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Integration of Palliative Care Principles into the Ongoing Care of Children with Cancer: Individualized Care Planning and Coordination

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Synopsis

The Individualized Care Planning and Coordination Model is designed to integrate palliative care principles and practices into the ongoing care of children with cancer. Application of the model helps

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clinicians to generate a comprehensive individualized care plan that is implemented through Individualized Care Coordination processes as detailed here. Clinicians' strong desire to provide compassionate, competent and sensitive care to the seriously ill child and the child's family can be effectively translated into clinical practice through these processes.

"To cure sometimes, to relieve often, to comfort always -- this is our work."

Author Unknown

Suffering is nearly universal in pediatric cancer patients and their families. Addressing this suffering is an ethical imperative. High-quality palliative care is now an expected standard during the treatment of children with life-threatening illnesses. An American Academy of Pediatrics (AAP) policy statement recommends that "all general and subspecialty pediatricians, family physicians, pain specialists, and pediatric surgeons need to become familiar and comfortable with the provision of palliative care to children."¹ The goal of palliative care is the best quality of life for patients and their families that is consistent with their values and priorities. Pediatric palliative medicine may be further defined as "the art and science of patient- and family-centered care aimed at enhancing quality of life, promoting healing and attending to suffering."² Inherent in these definitions is the need to integrate quality palliative care into the mainstream of medical treatment of all children suffering from chronic, life-threatening and life-limiting illnesses, regardless of the curative intent of therapy.

Improving the quality of palliative and end-of-life care through Individualized Care Planning and Coordination

Most parents of children with cancer have dual primary goals: a primary cancer-directed goal of cure and a primary comfort-related goal of lessening suffering.³ Early introduction of palliative care principles and practices into their child's treatment is both respectful and supportive of these goals. The Individualized Care Planning and Coordination (ICPC) Model (Figure 1) is designed to facilitate this integration.⁴ Individualized Care Planning emphasizes the value of subjective experiences in the context of meaningful personal relationships and employs a patient- and family-centered approach in information delivery, needs assessment, and understanding of the patient's and family's illness experience. It aims to enhance communication about difficult issues by discerning patient and family values and priorities before critical decision points are reached. Application of the ICPC model helps patients, families and their clinicians negotiate care options in the presence of uncertainty by assessing the patient's and family's understanding of prognosis, elucidating their goals of care and allowing them to choose from available goal-directed treatment alternatives. A comprehensive individualized care plan that balances medical and personal goals based on the relationship that has been established and the treatment options that have been chosen can then be generated.

Individualized Care Coordination, the process of implementing the individualized care plan, will be detailed here. Our purpose is to address specific clinical gaps in the care of children with cancer. We will highlight the deficiencies in the current provision of care, identify the national standards of care, recommend specific processes that should be integrated into pediatric oncology to fulfill the national standards, and identify research and education needs. The specific Individualized Care Coordination processes that are the subject of palliative and end-of-life care quality improvement efforts and will be discussed here include advance care planning; ethics consultation; care coordination; care continuity; symptom control; emotional, social, and spiritual care; end-of-life care; and bereavement care.

The further integration of palliative care into pediatric oncology practice can harness the inherent "healer" nature of cancer clinicians to enhance the quality of patients' and families'

lives. Clinicians' strong desire to provide compassionate, competent, and quality care to the seriously ill child and the child's family can be effectively translated into clinical practice through Individualized Care Planning and Individualized Care Coordination processes, allowing the primary care team as a unit and the health care system as a whole to better address their specific palliative and end-of-life care needs. The National Quality Forum (NQF), Institute of Medicine (IOM) and the National Institutes of Health (NIH) have identified palliative and end-of-life care as a national priority and proposed that palliative care should be a key component of high-quality medical care for children with advanced illness. The NQF has outlined preferred practices for ensuring the provision of high-quality palliative care. These practices are integrated into pediatric oncology programs at present with varying degrees of adequacy, but application of the Individualized Care Coordination processes is likely to fill many of the gaps (Table 1). Obtaining reimbursement for these processes is currently difficult, but codes to facilitate billing can be found in Table 2.

Attention to the relational aspects of the ICPC model is of utmost importance as parents' perceptions of the quality of care emphasize caring and communication themselves more than any specific interventions or biomedical parameters.^{5, 6} More importantly, these care processes must be evaluated in regards to the impact on the quality of palliative care delivered (e.g. quality indicators for comfort care, interdisciplinary collaboration, enhanced health care provider communication, care of the imminently dying child, etc) and on patient and family outcomes (e.g. coping, family cohesion, satisfaction with care, improved symptom control, greater patient and family participation in decision making, optimal physical and psychosocial functioning, optimal quality of life for patient and family and/or uncomplicated bereavement).⁷

In order to improve palliative care competence and improve quality, a number of approaches have been used to reduce the palliative care educational gap.⁸ Important needs include curricula to "educate the educators" and faculty guidelines for teaching palliative medicine at the bedside and during rounds; both must be supported by standardization of didactic learning opportunities.⁹ Several tools are now available, including Education in Palliative and End-of-Life Care (EPEC), End-of-Life Nursing Education Curriculum (ELNEC), and Initiative for Pediatric Palliative Care (IPPC). However, none of these curricula have been assessed for improvement of the quality of care. Another example is the Harvard Medical School program in Palliative Care Education and Practice (PCEP) curriculum for palliative care faculty which integrates clinical content with educational methods to enhance clinical faculty's capacity to model and teach.^{9, 10} Although these interventions have not yet been linked to quality improvement outcomes, any effort to improve the quality of palliative and end-of-life care in pediatric oncology must be accompanied by an educational strategy to enhance the level of competence among health care providers in regards to both palliative and end-of-life care skills and understanding of Individualized Care Planning and Individualized Care Coordination processes.¹¹

Advance Care Planning

Decision making is a challenge for all involved in the care of pediatric cancer patients. Parents surveyed 6 months to 2 years after their child died of cancer reported few opportunities to participate in treatment decisions until near the end of their child's life. The four most common difficult decisions they identified were whether to pursue more chemotherapy or to discontinue disease-directed treatment; whether to choose a phase I therapy versus no cancer treatment; whether to maintain or withdraw life support; and whether to adopt a "do not resuscitate" (DNR) order.¹² Like adult cancer patients, pediatric cancer patients and their parents identify hope for a cure or for longer survival as a major factor in the decision to receive phase I chemotherapy versus palliative care only.¹³⁻¹⁸ Not only are each of these decisions

emotionally laden, but the ways in which they are approached by patients, families, and care providers often differ.

