS. Within a military treatment facility, families need coordination of several appointments in one day when care is complex and/or when they travel long distances to get care in a military treatment facility. Within TRICARE, they need someone to help them figure out TRICARE requirements, to keep track of the timing of needed re-authorizations, to negotiate requirements for services such as medical supplies and to communicate with TRICARE contractors who tell parents they will communicate only with physicians. Both parents and physicians need care coordinators who are knowledgeable about TRICARE and community resources.

Specific needs that are not well met include follow-up for complex patients with long-term needs, follow-up for consults that are not completed, facilitation of provider-to-provider communication, care coordination of community resources that go beyond medical care, assistance for physicians who don’t have time to do all needed care coordination, and coordination for families whose children require care in civilian hospitals. Neither physicians nor families know how to navigate the TRICARE system, and families sometimes struggle with resolving bills or become frustrated trying to navigate the system independently. Case management for TRICARE-covered care is more available than coordination of care across community resources.

2b. Available care coordination

Madigan AMC health care providers spoke highly of the Referral Coordination Center, which finds resources to fulfill referrals for TRICARE-authorized medical appointments either at the military treatment facility or in the civilian medical community. There are, in addition, a few mental health case managers with TRIWEST, but there are many fewer nurse case managers than there were under the previous contract. A care coordinator in the Developmental Clinic at Madigan AMC helps families order durable medical equipment; navigate TRICARE, SSI and of Developmental Disabilities services; find
respite care, therapies, and home nursing; coordinate end-of-life care; meet paperwork requirements; and arrange all needed care and services when families first arrive in the area. Physicians also provide care coordination, which requires a lot of time without generating Relative Value Units RVUs. There are also social workers in the Neonatal Intensive Care Unit (NICU) and inpatient units at the military treatment facility.

Care coordination is provided in the National Capital Area by pediatric nurse case managers at WRAMC who focus on equipment, home care, hospice care, moves from other locations and transition to other payers (each nurse case manager does about 1,400 case management interventions per year); clinical nurse specialists for hematology-oncology and for cystic fibrosis who coordinate equipment, home care, hospice care and with schools; a nurse discharge planner for the NICU at NNMC; case managers through HealthNet who focus on home care and equipment for medically complex children; family medicine physicians and pediatricians; and a nurse care coordinator in the pediatric clinic at Malcolm Grow AFMC. The referral management center at Malcolm Grow AFMC helps arrange appointments. TRICARE service centers help physicians and families figure out what TRICARE covers. Family support centers may help families find support and financial help in communities. Some limited care coordination may be available through Army Community Services (ACS). Exceptional Family Member Program (EFMP) offices in Europe provide some care coordination. Early intervention (birth to three) programs have service coordinators to help coordinate community resources. Available care coordinators help parents find care, make arrangements to get care and get care paid for. When parents describe available care coordinators and case managers, they always express appreciation and explain how they made it easier to get the care their children needed.

2c. Transitions

“On average for the special needs families when they relocate, it takes six to nine months before you get all your care providers, educators, and anyone that has to deal with that child, it takes six to nine months to get settled in.”

Transitions require additional care coordination in order to proceed smoothly. Care coordination is especially needed at the time of a transition from pediatric to adult care and services (during ages 18-21), from active duty service to retirement, from a military treatment facility to a Children’s Hospital or back again, from hospital care to home care or hospice care, when a family uses civilian health care with TRICARE (whether Prime or Standard), to coordinate care between military treatment facilities, at the time of a move between bases or a medical evacuation from overseas, at the time of a deployment or when TRICARE contractors or procedures change. Rules change, service delivery changes, new authorizations are needed and parents don’t know who to contact to find resources. Even if coordination, care and services were going smoothly, a move or other transition creates a huge need for care coordination.
3. Long-Term Care Needs of Survivors

3a. Needs and resources for cancer survivors

Cancer treatment can take several years. If a remission is achieved, there follows a period of watching for a relapse and wondering about options for further treatment if cancer recurs. If long-term remission is achieved, then questions arise about the late effects of chemotherapy or radiation. Parents feel a burden of responsibility to watch for relapse and late-effects and to help their children deal with long-term consequences of cancer therapy. A late-effects clinic has been established in the National Capital Area, but not all long-term survivors have been connected with it, and not all questions and issues have been addressed by this clinic or pediatricians. There remains a need to help parents maintain vigilance and answer questions that arise for cancer survivors over time. Children and families also have some needs for support and emotional healing after an experience with cancer.

3b. Long-term follow-up

Many children with life-threatening conditions live for many years with incredibly complex needs for care and support. They need good primary care, but they need much more than that. They need an extensive array of subspecialty care, equipment, supplies, and support. They need medical care and coordination and follow-up that goes far beyond what is required for well-child care and resolution of acute illnesses. They need care not only directed toward cure or improvement, but also focused on achieving a good quality of life. They need every bit as much care, coordination and support as children who are at the end of their lives. The need for care can go on for a very long time.

3c. Continuity

When parents and children live with complex conditions that require sophisticated understanding and complicated care, it is especially hard to change physicians due to a move of the family or a move or unavailability of the physician. Once a physician understands the child’s needs, it is hard to lose continuity of care with that physician. Parents worry about disruptions in communication and about physicians who may not have knowledge and experience with their child’s health condition. They will sometimes go to great lengths to maintain the continuity they need—for example, one parent voluntarily remaining in one geographic location while the other moves with the military. Dealing with lack of continuity exacts an additional emotional toll from parents. Some parents have been in one location with the same physicians for a long time; some have physicians who have given them phone numbers and pager numbers that make it possible for them to experience more continuity of care. Parents always appreciate this and feel more confident about their children’s care.
Physicians described two important aspects of continuity of care—seeing a care provider who understands the child’s and family’s needs over time, and having access to a physician via phone, cell phone or pager to ask questions about scary things that happen or care that needs attention. Health care providers acknowledged that continuity with a physician can be difficult to accomplish with limited appointments being available, but they are willing to help the family work around the system to accomplish continuity of care. The continuity clinics for residents can sometimes address this need, but often the residents are not available for continuity clinic when their patients come so there is some breakdown here. Sometimes relationships with pediatricians or family medicine physicians break down during long-term complex care as the subspecialists become the main source of continuity instead. If a child enters a formal hospice program, continuity may be disrupted again—although care providers from the hematology-oncology program do remain involved as a child approaches death. If a child gets better, they need to transition to a primary care physician for continuity. Continuity of care is sometimes harder in the MHS, where both families and physicians move and deploy. Still, planning and attention to the importance of continuity can make these transitions a bit easier.

4. Descriptions of a Medical Home

Few health care providers were familiar with the concept of a medical home. One did provide a succinct and accurate definition: “It’s the idea for patients to have one facility or group of doctors or medical clinic that is their medical home and they are not tied to one person but there is a set that manages their shot records and their chronic health needs. The place where things are coordinated. That’s their base.” A family medicine resident described the concept in detail and called it “the core of family medicine.”

A medical home in general pediatrics or family medicine is generally not available in the MHS. The hematology-oncology clinic provides many aspects of a medical home for children in treatment there, with hematology-oncology physicians also serving as primary care managers. Some but not all pediatricians, family medicine physicians and other health care providers are familiar with the medical home concept, but care in the military treatment facility is not organized to provide a medical home. Some aspects of a medical home are available in some places – case management at WRAMC, family physicians who coordinate some care and individual general pediatricians or pediatric subspecialists who make themselves available for continuity and coordination of care. There are pediatric resident continuity clinics, but it has been hard to establish continuity of care in these clinics. There are also family medicine resident continuity clinics, but the family medicine residents do not follow medically complex children.
5. Roles and Administration

5a. Administrative issues

Administrative problems and conundrums have slowed down the health care system and over-burdened physicians to the point where there is less time for adequate patient care because of unnecessary, redundant and in-the-end ineffective administrative responsibilities. Physicians have few secretaries or support staff, and without ancillary support there is less time for physicians to meet with patients and engage in providing actual health care. A large amount of bureaucratic “red tape” limits physicians’ productivity and effectiveness, as they must deal with greater amount of paperwork for small approvals, such as orthotics, physical therapy, speech therapy and home health care equipment. The time required to fill out the paperwork, fax letters, handle missing paperwork or jammed fax machines, and then re-write letters for specific terminology or to appeal a denial challenges physicians’ efficiency and results in a great deal of wasted time and fewer contact hours with patients.

Military treatment facilities are understaffed and under-resourced. Families have trouble scheduling appointments and are sometimes sent to the emergency room for non-emergency situations. The EFMP representatives are also overloaded; more staff would be needed to enable these staff to help families find information and support. It sometimes seems to families that physicians are doing tasks that could be done by staff in other positions, were staff available to fill these other roles. Inadequate maintenance of hospitals and clinics was also mentioned by parents as a concern. Lack of information about military regulations, policies and administrative procedures sometimes complicates care as well. For example, lack of clarity about procedures following the death of a child created additional heartache for one family.

5b. Family medicine excluded

Some family medicine physicians and residents are excluded from caring for children with life-threatening conditions, despite a willingness to coordinate these children’s care and remain their primary care manager. While they cannot provide subspecialty care, they could fill an important role in providing support to families and coordinating medical care and communication among a child’s physicians.

5c. Need coordination between military treatment facilities in the National Capital Area

While most services are available between the different military treatment facilities in the National Capital Area, it is difficult to coordinate and communicate between facilities when different specialties are at different sites.
5d. Definitions and eligibility for services: vocabulary

Some health care providers identified a fine distinction in the vocabulary of a life-threatening condition versus a life-threatening condition. For a general definition, health care providers described life-threatening conditions as a more immediate, intense threat on the child’s life where death could be expected within the next year, and described life-threatening conditions as a condition putting the child at risk for a long time period, with no specific time-line for death. This distinction may help physicians advocate for additional support for families when a child’s life is imminently threatened by illness.

5e. Issues with TRICARE rules, interpretations of benefit, and TRICARE Management Activity oversight

Apparent inconsistencies in interpretation of the TRICARE benefit lead to confusion and frustration for both parents and health care providers. For example, some parents have been told they cannot leave their houses when a nurse is providing respite care; others have been told they must sleep while the nurse is there; others have been able to leave their child in the care of the nurse and accomplish errands or health care appointments. Rules also change with little communication, creating not only confusion but also denials and delays in services. Some military treatment facility health care providers see a role for TRICARE Management Activity (TMA) in overseeing consistency of benefit interpretation across TRICARE contractors.

THEME GROUP 2: RELATIONSHIPS

6. Advocacy

Parents who participated in this study persist until they get the care their children need. They often have to fight to get what their children need in the health care system and in schools, and sometimes have to fight to get health care bills paid. They take them to doctors and emergency rooms until they find out what they need; they pursue medical care at military treatment facilities, civilian providers and in community organizations; and they find the physicians and care coordinators who will help them find and get what they need. Parents express gratitude for the health care providers who advocate for their children. Some parents also think about and try to influence care for children and families in general. These parents also go to great lengths and personal sacrifice to care for their children, meet their physical needs and improve their children’s quality of life as much as possible.

Many health care providers in the National Capital Area are equally determined, faithful advocates for individual children and families, finding and connecting families with needed services, contacting TRICARE or case managers directly, making phone calls and...
completing paperwork. They also recognize the important role that parents fill as advocates for their children, and they encourage and support them in this role.

7. Relationships and Communication with Health Care Providers

7a. Health care provider/family communication

Comments about communication between health care providers and families came from different types of health care providers: a hospice nurse, a neonatalogist, a pediatric hematologist/oncologist, a pediatric cardiologist, a NICU discharge planner, a family physician, a pediatric intensivist. They discussed many special circumstances in which sensitive, relationship-based communication is important to families. Families need different communication during different phases of care (diagnosis, treatment, end-of-life). A child’s mother and father may each need different communication. A family may be overwhelmed by a lot of information from many providers and need someone to help them sort it out. Conversations about end-of-life care and what dying is like should occur between parents and a physician with whom they have a relationship, before they get to the Pediatric Intensive Care Unit (PICU). In hospice care, families build close relationships for communication with those who visit their homes, but still want to hear from the physicians who cared for their children earlier, just to know they care. Children with long-term conditions like cystic fibrosis and their families need supportive communication to build motivation to take care of themselves when well. Overseas, communication may be hampered if a child is born or diagnosed in a host nation hospital and the physicians either do not speak English or do not talk to parents; a translator may be needed. Parents of children with special health care needs want relationships with pediatricians, and many pediatricians go out of their way to build these relationships and be accessible to families. Family physicians can also build these relationships with families and can sometimes convey families’ needs to other team members. Respect for families and their differing needs is paramount.

Parents expressed some angst about communication with physicians. They find themselves explaining their child’s conditions to physicians who do not know about unusual health conditions or their children’s individual problems - sometimes with the burden of knowing that their child’s life may depend on their communication of urgency and accurate information. They have learned to speak up loudly on behalf of their children. They educate new physicians about their child’s history, and sometimes grow weary of the emotional energy required to tell painful stories again and again. They have a deep need to have doctors listen to them and believe them. The time of diagnosis creates special communication challenges; several parents received confusing, contradictory and upsetting information in insensitive ways. Many parents expressed the need to build trust and good communication with physicians and a deep appreciation for the physicians with whom this had occurred. Once parents establish a relationship of trust with a physician they can contact with a need, it makes all the difference for them.
7b. Health care team communication

Families need to know that the health care team members are communicating among themselves about test results and treatment plans and that someone is communicating about these plans with the families. Health care team communication works well within a small team (like the hematology-oncology team or the cystic fibrosis team), and quite well between providers in the same military treatment facility. If available to a family, a primary care physician can coordinate this communication. Challenges to health care team communication arise when the team includes providers both in the military treatment facility and in the community. Most often, physicians at the military treatment facility do not receive information about test results or subspecialty consults for referrals to the civilian community. Often, the parent becomes the one who conveys information to a physician at the military treatment facility about test results, needed labs and subspecialists’ information, without anything in writing. Case managers, social workers and referring physicians help facilitate team communication, even between the military and civilian communities.

7c. Cultural issues

Parents discussed several aspects of culture than can affect communication between families and health care providers. One is the language spoken - do the health care provider and family speak the same language well, and if not are there some resources for helping them communicate well? Several families had experienced physicians with whom they could not communicate easily because of language differences. A second area comprises the culture of an individual family’s belief systems, values, religion, and priorities as they affect care for the child and communication with providers. Third, the military culture has an effect on communication, particularly when attitudes about rank and authority exert an influence. Finally, there is a culture of parents who have children with serious health care needs. These parents often become strong advocates for their children, and their advocacy is not always understood or interpreted by health care providers as a strength.

8. Decision Making

Parents find it very hard to make decisions for their child, and often have to do so in the face of great uncertainty about outcome, big risks, and huge implications for quality of life. They want to be included in decisions, but need the information necessary to make good decisions and don’t want to feel like they are all alone in making the decisions. Sometimes they have to make decisions between options that all have a likelihood of negative outcome.
THEME GROUP 3: FAMILY NEEDS

9. Social and Emotional Needs

9a. Families’ emotions and need for support

Physicians, care coordinators and social workers recognized the emotional needs of families in some detail. They described parents’ stress, grief, isolation, and difficulty coping. They noted needs for one-to-one counseling, support groups, respite care, help with appeals, and help funding community resources. They noticed needs for concrete support in the hospital – meals for breastfeeding mothers, a comfortable place to sleep, support for staying with a sick child. They described respite care as an opportunity for parents to spend time with their healthy children or attend medical appointments for themselves and other children. They also realized parents’ need for someone to listen to their stories – someone to listen without counseling, just listen and try to understand.

Parents of children with life-threatening conditions in an actively-deploying military community described social and emotional needs in three broad categories: dealing with the intense emotions evoked by their children’s suffering, coping with continuous and strenuous care demands, and living in settings with limited informal social support. They feel scared, worried, sad, anxious, weary, angry, isolated, discouraged, frustrated, upset, confused, and stressed. They sometimes have trouble communicating as spouses and experience stress on their marriages. They are often mentally and emotionally exhausted. Their children’s care demands are often exhausting also, requiring 24-hour daily care, heavy lifting, complex and repeated care procedures, and long-term care. They need help with care, time for their other children, time with their spouses, time to sleep, and a break from continuous care-giving. The military situation sometimes makes it hard to find informal social support. Families move near a major military medical center to get health care for their children, but this often leaves them far from family and friends. Deployments mean separations from spouses and no break at all for the parent or grandparent who cares for the child. Concrete social supports like temporary housing, accessible base housing, help with a child’s care, respite care, child care for healthy children during hospitalizations of the sick child and transportation to health care when their cars have been left overseas make a big difference when available, but are not always available.

9b. Children’s needs for emotional support

“We ought to have a vibrant Child Life program that interacts integrated with social work and case management and psychologists.”

Parents worry about their children’s social needs (a wig when they don’t have hair, participation in social activities), coping with procedures and medicines, pain and fears. They see the psychological stress of being different or losing abilities and worry about
how to talk about death and how to support living children after a child dies as they
grieve and need support. They worry about long-term anxiety in their children and how to
ameliorate it. They wonder how to provide as much of a normal life as possible, and often
struggle to do so. They do not want their sick children to be alone in the hospital, and
wish the hospital had a more comfortable and interesting environment for them. Many
parents have seen Child Life and social workers at Children’s Hospitals and wish for
these services at the military treatment facility. They see the needs of their healthy
children for time with their parents, care while a brother or sister is in the hospital and the
opportunity to participate in childhood activities. They also see a need for support groups
or other ways to help siblings cope with their brother or sister’s special needs. They worry
about their children witnessing or experiencing too much suffering. They see strength in
their children and are proud of them for helping one another, but they still worry that their
needs are compromised by the demands on a family of a condition that requires constant
care and creates continual uncertainty and stress. They see their children’s reactions to the
lack of understanding from healthy children and adults around them.

9c. Health care providers need support

Some health care providers mentioned their own reactions to caring for children with life-
threatening conditions and their families. Some wished for more time to build
relationships with these patients. A few health care providers mentioned that it is hard for
them to think about people dying, and they mentioned meeting among themselves to talk
about it. One mentioned an educational program about pediatric palliative care that was
educational and provided some support for her. Some health care providers go to
memorial services for children who die, and one mentioned a chaplain who had been
available for the staff when they were caring for an especially complicated baby and his
parents. Parents notice and comment upon the emotional responses of physicians and
nurses to their children, especially when their children die. They appreciate their
compassion and how they have emotional support as caregivers. They see and appreciate
the sacrifices these health care providers make in spending time with and caring for their
children.

