

# QUEBEC STANDARDS OF PRACTICE FOR PEDIATRIC PALLIATIVE CARE



---

# QUEBEC STANDARDS OF PRACTICE FOR PEDIATRIC PALLIATIVE CARE

---

English Translation

**Working Group on Standards  
of Practice for Pediatric Palliative Care**

## Supervision

Brigitte Laflamme, Assistant Director, Québec Centre for Cancer Control, *Ministère de la Santé et des Services sociaux*

Dr. Antoine Louffi, Director, Québec Centre for Cancer Control, *Ministère de la Santé et des Services sociaux*

## Writing

Dr. Linda Côté-Brisson, Working Group Chair and Coordinator, Palliative Care Physician, *Centre hospitalier universitaire de Québec, Hôtel-Dieu de Québec*

## Writing Assistance

Dr. Jacques Brisson, ScD, Epidemiology, Population Health Research Centre, *Université Laval* and *Institut national de santé publique du Québec*


Jocelyn Châteauneuf, Research Officer, Québec Centre for Cancer Control

Mélanie Kavanagh, Research Officer, Québec Centre for Cancer Control

## Administrative Support

Hélène Mercier, Secretary, Québec Centre for Cancer Control

## English Language Version:

Facilitation:  **Canadian Hospice Palliative Care Association**  
**Association canadienne de soins palliatifs**

**Supervision** – Greg Adams, Office Manager, Canadian Hospice Palliative Care Association

**Translation** – Josephine Versace, Certified Translator, OTTIAQ

**Revision** – Dr. Linda Côté-Brisson, Working Group Chair and Coordinator, Palliative Care Physician, *Centre hospitalier universitaire de Québec, Hôtel-Dieu de Québec*

**Production** – Translation and production of the English language version of this document has been supported by a financial contribution from the Ronald McDonald House Charities®



Published by:

**La Direction des communications du ministère de la Santé et des Services sociaux**

Copy authorized by: Les Publications du Québec

This document was published in French in limited quantity and is now available only in electronic format.

[www.msss.gouv.qc.ca](http://www.msss.gouv.qc.ca); section: **Documentation**; heading: **Publications**

The original French document, entitled *Normes en matière de soins palliatifs pédiatriques*, was published by the *Ministère de la Santé et des Services sociaux* (MSSS).

The MSSS declines all liability with respect to this English translation and any damage, loss or prejudice that may be incurred in connection with it. In the event of an inconsistency between the English and French versions of the document, the latter shall prevail.

Legal Deposit

Bibliothèque et Archives nationales du Québec, 2006

Bibliothèque nationale du Canada, 2006

ISBN 13: 978-2-550-47641-2 (French printed version)

ISBN 10: 2-550-47641-7 (French printed version)

ISBN 13: 978-2-550-47642-9 (French PDF version)

ISBN 10: 2-550-47642-5 (French PDF version)

The reproduction of this document, in whole or in part, is permitted provided that the source is indicated.

© Gouvernement du Québec, 2006



## A MESSAGE FROM THE MINISTER

It is with pleasure that I present to you the document entitled *Normes en matière de soins palliatifs pédiatriques (Québec Standards of Practice for Pediatric Palliative Care)*. Developed by a specially mandated working group, this document is intended for healthcare teams working with children and their families. It constitutes a point of reference that can be used to establish standards of practice so that children, adolescents and their families receive the special attention they require because of their unique needs and the inherent difficulty in facing a premature death.

These standards now position Québec as a leader in pediatric palliative care. Putting them into practice will serve as one more example of Québécois' willingness and ability to innovate by providing services adapted to the needs of children and their families.

I hope these standards become a reference in the field of pediatric palliative care. I encourage you to give them your full attention: their success rests on the commitment of every individual and healthcare team working with sick children and their families.

Philippe Couillard

Minister of Health and Social Services



## Message from the Québec Centre for Cancer Control

The *Québec End-of-Life Palliative Care Policy* states that children and adolescents in palliative care and their families deserve special attention. In the winter of 2004, the Québec Centre for Cancer Control appointed a working group to develop and establish standards of practice for pediatric palliative care.

I am pleased to present their work to you, and I wish to thank the group for their unremitting diligence and commitment, particularly Dr. Linda Côté-Brisson, who coordinated the project with great determination.

The standards and criteria in this document were designed to foster an interdisciplinary approach and a commitment to continuous improvement for pediatric palliative care. They also shift the emphasis to the needs of children and their families. These standards are based on a review of the literature and on extensive consultations with experts, parents, health care providers, community resources and volunteers.

Special emphasis was placed on certain aspects of pediatric palliative care practice through the study of organizational models specifically developed for this clientele. In addition, criteria are suggested for each standard so that they can easily be implemented.

The document also includes a monitoring and evaluation tool to help in the implementation of the standards. This is an easy-to-use and practical tool for all healthcare teams seeking to provide pediatric palliative care or improve the quality of existing care.

Antoine Loutfi, M.D., FRCSC, FACS  
Director  
Québec Centre for Cancer Control

Brigitte Laflamme  
Assistant Director





## Summary

In the fall of 2004, the Québec Centre for Cancer Control, *Ministère de la Santé et des Services sociaux* (MSSS, Québec's ministry of health and social services), created a working group to establish standards of practice for pediatric palliative care in Québec. The resulting work promotes a standardized and coordinated approach that ensures that children and their parents receive quality palliative care, wherever they live or receive care.

The standards serve as a point of reference and seek to achieve excellence. Criteria have been developed for each standard so that they can translate into specific measures and concrete actions. Using these criteria, healthcare teams and institutions can assess their performance, focus on areas in need of improvement and find solutions to problems they have identified.

The standards are intended for all healthcare teams who treat children with palliative care needs, provide services to their families, and for those who organise services and training in the field of pediatric palliative care. The care teams include the primary care team as well as the palliative care team, regardless of where they work within the healthcare network.

Over the course of its mandate, the working group reviewed international definitions of pediatric palliative care. A review of the scientific literature, relevant Internet websites, and grey literature served as the basis for the development of the standards. Special focus was placed on certain aspects of pediatric palliative care, such as the needs of children and their families, quality of care, stages of pediatric palliative care and organizational models developed specifically for children. The working group drew upon the experience gained through both adult palliative care and the pediatric palliative care initiatives conducted in Québec and the rest of Canada, as well as consulting with key stakeholders in the province. The group studied various policy- and standard-based palliative care initiatives conducted in other countries, including Australia, the United States, France, the United Kingdom and New Zealand.

The standards were divided into four areas of focus:

- I) child- and family-centred care;
- II) interdisciplinarity;
- III) continuous quality improvement;
- IV) clinical governance.