Evidence suggests that avoiding or delaying discussions about end-of-life decisions may influence the type and quality of care. A survey of bereaved parents and their child's former physician showed that when both the parent and the physician recognized that there was no realistic chance for cure 50 days or more before the child's death, there was a statistically significantly earlier discussion of hospice care, better parental ratings of the quality of care delivered by the home care team, earlier institution of a DNR order, and less cancer-directed treatment during the last month of life.³ The Advance Care Planning process can facilitate end-of-life care decisions by improving parents' emotional support, quality of information, and medical understanding and by enhancing the listening skills and sensitivity of health care providers.^{19, 20} Further, as stated earlier, parents value communication and relationships over biomedical measures of success.⁵ Therefore, the Advance Care Planning process supports what parents value and is likely to enhance satisfaction by addressing parents' perceptions of good quality.

An environment conducive to optimal Advance Care Planning enhances decision making. As described by the American Society of Clinical Oncology (ASCO), communication should be "both family centered and child focused."²¹ Optimally, end-of-life decisions should flow naturally from an ongoing conversation between the patient, family, and medical care team about care priorities. Essential to this process is a trusting relationship established through Individualized Care Planning in which information can be shared non-judgmentally.^{4, 21} Parents value emotional expression and support from care providers, and "being supported by staff" was among the factors most frequently identified as influencing their decision making.²² Also, parents indicate that they prefer to know at the time of diagnosis that their child may not survive and want the treating team to alert them to changes in their child's clinical status and to available care options.¹²

Adults identify a sense of control of decisions as an element of quality end-of-life care, and patient involvement in decision making is key.^{23–25, 21, 26, 27} Less clear is how and at what age pediatric patients should participate in end-of-life decisions. Engaging the child recognizes his stake in the decisions being made and respects his capacity for informed decision making. Eighty-nine percent of parents of childhood cancer survivors reported that they would allow a child as young as 4 years to be involved in a decision to pursue experimental chemotherapy.²⁸ Also, in a study of end-of-life care preferences, children as young as 10 years recognized that they were involved in an end-of-life decision, understood its consequences, and demonstrated the capacity to weigh complex issues, including potential risks to themselves and others.²⁹ Parents of children with cancer also identify "making decisions with my child" as a major factor in their own decision making.¹² Parents, surrogates and health care providers must recognize the subjective nature of suffering and respect the child's autonomy and capacity to make decisions, particularly if the patient is an emancipated or mature minor.³⁰ If possible and indicated, caregivers should invite children to participate in decisions about their own care and honor their wishes, recognizing the personal context in which the illness unfolds.²⁶ Recognition of the unique contributions of the parents and the child to the discussion and integration of their input into the decision process ensures a truly family-centered approach to care.

As a facilitator of decision making, the clinician must understand the child's and family's perspective on the illness and its impact on their lives. Beliefs, values, hopes and fears shape their perspective and must be understood to guide them through the process. Patients and families also need clear, accurate information about prognosis in order to weigh the benefits and burdens of treatment options and prepare to make difficult decisions about their care,

particularly at the end of life. However, physicians report providing a frank estimate of survival likelihood only 37% of the time; 70% of discrepant survival estimates were overly optimistic.³¹ Despite the evident underdisclosure of prognosis, “information from health care professionals” was the factor most frequently reported by parents of children with cancer to influence their decision making.¹²

Effective communication of the prognosis is the foundation for establishing realistic goals of care. Over time, goals may shift as prognosis changes or as the patient’s and family’s priorities change. Goals of medical treatment must be integrated with personal goals to ensure holistic decision making. Neglect of the emotional and social aspects of care goals can lead to medical decisions that increase patient and family suffering.³² After care goals are established, treatment options can be weighed in terms of their benefits, burdens, and contribution to achieving the identified goals.

The Advance Care Planning process must be documented in the medical record where it can be easily shared with members of the interdisciplinary care team and across health care settings. We have found the four-box method for clinical ethics developed by Jonsen et al. to be a particularly useful tool to organize and document the rationale behind the decisions made. (Table 2).^{20, 33}

Ethics consultation

Generally, clear and open communication throughout the illness trajectory yields a consensus about care. Conflict may occur when the patient or family receives inadequate information about prognosis and treatment options or has limited opportunity to process this information and consider their goals and priorities. In pediatric oncology, some families will have unrealistic expectations and, even with the best communication (e.g., utilization of the Advance Care Planning process), will demand treatments that are medically inappropriate on the basis of existing standards. In these cases, frequent weighing of the benefits and burdens of medical interventions with the help of a patient advocate and the involvement of an ethics committee are recommended to allow deliberation about medical decisions in a safe atmosphere.

In palliative and end-of-life care, the Ethics Consultation process should function as the back-up of the Advance Care Planning process, as the primary responsibility for medical care and resolution of ethical problems in patient management lies with the physician, the health care team, the patient, and the patient’s parents/family/guardian. An ethics committee should be available, particularly at times of conflict, to provide consultation about ethical dilemmas related to patient care, facilitate physician-family-patient communication, and assist in the resolution of complex situations. This process should be confidential and aimed at facilitation of communication, conflict resolution, and support of relationships rather than making specific treatment recommendations.

The ethics committee also plays a palliative care role in regard to the development and implementation of care policies that support the decision making process, enhance symptom control, promote care coordination and continuity and facilitate care of the child and family throughout the illness trajectory including bereavement, and across multiple care settings.