9d. Available support, counseling, and other mental health resources

Health care providers know of some limited one-on-one counseling for adults or children
and parents. They know about Military OneSource, but think a website is inadequate.
They are very aware that parents need a break, during deployments but also just because
of the demands of caring for sick children. A care coordinator knows of community
resources and funding for respite care and helps parents find these resources.

Parents described EFMP support group meetings and social activities, respite care
through ECHO, Medicaid and the state Division of Developmental Disabilities, Muscular
Dystrophy association support groups, accessible base housing and equipment that made
a house functional for a child with disabilities. They described siblings who helped and
loved each other and family who lived in the area, flew in or moved to the area. They often had spouses who helped with care and support when they were not deployed, neighbors who helped care for children and friends who helped healthy siblings participate in activities. Formal and informal support was available from support groups for children with special needs, Special Olympics, talking with other parents, social workers and Child Life workers at Children’s Hospital and Madigan AMC, the county Zero-to-Three program and a social worker in the NICU. They also experienced support from health care providers at the hematology-oncology clinic and developmental clinic, counseling and marriage counseling through the Life Skills Center, the family support center and Air Force Aid Society. Some have obtained help in receiving TDY pay and getting belongings shipped from overseas. Other sources of support included the Footprints support group for parents of children with cancer, the Fisher House, friends from church and workshops for siblings. They found ways to support one another within their families, such as taking walks together, finding a way to take a family vacation, reading books about special needs, watching movies at home and enrolling healthy children in activities they enjoy. Some commanders made it possible for an active duty parent to take time off or return from the field to participate in critical care. The active duty parent found some support and a break from child care by going to work; sometimes the caretaking parent found a way to work part-time or go to school, thus also relieving the constant stress of caregiving. Parents also found joy in their children and strength in themselves, their families, and their network of friends as they met the challenges they faced with their children’s needs.

The pediatric hematology-oncology service provides a great deal of support for children with cancer and their families through a clinical nurse specialist, case managers, physicians, and a parent support group. This service sometimes goes to families’ homes and children’s schools to provide support; they routinely spend a great deal of time with a family when a child is dying. Many health care providers are personally supportive in their interactions with children and families and aware of the importance of sensitivity. Some find themselves in the role of informal counselor for families. Health care providers in general know of some child psychology and psychiatry services, chaplains, some pediatric social work and case management. The NICU also provides a social worker, a discharge planner and a support group with educational resources for parents, as well as extra support if a baby is going to die. They follow-up with parents of babies who have died. The NICU also knows of some military and community support resources (New Parent Support program, Navy/Marine Corps Relief), but sees them as “diminishing rapidly.” The NICU knows that 8 counseling sessions are available to parents through the TRICARE network but they do not know of parents who have used this benefit, although they have made referrals. The Cystic Fibrosis clinic has a full-time nurse who provides follow-up, support and information for both children and parents. She knows of websites for children and links them by email, which is a better source of support for children with cystic fibrosis because in-person support groups expose them to infections. Parents of children with cystic fibrosis are also linked by email. Hospice services are available, and they provide support and some respite for families. Family medicine physicians know of
behavioral health services available through Family Medicine clinics and Life Skills clinics in the Air Force. Short-term behavioral health services are available to help families figure out if they need more extensive care through the TRICARE network. Case managers point parents to support groups. There is limited Child Life in the hospital. Some health care providers know about the ECHO program through TRICARE; they are also familiar with family support centers, Army Community Services, family advocacy and social work, and some are aware of Military OneSource. There is a clinical nurse specialist through the EFMP program. In general, more support is available through special clinics/services (hematology-oncology service, Cystic Fibrosis clinic, NICU). There are general behavioral health services but they are not especially equipped for families with children with life-threatening conditions or children who die. An individual physician, nurse, social worker, or case manager can make a big difference for a particular family.

Families experienced a wide variety of informal social and emotional support, from family, friends, colleagues at work, neighbors and churches. Community and non-profit organizations provided respite care programs, funds for respite care, parent support groups, sibling support groups, education, and advice. Parents devised their own coping strategies – making scrapbooks, stopping at Starbucks, eating take-out food, buying another car when theirs was overseas. Doctors, nurses and social workers provided important emotional support in the context of providing care – listening, understanding, writing referrals, writing prescriptions for medications labeled properly for camp, holding a baby, and even crying with parents during especially difficult times. “Experienced parents” of children with special needs helped each other. Doctors, nurses, and social workers shared books and websites. Several families commented about support that was available because they were able to live in one location for a long time or return to an area where they had lived before. Formal support was occasionally available also – a social worker in a hospital, a counselor, medication to help parents cope or sleep, a Medicaid waiver program to pay for home nursing, emergency leave, compassionate re-assignments, pastors and chaplains. Flexibility in response to extenuating circumstances helped, too – a supportive commander, last-minute appointments, someone watching a child in the hallway so a parent could go to the bathroom or stay with a sick child for a procedure or welcoming young siblings in the hospital.

9e. Barriers to support and mental health resources

“They said, ‘You are on compassionate reassignment, you’re supposed to have your family help you.’ I said, ‘My family is in Nebraska.’ ‘Okay,’ they said, ‘friends or neighbors.’ I said, ‘I don’t know anyone. I just moved here.’ They said, ‘Don’t you have a neighbor?’ I said, ‘She works.’ I asked my case manager ‘So what are you doing tonight?’ She said ‘Oh, I have such and such to do.’ I go, ‘So you probably couldn’t come over and watch my son while I go to the store.’ She said, ‘Well, that’s not fair, I have obligations.’ I said, ‘So do other people.’”
“Well, we were supposed to have a compassionate reassignment after my husband lived in Germany for three and a half years and the compassionate reassignment was supposed to be to the West Coast. They sent us to Virginia. I just looked at this one guy and he said, ‘What made you think you were going to get the West Coast?’ I said, ‘It’s a compassionate reassignment. Everyone we know in the world is on the West Coast, but you are sending us to the furthest east that you can.’ And it didn’t make a bit of difference. No difference whatsoever.”

Many parents of children with life-threatening conditions do not have the energy to attend support groups or figure out how to negotiate the system of services. Health care providers do not always have enough time to listen or training to listen effectively or counsel informally. Referrals needed for formal counseling can be a barrier – resources in a primary care setting would be easier to access. Formal counseling and social work resources in the military treatment facilities are very limited – even more limited for children than adults. Some counseling is available through TRICARE, but low reimbursement rates make it hard to find providers. In addition, few available counselors have experience with issues regarding very sick children or children who die. Families also need care coordination to access counseling, respite care and the various community resources that could provide support. There is some care coordination but not enough. Finally, parents have been told not to leave the home when respite care is provided through the ECHO program limiting its effectiveness.

Barriers to respite care from parents’ perspectives include difficulty qualifying, difficulty finding providers if you do qualify and requirements for parents to stay with nurses who provide respite under ECHO. Distance from family and friends is another barrier. Many families were compassionately reassigned to a major military treatment facility to get medical care, but their families are on the opposite coast or overseas, and they left a familiar base to go to a place where they do not know neighbors or have a network of friends. Parents also have a hard time finding informal support because no one wants to talk about hurtful, sorrowful stories, and sometimes because their children have rare diseases and they cannot find other parents with similar experiences. Formal support services are hard to access because counselors are not effective for their needs, they worry about implications for their careers if they seek mental health support, and there are no pediatric social workers or child life workers available to them at the military treatment facility.

Other barriers to meeting families’ emotional and social needs in the National Capital Area include the following: limited staff in psychology, psychiatry (especially pediatric), behavioral health, social work and nursing; limited case management or care coordination; lack of providers knowledgeable about palliative care or dying children and the related needs of families; physicians and nurses not knowing about available community resources; limited funding for military community resources; and limited knowledge about how to access the system. Services are available but inadequate in scope
and amount. Recently, services have focused primarily on active duty service members and service members wounded in Iraq and Afghanistan, with less available for children and their families.

10. Financial Toll

When children need care not covered by the military treatment facility, care can quickly become expensive. In addition to co-pays and cost-shares, families need to pay travel costs, sometimes driving long distances to get their child’s care, and must pay for specialized child care and child care for other children during hospitalizations - especially if one parent is in Iraq. Families struggle with SSI and Medicaid income requirements, sometimes qualifying as E-4 or E-5 but losing benefits when the military service member is promoted. Diapers and formula, for example, are covered by Medicaid but not TRICARE and their costs can become a financial burden. Families sometimes also get thousands of dollars in bills inappropriately and spend a great deal of time and energy fighting them. Overall, though, most families are very grateful for access to military health care, and many remain in the military because they could not get health insurance for their child otherwise.

Items typically not covered by TRICARE or not adequately covered include special formulas, diapers, home nursing, respite care, some equipment, home ramps and other modifications, special clothing, special toys and expenses of moving to get care. Families also need to pay for child care for other children during treatment, funerals and other expenses. Even when care is covered by TRICARE, they may have prescription co-pays or co-pays and cost-shares for civilian health care. Medicaid helps but few families qualify, or they qualify only for a short time. Army Community Services and Relief Societies may offer a small grant or loan and supplemental insurance, which helps parents if they have it, helps too. Still, the financial toll can be substantial.

11. Search for Meaning/Spiritual Care

Both children and parents need spiritual care and a chance to talk about spiritual issues and questions about the meaning of what is happening to them. Sometimes they want to talk with a nurse or other health care provider about these things. A chaplain service is available at most military treatment facilities and can arrange for religious rites such as baptism. However, some chaplain services tend to offer more religious practice than support or counsel about the spiritual questions and need for care that arise when a child is very sick, and many families rely on their own pastors or religious leaders rather than hospital chaplains.

Parents of children with serious illnesses seek meaning for their children’s lives and their own lives. They may try to understand how God fits into the things that have happened to them and their children. Many turn to God or a religious community or leader for support, religious rituals and an understanding of what their lives mean. Sometimes they yearn for
something of themselves or their lives from the time before they had a sick child. They may see having to fight for the care and services their child needs as an injustice - the care should be available to them without a fight. Many parents move through this search and emerge with a desire to help someone else who has a child with serious health issues, to make life better for other children and families. These parents love their children and see all the special, wonderful things about them. They are grateful for the time they have with them and the things they learn from them.

THEME GROUP 4: PALLIATIVE CARE

12. Palliative Care

Parents focus on quality of life for their children. This may mean being with people who love them, finding a way for the child to communicate or walk, or supporting children’s participating in typical activities such as school. Quality of life may mean listening to voices, laughing and being at home. Helping a child be comfortable and controlling symptoms is very important. Palliative care may also mean making decisions together, honoring a child and family’s wishes or taking care with a child’s appearance.

Health care providers’ understanding of palliative care varied widely in the National Capital Area. Some see it as pain management while a child is dying, some as care that enables a child to live but with limitations rather than a full cure, some as interventions to increase comfort and quality of life while living, some as all of these. Several health care providers described a sharp line between curative care and palliative care, such that palliative care is only provided when all hope for cure or recovery has past. Others saw palliative care integrated with curative care - trying to help a child live but also trying to make them comfortable and enable them to enjoy life.

13. End-of-Life Care

Health care providers’ experience with end-of-life care varies widely, from none or nearly none to a great deal. Those with more experience emphasize the importance of beginning conversations with families about end-of-life care early, long before the last crisis, preferably in the context of a well-established relationship with a pediatrician. Families’ choices vary; their preparation and a chance to talk about the choices is very important. Some families want their child to remain the hospital to die. When this is a family’s choice, Military treatment facilities have the flexibility to create a supportive environment. Others want their child to be at home to die. In this instance, a transition to hospice care is usually possible. Military treatment facility physicians and nurses sometimes stay involved in a child’s care and a family’s support after the involvement of hospice services; some communication with physicians and nurses who have been
involved with a child’s care is very important to families. Hospice nurses are very attuned to pain management and handle this well, and some pediatric hospice workers are available.

Parents and children need information about what death will look like and an opportunity to talk about it before the last crisis. Parents don’t want their children to be alone. Parents and close family often want to be in the hospital together if a child dies there, and they may need a comfortable sleep chair in the last days. Parents need information and communication and an opportunity to make decisions together. Parents need some support after a child dies, and wish a physician would call afterwards to see how they are doing. They also need help with logistical details - a “death checklist” with information about what forms to fill out and what details need to be handled. The hospital can provide a supportive environment for a child and family at the time of death, and parents appreciate this immensely when it happens.

THEME GROUP 5: EDUCATION

14. Education for Health care Providers and Families

14a. Parents’ education needs

Parents described a need for a clear understanding of their child’s diagnosis, the treatment plan, associated symptoms, and possible outcomes. A need was clearly identified for education in how the child’s diagnosis would impact their development and future abilities. Parents also need practical education in how to care for their child in the home and handle necessary medications and equipment. Beyond their child’s specific medical needs, parents identified a need for education about available resources for their diagnosed child and also for the child’s siblings. There is a need for parent education in how to advocate for themselves and their children, and education in the appropriate points of contacts and how to reach them. The need for education about the MHS and the military health benefit, as well as local procedures and practical information about the hospital, was also identified. Education on the death process was a clear need, especially among parents who had lost children, and parents saw a need for education in what dying looks like, what the health care providers will do at the end-of-life, and what happens after death.

Health care providers also identified a need for parent education about end-of-life care and hospice, and saw a need for parents to understand the death process and feel prepared for the possibility or reality of a child’s death.
14b. Health care providers’ education needs

While the MHS provides excellent medical care to children with life-threatening conditions, there are a number of educational needs for health care providers caring for these children. Physicians and care coordinators need education and frequent updates on the policies, regulations, and programs both within the hospital administration and within TRICARE, possibly from a central, accessible information center, and should specifically receive education about military-specific programs for children with special health care needs, such as EFMP and ECHO. In order to feel comfortable and provide appropriate care, health care providers need exposure to caring for these children’s ongoing or chronic health care needs, even if the provider will only see these children in an occasional emergency situation. Individual providers may further need targeted education on how to address a pediatric patient’s specific medical need when the provider has limited experience in that area, such as a rare condition or a specific piece of equipment. All physicians, nurses, and care coordinators who provide care to these children need education about pediatric palliative care and pain management. End-of-life care is also a specific area in which health care providers need education, both in how to provide end-of-life care to pediatric patients and also how to guide parents of dying children through the death process and beyond with necessary paperwork and appropriate psychosocial support. Beyond caring for these children’s specific medical needs, health care providers need education in how to advocate for children and families and must be knowledgeable about available support services and resources for families. They also need training in counseling and communication skills, cultural sensitivity, and handling both their own and the families’ emotional reactions.

14c. Resources for education

Parents at Madigan AMC identified two specific educational resources. A booklet outlining the diagnosis, treatment plan, possible reactions, and contact information was given to parents at Children’s Hospital for them to take home, allowing parents to clearly understand each step of their child’s medical care. Another resource was found in classes paid for by TRICARE for parents to learn how to give medications at home and take care of their child’s basic health care needs without bringing them in to the clinic.

Parents in the National Capital Area identified several specific resources that have been helpful to them in caring for their children with special health care needs. The National Institutes of Health was mentioned for its exemplary care coordination and the support given to parents, and other institutions could benefit from contacting the National Institutes of Health to see how they handle this particular area of care. Compassionate Friends was another specific resource identified for its bereavement care, and could be a resource for institutions looking to provide better care for grieving families. Parents also found it helpful to receive information about the military health benefit and the MHS, such as the TRICARE benefits manual or the ECHO program, in a simple brochure format that they could take home with them and refer to in the future.
A number of existing sources of information and practical knowledge about pediatric palliative care were mentioned by health care providers in the National Capital Area. Existing mechanisms for health care provider education in the MHS include TRI Service required Continuing Education through computer modules, home visits and required residency education. Palliative care curricula and pain management education already exist within the medical education field, and these resources can be accessed and adapted for use at specific institutions. Home visits are another valuable resource for information and knowledge, allowing a health care provider the opportunity to learn about chronic, complex care in a different, often more intimate environment than in-clinic appointments. Finally, the internet is a helpful resource with a wealth of information not only for health care providers but for parents raising a child with special health care needs as well.

**THEME GROUP 6: MILITARY**

**15. Military Issues**

For most families, unique military administrative issues are a major determinant in the experience of air evacuation or transfer to a higher level of medical care. For most, the experience of moving and settling into a new location, beyond being traumatic because of the child’s condition, is also confusing, lengthy, costly, and disrupts their ability to attend to their child. Administrative issues such as the type of orders, the type of leave, whether the sponsor is reassigned to a valid military role, availability of appropriate housing and unexpected changes in pay (often to the detriment of the service member) make a bad situation even more difficult to negotiate. Disruption of the support system they had previously established contributes to their sense of powerlessness. The situation is worse for families coming from overseas to stateside Military treatment facilities, leaving behind their car, their housing uncleared, and having to establish temporary living arrangements near the military treatment facility without a car, without the location housing allowance, without furniture, without friends and with an overwhelming need to understand their child’s medical condition, learn to trust their child’s new doctors and keep their family together.

The support or antipathy of command strongly influences the transition experiences of the families as does finding or not finding someone with knowledge and ability to apply suitable regulations. Most families did not find EFMP efficient or effective, leaving the family to coordinate many issues which could have been addressed by others on the installation.

Stress of frequent and lengthy deployments, both of the active duty member and the primary care physician for the child, adds another difficulty for families wherein the uncertainty associated with their child’s medical condition is exacerbated by the absence of trusted advisors and helpmates. Yet, many families emphasize their commitment to
the military community and culture, and to the service of their county. They wish that their commitment and willingness to sacrifice was matched by a commitment on the part of the command to make their difficult transitions easier.
FINDINGS:
Analysis of CHAMPUS/TRICARE Coverage of Medically Necessary Services for Children with Life-Threatening Conditions

The CHAMPUS/TRICARE benefit provided to beneficiaries in the MHS (MHS) was analyzed for the availability and accessibility of services pertaining to care for children with life-threatening conditions (LTC) that are found in a comprehensive pediatric palliative care and hospice program. The actual health care benefits likely to be used by a military family and child with a life-threatening illness were analyzed with specific citation, description, definitions and comments. (See Appendix 8: Military Health System Analysis Report - Care for Children with Life-Threatening Conditions, for the complete report on analysis of the benefit.) Medical services needed to serve children with life-threatening conditions and their families may include: medical care, occupational, physical, and speech therapy, respite care, home health care, custodial care, homemaker services, skilled nursing facility care, prescription drugs, dental care, counseling services including pre-bereavement and bereavement care, care coordination/case management, hospice program, expressive therapies (music, art, play), durable equipment, durable medical equipment, structural alterations to dwelling, and transportation by other than an ambulance.