A broad consensus exists among pediatric palliative care professionals that a child- and family-centered approach to care, in which the child is the primary concern, should be favoured. The child's quality of life and that of the family are inextricably linked, and maintaining this quality of life constitutes the primary goal of palliative care. The 'family', in this context, includes the mother, father, siblings, grandparents and any other individual who may have a significant bond with the child or parents. A child- and family-centered approach to care helps children and their families reach their physical, psychological, social and spiritual goals. Standards of child- and family-centered care deal with meeting the needs of children and their families, communicating, participating in decision-making and providing continuity of care.

Working as part of an interdisciplinary team allows healthcare providers to join their efforts and make the best use of their complementary expertise. An interdisciplinary team involves collaboration between health care providers, children and their parents. The composition of a team offering palliative care to children depends on the expertise necessary to respond to the required needs. The support provided by healthcare institutions is critical to the success of any interdisciplinary team. The standards of practice therefore

address the make-up of an interdisciplinary team, how the team works and the support it should be able to count on.

Healthcare providers and teams must maintain their competencies in pediatric palliative care through appropriate training and current evidence-based practice. To training should be added a continuous quality improvement program integrating an evaluation of practices and service organisation, and the participation of the team or some of its members in research. The standards therefore address pediatric palliative care training requirements, evidence-based practice, evaluation of practices, and research.

Clinical governance is founded on a common vision of the objectives to be achieved. By working together, administrators and clinicians can maximize resources, structures and processes to achieve their quality objectives. Clinical governance creates an organizational climate that is conducive to achieving excellence and promotes quality clinical work. Recognizing the unique health needs of children and their families is a necessary part of sound clinical governance in pediatric palliative care. Institutions, health and social services centres (HSSC), health and social services agencies (HSSA) and the MSSS must in turn apply this recognition to the decisions they make. The working group's standard for clinical governance seeks to promote policies, resources and institutional structures which foster continuous improvement in the quality of the pediatric palliative care provided in Québec.

Appendix 3 of this document includes a monitoring and evaluation table to help implement the standards of practice for pediatric palliative care according to the four focus areas mentioned above. This stand-alone document allows healthcare teams to monitor the implementation of the proposed standards. Using a simple rating scale, teams can evaluate each standard and record any improvements required in the space allotted in the table.

The appendix is an easy-to-use, flexible and practical monitoring and assessment tool that encompasses the various facets of pediatric palliative care and is based on the working group's proposals. It is available in electronic format, in French, at [www.msss.gouv.qc.ca](http://www.msss.gouv.qc.ca) by following the link to 'Documentation' and then to 'Publications', and in English at [www.chpca.net](http://www.chpca.net) by following the link "Initiatives" and then "Standards and Norms of Practice."

Thanks to the recent adoption of the Québec End-of-Life Palliative Care Policy and the efforts of many stakeholders in the fields of pediatrics, pediatric palliative care and adult palliative care, the province is currently in a favourable period for continuous improvement in pediatric palliative care. These standards can further support Québec's quality improvement efforts. Establishing the standards represents one step. Now, we must create the framework that will encourage the application of the standards once they are adopted.

## List of Abbreviations

ACT	Association for Children with Life-threatening or Terminal Conditions and their Families
AETMIS	Agence d'évaluation des technologies et des modes d'intervention en santé
CCHSA	Canadian Council on Health Services Accreditation
CHUQ	Centre hospitalier universitaire de Québec
CHUS	Centre hospitalier universitaire de Sherbrooke
CNPCC	Canadian Network of Palliative Care for Children
HSSA	Health and Social Services Agency
HSSC	Health and Social Services Centre
INSPQ	Institut national de santé publique du Québec
MSSS	Ministère de la Santé et des Services sociaux
MUHC	McGill University Health Centre
RUIS	Réseaux universitaires intégrés de santé (Integrated University Health Networks)
UAMC	University-affiliated Medical Centre
UPC	University Pediatric Center
UMC	University Medical Centre

## Members of the Working Group on Quebec Standards for Pediatric Palliative Care

- Céline Bergeron, Clinical Nurse Specialist, *Centre hospitalier universitaire de Québec, Centre hospitalier de l'Université Laval (Centre mère-enfant)*
- Dr. Brigitte Bernard, Assistant Medical Director, Health Services and Academic Medicine Branch, *Ministère de la Santé et des Services sociaux*
- Dr. Linda Côté-Brisson<sup>1</sup> \* Working Group Chair and President, Pediatric Oncologist, Palliative Care Physician, *Centre hospitalier universitaire de Québec, Hôtel-Dieu de Québec*
- Dr. Claude Cyr\*, Pediatrician, Chief of Pediatric Palliative Care, *Centre hospitalier universitaire de Sherbrooke, Hôpital Fleurimont*
- Lysanne Daoust\*, Liaison Nurse and Palliative Care Nurse Coordinator, *Centre hospitalier universitaire Sainte-Justine*
- Danielle Drouin\*, Clinical Nurse Specialist in Pediatric Palliative Care, McGill University Health Centre, Montreal Children's Hospital
- Dr. Justine Farley, Chief of Palliative Care, St Mary's Hospital Centre; President, *Réseau de soins palliatifs du Québec*
- Julie Huot, Research Officer, Québec Centre for Cancer Control, *Ministère de la Santé et des Services sociaux*
- Dr. Nago Humbert\*, PhD, Human Biology, Faculty of Medicine, Lyon, France; Medical Psychology Specialist, Director, Pediatric Palliative Care, *Centre hospitalier universitaire Sainte-Justine*
- Mélanie Kavanagh, Research Officer, Québec Centre for Cancer Control, *Ministère de la Santé et des Services sociaux*
- Dr. Stephen Liben\*, Medical Director, Pediatric Palliative Care, McGill University Health Centre, Montreal Children's Hospital
- Dr. Mary Ellen Macdonald, PhD, Medical Anthropology, McGill University Health Centre, Montreal Children's Hospital, Postdoctoral Fellow
- Dr. Guy Parizeault, Pediatrician, *Clinique de pédiatrie de Chicoutimi* and *Centre de santé et de services sociaux de Chicoutimi*
- Dr. Hélène Roy, Pediatrician Chief of Pediatric Palliative Care, *Centre hospitalier universitaire de Québec, Centre hospitalier de l'Université Laval (Centre mère-enfant)*

\* These persons were members of the pediatric working group that contributed to the pediatric palliative care chapter of the *Politique en soins palliatifs de fin de vie* (Québec End-of-Life Palliative Care Policy)