Care Coordination

The Care Coordination process involves interdisciplinary communication and collaboration that links children with special health care needs to the appropriate services and resources throughout the disease trajectory. The goal is to limit fragmentation of care by orchestrating the delivery of medical services while advocating for comfort and quality of life. Children with cancer and their families must navigate an extremely complex modern health care system

involving multiple caregivers from a variety of backgrounds and disciplines. Pediatric oncology has long functioned as the model for multidisciplinary care, but in reality care is extremely fragmented. Families must become experts in inpatient care, outpatient clinics, and the home health system and, to keep their child's life as "normal" as possible, they must stay connected with community resources, including school, church, etc. This process is complicated by economic and sociocultural barriers, as there is no single point of entry into the multiple systems of care.^{34, 35} The IOM has identified care coordination and care of children with special health care needs as priority areas for quality improvement and has recognized the "medical home" as the optimal venue for care coordination and family-centered care.^{36,37}

Pediatric oncology programs are considered the medical home for children with cancer. The AAP describes the medical home as a means of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.^{34, 35} The goals of the medical home are therefore process-oriented rather than static. They include an integrated plan of care; documentation and database management; sharing of information across disciplines, providers and settings; patient and family education and support; and ongoing evaluation.

Barriers to pediatric oncology programs' achievement of these goals include: utilization of resources that do not fall under the umbrella of the medical home; inadequate reimbursement for additional administrative responsibilities, including documentation and counseling; lack of continuity in care across multiple service providers; lack of communication and collaboration between the oncologist and other specialists; lack of communication between the care team and community agencies; undefined roles of the care team and community agencies; time considerations; and cultural and language barriers.

Collaboration has been identified as the central principle of care coordination by the AAP.³⁵ The NIH also notes that effective communication between disciplines is a particularly important aspect of palliative care in pediatrics.^{27, 38} Multiple disciplines are well represented in current clinical settings, but often they provide their services in isolation from one another and with limited communication. Interdisciplinary teams share information, and their work is guided by the individual patient's needs. The medical home is best served by integrating elements of a transdisciplinary approach into an interdisciplinary framework, in which roles and responsibilities are shared and there are few seams between the members' functions.³⁹ While this approach is limited in specialized medical procedures and interventions, it is valuable in the exchange of general planning, psychosocial and spiritual information.

The interdisciplinary team meeting is at the center of the Care Coordination process and promotion of an interdisciplinary and transdisciplinary approach to the patient and family. While pediatric oncology centers often meet to discuss patients (e.g., tumor board, psychosocial rounds, etc), the interdisciplinary team meeting seeks active participation of members from a variety of disciplines to discuss specific patient and family care issues. A summary of these meetings is usually documented as part of a comprehensive care plan. Participation of the patient and/or family in these meetings may be recommended in some circumstances. Their purpose is to come to a common understanding of the patient's clinical condition and treatment goals. They are the perfect opportunity to communicate as a team about specific decisions made during the Advance Care Planning process and important physical, social, emotional and spiritual aspects of care while enhancing interdisciplinary collaboration to implement a comprehensive care plan for the child and family. To better integrate care coordination into the mainstream of pediatric oncology care, interdisciplinary partnership should be promoted, a transdisciplinary approach should be taken, and interdisciplinary team meetings should be

implemented as part of routine care, particularly for patients with poor prognosis or those with advanced cancer.

Care Continuity

The benefits of early integration of palliative care and the many needs of pediatric oncology patients and their families underscore the importance of a coordinated interdisciplinary approach that links hospital, home health and hospice settings.^{40, 41} An increasing number of children with complex chronic conditions in the U.S. are dying at home, possibly as the result of shifting attitudes and decisions about palliative and end-of-life care and the greater capacity of the health care system to provide home-based services.⁴² The Care Continuity process allows access to coordinated, high-quality palliative care in which key therapeutic interpersonal relationships are maintained throughout the illness and across a variety of settings which can help the child and family regain a sense of personal control over their care.

The development of partnerships between pediatric oncology programs and local home health and hospice agencies is a key strategy to enhance the quality of palliative care throughout the patient's illness. From a hospital perspective, integration of palliative care principles and practices into the continuum of care (i.e., elaboration of a comprehensive care plan) and the creation of bridging programs between cancer center care and services provided in the community would be most beneficial. From a community perspective, pediatric hospice programs that are established within or in partnership with a home health agency and that collaborate with the cancer center would allow a more effective response to the patient's and family's needs from the point of diagnosis onward.

Until national health policy is implemented to compensate providers for Individualized Care Coordination processes including Advance Care Planning, Care Coordination and Care Continuity, individual pediatric oncology centers and home health and hospice programs must find creative solutions to overcome the many structural, financial, professional, regulatory, institutional and organizational barriers to these partnerships.⁴³ Possible strategies include identifying local advocates from a variety of disciplines, teaching interdisciplinary palliative and end-of-life care, providing medical leadership, and establishing a liaison nurse to represent palliative and hospice care within the hospital setting.⁴⁴ Integrating the palliative care physician consultant and a hospital-based individualized care coordinator into complex pediatric oncology cases is also useful. The value of interdisciplinary care planning and coordination and the use of patient care conferences to promote communication and collaboration between hospital, home health and hospice providers cannot be overemphasized.

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Working toward positive partnerships in the palliative and end-of-life care of pediatric oncology patients through the Care Continuity process also involves critical evaluation of strengths and weaknesses. Useful principles to guide the evaluation process include acknowledgment of the need for partnership, clarity and realism of purpose, commitment and ownership, development and maintenance of trust, establishing robust care plan arrangements, and organizational monitoring, review and learning.⁴⁵

Symptom Control

Few things are more heartrending than the suffering of a young patient ravaged by cancer and its treatment. Timely and skilled management of pain and symptoms is the cornerstone of palliating suffering.⁴⁶ Integrating palliative care principles and practices into the mainstream of pediatric oncology programs requires appropriate attention to expected and unexpected symptoms from the point of diagnosis onward through a specific Symptom Control process. The patients themselves have told us that distressing symptoms are highly prevalent and of a

high intensity during cancer treatment.^{47, 48} The pediatric pain literature now clearly demonstrates that “there is no such thing as a little stick” and that the effects of underdiagnosed and undertreated pain as well as unrelieved procedural pain are long-lasting.^{49, 50} The same may apply to many other symptoms yet to be studied in this manner. Symptom management and attention to the suffering of children experiencing a cancer-related death must be comprehensive.^{51, 52}