Most of these services are provided to all TRICARE beneficiaries under the Basic Program or to family members of active duty service members under the Extended Care Health Option (ECHO) Program. Some of these services are not available under CHAMPUS/TRICARE to any beneficiary. (See Appendix 9: Benefits Available in TRICARE/CHAMPUS for Children with Life-threatening Illnesses and Their Families.)

CHAMPUS/TRICARE authorizes extended home health care only to children who meet a high threshold of disability and who are dependents of active duty service members. The patient’s condition must qualify under one of the following eligibility criteria: mental retardation, serious physical disability, extraordinary physical or psychological condition, an infant/toddler with serious disability, or multiple disabilities. ECHO includes Extended Home Health Care (EHHC) that provides benefits to patients who (i) meet ECHO definitions and (ii) who are homebound and (iii) require medically necessary skills services that exceed the Basic Program home health care benefit, or (iv) require frequent interventions such that respite care is necessary. Pre-authorized ECHO/EHHC services are paid for by the government up to $2,500 per month. There is a monthly co-pay based on the rank of the sponsor. Family members receiving services under ECHO cannot receive those same services under the Basic Program, but can receive other services under the Basic Program such as prescription drugs, acute care visits, and medically necessary hospital care. (See Appendix 10 for the Table 12 on Summary of Benefits.)

There is currently no unique TRICARE-defined hospice benefit; rather, the Basic Program authorizes hospice care in a Medicare-approved hospice and only when the patient meets Medicare/Medicaid criteria: life expectancy of less than six months and the requirement to forgo disease-directed care. Most available Medicare-approved hospices care for adults, and skilled

41 Title 32, CHAMPUS, Part 199.5 - TRICARE Extended Care Health Option
care for children may not be available. The services, however, are interdisciplinary, delivered under a plan of care, include intermittent skilled nursing as well as health aide and homemaker services, and provide counseling to beneficiary and family members prior to the death. Bereavement counseling is explicitly excluded as a benefit under CHAMPUS/TRICARE unless the beneficiary meets a definition of mental illness.  

There are significant gaps in services available to children with LTC and their families when the Institute of Medicine (IOM) recommendations for pediatric palliative care and hospice services are addressed. Specifically, the IOM recommended that “Public and private insurers should restructure hospice benefits for children to … eliminate eligibility restrictions related to life expectancy, substitute criteria based on diagnosis and severity of illness, and drop rules requiring children to forgo curative or life-prolonging care (possibly in a case management framework.)”  

The IOM report also calls on policy to “reimburse bereavement services for parents and surviving siblings of children who die.” These benefits are unavailable through the CHAMPUS/TRICARE benefit structure. The IOM also recommends specific clinical care practices. Many of these aspects of clinical care could be delivered (and in some cases are being delivered) to children with LTC if staff are available with the time, training, and experience in the MHS direct care system. (See Appendix 11: MHS Benefits and Services vs Institute of Medicine Recommendations).

The Children’s Hospice International has developed a model Program for All Inclusive Care for Children and Their Families (CHI-PACC) in coordination with the Centers for Medicare and Medicaid Services. (See Appendix 12 “Services/Resources Proposed in Developing CHI PACC® Models” Chart.) The CHI-PACC Implementation Manual provides a list of core domains for clinical care. The clinical care called for is only available in the MHS where adequately trained and experienced staff is available and have time to provide it, either through the direct care system or through purchased care. If using purchased care, the following care and service listed in the CHI-PACC core domains cannot be reimbursed: care coordination, respite care, flexible home health care, and bereavement counseling. Furthermore, bereavement counseling, an important component of clinical care, is explicitly excluded as a benefit under TRICARE/CHAMPUS. Appendix 13 discusses the availability of this clinical care through the MHS.

The National Consensus Project represents a consortium of five leading national organizations (American Academy of Hospice and Palliative Care, Center to Advance Palliative Care, Hospice and Palliative Care Nurses Association, Last Acts Partnership, and National Hospice and Palliative Care Organization). The project has compiled a list of preferred practices for palliative and hospice services that are based on evidence of effectiveness, unique to palliative/hospice

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42 Title 32, CHAMPUS, Part 199.4.- Basic Program
care, and endorsed by these professional organizations. For these reasons, these preferred practices are used as one standard against which to measure the benefits and services available through CHAMPUS/TRICARE for children with LTC. Appendix 14 lists the preferred practices versus the benefits and services available to children in the MHS.

In summary, the key services necessary for the provision of a comprehensive program of pediatric palliative care, that are not available through the current CHAMPUS/TRICARE benefit are care coordination, respite care, flexible home health care, and bereavement counseling, and the ability to provide supportive care to enhance quality-of-life concurrently with life-sustaining treatment.

FINDINGS:
Eligibility Criteria and Estimate of the Population

Eligibility Criteria
Methods are available for estimating the numbers of children with “special health care needs” in a population. See Appendices 15, 16, and 17. However, methods to estimate the actual numbers of children with life-threatening conditions (LTC), which is a subset of the children with special health care needs, are not readily applicable to the military population, and they depend upon the definition of LTC and the purpose for which the estimate is being done. As a first step in estimating the numbers of these children in the military population, several methods of defining cases of children with life-threatening conditions (LTC) were examined:

1. **Based on pre-determined ICD-9 codes.** The ICD-9 codes proposed by Kentucky for eligibility criteria for a Medicaid waiver for a pediatric palliative care program (See Appendix 17, pages 5-6.) were reviewed and the frequency of specific ICD-9 codes appearing in records of children who were seriously ill and enrolled in a case management program in the MHS were tabulated. Redundant coding for the same patient and omissions in coding made this method of defining children unreliable for data retrieval for the purpose of program design or planning.

2. **Based on cost data.** States preparing an application for a CHI PACC® Medicaid waiver calculated costs retrospectively for hospice and related services paid for children through Medicaid and then constructed a way of identifying children that they could serve through flexibility of the benefit, while maintaining cost neutrality. In the DoD, the difficulty of accounting for direct care costs makes this method unreliable. Further, conceptually, cost does not always correlate with the presence of an LTC, at least in the years prior to the year of death.

3. **Based on characteristics of the condition.** The descriptive definition of “Conditions Appropriate for Pediatric Palliative Care,” proposed by ACT 47 in 1997 and endorsed by Himelstein, Hilden and Boldt in 2004 is widely used by pediatric hospice policy makers. This is the definition of eligibility chosen for this study for medically necessary pediatric hospice services in the MHS. The Himelstein definitions of conditions requiring pediatric hospice care describe a different death trajectory for each condition. In *When Children Die* the Institute of Medicine describes different patterns of death in children, ranging from death

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moments after birth or trauma, to death months and years after a diagnosis of a LTC with the utilization of health care services varying from intermittent to continual. A case definition based on characteristics of conditions, therefore, has implications for program design, service delivery, and costs, making this a reasonable definition to use for retrieval of data on numbers of children and costs. ICD-9 codes were selected for each condition that would account for the majority of children with that condition and would be a reasonable search string in the DoD medical databases.

The following table (Table 1), based on the work of ACT and Himelstein, displays the case definition and the ICD-9 codes used for the searches:

**Table 1**

**Life-Threatening Conditions in Children**

<table>
<thead>
<tr>
<th>Designation for data retrieval purposes</th>
<th>Description of condition</th>
<th>Examples chosen for this study</th>
<th>ICD-9 codes used to search databases</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>“incurable”</strong></td>
<td>Progressive conditions in which treatment is exclusively palliative from diagnosis.</td>
<td>Spinal muscular atrophy, trisomy 13 or 18, severe infantile asphyxia</td>
<td>335.0, 335.10, 335.11, 758.1, 758.2, 758.3, 768.0, 768.1, 768.2, 768.5</td>
</tr>
<tr>
<td><strong>“manageable”</strong></td>
<td>Conditions requiring long periods of intensive treatment aimed at prolonging life and improving quality of life.</td>
<td>Cystic fibrosis, muscular dystrophy</td>
<td>277.00, 277.01, 359.1</td>
</tr>
<tr>
<td><strong>“curable”</strong></td>
<td>Conditions for which curative treatment is possible but may fail.</td>
<td>Any childhood malignancy</td>
<td>191.x, 204.xx, 206.xx, 207.xx, 208.xx, 209.xx</td>
</tr>
<tr>
<td><strong>“co-morbid”</strong></td>
<td>Conditions with severe, non-progressive disability causing extreme vulnerability to health complications.</td>
<td>Spastic quadriplegia, presence of a tracheostomy with any diagnosis</td>
<td>343.2, V55.0</td>
</tr>
</tbody>
</table>

Data was extracted from the MHS Master Data Repository (MDR), which contains administrative inpatient and outpatient records for all care provided in MHS facilities as well as care from other sources that has been purchased by the MHS. For each inpatient discharge or outpatient encounter, data were available on diagnoses, procedures, associated costs or payments, and certain patient demographics. The data existed in separate tables (e.g., home health), by both year and record source, but could be linked by a unique patient identifier field across all tables. These data were organized and combined in the following manner. All inpatient and outpatient records for dependent children aged 24 years and below, from FY2001-FY2002 were selected.
from the original tables. Any child with LTC alive during the study period was included (See Table 2). Deaths were identified based on either a Defense Eligibility and Enrollment Record System (DEERS) record date of death within the two years in question or by a clinical record having a disposition code indicating death. Records for both years were combined, creating a non-duplicate record analytic data set for the period under examination.

Using the previously published Himelstein “criteria” (see Table 1 above for definitions), four trajectories of patients were selected from the data: those with incurable disease, manageable disease, curable disease, or those with significant co-morbidities that are often associated with hospitalization and death. For each of the four categories, total encounters, inpatient admissions, use of special services, and associated costs were tabulated separately by whether or not the patient had died during the two-year period of observation. All data manipulations and tabulations were conducted using SAS software version 9.1.

**Estimation of the Population**

Two methods were used to determine the approximate number of children who meet the case definition for LTC who are entitled to care in the MHS.

- *An estimate* was made based on the numbers of children registered in DEERS, and to which prevalence rates from the United Kingdom (UK) were applied. A search of the literature found three reports of prevalence data for children with LTC that were judged appropriate for use in this study because: (1) the definition of LTC closely matched that chosen for this study; (2) data came from actual counts of UK records, and (3) the purpose of the studies was for program planning. The prevalence rates found are:
Applying these prevalence rates to the numbers of children in DEERS provides an estimate of from 2,642 to 4,543 children entitled to care in the MHS during FY01/02 who have a life-threatening condition.

The numbers of children in DEERS by age groupings were tabulated as follows (Table 3):

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Numbers of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 yr</td>
<td>180,909</td>
</tr>
<tr>
<td>1-4 yrs</td>
<td>471,752</td>
</tr>
<tr>
<td>5-9 yrs</td>
<td>584,566</td>
</tr>
<tr>
<td>10-14 yrs</td>
<td>591,247</td>
</tr>
<tr>
<td>15-19 yrs</td>
<td>579,227</td>
</tr>
<tr>
<td>20-24 yrs</td>
<td>233,853</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>2,641,554</strong></td>
</tr>
</tbody>
</table>

56 Children who died or disenrolled from the MHS during FY01 are included using their FY01 age, all others using their FY02 age. These departures add roughly 250,000 children to the total vs a midpoint population count.
57 Includes only children still entitled to care, i.e., those with permanent dependency and those in college. Does not include spouses in this age range.
2. A count based on the ICD-9 codes chosen for each case-definition was executed through the data searches of the Defense Enrollment Eligibility Reporting System (DEERS), Standard Inpatient Data Record (SIDR) inpatient direct care, Standard Ambulatory Data Record (SADR) outpatient direct care, Health Care Services Record (HCSR) institutional purchased care and Health Care Service Record Non-institutional (HCSRN) non-institutional purchased care) records described above. The counts determined for FY 2001 through FY 2002 were as follows (Table 4):

**Table 4**

*Counts of Children with Life-Threatening Conditions in the MHS (by Condition), FY01/02*

<table>
<thead>
<tr>
<th>Designation for this condition</th>
<th>Description of condition</th>
<th>Numbers of children alive at any point in study period FY 01/02</th>
</tr>
</thead>
<tbody>
<tr>
<td>“incurable”</td>
<td>Progressive decline to death</td>
<td>728</td>
</tr>
<tr>
<td>“manageable”</td>
<td>Intermittent periods of intensive care to maintain quality of life</td>
<td>964</td>
</tr>
<tr>
<td>“curable”</td>
<td>Curative treatment is possible but may fail</td>
<td>1239</td>
</tr>
<tr>
<td>“co-morbid”</td>
<td>Severe, non-progressive with extreme vulnerability</td>
<td>940</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>3,871</strong></td>
</tr>
</tbody>
</table>

The prevalence rates of children with LTC found in the literature (0.1%, 0.12%, 0.17%) and that determined in this study (0.15%) are in close agreement and provide reassurance of the accuracy of the methodology of counting cases of LTC used for this population (See Table 5).

**Table 5**

*Percent of Children with Life-Threatening Conditions in Four Studies*

![Graph showing prevalence rates of children with LTC in four studies]
Estimation of Number of Deaths
To estimate the numbers of deaths per year among the population of children with LTC, data provided in the Institute of Medicine, *When Children Die*, pp 41-71; 2003 “Deaths: Leading Causes for 1999” from NCHS, 2001 data58 was extrapolated and these rates were applied to the total number of children in DEERS in each age category. (See Table 6)

**Table 6**
Estimated Number of Children Dying From Complex Chronic Conditions in the MHS per Year

<table>
<thead>
<tr>
<th></th>
<th>&lt;1 yr old</th>
<th>1-4 yrs old</th>
<th>5-9 yrs old</th>
<th>10-14 yrs old</th>
<th>15-19 yrs old</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rate (all causes/yr)</td>
<td>705.6/100,000</td>
<td>34.7/100,000</td>
<td>17.4/100,000</td>
<td>21.1/100,000</td>
<td>69.8/100,000</td>
<td></td>
</tr>
<tr>
<td>Rate not related to trauma or immediate newborn</td>
<td>19.6/100,000</td>
<td>9.2/100,000</td>
<td>11.5/100,000</td>
<td>17.1/100,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td># of children in MHS</td>
<td>181,000</td>
<td>472,000</td>
<td>585,000</td>
<td>591,000</td>
<td>579,000</td>
<td>2,408,000</td>
</tr>
<tr>
<td>Estimated # children dying from complex chronic conditions/year</td>
<td>319</td>
<td>93</td>
<td>54</td>
<td>68</td>
<td>99</td>
<td>633</td>
</tr>
</tbody>
</table>

This estimate of 633 child deaths/yr from LTC was compared to a count obtained by a search for deaths in the FY01/02 DEERS and M2 database using the ICD-9 codes in each case definition. The number of deaths counted was 105. These data were a known undercount because the M2 database did not record children who died at home and missed some children who died in civilian institutions. Furthermore, the rate estimated from the NCHS data may include children whose diagnosis and method of counting LTC does not fit the definition used in here. While 105 children is likely an undercount, an estimate of 633 from NCHS “Causes of Death” data may be an over estimate. A thorough search of the literature found one study deriving a death rate from LTC as 10% of those with children identified with LTC59. Using this rate would estimate 400 deaths per year among DoD children with LTC. Hence, this number was chosen as the most reasonable estimate. (See Table 7)

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Table 7
Summary of Numbers of Children Suggested for Program Planning

<table>
<thead>
<tr>
<th>Non-trauma deaths per year in MHS</th>
<th>Estimate based on 2,408,000 children ages 0-19 yrs and prevalence of life-threatening illness of 0.17% (Britain) with 10% deaths/year</th>
<th>Based on projections from IOM death rate tables</th>
<th>Counted from study period FY01/02 in DEERS and M2 databases</th>
<th>Numbers Suggested for Program Planning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numbers of children with life-threatening conditions in MHS</td>
<td>400</td>
<td>633</td>
<td>105</td>
<td>400</td>
</tr>
<tr>
<td></td>
<td>4093</td>
<td>N/A</td>
<td>3976</td>
<td>4000</td>
</tr>
</tbody>
</table>
FINDINGS:
Resources for Children

Background
Children with life threatening conditions and their families can benefit from a variety of resources to support their numerous and complex needs. Although third party health care funders provide services and funding to meet many of the medical needs, often other non-medical supports are overlooked or left to the family to locate, fund and access.

As described by the American Academy of Pediatrics, children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. Children with life-threatening conditions would be included as having special health care needs. These resources and services that support children and families in these extraordinary situations and are beyond the typical need and are often provided by organizations other than those funding health care services. These services may include such services as family support, family counseling and education, care coordination and respite care. Other related services can be early intervention, special education, transportation, and social services. In some situations, using naturally existing community supports can reduce or offset costs of care to traditional health care systems while supporting the family beyond the immediate and obvious medical service needs.

A component of the Children’s Hospice project is to evaluate community resources that may be available to children of military families in the National Capital Area (NCA) with a focus on children with life threatening conditions. See Appendix 18: Resources for Children for full analysis. As part of this evaluation, community based resources are examined to identify types of existing community-based services, as well as their availability from several perspectives including location and accessibility. The primary purpose for this evaluation is to identify opportunities for supportive services that exist outside of the scope of the military health care system that may be unknown to or underutilized by families who could benefit from such support and promote the concept of palliative care. This aspect of the study is designed to answer the following questions:

- What types of supports are available to children with life threatening conditions and their families?
- Where is information about community resources located?
- What is the process for accessing community resource information?
- What are some of the barriers for families in identifying and finding resource information?
- What strategies can be incorporated in a new model design to optimize access to information about community resources?

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60 A New Definition of Children With Special Health Care Needs PEDIATRICS Vol. 102 No. 1 July 1998, pp. 137-139, http://pediatrics.aappublications.org/cgi/content/full/102/1/137
**Method**
The method of resource review includes a broad literature review; development of a resource assessment tool and identification and analysis of federal, state, and local programs and resources. Military specific resources were also reviewed in light of the needs of children with life-threatening conditions. The literature review is conducted through a health science library, local public libraries, a military site library, the Internet as well as journals, resource directories, local newspapers, brochures, local health department literature and information provided at community based events.

In addition to this literature review, a resource assessment tool is developed and designed to serve as a template for collecting resource information in any community or geographic area. See Appendix 19: Resource Assessment Tool. The purpose of the resource assessment tool is to ensure that data elements collected about resources are useful and captured through an organized method. Specific resources and their attributes are collected and entered into a database using the resource assessment tool. The resources collected are compared to the types of resources children with life-threatening conditions could benefit from. They are further characterized as federal, state, local or military specific.