# Table of Contents

Summary.....	7
List of Abbreviations.....	9
Members of the Working Group on Québec Standards for Pediatric Palliative Care .....	10
Table of Contents.....	11
List of Tables.....	12
Liste of Figures .....	12
Introduction .....	13
1. Objectives .....	13
2. Framework .....	15
3. Pediatric Palliative Care .....	17
3.1. Definition.....	17
3.2. Target Population .....	18
3.3. Stages Experienced by Children and their Families .....	19
4. Situation Overview .....	20
4.1. Prevalence.....	20
4.2. Mortality .....	20
4.3. Importance of the child less than 1 year of age .....	21
4.4. Complex Chronic Conditions .....	21
4.5. Dying Close to Home.....	23
4.6. Deaths in Hospital Centres .....	24
4.7. Current Services Available in Pediatric Palliative Care.....	24
5. Guiding Principles .....	25
6. Standards of Practice for Pediatric Palliative Care .....	26
6.1. FOCUS AREA I: Child- and Family-Centred Care.....	26
6.1.1. Meeting Child and Family Needs .....	27
6.1.2. Communication and Participation in Decision-making .....	33
6.1.3. Continuity of Care .....	36
6.2. FOCUS AREA II: Interdisciplinarity.....	39
6.2.1. Members of the Interdisciplinary Team .....	39
6.2.2. How an Interdisciplinary Team Works.....	40
6.2.3. Supporting the Interdisciplinary Team.....	41

6.3.	FOCUS AREA III: Continuous Quality Improvement .....	43
6.3.1.	Training .....	43
6.3.2.	Evidence-based Practice .....	45
6.3.3.	Evaluation and Research .....	46
6.4.	FOCUS AREA: Clinical Governance .....	48
6.4.1.	<i>Standards of Practice: Clinical Governance</i> .....	49
7.	Dissemination and Knowledge-Sharing.....	50
	Conclusion .....	50
	References.....	51
	APPENDIX 1:.....	65
	Consultants and Collaborators.....	65
	APPENDIX 2: Care Pathways.....	69
	APPENDIX 3:.....	71
	Standards of Practice for Pediatric Palliative Care – Monitoring and Evaluation Tool.....	71

## List of Tables

Table 1.	Children and Families in Need of Palliative Care .....	18
Table 2.	Cause of death in children aged 0 to 19, Québec, 1997-2001 .....	20
Table 3.	Age of death by non-trauma causes in children aged 0 to 19, Québec, 1997-2001 .....	21
Table 4.	Deaths due to complex chronic conditions in children aged 0 to 19, Québec, 1997-2001.....	21
Table 5.	Place of death in children aged 0 to 19, non-trauma cases, Québec, 1997-2001 .....	24

## List of Figures

Figure 1.	Deaths in children aged 0 to 19 years due to complex chronic conditions, by age and cause of death, Québec, 1997-2001.....	22
Figure 2.	Percentage of deaths by region of residency in non-trauma cases, Québec, 1997-2001 .....	23

“The death of a child or an adolescent touches the entire family, as well as the child’s or adolescent’s circle of friends and acquaintances. Although death is a part of life, the death of a child is never in the normal order of things; the family feels the impact of such a loss for a long time. Caring for a dying child is one of the most difficult responsibilities a health professional can face.” [1]<sup>I</sup>

## Introduction

In the spring of 2004, Québec developed an end-of-life palliative care policy, the *Politique en soins palliatifs de fin de vie* [2] (Québec End-of-Life Palliative Care Policy), in which the specific needs of pediatric care in the province were addressed. One of its recommendations was the development of standards of practice for pediatric palliative care. In the fall of 2004, the Québec Centre for Cancer Control at the *Ministère de la Santé et des Services sociaux* (MSSS) established a working group to act on this recommendation.

The working group’s twofold mandate included: 1) establishing Québec standards of practice for pediatric palliative care; 2) recommending mechanisms to promote their dissemination and appropriation, and the sharing of best practices in pediatric palliative care.

The establishment of provincial standards of practice in pediatric palliative care for Québec is part of an international movement in which the specific needs of children<sup>II</sup> and their families<sup>III</sup> are taken into consideration in the development of palliative care policy and standards and in the organization of palliative care services. The standards are intended for treatment teams<sup>IV</sup> and palliative care teams who care for children with palliative care needs and provide services to their families. At the same time, the standards are directed at the administrators of institutions in which the teams work, integrated university health networks (RUIS), health and social services agencies (HSSA) and the MSSS.

The standards are based on the experience gained in pediatric palliative care in Québec. It is our hope that they will help achieve the objectives set out in the Québec End-of-Life Palliative Care Policy: to ensure fair access to services, to ensure continuity of service between the various care-delivery sites, to ensure quality services provided by the interdisciplinary teams and to raise awareness among health care providers that children, too, can die.

## 1. Objectives

A standard inherently includes an objective and a level of excellence to target. Every standard must be based on best available data [3]. The development of healthcare standards is therefore a means to ensure continuous quality improvement in healthcare and healthcare services.[4]. Healthcare standards serve as a benchmark for assessing the quality of healthcare and healthcare services. They are used to facilitate decision-making for administrators and stakeholders, encourage the adoption of best practices and promote

---

<sup>I</sup> Numbers in parentheses refer to references listed on page 50.

<sup>II</sup> A ‘child’ refers to all persons whose diagnosis was made before the age of 18 and whose death is anticipated before that of the parents.

<sup>III</sup> A family includes parents and siblings, grandparents and any other individual who has a significant bond with the child or parents.

<sup>IV</sup> ‘Treatment Team’ (in French ‘équipe soignante ou traitante’) refers to a team that has an ongoing relationship with the patient from the diagnosis of a life threatening illness and includes among others: pediatric teams, specialist pediatric teams, obstetrical teams, and neonatology teams.

consistency in healthcare services and practices. By basing their actions on standards, healthcare teams can measure their performance, identify areas that need improvement, and find solutions to problems.

Québec's standards of practice for pediatric palliative care promote a standardized and coordinated approach designed to ensure that children and their families receive quality palliative care, wherever they may live or receive care. The pediatric palliative care standards have specific objectives, which can be defined as follows:

- ✓ promote a child- and family-centred approach to pediatric palliative care practice and to the organization of services;
- ✓ establish benchmarks for quality practice in palliative care;
- ✓ define clinical and administrative roles and responsibilities;
- ✓ promote continuity of care;
- ✓ bring services to children's living environments;
- ✓ foster partnership to improve continuity and coordination of healthcare and services;
- ✓ create a framework for evaluating potential shortfalls between the healthcare and services provided and the stated objectives

The standards in this document are aimed at all teams caring for or accompanying children with palliative care needs and working with their families. They are also intended for those who organize services and training in pediatric palliative care. The teams addressed here include all treatment and palliative care teams, regardless of where they work within the healthcare network.