Children and adolescents who die of cancer experience many physical symptoms, including pain, fatigue, behavior changes, breathing changes and dyspnea, reduced mobility, nausea and vomiting, anemia and bleeding, loss of appetite and many others.^{52–57} Pain, poor appetite and fatigue are usually cited as the most common symptoms. Many of these symptoms are widely reported to be untreated or unsuccessfully treated.^{52, 56} This deficiency is at odds with the main goals of parents, which include both cure or life-prolongation *and* relief of suffering.³

These children and their families suffer not only physically but psychologically. Patients are reported to experience sadness, difficulty in discussing their feelings about dying with their parents, and fear of being alone. Parents most frequently experience fear of the child’s death and fear of the child’s physical symptoms.⁵⁸ Other psychological symptoms frequently encountered in pediatric oncology include anxiety, excessive worry, depression and irritability.^{52, 59}

Effective symptom control is essential to provide high-quality palliative care. However, there are few reliable, valid, and developmentally appropriate instruments for measurement of symptoms in children, and the symptoms that are most concerning to the child at end of life have not been identified.⁴⁶ Appropriate instruments to measure these symptoms and the distress they cause in children dying a cancer-related death should be developed and researched. Interestingly, in children with cancer the presence or even the severity of a symptom may not predict the distress it causes to the dying child, family, and health care providers.^{47, 59} Our experience suggests the need for a specific Symptom Control process in order to provide a more systematic approach to symptom assessment. An interdisciplinary approach is crucial as significant spiritual, emotional and existential distress is frequently identified.

Conscientious symptom assessment and management must be incorporated into mainstream pediatric oncology in a more systematic way. In fact, distressing symptoms should be treated as a medical emergency and monitored at regular intervals. Although the cancer-related death of a child can frequently be anticipated and the symptomatology is well-described, many issues interfere with optimal symptom management at end of life. The literature suggests that palliative care specialists are consulted mainly for children with unmanageable symptoms or children in the home setting who have complex symptom management needs. Parents indicate that their dying child’s symptoms at the end of life were better controlled or less problematic when a provider with a specialized level of training in palliative care was available.^{52, 60, 61} Clinicians with expertise in symptom management should be integrated into the primary oncology team to allow an ongoing therapeutic relationship with the child and family and to promote symptom control education.

The National Comprehensive Cancer Network (NCCN) has developed clinical practice guidelines for management of cancer- and treatment-related emesis, anemia, fatigue, distress, and pediatric pain. These guidelines and other appropriate symptom management techniques should be integrated into pediatric oncology programs so that distressing symptoms are managed from the point of diagnosis onward. Evidence-based symptom control practices (e.g., haloperidol for terminal delirium) should be properly implemented and evaluated, including effective non-pharmacologic approaches (e.g., hypnosis, acupuncture, relaxation techniques), and continuity of services across settings should be emphasized. Because clinical care

providers for children at the end of life report being unfamiliar or uneasy in identifying and treating symptoms, provider education about symptom management must be promoted.^{60, 62, 63} In addition, pediatric oncology programs must be better equipped for symptom management in the home setting, where parents often choose to have their child die.^{64, 65}

Emotional, Social, and Spiritual Care

Compassionate, competent and sensitive care of the seriously ill child and the child's family requires ongoing, interdisciplinary patient- and family-centered assessment of emotional, social, and spiritual needs. This assessment identifies the values and priorities of the parent/s and the ill child (when possible) and provides an indicator of the effectiveness of the comprehensive care plan.^{66–68} Family culture (values, beliefs, attitudes and dynamics) defines what a family perceives to be medically appropriate care in different situations.⁶⁹ Clinicians collaborate with the child and the family to incorporate their values and priorities into care planning and care goals.^{4, 70} Ongoing, regular assessment of patient- and family-centered needs allows the family and the clinical care team to jointly formulate a care plan to deal appropriately with the immediate clinical situation and lays the foundation for future collaboration in the formulation of comprehensive care plans.⁷¹

An ongoing emotional, social and spiritual assessment requires that clinicians listen intensely and respectfully to gain an understanding of the child's and family's relationships, preferences and priorities.⁷² Such care priorities may shift rapidly with the child's clinical condition or treatment options. As a result, clinician assessment of patient and family needs must be an ongoing combination of formal and less formal assessment queries. Informal assessments can be brief—for example, a single query to revisit care priorities after a clinical change. Formal assessments tend to be documented on care planning forms that become a part of the child's medical record.

There are a limited number of available instruments for formal assessment of emotional, social and spiritual needs of the child or family. Clinically useful palliative care instruments (which include emotional, social, and spiritual parameters) are developmentally appropriate for children, brief, clearly worded, use a limited time frame (such as the past 24-hours or current week) because of the likelihood of rapidly changing conditions, and are sensitive to change. Very few comprehensive instruments exist and none has been validated in the pediatric oncology setting at end of life. More such instruments are needed to prevent the under-assessment and under-treatment of suffering in children with cancer and their families.⁷³

Clinically, it is useful to apply both a generalist and a specialist approach to the provision of emotional, social and spiritual care. Physicians, for example, can aim to be psychosocial generalists and medical specialists, whereas social workers and psychologists can aim to be psychosocial specialists and have a general understanding of disease management and assessment of physical comfort. As another example, doctors and nurses can assess the broad spiritual concerns of patients and families in order to refer them to appropriate spiritual advisors, whereas chaplains must take into account the medical issues, plan of care, and prognosis to understand the context of spiritual needs and anticipate impending spiritual crises. All team members, given training, experience, and motivation, have the capacity to provide a generalist level of social, emotional and spiritual care.^{74, 75} It is crucial that these assessments be free of judgment and free of the clinician's own agenda. Collaborative working relationships, interdisciplinary team meetings, care coordination and patient care conferences are essential in the emotional, social and spiritual care of children with cancer and their families.

End-of-life Care

The principles and practices of palliative care can best be incorporated into the care of children dying a cancer-related death if specific processes are implemented. Parents report that end-of-life decisions are among the most difficult they face on behalf of their seriously ill child.¹² The End-of-life Care process includes advance care planning that focuses on the preferences of the patient and family, including desired location of death, potential care interventions, and other decisions such as DNR status or withholding/withdrawing artificial life sustaining therapies. However, parents also state that they want to be involved in care decisions during their child's final days and they appreciate the opportunity to do so. They want to be kept informed of changes in the child's condition and to participate in adjustments to the care plan. We do not fully understand the parental decision process or what factors influence it. Neither do we know the appropriate age at which children should be included in end-of-life decision making. Study findings indicate that many seriously ill children and adolescents can navigate a complex decision process in which risk is considered.²⁹ The Advanced Care Planning process should be used to better support and understand decision making in the care of the imminently dying child by ascertaining the patient's and family's priorities, values and goals. Patient and family preferences may help to determine referral to hospice care, the desired location of death, plans for funeral arrangements, and DNR status.