As part of the methodology of studying resources for children, the process for accessing resources has been dissected and is depicted as a data flow diagram. The purpose of this diagram is to identify possible areas of vulnerability that may preclude completion of the process to the point of service delivery. The basic tasks identified are: identification of a resource need by family, professional or other non-professional; research for possible option for desired resource; application to obtain resource; identification of a service provider; locating a funding source; delivery of the service; and reimbursement for the cost of the service or resource. See Appendix 20: Process for Accessing Resources; Data Flow Diagram.

**Findings**
The MHS is rich in resources to support families and troops and does so in a number of ways. Military HOMEFRONT is a website designed to provide reliable quality of life information to help troops and their families, leaders and service providers. A feature of the Military HOMEFRONT website is the electronic discussion forum that serves as a mechanism for parents to utilize the experience and wisdom of others to assist in problem solving issues that arise when caring for a child with extraordinary needs. Specialized Training of Military Parents (STOMP) is yet another example offering an electronic discussion forum for parents of children with special needs. Although some of the information may be personal opinion or experience, encouraging parents to ask “how to” questions and network using the website may assist other families by identifying some strategies and techniques to assist in solving resource related problems. It appears that the electronic discussion forum is currently underutilized and optimizing awareness or knowledge of this resource could improve usage and assist more families.
In addition to information provided on the web site, the military system provides access to Military OneSource. Military OneSource is an employee assistance program for active service members and their families. This program has the capacity to provide targeted resource information provided by a master’s prepared individual called a Consultant Specialist. Additionally, Military OneSource houses and distributes publications upon request that support the distribution of resource information for the military system. See Appendix 21: Military OneSource Report. The Exceptional Family Member Program (EFMP) exists across all branches of the military and its purpose is to identify family members with special medical needs and/or educational needs and considers those needs in the personnel assignment process. In some branches of the service the program also provides a family support function.

External to the military specific resources discussed above and based on an extensive review of potential resources for children with life-threatening conditions, there appears to be numerous possible sources of support available to military families that could supplant the many needs of these families. Many of these resources are either nationally based, government related and therefore are available in all or many areas of the country, or otherwise commonly available in most communities. Hence, the information gleaned from this study can be generalized to communities other than the NCA. Appendix 22: The Resource Profile Chart depicts a variety of resources that exist and further identifies areas of the system that parents, professionals and others could pursue to access such resources. The Resource Profile Chart can serve as a reference for developing PPC programs and providers who are seeking sources for resources to support children and their families.

The exercise of locating information about resources can be time consuming and frustrating. Using the Internet to locate information requires some level of skill to conduct an effective search. Too often, queries for these resources yields an overwhelming and an unmanageable volume of results that is not effective in finding specific useful information. In some situations, information can be outdated, incomplete or lack credibility. Keeping in mind the many burdens on families while caring for an ill child, time consuming research to find resources is incompatible and often is not pursued effectively by the family to get the support that they desire.

It is important to note that most organizations and programs that house resources for families have specific factors and guidelines that determine a child’s and family’s eligibility for the specific service. Often there are varying criteria that must be met to determine eligibility and application processes that end abruptly or are delayed due to incomplete paperwork exercises. Some services have costs associated that may or may not be affordable to families. See Appendix 23: Resource Overview Analysis.

Locating basic information regarding a resource is typically the first step toward accessing that resource. However, the information may not be useful unless it yields actual delivery of the needed service. Much of the problem seems to lie in the barriers to accessing services rather than in their lack of availability. Types of barriers include limits set by specific diagnostic or financial eligibility criteria, geographic limitations, lack of knowledge or skills with the pediatric population, prohibitive costs, waiting lists or enrollment caps or poor quality of providers.
Results of this work have led to the following considerations specific to accessing resources for children with life-threatening conditions in the military system:

Education
- Educate families and providers regarding the types of resources that exist and where they may be located.
- Educate families of children with life threatening conditions to utilize existing military services such as Military OneSource and Military HOMEFRONT.
- Educate Military OneSource staff on the variety of specific resources that exist for families who have children with life threatening conditions to enhance dissemination of information to families who are seeking community support.
- Encourage and educate on family networking through such chat forums as Military HOMEFRONT and Specialized Training of Military Parents (STOMP). This type of networking provides families with experience and information on strategies to problem solve system barriers. A parent may get information to assist them in navigating systems and accessing services to support their children’s needs.

Coordination and Facilitation
- Consider care coordination as a means to assist families in accessing existing resources both in the military and private sectors.
- Develop linkages for families with Military OneSource to optimize an information and referral role they are currently contracted to deliver to active military personnel.
- Encourage the collaboration of existing community programs that provide various types of coordination such as public libraries, Infant and Toddler Programs, school programs, Military OneSource, etc. that already exist within the military or civilian world.

System Design
- Design information systems to support the dissemination and access to resource information focused on supporting children with life threatening conditions. See Appendix 24: Web Based Resource Database Note.
- Incorporate quality indicators and metrics to measure usage and access to all possible resources that support families. By optimizing the use of resources within the military system, such as TRICARE and Military One Source, and supplementing these with resources that families can access outside of the military system, a full spectrum of services appears to be available to support families. This type of quality review may assist the developing model to better identify potential areas for process improvement, especially related to the process for accessing the resource, and help to address some of the areas of vulnerability.
FINDINGS:
Care Coordination

Care coordination is emerging as a major focus of this project and is consistently identified as a key service for pediatric palliative care. Often, the term care coordination is used synonymously with case management and/or care management. There are various definitions for these terms and these definitions share some important commonalities.

The case management industry often uses the definition from the Case Management Society of America. Case management is defined as “a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual’s health needs through communication and available resources to promote quality cost effective outcomes.” The American Academy of Pediatrics uses the term care coordination and defines it as a process that facilitates the linkage of children and their families with appropriate services and resources in a coordinated effort to achieve good health. The Maternal Child Health Bureau defines care coordination services for children with special health care needs as “those services that promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families.”

TMA refers to this service as case management and typically includes activities such as disease management, benefits management and utilization review, while care coordination occurs when an individualized plan of care is implemented by a variety of service providers. Care coordination is often the preferred term used in context of family centeredness as parents play such an integral role in the management of their child's care. Therefore, for the purposes of the Children’s Hospice Project, case management will be presented within a conceptual framework best described as child and family centered and the term care coordination seems to better describe this service for children with life threatening conditions. Although the verbiage used to define case management and care coordination differ, the concept and process remains consistent.

Care coordination activities may offer benefits to families and to providers. Some specific activities that care coordination can provide in relationship to accessing resources may include but are not limited to the following:

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61 The Case Management Society of America is an international, non-profit organization founded in 1990 dedicated to the support and development of the profession of case management and is a recognized industry resource for the provision of case management practices. [http://www.cmsa.org/Portals/0/PDF/MemberOnly/StandardsOfPractice.pdf](http://www.cmsa.org/Portals/0/PDF/MemberOnly/StandardsOfPractice.pdf), Last accessed January 5, 2007.


• Assess the individual needs of the child and family
• Develop an individualized plan of care for the child incorporating the multidisciplinary team
• Understand the range of available community resources and public benefits
• Identify, locate and monitor community resources to assist the child and family
• Facilitate access to health and other services that support the needs of the child and family
• Optimize resources that are available to the child, while avoiding duplicative or unnecessary services and costs
• Facilitate effective communication between families and providers
• Assist the family to become more effective advocates for their child's needs

"Care coordination is a central, ongoing component of an effective system of care for children and youth with special health care needs and their families". 66 This same concept is widely accepted by the American Academy of Pediatrics (AAP) based on their support of the medical home concept. As defined by the AAP, a medical home is an approach to comprehensive primary care that is accessible, continuous, comprehensive, and family centered, coordinated, compassionate, and culturally effective. The AAP Committee on Children with Disabilities recently concluded that care coordination is an integral component to the efficient management of the multiple complex issues related to caring for children with special health care needs to result in optimal outcomes for children and their families. In addition, based on the needs of children across multiple health and human service systems, care coordination is a process that links children and families to services and resources.

Although the medical home concept promotes coordinated care for children with complex health care needs, it is often not provided by the pediatrician based on lack of time and staff. 67 When care coordination is provided by professionals for children with medically complex needs, it is commonly accomplished by nurses and social workers; however primary care physicians, physical and occupational therapists or other professionals can lead or participate in the coordination process.

Care coordination is not a profession in itself, but an area of practice within one’s profession. There are no specific educational requirements to be a care coordinator, but certification in the specialty is possible. In some settings, experienced parents sometimes fill the role. This practice varies greatly depending on the program and needs of the population for which care coordination is being implemented.

Some barriers to providing effective care coordination for professionals are lack of knowledge and information about either the condition, community resources or coordination process, as well as the extra time and effort needed to provide such services, lack of adequate reimbursement for care coordination and the existence of multiple care coordinators.

66 Care Coordination: Definition and Principles, Massachusetts Consortium for Children with Special Health Care Needs prepared by the Care Coordination Work Group, Oct 2005.
There are pockets and degrees of care coordination being delivered within the current military system that could be optimized to support children with life-threatening conditions but do not specifically target the population. For example, individualized care coordination is available to children who are eligible for Extended Health care Option (ECHO) benefits and is provided by many pediatric hematology-oncology clinics, and may be provided through the direct care system by a pediatric clinic-based nurse or the social worker. However, the direct care system resources are often not robust enough to meet the need of every child with a life-threatening condition or their family. Training is needed for most care coordinators in understanding the needs of this unique population, in coordination of palliative care, and in approaching end-of-life issues.

Care coordination is a service commonly found in state level programs and waivers and is often present in those state and federal programs serving children with special health care needs. For example, care coordination is a component service provided with early intervention programs, and developmental disability programs as well as the community based waivers for children. Care coordination is also identified by Children's Hospice International as a key component of the CHI PACC® model.

Although care coordination practice standards include the processes of assessment, planning, implementation, evaluation and advocacy, there are some existing community resources that provide elements of these process steps. For example, Military OneSource has “coordinators” on staff whose focus is described as disability issues. The scope of involvement with the family is information and referral regarding resource supports. This is similar to the role of a public librarian in the general community setting. In many situations, library staff are skilled at searching for information about resources in the local community, however are not equipped to deal with the more specific needs of a child with a life-threatening condition.

Care coordination can be an effective strategy to promote appropriate access to quality care that is safe, timely, and cost effective by maximizing the use of available resources. See Appendix 25: Military Health System Analysis Report - Care for Children with Life-Threatening Conditions pages 33-35 for the TMA cost analysis report. Considering the limited availability and constraints of care coordination within the current system, children with life-threatening conditions who have such complex care needs could benefit from such a service to support palliative care. However, obtaining care coordination through TRICARE depends on the effectiveness and criteria established for case screening. Children with life-threatening conditions are at risk to be overlooked in this process.

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FINDINGS: Education

Background
Education is consistently identified as a key component to support the growth and development of programs for palliative care. It transcends all levels of a program and is a need for the child and family as well as the providers of care. In addition, other community entities that interface with a child, who has a life-threatening condition, could benefit from some targeted training when they are working with these families. The development of a pediatric palliative care program within military treatment facilities requires that providers have a clear understanding and working knowledge of the medical, nursing, psychosocial, and spiritual aspects of PPC. Because the concept of pediatrics in palliative care is relatively new when compared to the adult model of palliative care, there are limited educational resources available at the present time that focus solely on children.

Perspectives for Education of Providers
The information obtained from the site visits to pediatric palliative care programs suggested a variety of approaches for educating the providers in PPC within an institution. One option was to provide formal training, using one of the standard curricula, for a daylong conference or in individual training modules. Hospitals chose to either sponsor training hospital-wide, using formal educators in specific curricula, or to send some of their providers to attend training to become palliative care educators for the rest of the staff. The Children’s Mercy Hospital used a more generalized approach by providing education initiatives and care-oriented updates in palliative care at departmental meetings and grand rounds, targeting a wide scope of professional disciplines, to include physicians, nurses, social workers and child life workers. An individualized physician education initiative, offered at Children’s Mercy and Seattle Children’s Hospitals, allowed residents to spend a month’s rotation with the palliative care team for a direct, hands on experience. Denver Children’s Butterfly Program developed an Outreach Program to educate hospice programs and providers in their geographic referral area.

Much of the education of both staff and families at the sites visited was informal. Bedside teaching, family care conferences, and discussions with providers oriented to specific patients and families offered numerous opportunities to promote the principles of palliative care, while simultaneously providing treatment. Some hospitals established informal networks of interested providers and families, who met periodically for educational sessions or informal discussions on pediatric palliative care topics, such as the “Good Grief at Noon” sessions at The Denver Children’s Hospital.

The Harriet Lane Children’s Center (HLCC) at The Johns Hopkins University Hospital chose to use education only as their formal PPC program. The PPC initiative at the HLCC was not oriented towards direct patient care. The main focus of the program was to provide education and support for the staff, both inpatient and outpatient. At its inception, the decision was made to work first with staff by helping them acquire skills which would then enable the staff to provide PPC effectively. When consulted, members of the HLCC Palliative Care Program facilitated patient care conferences with the care providers with a focus on how to integrate palliative care
into their care plans. The palliative care education team was also dedicated to providing emotional support to the primary care team and helped the providers reconnect with the “meaning” of what they were doing. The education program team began with small, incremental changes in the thinking and orientation of providers, targeting the staff of those departments that expressed the most “angst” regarding issues related to dying children. (See Appendix 26 for individual reports on site visits and Appendix 27 for Site Summary Report.)

**Perspectives on Education for Families**

Families, who have a child with a life-threatening condition, need to be aware of the resources available to them in order for them to be more informed of the child’s disease process, to be able to navigate the intricacies of the health care system, and to derive emotional support during the course of their child’s illness and beyond the end-of-life. During visits to the various programs providing PPC, it became clear that much of the education for families on issues related to their child’s illness or on how a more holistic approach could meet the family’s needs was done on an informal basis through bedside conversations or family care conferences. The NQF identifies the following palliative care areas for education of the child or adolescent and family:

- Disease process/diagnosis
- Treatment alternatives/options
- Goals/plan of care, pain management
- Symptom management, psychological effects
- Medications
- End stages and the dying process
- Advance directives
- Legal issues
- Bereavement counseling
- Spiritual counseling
- Respite options
- Resources

**Palliative Care: Education for Providers**

The education curricula which are currently available that could be beneficial to the implementation of PPC include:

- The Initiative for Pediatric Palliative Care (IPPC)
- End-Of-Life Nursing Consortium (ELNEC)
- Education on Palliative and End-of-Life Care (EPEC)
- The National Palliative and Hospice Care Organization’s (NHPCO) Children’s Project on Palliative/Hospice Services (ChiPPs)
- The Program in Palliative Care Education and Practice sponsored by the Center for Palliative Care/Harvard Medical School.

(See Appendix 28: Education Curricula on Pediatric Palliative Care)

There are also a variety of PPC conferences held throughout the country that might be helpful to providers as well as families. Both the CHI PACC® model and the NQF National Consensus
Project provide an in depth summary of what constitutes state of the art palliative care and should be used as a template when deciding on educational curricula. (See Background pages 5-10.)

IPPC is one of the most extensive curricula in pediatric palliative care. The curriculum is both an educational and quality improvement effort, aimed at enhancing family-centered care for children living with life-threatening conditions. It consists of five separate modules, which are available on the Internet free of charge. Each module has a number of related activities. The curriculum addresses the knowledge, attitudes, and skills that health care providers need in order to better care for children and their families. The five modules are:

- Engaging with Children and Families
- Relieving Pain and Other Symptoms
- Analyzing Ethical Challenges in Pediatric End-of-Life Care Decision Making
- Responding to Suffering and Bereavement
- Improving Communication and Strengthening Relationships.

The target audience for this curriculum is any member of the PPC team (physicians, nurses, social workers, chaplains). IPPC also offers regional retreats throughout the year. Specific dates can be found on the IPPC website.

ELNEC is a national educational initiative to improve end-of-life care in the U.S. Its curriculum provides end-of-life training for undergraduate and graduate nursing faculty. The ELNEC Pediatric Palliative Care course has been adapted from ELNEC Core Curriculum and will be offered twice in 2007. Information about pediatric trainers in each state is available on the website.

NHPCO’s Children’s Project on Palliative/Hospice Services seeks to make the best-known practices in the field of PPC more widely available to care providers via newsletters, information about conferences related to PPC, and materials for PPC providers available for purchase.

The EPEC project is more adult-oriented in its approach, but does offer a solid curriculum in palliative and end-of-life care. The project offers individuals the opportunity to participate in a “Become A EPEC Trainer” conference which is a two day conference discussing the principles of palliative care and effective teaching approaches for dissemination. Once completed, a “trainer” may then use EPEC materials available for purchase to lead future EPEC training sessions locally. The target audience for this curriculum is physicians.

The Harvard Medical School Center for Palliative Care is currently offering an intensive two session course for medical and nursing educators who wish to become experts in the clinical practice and teaching of comprehensive, interdisciplinary palliative care. This program allows individuals to gain expertise in leading and managing improvements in palliative care education and practice at their own institutions. The course is delivered in two sections. The first part consists of seven days of intensive learning on all aspects of palliative care followed by a six-month interim where participants work on an individual project and contribute to weekly discussions of problematic cases presented by other participants through e-mail exchanges. The
second part is a second seven-day block that includes continued experiential learning and leadership. The target audience for this course includes physicians and nurses.

Finally, incorporation of a specific PPC curriculum into residency training programs is essential in order to ensure that future generations of pediatric providers in the military are comfortable with providing solid pediatric palliative and end-of-life care to their patients and families. This training is required by the residency accreditation boards and is often lacking at both the residency and medical school levels.

**Palliative Care: Education for Families**

Providers play a major role in offering information on palliative and end-of-life care to the families of children with life-threatening conditions. Part of the formal training on PCC is dedicated to inform providers about how to relate to families at the level of the families’ understanding and knowledge. When speaking to families or presenting educational materials to families, the information must be age appropriate, culturally relevant, delivered in a language best understood by the family, and in the manner in which the family learns best. Modules on joint decision-making and breaking bad news in the IPPC curriculum, for example, focus on these skills.

There are informal sources of education available to families on PPC. The NHPCO website offers a section on educational resources for parents including Tips for Parents, Children’s Neuroblastoma Cancer Foundation, and Parents Speak Out on End-of-Life Decisions for a Child. There is also a specific link entitled Children and Family Support which provides additional information on organizations that can assist parents with children with life-threatening conditions. “A Lion in the House” is a recently released film dealing with pediatric palliative and end-of-life care. The website, as part of its community engagement campaign, provides an extensive overview on pediatric palliative, end-of-life, and bereavement care written for parents. The American Academy of Pediatrics provides a list of brochures, articles, publications and support groups on palliative care for families and caregivers which is located on The National Center of Medical Home Initiatives for Children with Special Needs website.