Treatment teams play a central role in pediatric palliative care. They can be the ones providing all the palliative care to children and supporting their families. They might also be those who work in conjunction with palliative care teams to provide such care. Currently, the pediatric palliative care teams they work with are mainly from the following university medical centres (UMC): *Centre hospitalier de l'Université Laval (Centre mère-enfant)*, which is affiliated with *Centre hospitalier universitaire de Québec (CHUQ)*; *Centre hospitalier universitaire Sainte-Justine*; *Hôpital Fleurimont*, which is affiliated with *Centre hospitalier universitaire de Sherbrooke (CHUS)*; and the Montreal Children's Hospital, which is part of the McGill University Health Centre (MUHC). The four teams listed above will henceforth be referred to as University-Pediatric Centers (UPC). Even when palliative care teams play a more significant role, treatment teams must remain involved to promote continuity of care and ensure that children and their families do not feel abandoned.<sup>v</sup>

The standards are also intended for administrators of institutions in which the interdisciplinary teams work, health and social services agencies (HSSA), health and social services centres (HSSC); integrated university health networks (RUIS) and the MSSS. Administrators contribute significantly to pediatric palliative care by determining the kind of organizational environment in which interdisciplinary teams work. Administrators must therefore support interdisciplinary teams in meeting these standards. They must also share responsibility with healthcare teams to provide quality services and continuous quality improvement in pediatric palliative care.

---

<sup>v</sup> As reported by parents during the consultation sessions held in 2006 for the development of standards of practice in pediatric palliative care.

## 2. Framework

The working group appointed to develop the standards for pediatric palliative care included experts in pediatrics and pediatric and adult palliative care, researchers and professionals from the MSSS. The *Agence d'évaluation des technologies et des modes d'intervention en santé* (AÉTMIS) helped the working group compile the evidence drawn from the scientific literature and the grey literature. The *Institut national de santé publique du Québec* (INSPQ) supplied data from its own analysis of palliative care in Québec [5], and the Canadian Council on Health Services Accreditation (CCHSA) provided guidance through comments and suggestions.

The working group familiarized itself with the principles set out by the International Society for Quality in Health Care [3] and developed standards that meet the following criteria:

- 1) The standards must contribute to improving the quality of care.
- 2) The standards must be patient- and family-centred, and take into account management of services and service-delivery infrastructure.
- 3) The standards must be comprehensive and encompass the following factors: the skills of care personnel, the quality, continuity, efficacy and efficiency of care and services, and accessibility to care and services, all as they relate to patients' needs and security.
- 4) The standards must be well thought-out, established and evaluated according to a well-defined process.
- 5) The standards must be measurable and reproducible.

The working group reviewed an international sampling of definitions used to describe pediatric palliative care. In particular, the group focused on those put forth by the World Health Organization (WHO) [6], the Canadian Network of Palliative Care for Children (CNPCC) [7] and the Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) [8]. With slight modifications, ACT's definition was adopted as this definition was found to reflect most closely the core aspects of pediatric palliative care in Québec. Also, the target population receiving this care was defined mainly by research conducted while developing the *Politique en soins palliatifs de fin de vie* (Québec End-of-Life Palliative Care Policy) [9]. Finally, the working group also determined the guiding principles of the standards for pediatric palliative care.

The working group also turned to scientific articles, websites and available documentation as their basis for research and focused on issues, such as the needs of children receiving palliative care and the needs of their families [1, 8, 10-53], the quality of pediatric palliative care [54-65], the various stages of pediatric palliative care [12, 34, 66-75], the organizational models developed specifically for pediatric palliative care [8, 42, 45-47, 76-97], and the experience gained in adult palliative care, as demonstrated in the existing research papers [58, 98-108]. The working group found a large consensus in the literature regarding the needs expressed by children and families, and the solutions that were recommended to meet these needs.

The working group also reviewed current and past pediatric palliative care initiatives conducted in Québec, and drew conclusions from both the successes and failures, and adapted the proposed standards to Québec's existing pediatric care framework. From the outset and throughout the process of defining the standards, the working group consulted key individuals in Québec and this greatly enhanced their work. (see Appendix 1).

Drawing on the experience gained from initiatives conducted in other countries, the group examined various child and adult palliative care policies and standards in the United States [35, 58, 109-111], the United Kingdom [16, 42, 112-120], Australia [121-123], New Zealand [103, 124] and France [125, 126]. The standards adopted in Canadian provinces outside Québec were also reviewed [7, 127-130]. The CCHSA has also defined standards of practice for palliative care. In the winter of 2006, the Council initiated discussions with the CNPCC and other partners to ensure that the pediatric perspective be incorporated into the development of these standards. The working group also established ties with these two organizations so as to keep abreast of the work being done.

The way in which the standards are presented is modelled after that of the CCHSA. The first section defines the main themes on which the standards are centred. Criteria were then established to ensure that the standards were met. The criteria also provide a basis upon which performance indicators<sup>VI</sup> could be established. Although the establishment of indicators was not part of the working group's mandate, it should nonetheless be considered at a later stage. It should also be noted that standards are not static and evolve over time. A review process must therefore be developed to re-examine the standards of pediatric palliative care.

For the purpose of clarity in the writing of these standards, the term *interdisciplinary team* refers to both the treatment team providing pediatric palliative care and the palliative care team. It will be specified when referring to pediatric palliative care teams of university pediatric centers (UPC). In general, the standards and criteria were developed to apply to all facilities within the Québec health network susceptible to providing pediatric palliative care, including university medical centres (UMC), university-affiliated medical centres (UAMC), university institutes, medical centres not associated with Health and Social Services Centres (HSSC), HSSCs, rehabilitation centres and hospices. When a standard or criterion refers to a particular type of facility, the type of facility will be specified.

---

<sup>VI</sup> An indicator is a measurement tool, which is rate-based or defined as an event, which is used as a guide to monitor and evaluate the quality of client care and service, clinical support services, and organizational functions, in order to make continuous improvements (161).

### 3. Pediatric Palliative Care

A clear definition of pediatric palliative care and its target population is essential to assure a common understanding and shared vision of pediatric palliative care in Québec. An understanding of the various stages experienced by children and their families helps better understand their needs so that the care teams can respond with the appropriate services. Pediatric palliative care can begin as early as when the family receives the diagnosis of a potentially life-threatening condition, and continue through to end-of-life care, death and bereavement.

#### 3.1. Definition

The following definition, with some modifications, is taken from a definition proposed by ACT [8]:

*“Pediatric palliative care can be defined as an active and total approach to care embracing physical, psychological, social and spiritual elements. It focuses on the enhancement of quality of life for the child and support for the family, and includes the management of distressing symptoms, provision of respite and care through death and bereavement.” Bereavement care is part of palliative care, irrespective of the cause of death, and includes trauma and perinatal loss.*

The above definition describes an approach which helps children and their families reach their various physical, psychological, social and spiritual objectives. The philosophy underlying pediatric palliative care is, first and foremost, “to provide optimal comfort and quality of life, and sustain hope and family connection despite the likelihood of death.” [7] Pediatric palliative care provides comprehensive care to children and their families from the time a potentially life-threatening illness is diagnosed, throughout the child’s life, at the time of death and during the grieving process [6, 9, 12, 24, 58, 118]. “It affirms life, and regards dying as a process that is a profoundly personal experience for the child and family.” [7] Pediatric palliative care is coordinated and provided by an interdisciplinary team, which takes into account the individuality and strengths of children and their families. It is a flexible approach to care that is centred on the child and family, and sensitive to the family’s cultural and spiritual values, beliefs and practices.