The End-of-life Care process also includes enhanced care coordination to facilitate an interdisciplinary approach to the patient and family. A coordinated interdisciplinary effort is crucial in working with the child and family near the end of life. As death becomes imminent, many parents notice less interaction with the medical team. Certain members of the care team may become less visible as curative efforts are replaced by comfort measures, but this change is difficult for families to comprehend, and parents report feeling abandoned.⁷⁶ These feelings of abandonment may complicate grief issues after the child's death. A change in caregivers during the last, and often the most intense, days of illness can be stressful for both the patient and family. Maintaining open communication is essential for this reason. Parents report that receiving consistent information from a consistent team is very helpful at these times.⁶⁰ Team members, however, frequently report not knowing the patient's current clinical status, what decisions have been made, or the content of discussions between other clinicians and the family. A focus on care coordination, including patient care conferences and interdisciplinary team meetings, is essential to maintain the lines of communication and effectively provide the support needed by patients' families.

The End-of-life Care process includes care of the imminently dying patient and the patient's family but should be implemented well before death is imminent. Cancer patients near death have symptoms that are often not treated or are treated unsuccessfully, despite parents' great concern that their child not suffer at the end of life.^{52–58} Bereaved parents who report unrelieved pain in their dying child have been found to experience long-term distress.⁷⁷ Comprehensive, systematic symptom assessment should be ongoing for all children dying a cancer-related death. Aggressive symptom control is crucial during this time, as many patients suffer at the end of life, and their suffering also leads to poor family and caretaker outcomes.

Aside from physical symptoms, psychosocial and spiritual needs are consistently identified as very important to patients and their families.²² Psychological concerns are frequently under-addressed but should be managed as aggressively as physical symptoms. Many clinicians are not trained to address the spiritual concerns of patients and families and this aspect of care is also frequently unattended. Clinicians may understand and care about the spiritual and religious needs of the patient and family but may not know how to help.⁷⁸ Parents and children, however, state that they feel a connection to a religious or spiritual domain at end of life and belief in a "Greater Being" is very important for parents at the time of end-of-life decision making and care.^{12, 79}

Of note, communication is of utmost importance at all times, but its significance is heightened during the final days and hours of a child's life. Caregivers find it extremely difficult to shift from the "doing" mode to one in which we are willing to sit and "be" with the patient and family, witnessing the mysteries of suffering and death. Open, honest, thoughtful and caring communication at this time can provide emotional comfort in a situation filled with unknowns and fear. Finally, conducting end-of-life debriefing sessions can also help the staff cope with the tragedy of losing a patient who is at the dawn of his or her life.

Bereavement Care

Although survival rates for pediatric cancer are improving, many patients still die leaving bereaved families trying to cope. Adults experience a higher intensity of grief after their child's death than after a spouse's or parent's death.^{80,81, 82} Support for bereaved families must be a priority in pediatric oncology as bereaved parents have an elevated risk of psychiatric hospitalization even 5 or more years after their child's death and have a higher risk of early death and poorer health outcomes.^{83, 84}

The treatment of pediatric cancer places many burdens on families. Children receiving treatment for cancer are often hospitalized far from home for lengthy periods, geographically separating family members and reducing access to social support from friends and extended family. Parents often come to depend on the hospital staff for their psychosocial needs. When their child dies and these services are no longer available, families may feel abandoned by hospital staff.⁸⁵ The majority of families desire some continued contact with members of their child's care team and report that the contact is meaningful to them.^{60, 76, 86, 87}

Approximately 45%–59% of pediatric cancer deaths occur while the child is hospitalized.^{19, 81, 88} Unlike hospice, which has clearly established guidelines for care of bereaved families, many hospitals do not provide formal bereavement care.⁸⁹ The Bereavement care process should include an interdisciplinary and appropriately trained team; bereavement follow-up services should be offered for at least 12 months; and family members should be clinically assessed to identify those at risk of complicated grief.⁴⁰

A practical approach for providing care for bereaved families begins when the child is first admitted for treatment. The foundation is laid for future relationships during the early stages of the child's treatment. Using a "hope for the best, plan for the worst" approach enables care teams to help prepare a family for loss, which in turn may lower the risk of psychological disturbance after the death. The goal of integrating bereavement care into the mainstream of the child's care also suggests the need to develop and implement effective evaluation tools that permit the team to identify families at risk of complicated bereavement. Initial assessments by chaplaincy and social work can alert the team to families whose coping may be less than adaptive. The individuals most at risk are often those most reluctant to seek help; this factor can complicate attempts at intervention.⁹⁰ Individuals who lack a good social support network and those with a childhood history of neglect and abuse are at highest risk of complicated bereavement.

There are eight warning signs of complicated grief: trouble accepting the death; inability to trust others; excessive bitterness toward the death; uneasiness about moving on with life; detachment from other people to whom the person was previously close; the view that the future holds no prospect for fulfillment; and agitation since the death. These must be persistent and disruptive to the bereaved person, and must have lasted more than 6 months.⁹¹ In addition, family members displaying disbelief, yearning, anger, or depression six months after the death of the child may need further evaluation.⁹²

Thus, to identify and help people who may be suffering from complicated bereavement, the Bereavement Care process should be programmatic and must include regular contact between trained staff and family members over an extended period; which requires financial commitment to fund such support. A minimal hospital-based program for families whose child has died might include the following: the creation of a memento of the child, often a hand print or lock of hair, for the family; attendance at the funeral or memorial service by members of the primary care team when possible; a personalized condolence card sent by the team and telephone or written contact periodically, especially around the child's birthday, holidays and the anniversary of the child's death.^{60, 93–95} It is important that parents know they have "permission" to contact team members if they are experiencing problems, and that team members have the appropriate resources to make referrals to services in the parent's community. Many programs send appropriate books and other literature to families. Some hospitals hold annual events to honor the memory of children who have died and invite families to attend. While all of these efforts attempt to meet the needs of bereaved families, there is very little outcomes-based research to support their continued existence and justify their expense. Evidence-based practices should be developed and evaluated to improve interventions for bereaved parents. Expert opinion can be a useful starting point, but only formal assessment and outcomes measures can demonstrate that we are truly helping families and justify the expense of bereavement intervention.