**Family Needs: Education for Providers and Families**

It is critical that providers of PCC understand that their main role is a supportive one to children and their families. Providers must understand how to conduct a comprehensive assessment of the patient's and family’s needs and assist with finding and accessing the services. In addition to the medical care required, the provider is obligated to understand and find support for the psychosocial, emotional, and spiritual well-being of the family. The provider, therefore, needs training in how to develop a comprehensive plan of care with the family, how to provide those supports to the family, as well as how to resource those needs and services that go beyond the medical care. In reviewing the curricula that are available to train PPC providers, the IPPC modules on family centered care, ethics, suffering and bereavement, and communication offer a solid framework for delivering the psychosocial and emotional support.
The provider should enlist the assistance of any local spiritual leaders that the family has identified so that spiritual care for the patient and family can continue once the patient is discharged to the home. Individuals providing spiritual care must also be trained in and comfortable with helping patients, particularly children, with existential issues such as the meaning of life. Chaplains interested in providing PPC can participate in an IPPC regional retreat or familiarize themselves with the IPPC modules. Currently the Pediatric Chaplains’ Network is developing a standardized curriculum on pediatric palliative care. Further information is available on their website www.pediatricchaplains.org

Knowledge of what information may be available to both families and providers through military resources, such as the Exceptional Family Member Program, Military OneSource, and MilitaryHOMEFRONT, can assist in families in locating financial counseling and relief agencies and in getting emotional support outside of traditional mental health services. In turn, staff of such entities as Military OneSource, need education on the variety of specific resources that exist for families, who have children with life threatening conditions, to enhance dissemination of helpful and accurate information.

Families should be encouraged and educated on how to network through such chat forums as MilitaryHOMEFRONT and Specialized Training of Military Parents (STOMP). This type of networking provides families with experience and information on strategies to problem solve system barriers. A parent may get information to assist them in navigating systems and accessing services to support their children’s needs.

**Systems and Administrative Needs: Education for Providers and Families**

Access to services authorized in the MHS benefits can be complex and difficult to navigate for both families and providers. When providers don’t understand what is available through the benefit and how to access services through the purchased care part of the system, they are unable to assist families in accessing their needed resources. Families often find themselves in the role of prime advocate for their child and attempting to navigate the complex health care system themselves without sufficient knowledge or guidance. Both providers and families must fully understand what is authorized through the benefit and how to access those services. Case managers and care coordinators need to become exceptionally knowledgeable.

Establishing measurable goals and assessing patient and family satisfaction are key components of any program in order to ensure that processes are working. This is a way to “educate” the administrative components of a program on how to improve the provision of care. IPPC has quality improvement tools available to institutions. The first is Recommended Domains, Goals, and Sample Quality Indicators (for family centered palliative care) and the second is the Pediatric Palliative Care Institutional Self-Assessment Tool. This tool allows organizations to assess their status on issues related to family-centered palliative care for children with life-threatening illnesses and serves as a means for further discussion and planning. There are two components to the self-assessment tool, a hospital administrative form and a unit level form. The self-assessment tool would be an ideal means by which a military treatment facility could assess what existing services are available at the institution to promote effective PPC.
FINDINGS:
Site Visits

Site visits were conducted by members of the Children’s Hospice team to six PPC programs around the country. Sites were selected based on length of time in existence and, therefore, level of experience of the facility in providing pediatric palliative care. Each site had a different approach to the implementation of PCC, which afforded the team a variety of models for care and education.

The six sites visited were:

- Children’s Mercy Hospital: Pediatric Advanced Care Comfort Team (PACCT)
- Children’s Hospital Denver: Butterfly Program
- Johns Hopkins Children’s Center: Harriett Lane Compassionate Care
- St. Mary’s Healthcare System for Children, Bayside
- Johns Hopkins Health Plan: The Omega Life Program
- Seattle Children’s Hospital: Palliative Care Consulting Service

The strengths of each program were examined for the following parameters in order to determine what constitutes a good PPC program: 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. See Appendix 26 for the complete site visit reports, and 27 for the detailed comparison of the programs.

The information gleaned from the six site visits indicate the many ways an organization can approach initiating PPC. 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. Each one of the programs, however, is different in its approach to program design, staffing structure, and implementation strategies for PCC. The success and obstacles that each of these programs has experienced during the growth of their palliative care program can help guide the DoD in strategizing how to incorporate PPC into the MHS. There are several important components that the MHS could address with respect to programmatic development. Several of these components are listed below along with possible strategies that could be used for successful implementation of pediatric palliative care into military treatment facilities.

Each program has a different strategy for their approach to PPC: in- versus out-patient; direct service versus consultative; focus only on education or care coordination. All have at least one provider who is knowledgeable in the principles of PPC and serves as a program champion. The configuration of the teams varies in number, discipline, roles, and responsibilities, but all ensure that all domains of PPC are addressed and that the care is interdisciplinary. The population served is generally from the immediate geographic area that reflects the referral network of the hospital. The Butterfly Program also serves children from a larger geographic area, but only in
consultation with local providers and resources. The life-threatening conditions of the children usually includes a wide variety of diagnoses; however, some programs focus on specific subspecialty populations, such as cystic fibrosis or infants from the neonatal intensive care unit, as a strategy to introduce the concepts of PPC gradually. St. Mary’s Hospital is a chronic care facility and tends to have a population that is more severe and more neurologically involved. The services provided are also variable, but generally include development and implementation of an interdisciplinary plan of care and some level of care coordination. All have a plan for formal or informal education of the providers and families. (See education section, pages 57-61). Most programs do not have a specific research project on PPC, but will conduct surveys of the families to ensure patient satisfaction and quality of care and service delivery.

Except for Omega Life, which is part of the Hopkins Health Plan, all of the programs are based in children’s hospitals. Because the overall mission of these hospitals is wholly dedicated to the care of children, support for PPC by the administration and hospital governing boards is strong, unquestioning, and given without reservation. None of these programs has independent funding; therefore, most of the cost of these programs is underwritten by the hospitals.

In a military system environment where the fiscal priority is a war effort, the financial aspects of delivering care for a relatively small population of children seem impractical. However, in all the programs visited, the population of children with life-threatening conditions constituted a small portion of the overall population served within the broader organization or institution. Therefore, many of the programs expressed challenges related to growth of their palliative care efforts. Without exception, taking small yet consistent and deliberate steps to promote the development and advancement of palliative care was identified as a key strategy in the implementation of the specialized program. Education and some effort to provide coordinated care to the population were heavily weighted as an opportunity for improvement in delivering palliative care. In some settings, staff roles were re-defined or slightly modified to address the needs of the palliative care population. In addition to taking deliberate and consistent steps to implement program elements at the various sites, the need to create a cultural change in the way care is provided and viewed at the end-of-life is a significant accomplishment that helps to pave the way for growth of the palliative care effort. Collaboration within an individual facility and the development of partnerships with existing community efforts can promote the growth of PPC and improve the delivery of care for children and families from time of diagnosis of a life-threatening condition to end-of-life.
FINDINGS:
Designing a Quality Program Plan for Pediatric Palliative Care in a Military Setting

In organizations with effective quality management systems, quality becomes a central point of the organization’s operations and not just an afterthought or add-on. Quality can be defined as the results the program provides for the people it serves. When an organization develops a plan for providing palliative care, it is important to consider how quality will be defined and measured prior to program implementation.

Quality management involves a deliberate and systematic approach to increase the likelihood of desired outcomes to ultimately improve quality of care and services. This is done through continuous monitoring, analysis, correction and performance improvement.

Similarly, the Wisconsin Department of Health and Family Services explains: “The quality management system is designed to measure the extent to which consumers are achieving their desired clinical, functional, and personal–experience outcomes, and to improve the program’s performance in supporting outcome achievement.”

Some possible ways to use and interpret results are:
- To establish baseline information
- To identify areas for further inquiry
- To identify areas for focused quality improvement
- To measure program or system performance.

Quality management is most efficient and effective when it is done as close to the child or family as possible. An efficient quality management system uses data and information that are already being collected for other program purposes. For example, information from assessments and care plans, from grievances and complaints, and from billing records can contribute towards the quality management system. Satisfactions surveys can yield feedback and information that can be incorporated to promote positive program changes.

This section is intended to provide a guide for entities within the MHS that have an interest in implementing palliative care to assist them in incorporating processes that promote quality. It can be used in its entirety or as a component to an already existing quality plan. The plan outlines a framework that can serve as a template for developing programs and incorporates concepts from CHI PACC® programs as well as the NQF National Framework and Preferred Practices for Palliative and Hospice Care Quality.

In addition, gaps identified by military families and providers relating to their experiences with providing care to children with life-threatening conditions have been incorporated in the

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monitors and outcomes for quality. The monitors are designed to develop effective child/family partnerships. The MHS faces the challenges of soldier deployment and relocation as a norm and, therefore, it is even more important to promote seamless transitions across the healthcare system for children and families dealing with such complex situations. Key elements in providing palliative care include education and effective coordination and communication with families and other providers of service.

The Quality Plan typically includes the following sections:

- Purpose of the Quality Plan
- Goals for Quality Plan
- Framework for Quality Improvement in Palliative Care
- Oversight of the Quality Program including a description of roles
- Quality Improvement Monitoring Process
- Quality Improvement Education
- Review of the Program and Update of the Quality Plan
- Palliative Care Monitors and Anticipated Outcomes
- Family Satisfaction Survey

A sample Quality Plan for palliative care has been prepared for use as a template. See Pediatric Palliative Quality Plan; Appendix 29. The plan is an example and should be customized to reflect the scope and specific goals for the individual program. If the program’s primary focus is education, then it would be appropriate to choose indicators that reflect the educational goals or modify them to fit the scale of the program.

Palliative care monitors that accompany a Quality Plan are defined in the Palliative Care Monitors and Outcomes Document. The organizational and child/family/provider monitors are developed based on NQF domains, CHI PACC® standards and Joint Commission standards for hospital, home health, and hospice. In addition, the monitors are designed to reflect gaps identified by military families as part of the Children’s Hospice Project. See Palliative Care Monitors and Outcomes; Appendix 30.

The final component for the Quality Plan is the Palliative Care Satisfaction Survey designed for military families is based on findings identified from focus group assessments, see pages 67-97, discussed earlier in this document. See Palliative Care Survey; Appendix 31. The goal is to capture and identify trends within a program that can result in opportunities for improved processes and interventions, ultimately increasing family satisfaction during their palliative care experience. A program that can measure its’ effectiveness and demonstrate success will be better positioned for growth and sustainability.
RESULTS:
Gap Analysis

The gap analysis collates and synthesizes the findings of this feasibility study by bringing together the needs of families and providers, the MHS benefit, and the availability and limitations of resources and services in order to identify the existing gaps. The gap analysis is organized according to the needs assessment themes as informed by the results of the qualitative research on family and provider needs in the MHS. The corresponding resources and services that are available, and any associated limitations of availability and accessibility, are briefly described. The resources considered encompass the benefit itself and what is provided within the direct care system, community resources and services, education programs, and those systems and services that are required under the standards of the JCAHO, which are mandatory for all healthcare institutions. Each theme provides a quote from either a family member or provider to clearly illustrate the need, plus a statement summarizing the issues reflected in the theme. For each theme, there is a gap statement to succinctly delineate the needs and suggested options for addressing the gap.
THEME GROUP 1: SYSTEMS, ACCESS TO CARE, AND COORDINATING CARE

Theme 1: Access to Care and Services

“So in the beginning you may have a resource on paper, but if there is not a body providing the service [you can’t get the service]. And that’s the same with the nursing services in the [Medicaid] model waiver. We have been truly blessed by the nurse that has come into our lives. It wasn’t easy getting our model waiver. It wasn’t easy finding the individual whose schedule would mesh with ours and who has the right personality for our family. So once again, you may have a resource on paper, a resource that’s approved, but it may still take a while to find the individual that’s really going to fulfill that need for you. And do you remember how long it took from the time when we were approved on the model waiver to until our nurse came? It was about 6 to 8 months. So once again you have truly a remarkable resource that we couldn’t utilize for a significant amount of time.”

A Parent

Theme summary statement:
While comprehensive, the MHS is complex, confusing, and at times inflexible. Health care and other services for children with life-threatening conditions and their families are often available but both families and healthcare providers encounter barriers when accessing the benefit.

Resources and limitations:
The MHS includes a world-wide system of military treatment facilities and purchased health care available through TRICARE contractors, designed to deliver health care covered in the TRICARE benefit. Children with life-threatening conditions, who are beneficiaries of the MHS, are entitled to all medically necessary health care. The benefit through the MHS is generally robust, but has certain limitations for these families. Families and providers find it difficult to understand how to access many of the services that are available through TRICARE contractors. The Extended Health Care Option (ECHO) has strict requirements, which limit access to services under this program, and ECHO is not available to dependents of retirees. Case managers within the direct care system and through the Managed Care Support Contractors are available to assist families with access to care and services. However, often there are insufficient numbers of case managers or they lack sufficient knowledge to assist families with issues outside of medical care. Providers may attempt to assist families with access but may also lack sufficient knowledge as well as time.

The military community has numerous programs for information on resources and support for families: the Exceptional Family Member Program (EFMP), Military OneSource, and MilitaryHOMEFRONT. MilitaryHOMEFRONT is a web portal and described as "the central, trusted, and up-to-date source for Service members and their families to obtain information about all Department of Defense Quality of Life programs and services." These programs are often limited in their knowledge of resources and services for families of children with life-threatening
illnesses and may provide only information on the resource, but no assistance with access. Federal, state, and local programs are available, but there are significant barriers to accessing these programs, including lack of awareness of the resources, variability of availability from region to region, eligibility criteria, fiscal requirements, inadequacy of resource capacity, and unavailability of appropriately knowledgeable and trained providers.

GAP STATEMENT

Processes are needed to improve families’ access to needed services within the Military Health System. Similar access issues arise for military and publicly available community supports and resources. Even with good access to existing care and services, gaps still exist for some services, particularly those that do not fall within the TRICARE benefit.

Options for addressing gaps:
1. Provide education and individualized information for parents of children with life-threatening conditions and the physicians, nurses, therapists, case managers, and care coordinators who help them find and obtain access to needed services.
3. Work with other organizations to identify additional resources.
Theme 2: Care Coordination

“During an already chaotic and stressful time, families are providing the large majority of the care coordination. It is exhausting and the process is exhausting.”  
A Parent

Theme summary statement:
Some care coordination is available within the MHS, and it is helpful to the families when it occurs. But there remain limitations in the care coordination available to military families from both military and community resources. Families are providing the large majority of the care coordination, and it is exhausting and inefficient, leaving gaps in the services the child and family receives.

Resources and limitations:
JCAHO standards support that, whenever services are provided to a child or adolescent, family or guardian involvement is facilitated and coordination is provided throughout the process. Care coordination appears to be an option that is encouraged by the Medical Management Guide, published in 2006 by the TRICARE Management Activity (TMA). Care coordination is described as a component of case management and discharge planning. The Guide further describes identification of potential candidates based on the following criteria:
- Cases complicated by psychosocial or environmental factors
- Cases impacted by family and/or military circumstances
- Catastrophic, extraordinary conditions that incur high costs or large amounts of resources
- Chronic conditions complicated by traumatic events
- High-risk, multiple, or complex conditions or diagnoses
- Need for close coordination between the patient and healthcare team
- Requirements for extensive monitoring and coordination.

Case managers within the direct care system and through the Managed Care Support Contractors (MCSC) are sometimes available to assist families with access to care and services. Most case managers help families with care provided by the TRICARE benefit. Military treatment facilities use case managers to overlap services between case management and that of care coordination. Case managers do provide both case management and care coordination when families under case management move from one duty station to another. The MCSC provide case management for beneficiaries when they are high cost or have a high utilization of the system. The MCSC case managers also provide care coordination when a beneficiary in their care moves from one duty location to another.

Often there are insufficient numbers of case managers or they lack sufficient knowledge to assist families with issues outside of medical care. Some case managers in the MHS help families find community-based resources or other sources of funding for health care, but this is less frequent than case management for TRICARE-covered services. Providers may attempt to assist families with access but may also lack sufficient knowledge as well as time. General pediatricians and family medicine physicians provide some coordination of medical care and may be available to
facilitate communication between members of the healthcare team. However, primary care managers are not always available to coordinate care for children with complex medical needs.

The Army Exceptional Family Member Program (EFMP) provides some coordination through the EFMP Installation Coordinator. The EFMP installation coordinators may provide some care coordination of non-medical needs when the family is relocating through referrals to the gaining installation. The Beneficiary Counseling and Assistant Coordinator (BCAC) is another resource for assisting a family with care coordination issues. The BCACs are the persons most familiar with resources outside the doors of the military treatment facilities. However, the availability, capability, and knowledge of these coordinators is variable and not specific to this population. Military OneSource has “coordinators” on staff whose focus is described as disability issues. The scope of involvement with the family is information and referral regarding resource supports. Families tend to find information from Military OneSource too general to assist them with the complex needs of children with life-threatening conditions.

Care coordination is a service commonly found in some of the state administered programs, particularly those serving children with special healthcare needs such as early intervention programs, developmental disability programs as well as the Medicaid community-based waivers for children. Military families are often not eligible for these programs.

GAP STATEMENT

Comprehensive care coordination and continuity of care is vital for families of children with life-threatening illnesses, but is inconsistently available. Often parents provide much of the care coordination their family needs, without the education necessary to fill this need efficiently and at great cost in time and emotional energy.

Options for addressing gaps:

1. Provide information for parents that will help them coordinate care more easily.
2. Provide education for existing case managers and care coordinators about the needs of children with life-threatening conditions and their families and about care and services available to address these needs.
3. Provide education for case managers and care coordinators about how to efficiently access care covered by TRICARE.
4. Provide more care coordinators for this population of children and families.
Theme 3: Long-term Care Needs

“[My daughter] will never be cured. There is no cure. [She] is vulnerable to every possible illness that can come along because her resistance is low because she’s got bad lungs, because she’s got this and because she’s got that. She’s got severe scoliosis, her bones are frail, her bones break easily. It’s just a lot. The only thing that we can do is that once she gets sick try to get her through that illness and make her feel comfortable but she will never be cured or healed. She’s very vulnerable to pick up everything and anything. For example, if there’s some illness going around the school, I can’t send her and I don’t. There was a bad virus going around and [she] had developed a rash on her face. I didn’t know what it was from so I immediately called our doctor and said this is the situation the rash isn’t that big but there’s this bad bug going around school. And automatically it was like no you can’t send her. That’s how we have to live our life. I never know from day to day what is going to happen. We’re at that point where we are have the understanding [she] will not be cured and that we have to keep her as comfortable and as healthy as we can for as long as we can.”