In pediatrics, palliative care providers must take into account the fact that children or adolescents are developing physically, psychologically, socially, cognitively and spiritually through the course of their illness. For this reason, their participation in educational and community activities must be encouraged [16]. The family unit must play a leading part in pediatric palliative care. The role and needs of each family member, including siblings and grandparents, must therefore be taken into consideration by the treatment team [15, 33, 34, 40, 131-135]. Respite services must also be provided to the family [8, 13, 36, 42-44, 47, 136-141]. Given that the course of serious childhood illnesses is often unpredictable, that certain symptoms can persist and that prognosis is uncertain, it is even more important to prepare for the likelihood of palliative care early on, even from the time of diagnosis, if necessary. For children receiving care into their adult years, it is essential that the transition to adult palliative care is a smooth one [16, 19, 39, 142, 143]. According to certain authors, this transitional period may sometimes span several years.

## 3.2. Target Population

The pediatric palliative care target population can be divided into six groups of children and families (see Table 1) [2]. The description of the sixth group was reworded to emphasize that bereavement care is included in palliative care, even for families who lose a child suddenly as a result of an accident, at birth or because of an abortion. The description of these groups remains broad, although in certain cases, it would be beneficial to have a more detailed definition of the children and families who need palliative care. The Children's Oncology Group and the Pediatric Oncology Group of Ontario have initiated discussions on this matter [144].

Table 1. Children and families in need of palliative care \*

Group 1	Children presenting with an illness for which a curative treatment is possible. Palliative care may be necessary during periods of uncertainty or when curative treatments are ineffective. Examples: cancer, severe cardiac, renal or hepatic disease.
Group 2	Children presenting with an illness, where premature death is inevitable. These children may need extended periods of intensive treatment to prolong their life and allow them to participate in activities typical of a child their age. Examples: cystic fibrosis, muscular dystrophy.
Group 3	Children presenting with a degenerative illness with no chance of recovery. Treatments provided to these children are strictly palliative and can extend over many years. Examples: Batten disease, mucopolysaccharidosis.
Group 4	Children presenting with severe neurological conditions, which increase the likelihood of complications leading to a sudden but non-progressive deterioration in their health. Examples: Accidents resulting in neurological impairment, severe cerebral palsy.
Group 5	Newborns whose life expectancy is very limited.
Group 6	Family members who have lost a child suddenly following an illness, through an external event** or perinatally. Example: Trauma, stillbirth, abortion.

\* There are 6 categories of children needing palliative care. The first four groups were defined in 1997 by the Association for Children with Life-threatening or Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health. The fifth group was defined by the Lighthouse, Children and Families. A sixth group was added following discussions by the Working Group on Pediatric Palliative Care.

\*\* According to the tenth International Classification of Diseases (ICD-10), an external cause can include a motor vehicle accident, a fall, accidental drowning or submersion, exposure to smoke, fire or flames, self-inflicted injury (suicide), assault (homicide), or any other non illness-related cause.

### 3.3. Stages Experienced by Children and their Families

A fundamental objective of these standards is being able to meet the needs of children and their families throughout the different stages they will go through. The stages will vary according to the illness, as well as the child's personality and the family dynamics. In order for children and their families to have an optimal quality of life, health care providers, children and their families need to understand the various stages they are likely to experience.

We believe that the care pathway model developed by ACT, entitled *A Framework for the Development of Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions*, can be used as a guideline to develop a systematic evaluation process and assessment tools that can be adapted to each of the six groups of children and families needing palliative care (see Annex 2) [66]. This model can also help practitioners understand the children's and families' journey. In Québec, the UPC teams could use the model to design a care pathway model adapted to their patient population, in collaboration with medical centres, HSSCs, hospices, schools, community organizations and other institutions involved with children and their families. The working group has initiated some discussion on the subject and recommends that work in this area should be continued.

## 4. Situation Overview

### 4.1. Prevalence

The number of children and families who could potentially require palliative care is relatively high. According to data reported by S. Lenton et al. [34], the prevalence of children aged 0 to 19 suffering from non-cancerous illnesses, yet whose odds of survival are limited and who need palliative care, is approximately 1.5 per 1000 in the United Kingdom. In 2003, the number of children in Québec between the ages of 0 and 19 was 1 750 000. Thus, if we apply the data from the UK to Québec's 2003 population, around 2 625 children would have a non-cancerous terminal illness requiring palliative care.

### 4.2. Mortality

Between 1997 and 2001, 4 199 children in Québec aged 0 to 19 lost their lives, which translates to an average of 840 deaths per year (see Table 2). In addition, between 1998 and 2002, 1 554 stillbirths were reported, which is about 311 per year on average.

Stillbirths and deaths due to perinatal conditions\* as well as deaths caused by complex chronic conditions, require specialized intervention from obstetrics and neonatology teams [69, 82, 94, 145-153]. Emergency room personnel are needed in managing deaths due to trauma, sudden infant death syndrome (SIDS) and other causes [154-156]. Children suffering from complex chronic conditions need to be followed by various pediatric treatment teams. A number of these children also need to be placed in intensive care at some time during their illness [33, 34, 69, 157, 158]. Once at home, many children require the home care services of HSSCs.

Table 2. Cause of death in children aged 0 to 19, Québec, 1997-2001

Cause of death	Deaths between 1997 and 2001 (number)	Annual Mean (number)	Deaths as a percentage of the total (%)
Trauma	1 587	317	37.8
Complex chronic condition	1 126	225	26.8
Perinatal condition *	891	178	21.2
Sudden infant death syndrome	133	27	3.2
Other causes	462	92	11.0
Total	4 199	840	100

Source: *Institut national de santé publique du Québec.*

\*Perinatal Conditions: certain conditions originating in the perinatal period ICD-10 codes [P00-P96](#)

### 4.3. Importance of the child less than 1 year old of age

A significant number of children receiving pediatric palliative care are under the age of one [12, 34, 83, 159]. Among the 2,612 children in Québec who died of non-trauma causes between 1997 and 2001 (see Table 3), 1 802 (69%) were under the age of one. Evidently, the vast majority of children who died of a perinatal conditions or SIDS were under the age of one (99.1% and 98%, respectively), but the percentage remains high for complex chronic conditions (53.8%) and other causes (39.6%)

Table 3. Age of death by non-trauma causes in children aged 0 to 19, Québec, 1997-2001

Age	Complex chronic conditions		Perinatal disease		SIDS		Other		Total	
	number	%	number	%	number	%	number	%	number	%
Less than 7 days	266	23.6	754	84.6	2	1.5	49	10.6	1 071	41.0
7 to 27 days	112	10.0	86	9.7	10	7.5	30	6.5	238	9.1
28 days to 1 year	228	20.2	43	4.8	118	88.7	104	22.5	493	18.9
1 to 19 years	520	46.2	8	0.9	3	2.3	279	60.4	810	31.0
<b>Total</b>	<b>1 126</b>	<b>100</b>	<b>891</b>	<b>100</b>	<b>133</b>	<b>100</b>	<b>462</b>	<b>100</b>	<b>2 612</b>	<b>100</b>

Source: Institut national de santé publique du Québec.