Coding and reimbursement for hospice and palliative care services

Reimbursement practices for many of the care processes described in the ICPC model may be possible utilizing existing coding and reimbursement mechanisms.⁹⁶ The process utilized for billing and reimbursement depends on the role of the provider, the relationship of the health care professional with the agency providing the care and whether or not the patient is hospitalized, or receiving home health or hospice services. Billing and reimbursement processes differ between public and private insurers and across States. In general, claims for services provided by health care professionals are submitted by using the Current Procedural Terminology (CPTTM) evaluation and management code system.⁹⁷ CPT codes may be used by physicians and other health care providers for outpatient and inpatient visits for the Advance Care Planning, Care Coordination, and Symptom Control processes as well as for other psychosocial care processes. Useful CPT codes for qualified physicians are outlined in Table 3. In addition to CPT codes, physicians may describe the reasons for their services by using one of the International Classification of Disease-Clinical Modifications codes (ICD-9-CM) produced by the National Center for Health Statistics.⁹⁸ When the palliative care consultant is also a pediatric oncologist, claims submitted for palliative care services must have a different diagnosis to minimize the risk of having the claim denied. ICD-9 codes commonly used in palliative care are listed in Table 4.

Attending physicians caring for hospice patients but who are not employed by the hospice may use CPT and ICD-9 codes to submit claims directly to Medicare Part B. Physicians employed by the hospice agency must submit patient care claims directly to the hospice agency. The hospice agency then submits these claims to Medicare Part A for reimbursement as part of their claims for the care of the patient. Consulting physicians that are asked to see a hospice patient must also submit their claims to the hospice agency which then reimburses the consultant directly based on preexisting contractual arrangements.

Under the Medicare Hospice Benefit, the *per diem* payment to the hospice covers all services provided by non-physician health care professionals. For patients who are not enrolled in hospice, non-physician professionals may be able to access fee-for-service reimbursement mechanisms either through Medicaid or private insurers. Useful CPT codes that can be used by non-physician providers are listed on Table 3. Health and Behavior assessment codes may

be used by qualified health care professionals for grief assessment and counseling (i.e., stress, coping, self-care, family cohesion). Neither evaluation/management codes for child life and spiritual care services nor procedure/service codes for care of bereaved family members of the ill child are available. Health and Behavior, and Psychiatric Therapeutic Procedure codes may be used for the evaluation of bereavement and/or management of pathologic bereavement but claims must be submitted to the insurer of the bereaved family member. Billing and reimbursement for physician and non-physician providers of palliative care services utilizing these billing and coding mechanisms may not be optimal and payment remains a challenge, particularly for bereavement care and when patients have not selected the Medicare Hospice benefit.

Conclusion

The goal of both pediatric oncology and pediatric palliative care involves curing as many children as possible while actively and effectively addressing suffering. According to the World Health Organization, “palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.”⁹⁹ An integrated palliative care approach to these children and their families requires that we acknowledge the current gaps in the structure of pediatric oncology programs and develop processes to fill these gaps. Implementation of Individualized Care Planning and Individualized Care Coordination processes will help meet these needs and facilitate the further integration of palliative care principles into the care of children with cancer. Through these processes, the therapeutic relationships established in the context of the medical home can best address the suffering of pediatric cancer patients and their families. Patient and family values, preferences, goals and needs will also be elucidated earlier in the course of illness so that appropriate goal-directed treatment options can be offered in times of uncertainty and emotional duress.

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Figure 1.

The Individualized Care Planning and Coordination Model is designed to facilitate the integration of palliative care principles and practices into the ongoing care of children with cancer. The individualized care plan is implemented through individualized care coordination.

Table 1

Preferred practices for quality palliative and hospice care categorized by Individualized Care Coordination Processes.(Adapted from National Quality Forum: A National Framework and Preferred Practices for Palliative and Hospice Quality.)⁷

General	<ul style="list-style-type: none"> • Provide palliative and hospice care by an interdisciplinary team of skilled palliative care professionals. • Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, 7 days a week.
Education	<ul style="list-style-type: none"> • Provide continuing education to all healthcare professional on the domains of palliative care and hospice care. • Provide adequate training support to assure that health care providers are competent in palliative care. • Hospice care and specialized palliative care professionals should be appropriately trained, credentialed, and/or certified in their area of expertise.
Advance Care Planning	<ul style="list-style-type: none"> • Formulate, utilize, and regularly review a timely care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals, and needs of the patient and family. • Present hospice as an option to all patients and families when death within a year would not be surprising and should reintroduce the hospice option as the patient declines. • Assess physicians'/healthcare professionals' ability to discuss hospice as an option. • Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions. • Determine who is(are) the primary decision maker(s) within the family unit. If the child is able to participate, determine the degree of his or her participation. • Document the designated surrogate/decision-maker in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care. • Document the patient/parent/surrogate preferences for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as conditions change. • Convert the patient treatment goals into medical orders such as the Physician Orders for Life-Sustaining Treatment (POLST). • Document Advance Directives and surrogacy designations. • For minors with decision making capacity, document the child's views and preferences for medical care, including assent for treatment, and give them appropriate weight in decision making. • Make appropriate professional staff members available to both the child and the adult decision-maker for consultation and intervention when the child's wishes differ from those of the adult decision-maker.
Ethics Consultation	<ul style="list-style-type: none"> • Establish or have access to ethics committees or ethics consultation across care settings to address ethical conflicts at the end of life.
Care Coordination	<ul style="list-style-type: none"> • Provide education and support to families and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patient. • Conduct and document regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis, and advance care planning, and to offer support.
Care Continuity	<ul style="list-style-type: none"> • To the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and externally, to all professionals involved in the patient's care. • Ensure that medical orders such as the Physician Orders for Life-Sustaining Treatment (POLST) are transferable and applicable across care settings, including long-term care, emergency medical services, and hospital care. • Make advance directives and surrogacy designations available across care settings, while protecting patient privacy and adherence to HIPAA regulations, for example, by using Internet-based registries or electronic personal health records. • Ensure that upon transfer between healthcare settings, there is timely and thorough communication of the patient's goals, preferences, values, and clinical information so that continuity of care and seamless follow-up are assured. • Develop healthcare and community collaborations to promote advance care planning and the completion of advance directives for all individuals, for example, the Respecting Choices and Community Conversations on Compassionate Care programs.
Symptom Control	<ul style="list-style-type: none"> • Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales. • Assess and manage symptoms and side effects in a timely, safe and effective manner to a level that is acceptable to the patient and family. • Measure and document anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales. • Manage anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.
Emotional, Social and Spiritual Care	<ul style="list-style-type: none"> • Assess and manage the psychological reactions of patients and families (including stress, anticipatory grief, and coping) in a regular, ongoing fashion in order to address emotional and functional impairment and loss. • Develop and implement a comprehensive social care plan that addresses the social, practical, and legal needs of the patient and caregivers, including but not limited to relationships, communication, existing social and cultural networks, decision making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment. • Develop and document a plan based on an assessment of religious, spiritual, and existential concerns using a structured instrument, and integrate the information obtained from the assessment into a comprehensive care plan. • Provide information and make spiritual care available either through organizational spiritual care counseling or through the patient's own clergy relationships. • Include spiritual care professionals appropriately trained and certified in a palliative care.