A Parent

“I would think people derive a lot of confidence from having one doctor who’s there for them throughout the course of something and who can help put the pieces together. We have a very disjointed healthcare system, especially for patients who are not medically educated. Sometimes they just need a family doctor to decipher the language. I also think that the families that have appreciated me the most, it hasn’t been for the medical stuff that I do, but it’s because I give them the ways to contact me. And I call them and tell them I’m going on leave this week, I’m not going to be available but someone else is available. There are not that many families that I do that for, but these families know that they can call me no matter what and those are the ones that because they can’t get in or they don’t have respite or they don’t have a car, they will just call and say she’s sick she’s needed a little more oxygen today, how many days can I watch her like this before you make me bring her in. I think families need someone, that’s what hospice does, they provide them someone they can call.”

A Family Physician

Theme summary statement:
Many children live for a long time with life-threatening medical conditions that require complex care. Other children, particularly those with cancer, may enter a long-term remission or even be cured, but even then their disease and treatment have life-long physical and emotional consequences that require care. Continuity of healthcare providers is especially important for these children and families, yet is difficult to ensure in the MHS.

Resources and limitations:
Each patient enrolled in TRICARE Prime has a primary care provider who, theoretically, is available to coordinate care for the child across multiple domains of medical and psychosocial need. The MHS also provides pediatric subspecialists who can sometimes provide continuity for all medical services while caring for a child’s main areas of medical need. Since both physicians
and families move and deploy, special attention must be paid to a child and family’s need for long-term, coordinated care, especially at times of transition. Although children will continue to receive health care as long as they remain beneficiaries, their needs will continue into adulthood and they may age out of the system. Children who are significantly disabled at age 18 may continue to remain beneficiaries of the MHS throughout their lifespan, when this option is exercised by their parents.

The medical home concept for care has been supported by the Maternal Child Health Bureau and promoted by the American Academy of Pediatrics. The medical home concept is designed to address the comprehensive needs of children beyond traditional medical needs. A medical home means primary care that is accessible, continuous, comprehensive, family-centered and coordinated. Although this concept of a medical home, designed to provide broader and more comprehensive care, may address the long term needs of a child with a life-threatening condition, the successful implementation of this concept varies among physician and medical system practices and is generally not supported by the managed care processes. Theme 4: Medical Home goes into more detail about the medical home concept.

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<td>While the TRICARE benefit provides for care that addresses a child’s medical needs, the complexity and duration of care needed by children with life-threatening conditions creates challenges that require extra coordination. Providing ongoing relationships with physicians, nurses, and care coordinators, who can come to understand a child and family’s complex needs, is especially difficult.</td>
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Options for addressing gaps:
1. Develop an approach to healthcare administration that plans for a medical home in pediatrics or family medicine for each child with a life-threatening condition.
2. Enhance care coordination by primary care physicians, case managers, and care coordinators available to these children and families.
3. Develop and implement specific processes to help families transition between military treatment facilities, from pediatric care to adult care, and between physicians when care needs change and when physicians move or deploy.
Theme 4: Medical Home

“So a medical home, I would appreciate that. I would appreciate that now, especially if we are going to stay here. And someone who could easily bring all of the records, everything about our family having to deal with illness, in one place so that it is easily transferable”

A Parent

Theme summary statement:
A medical home is a pediatric or family medicine setting that provides primary care for children with special needs and coordinates health care and other services that cannot be provided by primary care physicians. Few healthcare providers in this study were familiar with the concept of a medical home. A medical home in general pediatrics or family medicine is generally not available in the MHS. Some subspecialty clinics (e.g., hematology/oncology) provide many aspects of a medical home for children while they are receiving treatment through those clinics.

Resources and limitations:
There is no specific TRICARE benefit regarding a medical home. Every beneficiary enrolled in TRICARE Prime has an assigned primary care manager who could, and in some cases does, provide some aspects of a medical home, especially coordination of medical care. However, the MHS is not currently organized to facilitate provision of a medical home in a primary care setting for most children with life-threatening conditions.

The American Academy of Pediatrics promotes the concept of a medical home. Extensive educational resources about the medical home are available through the American Academy of Pediatrics'70 and American Academy of Family Physicians websites.71

GAP STATEMENT
While some military pediatricians and family medicine physicians are familiar with the concept of the medical home and provide many aspects of this approach to care in their practices, a medical home is generally not available to children with special needs in pediatric or family medicine clinics in the Military Health System.

Options for addressing gaps:
1. Provide opportunities for pediatricians in the Military Health System to participate in the American Academy of Pediatrics’ Medical Home Initiative.
2. Provide opportunities for family medicine physicians in the Military Health System to participate in education about the medical home through the American Academy of Family Physicians.
3. Enhance care coordination for children with life-threatening conditions and their families through primary care settings in military treatment facilities.

Theme 5: Military Health System roles and administration

“The PCM [primary care manager] is not really what it should be for the general pediatric patients. I mean they really don’t see the same person every time, they see different people. And even though on paper they have a PCM they don’t really have a PCM. We do serve as PCMs or our clinic serves as a PCM for those patients.”

A Pediatric Sub-specialist

“Physicians spend an hour or two doing things that a case manager can do in the absence of having one.”

A Pediatric Sub-specialist

Theme summary statement:
Administrative challenges at the military treatment facilities, such as lack of clarity regarding healthcare provider roles or limited availability of ancillary staff, affect access to health care for children with complex needs and availability of needed support for families. When children need care provided through TRICARE contractors, apparent inconsistencies in interpretation of the TRICARE benefit lead to confusion and frustration for both parents and healthcare providers.

Resources and limitations:
All military treatment facilities within the MHS are expected to meet the same JCAHO standards as all other hospital systems. These accreditation standards are designed to facilitate patient oriented administrative processes and continuous operational improvement.

Care coordination is endorsed by the TRICARE Management Activity as an effective means to meet the complex needs of complex illnesses and circumstances. Most military treatment facilities have some care coordination available, although not sufficient to meet the needs. TRICARE contractors can institute care coordination, however, this tends to focus on benefit management rather than proactive, individualized care coordination. Community-based care coordinators and service coordinators may be of some assistance to families who must negotiate administrative challenges, but this is not an area best addressed by the community.

Education for administrative staff about the TRICARE benefit and how to help beneficiaries access the benefit would help provide more consistent assistance for families. Clarification from the TRICARE Management Activity to the TRICARE contractors about interpretation of the benefit for children with complex and incurable health conditions may result in more consistent access to the benefit in different TRICARE regions.
GAP STATEMENT
Administrative challenges sometimes create barriers to access to care and services for children and families.

Options for addressing gaps:
1. Consider organizing primary care in ways that facilitate a medical home for children with special needs.
3. Provide guidance about interpretation of the TRICARE benefit in relation to children with special needs.
4. Provide education for physicians, healthcare administrators, and others about the medical home.
THEME GROUP 2: Relationships

Theme 6: Advocacy

“He didn’t have services for four months. We paid some out of pocket but he didn’t have services for four months because I was fighting in the appeal system and it took four months. I started fighting in February. I lost services in June. I didn’t wait until the end. I lost services in June and they didn’t have services from June to September. And I was fighting the whole time.”

A Parent

Theme summary statement:
Many parents of children with life-threatening conditions become determined advocates for their children, working long and hard to overcome barriers to the care and services their children need. They need help filling this role and education about how to advocate well. Many healthcare providers in the MHS are equally determined, faithful advocates for children and families. Parents express gratitude for healthcare providers who advocate for their children; healthcare providers also recognize the important role that parents fill in this regard.

Resources and limitations:
The complexity, exclusions, and ever-changing interpretations of the CHAMPUS policy manual, as well as local interpretations by TRICARE contractors, can make advocacy on the part of the healthcare provider difficult, frustrating, and ineffective. Processes are in place for patients and families to dispute a decision regarding TRICARE benefit coverage, to request assistance in coordination or obtaining services through the direct care system, and to make a formal complaint or request a formal investigation of an incident or policy regarding health care. The medical treatment facilities have in place individuals who act as ombudsmen and/or patient advocates. These individuals assist patients and families when a conflict arises between the healthcare provider’s decisions, clinic policy, and the needs and wishes of the patient and family. The military services and the Department of Defense each have a trained group of investigators (the Inspector General (IG)) who will investigate a failure to follow established policy or regulation, allegations of fraud or mismanagement, and, occasionally, individual patient complaints, if the complaint points to a system-wide concern.

Specialized Training of Military Parents (STOMP) can be an effective resource for parents who can benefit from other military parents’ experiences. However, information obtained from the STOMP listserv has the potential of being inaccurate or influenced by a parent’s personal experience and values. Misinformation is a possible outcome.

Protection and advocacy systems exist in each state to protect the legal and human rights of individuals with disabilities. The state protection and advocacy systems typically advocate for population-based issues and may not be as helpful for individual situations.
GAP STATEMENT

Families and providers are not trained or equipped to advocate for these children, and there is no specific resource to assist in filling this role for individual patients and families. Advocacy takes energy and time. Some parents are so consumed with the care of their sick child that they may not effectively advocate, particularly if they lack support and information from healthcare providers about how to fill this role.

Options for addressing gaps:

1. Provide education for both families and healthcare providers about how to negotiate the system of services.
2. Provide opportunities for parents who would like to help other families to contribute to improving care and services by sharing insights and suggestions from their experiences.
**Theme 7: Relationships and Communication with Healthcare Providers**

“Part is to question clarity not validity. Often in the medical profession you state something and the provider would say ‘Are you sure that happened?’ As if it’s invalid, as if you don’t know what you’re talking about. Somehow we need to move towards questioning clarity not validity. You know what your child does, you know what you observed. That’s part of creating an adversarial relationship. I am not going to have my child be treated but I’m going to have to prove to them that my child did that last night. Somehow a lot of this comes from staff development and training.”

A Parent

“It’s like why can’t you who have a relationship with this family talk about end-of-life issues and what they desire for their child when the natural progression of this disease takes hold. Rather than a stranger in the middle of the night when they are all stressed out because they know the child is acutely ill and possibly might die.”

A Pediatric Intensivist

“I would rather them say ‘I haven’t worked with this diagnosis or this chronic illness, could you explain how you take care of your child at home? And we’ll try to do our best to follow that here.’ You know, it makes a big difference!”

A Parent

**Theme summary statement:**
Communication between parents of children with life-threatening conditions and their healthcare providers is sometimes difficult, always important, and remains a very sensitive area for families who are dealing with serious medical situations that evoke deep emotion. Communication between parents and healthcare providers is affected by military culture, family background, and whether healthcare providers and families speak the same language. Communication among the many healthcare providers who provide care for a child is equally important. Healthcare team communication generally proceeds well within a military treatment facility but often proves more challenging when the team includes providers both in the military treatment facility and in the community.

**Resources and limitations:**
The primary care manager is in the ideal position to establish the pro-active communication with a family about their child with a life-threatening illness and about possible complications and decisions that they may face in the future and to coordinate communication among members of the healthcare team. Often, however, continuity of care with a primary care manager is disrupted when a child has complex needs requiring on-going subspecialty care.

Many educational resources about pediatric palliative care include education about communication between healthcare providers and families. Some more general approaches to physician/patient or healthcare provider/family communication may also be helpful for providers who work with this population of children and families.
Formal and informal training in communication skills with families is available through residency training programs and can be provided as a part of continuing medical education. Some training programs are utilizing the Initiative for Pediatric Palliative Care (IPPC) curriculum as a means to educate their staff in topics of communication, particularly for end-of-life issues. The IPPC training is divided into modules and includes a module entitled “Improving Communication and Strengthening Relationships.” The goal of this module is to enhance healthcare professionals’ communication and relational skills.

JCAHO identifies the standard that families have the right to participate and that providers ensure family participation in all aspects of their care. This standard requires that any communication with families must be appropriate to their level of understanding and ability to learn. Language barriers between providers and families can contribute to communication issues. Language interpreters are usually identified within each military treatment facility and should be available to assist with communication with families whose primary language is not English. Resources that offer services to assist with language barriers include the Women Infant and Children (WIC) programs, developmental disability programs, infant and toddler early intervention, departments of social services, the military direct care system (available during hospitalization), as well as other local community groups.

**Gap statement:**

Although some healthcare providers and supportive organizations are beginning to access training in the area of palliative care, there is no specific requirement, and provider training is variable. Thus many providers remain untrained in effective communication techniques for palliative care. Translation services are not available consistently in all programs that serve children and families.

**Options for addressing gaps:**

1. Provide formal education for healthcare providers and informal education for families about communicating effectively in difficult circumstances.
2. Develop a pediatric palliative care team that focuses on communication, perhaps using the Decision Making Tool developed at Children’s Hospital of Seattle.
3. Provide extra support for healthcare providers and/or families who must engage in stressful, difficult communication and decision-making.
Theme 8: Decision Making

“In relation to the information, specifically we want the right information to make the decisions we have to make and we want to be included in decisions about our children.”

A Parent

“That speaks to shared decision making and them not taking the time to find out why you feel that way and share with you why they feel that way because they might alleviate a lot of fear if they would involve you in the shared decision making.”

A Parent

“Help the family look there and make some decisions about the end-of-life issues when it’s comfortable with everyone to do that or if it’s not comfortable and it needs to happen anyway. Sort of beginning to bridge some of those conversations even fairly early.”

A Parent

“A lot of times it was hard, really hard, it’s hard to see your child go through that and have to make all these awful decisions for them and make them hurt for the treatments or something. It’s not you, but it’s like you can’t give up. As long as, like I said she could understand, she’d say she had a bug in her head or something and I’d say ‘It’s back. Should we get it out?’ and she’d say ‘Yes!’ and I couldn’t stop. She never stopped so I couldn’t either. She kept on.”

A Parent

Theme summary statement:
Parents find it very hard to make decisions for their children, and often have to do so in the face of great uncertainty about outcome, big risks, and huge implications for quality of life. They want to be included in decisions, but need the information necessary to make good decisions and do not want to feel like they are all alone in making decisions. Sometimes they have to make decisions between options that all have a likelihood of negative outcome.

Resources and limitations:
In accordance with JCAHO standards for hospital care, the process that allows patients to fully participate in decisions about care, treatment, and services is the informed consent process.72 This is identified as an individual right; however, a mere list of rights cannot guarantee they are enforced. The Maternal and Child Health Bureau, at the Federal level, in partnership with State Title V Children with Special Health Care Needs (CSHCN) programs, family leaders, and other professional and advocacy organizations have focused a significant level of effort on defining, describing, and making family-centered, community-based care available to all CSHCN and their families.

The TRICARE Management Activity has endorsed and promoted the concept of family-centered care, which includes family participation in decision making, throughout the MHS. However, the training and experience of providers in these concepts and how they apply in daily practice is variable. Education to build communication skills of healthcare providers who work with children with life-threatening conditions and their families may address ways to engage in supportive shared decision making with children and families. Care coordinators, primary care managers, subspecialists, chaplains, and nurses can assist families in weighing options during times when difficult decisions need to be made. Family counseling is available as a benefit to families.

**Gap statement:**
Although federal and professional organizations promote the concepts of family-centered care, the medical home, and informed decision making in the delivery of healthcare for children, individual professionals and organizations practice these concepts with varying levels of knowledge, resources, support, and effectiveness.

**Options for addressing gaps:**
1. Provide education for children, parents, and healthcare providers (especially physicians) about shared decision making.
2. Provide decision aids and other informational resources for parents about treatment decisions they must make with or for their children.
THEME GROUP 3: Family Needs

Theme 9: Social and Emotional Needs

“They said, ‘You are on compassionate reassignment you’re supposed to have your family help you.’ I said, ‘My family is in Nebraska.’ ‘Okay,’ they said, ‘friends or neighbors.’ I said, ‘I don’t know anyone, I just moved here.’ They said, ‘Don’t you have a neighbor?’ I said, ‘She works.’ I asked my case manager, ‘So what are you doing tonight?’ She said, ‘Oh, I have such and such to do.’ I go, ‘So you probably couldn’t come over and watch my son while I go to the store.’ She said, ‘Well that’s not fair, I have obligations.’ I said, ‘So do other people.’”

A Parent

“It changes your thinking but you have to cope. When you are in a situation like this, it doesn’t end; I can honestly tell you that I love my child very much, but when Dr. D told me a few weeks ago and said that she can live a lot longer, like a few more years, I walked out of there thinking I’m going to be loony by the end. I can’t do it. That was my first thought. How am I going to be able to cope with it? She is already getting heavy, she is already putting strain on me. How am I going to do this? You only think that for a brief time because you are in a situation that you can’t get out of it. You can’t jump off a cliff and say bye see you later. I never thought about that because I love my family. I love my child and it’s not something that you can run away from.”

A Parent

“I have longed for something like [respite care] that especially that I am from the islands. We come from Guam. We have no family here and I have my other little kids and that’s why we had to have them learn how to deal with our child.”

A Parent

“Our current system relies very heavily on friends and family. Absorbing more of that and taking care of it would cost more than what we do now. Families are basically left to fend for themselves. It’s very difficult.”

A Pediatric Subspecialist

Theme summary statement:
Parents of children with life-threatening conditions in the military community describe social and emotional needs in three broad categories: dealing with the intense emotions evoked by their children’s suffering, coping with continuous and strenuous care demands, and living in settings with limited social support. The whole family is affected—the child with a life-threatening condition, parents, and other children in the family. Physicians, care coordinators, and social workers recognize families’ need for emotional and social support and do what they can to address the needs with limited resources. Healthcare providers who work with these children and their families need support, too.

Resources and limitations:
JCAHO requires that accredited facilities conduct a psychosocial assessment of a patient and family with the understanding that identified problems are addressed during the course of care. Mental health services are available as a TRICARE benefit. Social workers, psychologists, and
psychiatrists are available in military treatment facilities through behavioral health clinics, family medicine clinics, and life skill clinics. Many military treatment facilities limit appointments to active duty members. Up to 8 outpatient visits per year are covered by the TRICARE benefit without a referral or diagnosis, with appointments available through the network of providers organized by TRICARE contractors. Additional visits are possible with a diagnosis and approved plan of treatment. However, formal counseling may result in labeling the military parent as having a mental health diagnosis that can have implications for their military career opportunities.