### 4.4. Complex Chronic Conditions

Complex chronic conditions are “medical conditions, which can be reasonably expected to last at least 12 months (unless death intervenes), and that involve either several organ systems or one organ system severely enough to require specialized pediatric care, and probably some period of hospitalization in a tertiary care centre” [73, 160]. A number of conditions fall into this category and necessitate specialized pediatric care from a diverse range of treatment teams (see Table 4) [89, 160]. The most commonly involved specialties are cardiology, oncology, neurology and medical genetics.

Table 4. Deaths due to complex chronic conditions in children aged 0 to 19, Québec, 1997-2001

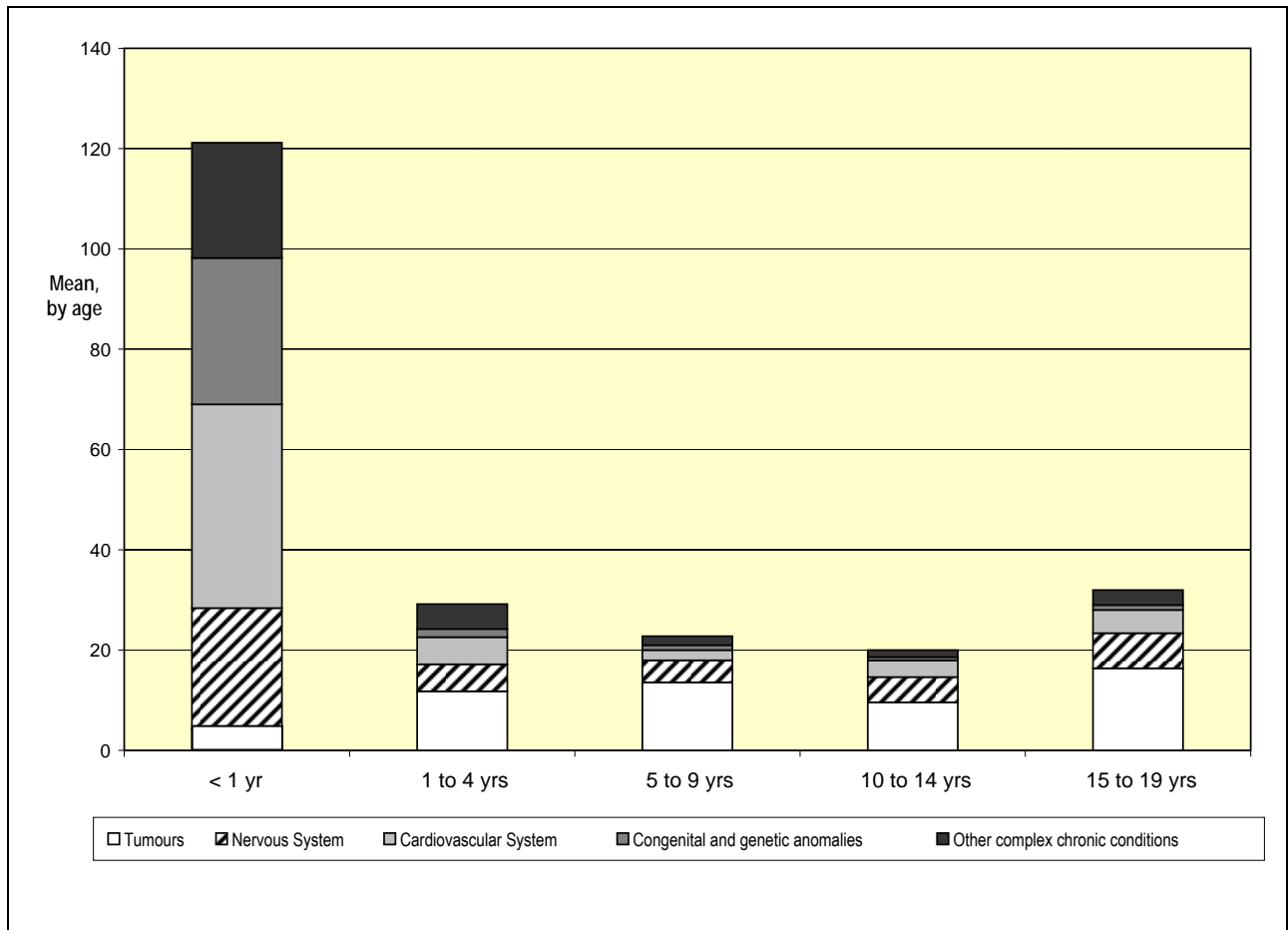
Causes of death	Deaths (number)	Deaths expressed as a percentage of the total (%)
Cardiovascular disorders	280	24.9
Tumours	278	24.7
Nervous system disorders	230	20.4
Congenital or genetic anomalies (not included in the other causes)	167	14.8
Respiratory disorders	73	6.5
Metabolic disorders	34	3.0
Urinary disorders	32	2.8
Digestive disorders	18	1.6
Hematological and immunological disorders	14	1.3
<b>Total</b>	<b>1 126</b>	<b>100</b>

Source: Institut national de santé publique du Québec.

Deaths due to cardiovascular disorders and congenital or genetic anomalies (not included in the other causes) usually occur within the first year of life, whereas deaths due to cancer usually occur in children one year of age or older (see Figure 1).

Children with complex chronic conditions often need to be hospitalized multiple times. The palliative phase in these children can cover a long time period, and these conditions require ongoing and complex care from multiple care sites and many different specialists.

Figure 1. Deaths in children aged 0 to 19 years due to complex chronic conditions, by age and cause of death, Québec, 1997-2001



Source: Institut national de santé publique du Québec.