- Build partnerships with community clergy and provide education and counseling related to end-of-life care.
- Incorporate cultural assessment, including but not limited to locus of decision making, preferences regarding disclosure of information, truth telling and decision making, dietary preferences, language, family communication, desire for palliative therapies and complementary and alternative medicine, perspectives on death, suffering, and grieving, and funeral/burial rituals.
- Provide professional interpreter services and culturally sensitive materials in the patient's and family's preferred language.

End-of-Life Care

- Recognize and document the transition to the active dying phase, and communicate to the patient, family, and staff the expectation of imminent death.
- Educate the family on a timely basis regarding the signs and symptoms of imminent death in an age-appropriate, developmentally appropriate, and culturally appropriate manner.
- As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for the site of death, and fulfill patient and family preferences when possible.
- Provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase, and address concerns and fears about using opioids and analgesics hastening death.
- Treat the body after death with respect according to the cultural and religious practices of the family and in accordance with local law.

Bereavement Care

- Develop and offer a grief and bereavement care plan to provide services to patients and families prior to and for at least 13 months after death of the patient.
- Facilitate effective grieving by implementing in a timely manner a bereavement care plan after the patient's death, when the family remains the focus of care.

Advance Care Planning Documentation Tool incorporating key components of the Individualized Care Planning process. (Adapted from Jonsen AR et al., and Hays RM, et al)^{20, 33}

Table 2

Demographic Information

Name:	Date:	Medical Record number:
Demographic Information		
Medical Issues	Quality of Life Issues	
1. From the medical team's perspective: List summary of patient's medical problems. History? Diagnosis? Is the problem acute? Chronic? Critical? Emergent? Is the patient's condition considered potentially curable? Is it incurable?	1. From the medical team's perspective: What are the prospects, with or without treatment, for a return to normal life? What physical, mental, and social deficits is the patient likely to experience during and after treatment? Are there biases that might prejudice the provider's evaluation of the patient's quality of life? Is there any consideration to forgo treatment in order to maximize quality of life? Are there plans for comfort and palliative care?	•
2. From the patient's and family's perspective: What are the plans in case of therapeutic failure? What are the patient and family's perceptions about prognosis for survival? Life expectancy? Suffering? What are the patient and family's perceptions about the medical goals and available goal-directed treatment options? Are there any particular medical decisions that the patient and/or family must make? (e.g. withholding cancer-directed therapy, participating in clinical trial, withholding or withdrawing treatment with curative intent, DNR)	2. From the patient's and family's perspective: How has being sick been for the child? Family? What are their needs, hopes, beliefs, values, expectations, fears, preferences? What does good quality of life mean for the child? Family? What are the most concerning or distressing symptoms that interfere with good quality of life? Is the patient's present or future condition such that his or her continued life might be judged undesirable?	•
3. In sum, how can this patient and family be benefited by medical care, and how can harm be avoided?	3. In sum, how can this patient and family be benefited by greater emphasis on quality of life, and how can suffering be minimized?	•

Patient and family's preferences	Contextual features	
1. Who is(are) the primary decision maker(s)? What are the information needs of the primary decision maker(s)? Has the primary decision maker(s) been informed of benefits and risks, understood this information, and given assent or consent? Is there evidence of incapacity of the primary decision maker(s) (e.g., age, cognitive or developmental status, mental illness?) Is the primary decision maker(s) using appropriate standards for decision making? Has the patient expressed prior preferences, e.g., Advance Directives? Is the patient, parent or surrogate unwilling or unable to cooperate with medical treatment?	1. What are the rights of the child relative to the rights of the family? 2. Are there family issues that might influence treatment decisions? (e.g., language barriers, psychosocial issues, place of residence in rural area?) 3. Are there health care provider issues that might influence treatment decisions? (e.g., no open research protocol) 4. Are there health care system issues that might influence treatment decisions? (e.g., limited resources, availability of treatment) 5. Are there financial and economic factors? (e.g., unfunded patient, illegal immigrant) 6. Are there religious or cultural factors? (e.g., end-of-life rituals, care of the body) 7. Are there limits on confidentiality? (e.g., divorced parents, extended family) 8. Are there problems of allocation of resources? (e.g., critical care, expensive technologies of limited benefit, home health and hospice care) 9. How does the law affect treatment decisions?	•
2. If the child-patient is capable of participating in the decision-making process: What is the extent of that participation?		•

Demographic Information

Name:	Date:	Medical Record number:
<ul style="list-style-type: none">• What is he or she stating about preferences for medical treatment?• What is he or she stating about preferences for quality of life?		10. Is clinical research or teaching involved?
3. If the child-patient is unable to participate in the decision-making process and someone else is making decisions on his or her behalf: <ul style="list-style-type: none">• What is the extent of their participation?• What is the parent or surrogate decision-maker stating about preferences for medical treatment?• What is the parent or surrogate decision-maker stating about preferences for quality of life?		11. Is there any conflict of interest on the part of the providers or the institution?
4. In sum, is the patient and family's right to choose being respected to the extent possible in ethics and law?		
Discussion		
Document discussion points		
Plan		
Document advance care plan		

Table 3

Evaluation and management codes for palliative care.