Counseling for normal bereavement is not an authorized benefit under CHAMPUS/TRICARE for patients with a “diagnosis” of normal bereavement. Some parents worry about implications for their careers of pursuing any counseling, although the MHS tries to provide education to allay this concern. Families may be able to access family counseling without a mental health diagnosis, and a behavioral health specialist may be available through family medicine clinics at some military treatment facilities. With education about pediatric palliative care, physicians and nurses may be able to provide additional emotional support for children and families informally, in the context of health care they already provide.

Military OneSource provides information and referral assistance for active duty service members and their family members to seek professional, non-medical counseling. Six visits per year per individual per issue are available at no cost to the service member or family.

Child life is a service typically available in a pediatric hospital setting. A child life specialist is a professional who is trained to assist children and families in understanding and managing difficult life events and stressful healthcare experiences. However, these services may not be available in all settings. A number of community-based organizations may offer bereavement support or support for families of children with special needs in some areas. Some organizations who may offer this resource include religious settings such as churches, synagogues and mosques, pastoral counseling centers, hospitals, mental health or social service agencies, funeral homes (some have after care hours), hospices, YMCA or similar organizations, and other less formal support and discussion groups. Services of organizations may vary from place to place and some charge dues or fees for their services. Some remote locations of the country may have less access to local resources. Sibling workshops or support groups are also sometimes available through community groups.
**GAP STATEMENT**

Although a variety of resource options exist to address the social and emotional needs of children with life-threatening conditions and their families, many of these children and families have many unmet needs for both emotional support and social support. This is particularly true for families who move either because of the active duty service member’s job or to relocate near military medical resources, as these moves often disrupt a family’s social support network.

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<tr>
<th>Options for addressing gaps:</th>
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<tbody>
<tr>
<td>1. Consider options for minimizing moves for families who have children with complex medical needs.</td>
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<tr>
<td>2. Develop a network of care coordinators across the Military Health System, with processes for assisting with transitions of care and services when families re-locate.</td>
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<td>3. Focus care coordination on meeting both medical needs and social support needs, so that care coordinators are educated, authorized and resourced to help families negotiate the TRICARE system to obtain medical care and locate military and civilian resources that can provide social support.</td>
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<tr>
<td>4. Provide some additional education about counseling that physicians can provide for families in the context of providing care.</td>
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**Theme 10: Financial Toll**

“It wasn’t so bad in the beginning, the formula. He was tube fed, the formula was being taken care of under the WIC program. So we didn’t realize...we didn’t know the expense of the formula. When he was too old for WIC then all of the responsibility to provide the food is ours. Now you go out there and see how much food costs. Then you had the dealings with TRICARE saying ‘Well he doesn’t have a condition that warrants us to pay for his formula.’ I’ve had some pretty ugly conversations with people. The basic thing was is if he wasn’t tube fed you would have to feed him somehow. Well, of course. Well, [to them] that’s the same thing as buying formula. His supply of formula is around $1300 a month. TRICARE said, ‘No, we’re not going to pay for it. We’re not obligated.’”

* A Parent

“I’ve also been a parent that was referred out to civilian services and gotten over $15,000 in bills.”

* A Pediatrician and Parent

“[Finances.] that’s a huge issue with these families. The families really struggle and I don’t know how to help them out. I don’t think there is enough out there to help them. There is this financial weight put on them. A lot of our families even the E-3’s they don’t qualify for Social Security disability benefits for these children or Medicaid benefits because of something with their BAH [housing allowance] and it looks like they have more money. And we’ve met with people from Social Security to try and discuss these issues. So you have these people who have no money and they are still not getting services.”

* A Discharge Planner

“My husband is like maybe you should get a second job. I am like, hello, he does not get it. He needs the education. He hasn’t been around. Finances are one thing, but I’m a stay at home mom. That’s my job. I’m my son’s nurse. Finances are a situation. Finances are a problem.”

* A Parent

**Theme summary statement:**

There is a significant financial toll for families of children with life-threatening conditions, even with access to needed medical care through the TRICARE benefit. Items typically not covered by TRICARE or not fully covered include special formulas, diapers, home nursing, respite care, some equipment, home modifications, special clothing, special toys, and expenses of moving to get care. Families also need to pay for child care for other children during treatment, funerals, and other expenses. Some other funding sources are available (Medicaid, Supplemental Social Security Income, state and community resources, military relief societies), but these sources of funds are inconsistently available to military families.

**Resources and limitations**

Financial planning can be an area that is overlooked when a parent is caring for a child with a life-threatening condition. Although there is a universal healthcare benefit, there may be a co-payment, depending on the TRICARE option selected and the availability of an appropriate
provider, vendor or service within the network. Medical treatment that is considered experimental is not covered. Many services and some supplies and equipment are not considered “medical” and, therefore, are not covered by the TRICARE benefit, but they still result in substantial cost for families. Non-medical expenses and alternative therapies are not covered. Case managers and care coordinators, where available, help families obtain payment for all TRICARE-covered care and pursue other sources of funds for uncovered services if funds are available. Both families and care coordinators need education about existing resources for funding of care, services, supplies and equipment that are not covered by TRICARE.

The financial planning process can be complicated and may require the input of experts to assist with the legal and financial implications. Many healthcare professionals either lack the expertise to advise a family in the area of financial planning or may not know to address financial issues at all.

The Social Security and Supplemental Security Income disability programs are the largest of several Federal programs that provide assistance to people with disabilities. While these two programs are different in many ways, both are administered by the Social Security Administration and only individuals, who have a disability and meet medical criteria, may qualify for benefits under either program. Most military families do not meet the criteria.

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<td>There are limited knowledge and resources available to families for either advice or support financially. Out-of-pocket expenses can be large when a child/family is emergently transferred to the continental United States for urgent treatment. Some items of equipment, supplies, special formulas, and some therapies can only be obtained by families if they pay out-of-pocket or find sources of payment in addition to TRICARE.</td>
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**Options for addressing gaps:**

1. Provide care coordinators based in military treatment facilities or military community organizations that can help families negotiate Social Security, Supplemental Security Income, Medicaid, Medicaid waiver programs, and other sources of funding.
2. Provide education for families and care coordinators about local state and community sources of funding for special healthcare needs.
**Theme 11: Search for Meaning/Spiritual Care**

“I love her, I would never have went back and change the situation. I never would have not wanted her to come. Just my beliefs have made a big difference. I think my support group with my church and my beliefs that this isn’t the end. She’s going to be okay. That has gotten me through a lot of knowing that it’s okay. That she is perfect and a real special spirit. I sense that from her. I enjoy. I find joy in being around her. Our family does too and anyone who meets her is just amazed at the feeling that they get from her. That’s really made a huge difference for me is my beliefs and knowing that it’s in God’s hands and that it’s going to be okay.”

* A Parent

“[My son is] about 10. I still consider him a blessing. I don’t know why I’m saying this but I probably wouldn’t have it any other way. He has taught us a lot more and he is here for a reason and I’m thankful to be his mother that God has trusted me with this wonderful human being. That’s how I have to look at it to survive. It’s very hard.”

* A Parent

“The chaplain service comes through and for individual patients that may be a big help but for the majority of patients they don’t count on our chaplain service, they count on their own ministers or religious people who help them with that.”

* A Pediatric Sub-specialist

**Theme summary statement:**

Both children with life-threatening conditions and their parents need spiritual care and a chance to talk about spiritual issues and questions about the meaning of what is happening to them. Sometimes they want to talk with a nurse or other healthcare provider about these things.

**Resources and limitations:**

According to JCAHO hospital standards, a spiritual assessment should be conducted specifically for end-of-life situations, and the facility should provide access to pastoral care, if requested by family.73 Families may not be aware that they should ask for this type of support. The TRICARE benefit authorizes counseling by a variety of providers, such as pastoral counselors, psychiatrists, psychologists, family therapists, and social workers, who may focus on meaning and the existential aspects of the family’s coping.

There are direct resources that assist families and children in addressing the positive meaning of the child’s condition that may include professional counseling and/or spiritual counseling. Professional counseling opportunities can be sought with assistance from Military OneSource or through the TRICARE network. These may include professional mental health counselors and licensed clinical social workers who can address difficult issues related to the end-of-life and the loss of a child.

In addition, chaplain services may be available to address these very personal issues of loss or anticipation of loss. Professionals and others who support children with life-threatening conditions may also seek spiritual assistance within the general community, if a specific religious denomination is preferred by a family. However, not all professional clinical and pastoral counselors are qualified to provide counseling. They also may not have the expertise to address the issues related to a dying child. Further, not all families are comfortable with a traditional religious approach to the meaning of life.

Some chaplains may be interested in pursuing clinical pastoral education with a focus on pediatric palliative care, or may want to participate in pediatric palliative care education as a member of a healthcare team.

**Gap statement:**

Not all professional clinical and pastoral counselors are qualified to provide counseling for parents under the extreme stress of the initial diagnosis of a life-threatening condition. They also may not have the expertise to address the issues related to a dying child.

**Options for addressing gaps:**

1. Identify chaplains who may have education in Clinical Pastoral Education who may also be interested in working with children with life-threatening conditions and their families, or with bereaved families.
2. Offer education to interested chaplains who would like to develop expertise in counseling bereaved families or children with life-threatening conditions and their families.
3. Identify non-medical counselors through Military OneSource who may be available to help families explore questions of meaning and purpose and coping when they have a child who may die.
THEME GROUP 4: Palliative Care and End-of-Life Care

Theme 12: Palliative Care

“They are now thinking that he is going to be on a 24 hour feeding instead of twice a day which is going to be very difficult because he is not on a wheelchair yet and he would be completely in his crib without moving. I’m having a hard time with that because he rolls. That’s the only thing that he does, he rolls. Even with that, he enjoys that and you can see the enjoyment in his face and that’s the only enjoyment that he has so taking that away is basically like taking my child away. I’m hoping and praying that they don’t do that so that he can have some kind of quality of his day.”

A Parent

“I just want to make whatever lifespan he has the best it can be physically, emotionally, spiritually, all of it. That’s my job; I’m his mom. So basically, that is it in a nutshell.”

A Parent

Theme summary statement:
Palliative care is a vital part of care for children with life-threatening conditions to improve both the child and the family’s quality of life and to help them begin to prepare for end-of-life care should it be the outcome. Parents focus on quality of life for their children, which usually means finding a way for children to be comfortable, to enjoy life in whatever way is important to them, and to help the child participate in family life, school, and typical activities to whatever degree is possible. Healthcare providers’ understanding of palliative care varies widely in the MHS.

Resources and limitations:
Currently there is no palliative care benefit within the TRICARE system. However, there are palliative care programs being implemented intermittently throughout the military healthcare system. To date, the programs are focused on adult palliative care and not on children. Some aspects of palliative care, usually more traditional pain or nausea control techniques, are available through the direct and purchased care system, if authorized as medically necessary care. Some types of palliative care that are effective for children may not be authorized, e.g., acupuncture, visual imagery, music therapy, massage therapy, art therapy. Support that addresses the quality of life of the child’s parents or family members is generally not covered by TRICARE. Education about palliative care is almost uniformly needed among healthcare providers

Policy and guidance is in place, typically following state regulations, which allow families to authorize DNR orders in the hospital, home, and school. Some healthcare providers in military treatment facilities have a special interest and/or special training in palliative care, but these healthcare providers are not available to all children with life-threatening conditions and their families.

Palliative care programs for children can be found in various healthcare models throughout the country. Some palliative care programs are not fully funded and, therefore, depend on the financial support of other flourishing programs. Children's Hospice International (CHI), with
technical assistance from experts in pediatrics, hospice and palliative care, and the Centers for Medicare and Medicaid Services (CMS), developed its CHI Program for All-Inclusive Care for Children and their Families® (CHI PACC®). CHI PACC® programs can only be available in states that actively pursue the CMS application process. To date, Florida and Colorado have been approved for the 1915 (c) waiver to deliver pediatric palliative/hospice care using Medicaid funding and the CHI PACC® model. Military families would need to be eligible for state Medicaid services to receive care through these programs.

**Gap statement:**
Although hospital- and community-based hospice programs are readily available throughout the country, there are relatively few formalized pediatric palliative care programs. In some areas of the country, children receive hospice-based services designed for the adult population.

**Options for addressing gaps:**
1. Enhance education about palliative care in military residencies for Pediatrics and Family Medicine.
2. Acquaint healthcare providers in the Military Health System with available local resources for palliative care at Children’s Hospitals and in local hospice programs.
Theme 13: End-of-Life Care

“There is no doubt in my mind that it is avoided in pediatrics. It’s not avoided with older people, but in pediatrics it is a taboo topic. It is a we-are-not-going-to-discuss it topic. I think that when you have a pediatric patient who has a life-threatening incurable whatever, that needs to be part of the treatment plan. Because sooner of later it is going to come into play. Granted there are going to be other pediatric patients who are going to be in this situation all of a sudden but they need to have a plan of attack that they know. They need to know.”

A Parent

“At the end people, doctors nurses, everyone, social workers. Someone should come in and explain the process of death. And what it looks like. It doesn’t look like what they show you on TV.”

A Nurse

“One of the big needs when we got out there is that they just need to know what might happen. If they know like in the dying process that the extremities are going to get cool and that the respirations might get irregular and there might be the death rattle. If they understand all of that, that it might happen, they are okay with it. It’s that fear of the unknown.”

A Nurse

Theme summary statement:
Important, intense, and particular needs arise around end-of-life care, DNR discussions, and hospice care. Children and families need information, time, and support for making decisions, and a supportive environment for a child’s end-of-life care. The experience of healthcare providers in the MHS with end-of-life care varies widely, from none or nearly none to a great deal.

Resources and limitations:
Comfort and dignity are to be optimized during the end-of-life, according to JCAHO standards, and applicable to all “dying” patients within a hospital facility. Hospitals should be addressing the wishes of the patients as they relate to end-of-life decisions. The hospital should have mechanisms to assist with the development of advanced directives and a responsibility to assist in honoring end-of-life wishes within the limits of the law and the hospital’s capability. For advanced directives, appropriate forms can be obtained from healthcare providers, legal offices, Offices on Aging, and state health departments. Some state social service agencies and local funeral providers may be approached to provide options to support funeral or burial resources.

TRICARE provides a hospice benefit when death is expected within 6 months, but this is an adult model of hospice and requires the family/child to forgo disease-directed care. Many adult hospice programs lack providers with pediatric training and experience. In addition to hospice services, policy and guidance are in place, typically following state regulations, which allow

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74 Hospital Accreditation Standards 2006, Joint Commission on Accreditation of Healthcare Organizations, published by Joint Commission Resources, Inc., related to RI 2.80, p. 146.
families to authorize DNR orders in the hospital, home, and school as well as to assist with other end-of-life issues such as organ donation.

When DNR discussions do occur, staff physicians usually participate in these discussions with families. Pediatric and family practice residents have little exposure to the conduct of these discussions. Healthcare providers need education about specific end-of-life issues like DNR orders and how to ensure that families’ wishes and decisions are recorded in all places necessary. Education about communication, decision making, palliative care, and community resources is also relevant to end-of-life care. When end-of-life care happens in the smaller military treatment facilities, the small size of the community sometimes makes it possible to provide support. If DNR discussions have not taken place, the result can be further suffering for the child and family as futile resuscitation measures are instituted.

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<td>End-of-life care for children is inconsistent, rarely planned with a child and family, and can increase the child and family suffering.</td>
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**Options for addressing gaps:**
1. Provide education about end-of-life care.
2. Build stronger collaboration with children’s hospitals and hospice programs that provide resources for end-of-life care for children.
THEME GROUP 5: Education

Theme 14: Education for Healthcare Providers and Families

“A lot of our physicians come into the army not really knowing much about the army, so possibly they need better exposure to the life of the regular enlisted, [that] would be helpful.”  
A Resident

“Another part of it is administrative. Because the support is available and the regs keep changing. Regular updates from the TRICARE administrative level on here is the current procedure, here is what is covered, here is how this stuff is accessed. What do you do when the parent drops their copy of a denial letter off for services? That sort of thing. Because that keeps changing and I’m never sure from one month to the next. I have to run around and find someone who may or may not know. So regular updates of some sort would be helpful to me.”  
A Resident

“My thing about end-of-life care and death and dying and hospice is that we don’t do a good job talking about it, we don’t do a good job training residents. Fortunately, we have very little exposure or sporadic exposure, which is fortunate for the patients, not so fortunate for the house staff who are going to graduate and become expert pediatricians and have no knowledge or experience in these areas.”  
A Pediatrician

“Sometimes it’s literally with training you. They are training you to do central lines, care management. Sometimes it’s training and they are training you in your role. And as a parent, you can take pride in the fact that you are participating in health care, it’s really family-centered. You know how to do it and you do it well. That helps you in your viewpoint in your role.”  
A Parent.

Theme summary statement:
Parents caring for a child with a life-threatening condition have a variety of education needs, including a clear, medically accurate understanding of their child’s medical diagnosis, specific treatment plan and prognosis, an understanding of how to address their child’s practical medical needs, and information about how to find needed support for their family. Healthcare providers need education about available care and services and how to help families access them, as well as about communication with children and families, palliative care, and end-of-life care.

Resources and limitations:
JCAHO standards for hospital care support the concept of education to meet the dying needs of patients. This support for education is intended for staff providers as well as families. In addition to the educational requirements for provider credentialing, hospital staff are expected to be educated about the unique needs of dying patients, their families, and caregivers. There are no specific education requirements for providers addressed in the benefit. For families, education and training to use medical equipment and to provide some therapies to their children, such as a
physical therapy home program, is a benefit. The patient and family should receive education and training in a way that is understandable and that accommodates various learning styles with the family’s comprehension evaluated.75

Education programs may be available within the major military medical centers as part of residency training and continuing medical education curricula. Several curricula oriented to the pediatric population have already been developed and are available for use by institutions seeking to educate providers on the principles of pediatric palliative care. One such curriculum is The Initiative for Pediatric Palliative Care (IPPC), developed by the Education Development Center, Inc. (EDC), an international non-profit educational research organization based in Newton, Massachusetts. IPPC is both an education and a quality improvement effort, aimed at enhancing family-centered care for children living with life-threatening conditions. The End-of-Life Nursing Education Consortium (ELNEC) project is a national education initiative to improve end-of-life care in the United States. These programs are less likely within smaller military treatment facilities and may require providers to seek external training programs at their own expense. The Uniformed Services University provides introductory education about palliative care for physicians who attend medical school there. Home visits are another valuable educational resource that has offered some healthcare providers in the MHS the opportunity to learn about chronic, complex care in a different, often more intimate environment than in-clinic appointments.