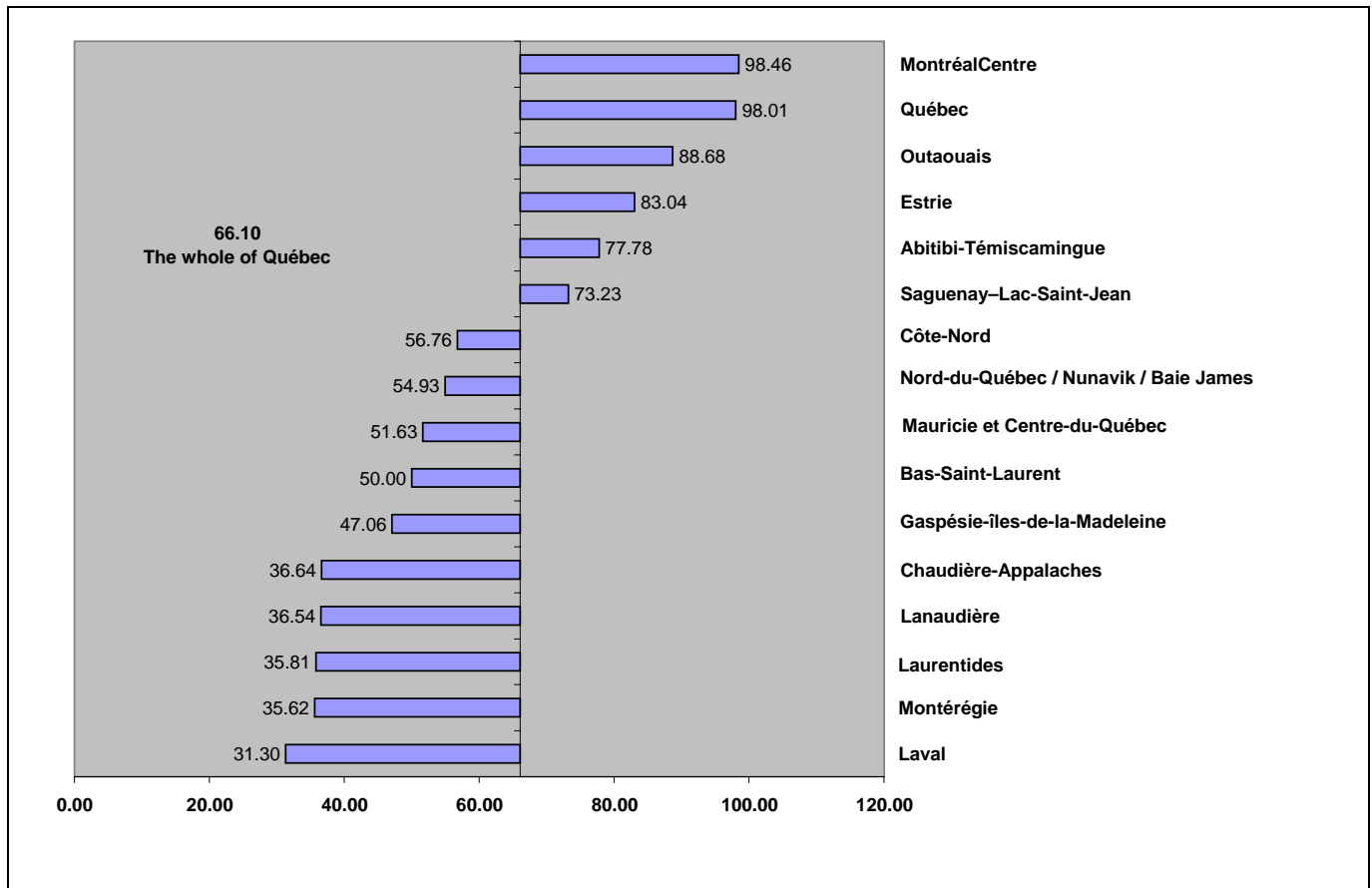
## 4.5. Dying Close to Home

Dying close to home, in non-trauma cases, is a possibility for children living in a University Region (région universitaire) but not necessarily so for children who live in other regions (see Figure 2). In Montréal-Center, Québec and Estrie, the percentage of children who are able to die close to home is 98.5%, 98.0% and 88.7%, respectively. In the outlying areas of Montréal and Québec, these percentages vary from as low as 31.3% to 36.6%.

For children suffering from complex chronic conditions, the number of deaths at home varies by pathology. Children with cancer die at home in 26.3% of cases, compared to 3.3%, 5.7% and 5.4% of children with cardiovascular, nervous system, and congenital or genetic disorders (not included in other causes), respectively. However, the percentage of children with complex chronic conditions who are able to die at home seems to be increasing. From 1997 to 2001, the percentage rose from 9.3 to 12.4.

Hospices are very rarely the place of death for children. Among children with cancer, only 1.1% dies in these settings.

Figure 2. Percentage of deaths in the region of residency in non-trauma cases, Québec, 1997-2001.



Source: Institut national de santé publique du Québec.

#### 4.6. Deaths in Hospital Centres

Between 1997 and 2001, 50.4% of non-trauma child deaths took place outside the four UPCs. The majority of deaths caused by perinatal conditions (65.4%), as well as almost 40% of deaths due to complex chronic conditions (39.1%) and other causes (38.9%), occurred in facilities other than the UPCs.

Table 5. Place of death in children aged 0 to 19, non-trauma cases, Québec, 1997-2001

Hospitals	Complex chronic conditions		Perinatal conditions		SIDS		Other		Total		Annual Mean	
	number	%	number	%	number	%	number	%	number	%	number	%
UPC	603	60.9	304	34.6	20	20.8	250	61.1	1177	49.6	235	49.6
Other	387	39.1	574	65.4	76	79.2	159	38.9	1196	50.4	239	50.4
Total	990	100	878	100	96	100	409	100	2373	100	474	100

Source: Institut national de santé publique du Québec.

#### 4.7. Current Services Available in Pediatric Palliative Care

At the moment, it is impossible to give a complete picture of the pediatric palliative care services available in each region of Québec, whether for medical centres or community organizations. Obtaining this data in the near future is therefore very important. A report of currently available services, including improvements that need to be made, is a necessary step towards providing children and their families with the best care possible.