Attending/Managing Physician			
New Office	Established Office	Initial Hospital	Subsequent Hospital
99201 10 min	99211 5 min	99221 30 min	99231 15 min
99202 20 min	99212 10 min	99222 50 min	99232 25 min
99203 30 min	99213 15 min	99223 70 min	99233 35 min
99204 45 min	99214 25 min		
99205 50 min	99215 40 min		
New Home	Established Home	Interdisciplinary team meetings	
99324 20 min	99334 15 min	99361 30 min	
99325 30 min	99335 25 min	99362 60 min	
99326 45 min	99336 40 min		
99327 60 min	99337 60 min		
99328 75 min			
Consult Physician			
Office/Home	Initial Hospital	Subsequent Hospital	
99241 15 min	99251 20 min	99231 15 min	
99242 30 min	99252 40 min	99232 25 min	
99243 40 min	99253 55 min	99233 35 min	
Health and Behavior Assessment^{iv}	Reassessment^v	Individual therapy	Group therapy
96150 15 min	96151 15 min	96152 15 min	96153 15 min
Psychiatric Therapeutic Procedures^{vi}	Developmental assessment		
Diagnostic Interview	96111 1 hour		
Office/Home		Inpatient	Psychological testing
90804 20–30 min		90816 20–30 min	96102 1 hour
90806 45–50 min		90818 45–50 min	Interactive^{vii} visit/Office
90808 75–80 min		90821 75–80 min	90810 20–30 min
Group therapy		Family therapy without patient present	90812 45–50 min
90853 15 min		90846 15 min	90826 45–50 min
			90828 75–80 min
			Family therapy with patient present
			90847 15 min
		Without patient present	Neuropsychological testing
		96154 15 min	96118 1 hour
			Interactive visit/Inpatient
			90823 20–30 min
			90826 45–50 min
			90828 75–80 min
		With patient present	Mental Status Exam
		96155 15 min	96116 1 hour

For each subsequent 30 minutes:
99355

Prolonged Servicesⁱ

Inpatientⁱⁱⁱ

99357

ⁱThese add on codes are used if the time spent in counseling and/or information giving is more than 50% of the visit. Proper documentation is required.

ⁱⁱTotal time the physician spends face-to-face with a patient. In pediatrics, some but not all payers recognize time spent face-to-face with the primary decision-maker within the family unit. The time spent on activities related to the visit but not face-to-face with the patient and or family is not to be added to the visit.

ⁱⁱⁱTotal time the physician spends in the hospital unit, including the time spent in face-to-face contact with the patient and family, chart review, documentation and care coordination.

^{iv}Utilized by qualified mental health providers (i.e., physician, clinical psychologist, clinical social worker, nurse practitioner, clinical nurse specialist or physician assistant) in the absence of psychiatric illness (i.e., coping, self-care, poor family cohesion, when they interfere with the care of the patient). Each 15 minutes of visit is claimed as a unit, a 60 minute visit is claimed as four units.

^vUtilized by qualified mental health providers (i.e., psychiatry, clinical psychologist) for the treatment of a psychiatric condition (i.e., anxiety disorders, depression, individual and/or family dysfunction during complicated bereavement).

^{vi}Interactive visit codes are used when the health care professional utilizes equipment and other resources to provide care (i.e., rehabilitation unit).

Table 4

Palliative care diagnoses - ICD-9 codes and description.

263.9	Inanition	780.01	Coma	780.96	Generalized pain
286.6	Dyspnea	780.09	Unconscious	789.00	Abdominal pain, unspecified site
298.9	Confusion	780.39	Convulsions	789.01	Abdominal pain, right upper quadrant
783.0	Anorexia	780.4	Dizziness	789.02	Abdominal pain, left upper quadrant
300.00	Anxiety state	780.52	Insomnia, unspecified	789.03	Abdominal pain, right lower quadrant
300.20	Phobia	780.54	Hypersomnia	789.04	Abdominal pain, left lower quadrant
307.9	Agitation	780.55	Disrupted 24 hr sleep wake cycle	789.05	Abdominal pain, periumbilic
308.3	Acute reaction to stress	780.6	Fever	789.06	Abdominal pain, epigastric
309.0	Maladjustment, depressed mood	780.79	Malaise and fatigue	789.07	Abdominal pain, generalized
309.28	Maladjustment, anxiety, depressed mood	780.9	Mental status change	789.09	Abdominal pain, multiple sites
309.83	Maladjustment, withdrawal	782.1	Rash	724.5	Backache, unspecified
309.9	Unspecified adjustment reaction	782.3	Edema	724.1	Pain in thoracic spine
311	Depressive disorder	783.0	Anorexia	724.2	Lumbago
313.0	Overanxious disorder	783.1	Abnormal weight gain	729.5	Pain in limb
338.3	Neoplasm related pain	783.21	Loss of weight	733.90	Pain in bone
459.0	Hemorrhage, unspecified	784.0	Headache	786.50	Chest pain
527.7	Disturbance of salivary secretion	785.1	Palpitations	719.45	Pain in hip
528.01	Mucositis due to antineoplastic therapy	786.05	Shortness of breath	729.1	Muscle pain
528.09	Stomatitis and mucositis	786.2	Cough	724.60	Sacroiliac pain
558.9	Diarrhea	787.01	Nausea with vomiting	784.1	Throat pain
564.00	Constipation	787.02	Nausea alone	723.1	Neck pain
698.9	Unspecified pruritic disorder	787.03	Vomiting alone	799.3	Debility
707.00	Decubitus ulcer, unspecified site	787.2	Dysphagia	V61.8	Other specified family circumstances
728.85	Spasm of muscle	787.91	Diarrhea	V62.82	Encounter for bereavement
		799.2	Nervousness	V66.7	Encounter for palliative care
		780.97	Altered mental status, delirium		