Other mechanisms for healthcare provider education in the MHS include Tri-Service required continuing education through computer modules and in-person education sessions, Pediatric and Family Medicine Consultants’ service-wide email to distribute notices and documents worldwide, continuity clinics for residents, and required residency education.

Additional methods used for training include more informal venues that can occur in various healthcare settings. These efforts can focus on the education of staff, families, or providers. Some examples include the development and distribution of informational brochures, CD’s, books or literature, facilitated discussions at staff lunch groups, small group lectures, resident/fellow rotations in a palliative care setting, child life internships, one-on-one training, grand rounds, or other special training events.

**Gap statement:**
Both providers and families lack sufficient knowledge about pediatric palliative care and how to identify and provide the support and services necessary for a comprehensive approach to care.

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75 Hospital Accreditation Standards 2006, Joint Commission on Accreditation of Healthcare Organizations, published by Joint Commission Resources, Inc., related to PC 6.30 (p.178) and PC 8.70 (p. 180).
Options for addressing gaps:
Please see the section on education findings for a thorough discussion of education regarding pediatric palliative care. (See Education Findings pages 57-61)
THEME GROUP 6: Military

Theme 15: Military Issues

“The military is our life and this is where we want people to hear us. They are the only ones that we have to hear us. So we want them to hear us.”

A Parent

“I think that the military should look into just leaving the families with high risk children in one place instead of moving them all over the place. ... Because that’s a pain to have to move from state to state and have to reestablish the benefits and everything else.”

A Parent

“It takes most services a month to get PCS orders. It would be nice to have something that was only available to order this family into medical transient status to the national capital region or a major U.S. city.”

A Pediatric Subspecialist

“So the cost to the military is, I think, we’ve got a whole lot of really stressed out families and that has to affect job performance and deployability and productivity of the serviceman. These families often feel trapped by the military to some degree as well. I think we have a huge unrecognized cost in decreased productivity and high stress levels in the soldier.”

A Pediatric Subspecialist

“With all the deployments, it not only affects the person being deployed it affects their whole family significantly, especially when they might be on their third deployment.”

A Pediatrician

Theme summary statement:
For most families, unique military administrative issues are a major determinant in the experience of a move between bases, air evacuation, or transfer to a higher level of medical care. For most, the experience of moving and settling into a new location, beyond being traumatic because of the child’s condition, is also confusing, lengthy, costly, and disrupts their ability to attend to their child. Disruption of the medical and social support system they had previously established contributes to their sense of powerlessness. Stress of frequent and lengthy deployments, both of the active duty member and the primary care physician for the child, adds another difficulty for families wherein the uncertainty associated with their child’s medical condition is exacerbated by the absence of trusted advisors and helpmates. Yet, many families emphasize their commitment to the military community and culture, and to the service of their county. They wish that their commitment and willingness to sacrifice was matched by a commitment on the part of the command to make their difficult transitions easier.
Resources and limitations:
Military medical providers are not necessarily familiar with or well trained in military issues and concerns for the active duty service member. This void becomes even more apparent when family members obtain care through non-military, network providers. There is no specific healthcare benefit under CHAMPUS that addresses this issue.

Education about military culture is important for healthcare providers who work with this population of children and families. Education about relevant regulations, provisions for special circumstances in military families, and resources available for support would be helpful for military administrative personnel and commands, as well.

The Exceptional Family Member Program (EFMP) is a military personnel function used during the assignment process to identify active duty service personnel whose family members have special needs. The purpose of early identification is to coordinate the assignment of the active duty service member with the medical and educational needs of their dependents. The program serves to ensure the availability of necessary medical services upon change of duty stations. MilitaryHOMEFRONT is a web portal and described as "the central, trusted, and up-to-date source for Service members and their families to obtain information about all Department of Defense Quality of Life programs and services." Additionally, the Department of Defense contracts with Military OneSource, an Employee Assistance Program administered by Ceridian, to assist active military members and their families in locating resources and services to meet any needs a military family may identify. Although these resources support the logistical issues of deployment and relocation, the detailed needs related to the emotional and clinical aspects of care for a child with a life-threatening condition are not well addressed by the current system resources.

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<td>Military issues such as transfers and deployments create unique problems and added stress for these families. Additional care coordination and services are needed to support families before, during, and after deployments.</td>
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Options for addressing gaps:
1. Enhance care coordination at the time of transitions due to military moves, moves necessitated by a child’s complex medical needs, and military deployments.
2. Provide education about military culture to healthcare providers in military residencies, military treatment facilities, and TRICARE network providers.
3. Provide education to administrative staff and commands about relevant military regulations, provisions, and support for children with special needs and their families.
RESULTS:
Summary of Expert Panel

A panel of experts in pediatric palliative care was assembled to meet with the Children’s Hospice team. Each member of the panel represented one of the locations visited by members of the team as part of the site visit surveys. The purpose of the expert panel was to discuss and process with the Children’s Hospice team key concepts and recommendations from their direct experience for the development of a PCC that could be incorporated into the MHS. An additional member of the panel was COL Carlos Parrado, an internist from Ft. Benning, GA, who identified a need for palliative care at his military treatment facility and began a program in 2001.

Dr. Parrado was invited to give a presentation on his adult palliative care program. His initial approach was to train 16 physicians in palliative care, using the established curriculum, Education on Palliative and End-of-life Care (EPEC). An additional 25 physicians were trained in 2005. Dr. Parrado discussed how elements of palliative care coincide with JCAHO standards and allow these standards to be met more efficiently. Dr. Parrado has maintained interest in palliative care at Ft. Benning by inviting experts in the field as guest speakers to his institution. He stressed that he did have “buy in” for a palliative care program by the chief of psychiatric services on his base, which appeared to be a critical factor in moving his project forward. While a funded palliative care team does not yet formally exist at Fort Benning, Dr. Parrado does have providers who serve as an interdisciplinary team with a focus on palliative care. This team is composed of an internist, family practice physician, medical residents, nurses, pharmacist, bereavement specialist, chaplain, and risk manager. Key elements that have been identified as lacking included physician communication skills with families, advanced care planning, and referral efficiency. Dr. Parrado and his team are continuing data collection on a variety of subjects, such as pain clinic referrals, admission of patients with debilitating diseases, frequent users of the Emergency Department, and use of narcotics in an effort to gain on-going support for palliative care services.

Key Implementation Strategies for Introducing Palliative Care into the Military Health Care System

The expert panel spent the remaining time discussing what they consider key implementation strategies for successful integration of pediatric palliative care into the military health care system. Several key themes were identified to include the need for a program champion, essential program elements and process elements, and the conduct of a site assessment.

First and foremost in moving this project forward is to identify key individuals within the military health care system that could be identified as project champions at each facility. This individual should be a respected person within the institution, who has the credibility of the commander. While it would be helpful for the individual to have had experience in palliative care, this is not necessarily critical. The individual, however, must have a passion for palliative care and be willing to learn about the field in depth. He or she must practice evidence based medicine and be willing to explain palliative care to colleagues as such even though palliative
care is not always evidence based. The individual should have access to management and be someone who would be willing to effect change at the institution regarding philosophy of care, perhaps even at a policy level. Data currently exists regarding cost savings to institutions when good care coordination and essential palliative care elements are in place and could be used as a justification for creating a pediatric palliative care program at the champion’s facility. It was suggested that a questionnaire be sent out to each military health care facility to identify potential individuals who would be project champions.

The topic of essential program elements was discussed. There are clearly some basic services that a facility should have in place in order to offer good PPC. These would include access to an individual trained in pain and symptom management, social work services, spiritual/pastoral care, and bereavement. The panel recognized however that each military health facility may differ with respect to how extensive these services are at the facility. The child and family should also have access to an interdisciplinary care team that is family centered and focuses on their physical, social, psychological, and spiritual needs. The make up of this team will vary at each military treatment facility depending on the facility’s resources, which means the project champion will need to be creative and flexible when assembling the team. Additional essential program elements include resources and support at end-of-life and advanced care planning (DNR documentation).

How the essential program elements are molded into a PPC program at each facility will depend on what essential process elements are in place at the facility. Once a project champion has been identified at a facility, he or she will need to define what constitutes the best possible PPC team for that institution. Care coordination is clearly an essential process element that will determine access to care. While it would be ideal to have an individual whose only job is care coordination, this may not be possible at many facilities. Creativity is the key and this role may need to be shared by an RN, social worker, etc. There will certainly need to be system wide education at each institution regarding pediatric palliative care. Patients and families must have an individualized plan of care that is reviewed on an ongoing basis and changed according to the level of service required. Ideally this plan would follow the patient and family at the time of a transfer to another facility. A framework for providing this continuity of care constitutes an essential program process. Finally quality assessment, outcomes, and research would allow for continued improvement in the delivery of PPC in the military. However, it must again be understood that these essential program processes may need to be added over time.

Finally there are several key elements that are critical for the site assessment that will need to take place at each facility with an interest in development of a pediatric palliative care program. Key will be the identification of a program champion from within each facility. That individual will be aware of the population of patients (types of diagnoses), who will receive PPC services at their facility. Existing services will need to be identified, such as personnel, who have an interest in pediatric palliative care, services available (social work, spiritual/pastoral care, mental health, care coordination), community resources within the military, and community resources acceptable to the military. A crucial piece of the site assessment is interest and support from the military treatment facility commander. Existing priorities of the facility will need to be identified to understand if a PPC program is feasible or not.
CONCLUSIONS

It is not feasible to implement the Children’s Hospice International Program of All-inclusive Care for Children and their families (CHI PACC®) within the MHS. It is feasible to implement the principles of pediatric palliative care within the MHS as set out in the CHI PACC® core standards.

The CHI PACC® model consists of four core principles:
- Comprehensive care delivered by an interdisciplinary team
- Simultaneous curative and palliative care
- Care from point of diagnosis with single entry into system
- Ample and flexible funding.

The major barrier to implementing a CHI PACC model as promoted by CMS is the inability of the MHS to make use of the model waiver strategy which allows flexibility of the benefit with cost neutrality of prior expenditures for a particular population. Based on the nature of the military demographics, and the fact that the military system has national and international reach, there is no mechanism for the system to apply for a waiver as the system is beyond the boundaries of a particular state. In addition, the CHAMPUS authorization for military health care is determined by law and does not allow for deviation from or flexibility of the authorized benefit.

The additional requirements for families imposed by the nature of military life, such as frequent transitions, relocation away from extended family and other support groups, and deployments, add to the complexity of ensuring comprehensive, coordinated care with continuity of providers and services. The key aspects of palliative care, that can ensure that the rest of the palliative care principles are implemented, are education of all who provide care and services to children with life threatening conditions and their families and care coordination across all aspects of care throughout the entire course of the child’s illness and in all settings of care.
Military treatment facilities commanders have the administrative flexibility to provide palliative care and care coordination to children with life-threatening conditions in their catchment area, using a variety of program designs as best fits their population, MHS resources (authorized by CHAMPUS and accessible through TRICARE or the military treatment facilities) and non-medical community resources.

It is recommended that:

1. Education and information appropriate to the provision of pediatric palliative care and access to necessary resources and services be made available to all health care providers and families of children with life-threatening conditions.
2. Care coordination is made available to facilitate communication, promote continuity during transitions, and assist in identifying and obtaining necessary resources and services for all children, with life-threatening conditions, and their families.
3. TRICARE Management Activity establish an interdisciplinary process team on palliative and end-of-life care for children and adults to review options, make guidance available, and address challenges within the MHS.
OPTIONS and IMPLEMENTATION STRATEGIES

Consistent with Department of Defense (Health Affairs) policy, military treatment facilities commanders have the administrative flexibility to provide palliative care and care coordination to children with life-threatening conditions in their catchment area, using a variety of program designs as best fits their population, MHS resources, available medical resource authorized by CHAMPUS (and available through TRICARE and the military treatment facilities) as well as non-medical military and community resources. The only restriction is the commander may not authorize a service outside the military treatment facility that is not a TRICARE benefit. Therefore it is feasible to implement pediatric palliative care programs in this environment.

Palliative care models have been developed in a variety of settings, and it is important to understand that one size does not fit all. Program models vary across the nation in their structure, staffing and service delivery model. Models differ according to the needs of the children and families they serve as well as factors such as the availability and qualifications of staff, budget constraints, and the population density of children with life-threatening conditions in the area of consideration. Without exception, each program observed during site visits completed for this project demonstrated the importance of taking small yet consistent and deliberate steps to promote the development and advancement of palliative care. Education and the provision of coordinated care to the population were also key strategies for improvement in delivering palliative care. In some settings, staff roles were re-defined or slightly modified to address the needs of this population. Each program also found it necessary to create a cultural change in the way care is provided and viewed at the end-of-life. Collaboration of providers and services within an individual facility and the development of partnerships with existing community efforts were critical to promote the growth of a PPC program and improve the delivery of care for children and families.

Flexibility in the design of a program is of particular relevance to the military health care system. Variations in the size of the military treatment facilities, the geographic distribution of the targeted population of those children with life-threatening conditions, and the settings of the delivery of medical services across the military system do not support the development of one exclusive model for the delivery of palliative care.

Through the use of assignment coordination and compassionate reassignments, many families with significant medical requirements are relocated to and concentrated near major military medical centers. Those families at smaller facilities and in duty assignments remote from military communities are more dependent on civilian services through the TRICARE provider networks.

There are a variety of program model design options that could be considered. One approach is to focus on patient care, with a dedicated PPC team that provides care directly or acts in consultation with the primary care and subspecialty physicians, who do provide care for these children. This team concept could be implemented on a case-by-case basis or directed towards certain specialty clinics within the facility. The consultative team approach has been shown to work in both the in-patient and out-patient settings (see the site visit report for The Children’s
Hospital, Denver, and Children’s Mercy Hospital, Kansas City). The “team” could be as small as a single provider, as long as the plan of care addresses and implements all the domains of palliative care. The key is to identify an individual within the military treatment facilities, who is knowledgeable and passionate about PCC and who can serve as a **program champion**. The necessary attributes of this individual were described in the Expert Panel section (See pages 98-99).

Another approach to a PPC model is to concentrate on a single process such as education or care coordination. The provision of additional care coordination, education about pediatric palliative care for health care providers or education for parents of children with life-threatening conditions would go a long way to filling many of the gaps in continuity, coordination, and communication that families find lacking in their child’s care.

Initiation of a pediatric palliative care program within a military treatment facility should begin with a local **site assessment** to understand the needs of the local population of children with life threatening conditions, the existing resources to support provision of palliative care in the specific locale, and the implications of implementing PCC on the existing staff. The following questions raise relevant issues that might be addressed in a site assessment:

1. What health care services are available for children with life-threatening conditions in our local military treatment facility, in the TRICARE network, and through community services in our area?
2. Who provides care coordination or case management for children in our military treatment facility, through the TRICARE contractor in our region, or through state and local programs for children with special needs?
3. What are the opportunities for providing continuity of relationships with physicians for children with complex medical needs in our military treatment facility? What resources are available to follow late-effects of treatment and address long-term needs of cancer survivors?
4. Which physicians and/or clinics provide a medical home for children with special needs in our facility? What opportunities do we have to organize the delivery of health care and care coordination so that more children with special needs could have a medical home?
5. What administrative challenges may create barriers to care for children with life-threatening conditions in our military treatment facility or with the TRICARE contractor in our region?
6. What education or support do parents of children with life-threatening conditions need in order to advocate effectively for their children in our healthcare system? Which healthcare providers in our military treatment facility are effective advocates for the children we serve?
7. What do the healthcare providers in our military treatment facility do well about communicating with children with complex medical needs and their families? What are the biggest challenges to good communication between healthcare providers and families? What processes do we have in place to facilitate communication between healthcare team members who provide care for a particular child?
8. What do the healthcare providers in our military treatment facility do to help parents make decisions about treatment for their children with life-threatening conditions? Do we use a communication tool or provide any particular approaches to education about options, risks and benefits of treatment?

9. What sources of social and emotional support are available for families who have children with needs for complex health care? What programs in our area provide practical support such as respite care, child care for healthy siblings, transportation or temporary housing?

10. What sources of financial support for times of crisis are available in our local military and civilian communities? What state or local funding is available for military families through Medicaid, Social Security, or Supplemental Security Income, and how can we help military families apply for this assistance?

11. What local religious communities provide support for families who have children with special needs? What education can we provide for healthcare providers about talking with families about their spiritual needs and questions about the meaning of the difficult circumstances they face with their children?

12. What do we do to improve the quality of life of children with life-threatening conditions and their families?

13. How do we approach discussions about DNR decisions for children? What additional education do our providers need about having DNR conversations with families? What are the local resources for pediatric hospice care?

14. What education about pediatric palliative care have the healthcare providers in our military treatment facility received?

15. What are the education needs of the military commands on our installation regarding children with complex healthcare needs? Who are the local experts regarding military regulations and processes for compassionate re-assignment, medical evacuation, permissive TDY, the Exceptional Family Member Program and other provisions of the military services for families who have children with serious medical needs?

Identification of services already in place at a facility will influence what personnel will make up the team and what model of service delivery may work best. Using resources that are already in place, particularly if new staff cannot be added due to budget constraints, provides a place to begin. This might require redefining existing job descriptions to include responsibilities for palliative care and providing appropriate education in palliative care principles and approaches to care.

There are clearly some basic services that any program should have in order to offer good pediatric palliative care. **Essential program and process elements** encompass what the program will do, who will do it and how. Of primary importance is an interdisciplinary approach that is family centered and focuses on the family’s physical, social, psychological, and spiritual needs. Additional important program elements include: an individualized written plan of care that reflects the family’s needs and choices and is flexible as the child’s status changes; some measures of quality of care and outcome; identified individuals who can assist families with care coordination. A care coordinator who understands PCC and has good knowledge of the available
resources and services for this population can ensure implementation of the family’s individualized plan of care, and provide continuity across all venues. Education of providers not only on the principles of palliative care but also on the communication skills necessary to ensure they listen to families’ needs and involve families in the decision-making process throughout the course of their child’s illness.

The major **strategy for implementation** is to initiate education and training of the staff, adapt personnel resources through either the expansion or realignment of traditional roles, and address the impact on any budget considerations. Most military treatment facilities will probably start small and build a PPC care program gradually. It may work well to begin with a clinic or unit with a large population of children with life-threatening conditions whose staff may be more receptive to the concept of pediatric palliative care, such as the Pediatric Intensive Care Unit, Neonatal Intensive Care Unit, or Hematology/Oncology service. Efforts to identify “turf” issues early to avoid confrontation and consideration of first offering support as a consultant to the existing care team may help provide a successful beginning.