## 5. Guiding Principles

The following is a list of the guiding principles used by the working group to establish standards of practice for pediatric palliative care in Québec:

1. The child or adolescent and the family are the focus of care. Family members include the mother, father, siblings, grandparents, and any other person who may have a significant bond with the child or parents. The individuality of the child and each family member must be taken into consideration.
2. A family is a social and cultural unit with its own set of beliefs and values, which must be taken into account when providing care.
3. The child is the primary concern, and therefore, must be involved in decisions in a way that is age- and developmentally appropriate. Parents should be considered as the primary caregivers and key providers of physical and emotional care and key decision makers of their child and as such, are considered partners with the care team
4. The child and family must be kept informed. Information must be delivered at the appropriate time. An honest and open approach is to be used in all communication with the child and family.
5. Care is delivered to the child and family using a holistic and family oriented approach, which entails consideration of the physical, psychological, social and spiritual needs of the child and family. All interventions with the child and family must be suited to each one's level of development, the goal being to improve the child's and family's quality of life. Bereavement care is offered to all family members for any cause of death, including perinatal loss.
6. The child must continue to participate in usual activities, including play and school, to the extent of the child's physical capabilities and willingness.
7. Respite services are essential for home-based care.
8. Palliative care must be accessible and available to the child and family at all times. Care must be delivered in a setting that respects the wishes of the parents and child, and has the appropriate resources required to meet standards of quality of care. Accessibility to palliative care must be maintained throughout the duration of the illness, regardless of how short- or long-lived.
9. Continuity and coordination of services must be ensured at all times. Particular attention must be paid during periods of transition between health care providers, episodes of care and sites of care.
10. Pediatric palliative care is provided by an interdisciplinary team. The members of this team must have specialized training in pediatric palliative care, and they have a responsibility to maintain their skills and competencies in this area.
11. Continued research and regular evaluation are a must, as they are instrumental in determining what clinical and organizational changes need to take place in order to improve pediatric palliative care.
12. Human, physical and organizational resources must be sufficient to ensure quality of care.

## 6. Standards of Practice for Pediatric Palliative Care

A standard is a written rule that explains how to meet basic requirements. It can also be viewed as a tool designed to guide professionals in achieving excellence and provide them with information on what the services they deliver should constitute from both a process- and results-oriented perspective. A standard must target excellence, be realistic, achievable, easy to understand and measurable, be developed by specialists, based on current knowledge, worded in positive terms and meet an acceptable level of performance. [161].

Basing themselves on the principles outlined in Section 5 and on the data gathered from the literature, the working group focused the standards on the following four main areas and their sub-areas:

1. Child- and Family-Centred Care
  - meeting of child and family needs
  - communication and participation in decision-making
  - continuity of care
2. Interdisciplinarity
  - interdisciplinary team members
  - how the interdisciplinary team works
  - support provided to the interdisciplinary team
3. Continuous Quality Improvement
  - training
  - evidence-based practice
  - evaluation and research
4. Clinical Governance

For each main area of focus and its sub-areas, the standards deemed to be fundamental to the delivery of quality pediatric palliative care are listed below and followed by their corresponding criteria. These criteria represent the steps, processes or activities that are required to meet the standard or reach the objectives set out in within it [161].

### 6.1. FOCUS AREA I: Child- and Family-Centred Care

A child- and family-centred approach to care, in which the child is the primary concern, is widely accepted in pediatric palliative care [12, 33, 34, 59, 112, 162-169]. Children have physical, psychological, social and spiritual needs. Their communication skills and understanding of their illness and the concept of death differ with age and maturity level. Their level of physiological development will have an influence on how their symptoms are expressed and how they react to medication. Healthcare providers must therefore understand children's developmental stages and adapt their approach accordingly.

Because it plays a crucial role in the lives of children of all ages, the family must also be of prime concern in child- and family-centred care. The child's quality of life and that of the family, the main concerns of palliative care, are inextricably linked. The parents carry a heavy burden of responsibility: they must make

important decisions regarding their child and provide personal and medical care at home [170]. They may shoulder this responsibility for a long time. The stress and suffering the couple experiences cannot be overlooked. Siblings are also vulnerable and their vulnerability must be taken into consideration as soon as the diagnosis is made so that potential harmful effects their sibling's illness may have on them in the long term can be prevented. The needs of grandparents and others who support the family must also be taken into account.

Child- and family-centred care:

- 1) takes into account the child as a whole, along with the child's and the family's reality;
- 2) takes into account the child's needs and level of development;
- 3) ensures that communication corresponds to the child's level of development;
- 4) gradually progresses to adult care services as the child gets older;
- 5) recognizes the family as a constant in the child's life and understands the critical role that families play in the health and well-being of their children and adolescents;
- 6) takes into account family cohesiveness;
- 7) recognizes children's and families' strengths and uniqueness, takes their varied coping skills into consideration, respects their dignity and helps them regain control over their lives; child- and family-centred care is flexible and takes cultural and socioeconomic diversity into account;
- 8) requires the open and continual sharing of information;
- 9) adopts best practices regarding confidentiality and parental consent;
- 10) is based on a partnership between healthcare providers, the children or adolescents, and the parents;
- 11) is coordinated in accordance with children's and families' needs and recognizes that psychological, social and spiritual support is an integral part of healthcare;
- 12) encourages support between families and networking.

All the evidence suggests that a child- and family-centred approach to care increases satisfaction, leads to better health outcomes and allows resources to be allocated more soundly. However, adopting such an approach will require changes on the part of not only healthcare providers, but also health system administrators [12].

The standards of child- and family-centred care were grouped according to three different perspectives: 1) the needs of children and their families, 2) communication between all those involved and their participation in decision-making, 3) continuity of care.

### 6.1.1. Meeting Child and Family Needs

The child and family needs that must be met in pediatric palliative care are diverse and multidimensional. As mentioned previously, identifying these needs has been the subject of much research.

### *6.1.1.1. Needs of the Child*

The needs of the child include:

- symptoms management and maintenance of mobility
- psychological and spiritual well-being
- maintenance of living environment and social ties
- practical support
- opportunity to pursue normal day-to-day activities
- end-of-life care

#### *Symptoms Management and Maintenance of Mobility*

Children or adolescents who receive palliative care suffer from physical symptoms that must be managed or alleviated, such as pain, fatigue, asthenia, drowsiness, irritability, shortness of breath, seizures, difficulty swallowing, loss of appetite, constipation, nausea and vomiting. Pediatric palliative care patients also need to maintain their mobility.

#### *Psychological and Spiritual Well-Being*

To deal with issues such as anxiety, uncertainty and fear of illness and of death, children need to receive care that will help them maintain their psychological and spiritual well-being.

#### *Maintenance of Living Environment and Social Ties*

Children facing a life-threatening illness may see their living environment and social ties fall apart as their illness progresses. A feeling of profound isolation and abandonment may follow, and the child's place in the family may be affected. The child's ties to a network of friends therefore needs to be maintained. Meeting other children and adolescents with the same concerns can also help a sick child deal with his or her feelings of isolation. Adolescent sexuality must also be considered.

#### *Practical Support*

Practical support helps provide children with comfort and security, and maintain their social life. For example, children can remain active inside and outside the home with special equipment; they can receive transportation to the various care sites; their home environment can be adapted to their state of health; they can use a wheelchair or any other apparatus that helps maintain mobility. All the above may be provided while taking into account the speed at which children's needs evolve. In addition, practical support may also consist in providing children with the medication they need.

### *Normal Day-to-day Activities*

Children and adolescents need to pursue normal day-to-day activities suited to their physical abilities and stage of development. Normal day-to-day activities include play and attending school. Play is often a way for children to understand and assimilate new experiences. However, for children and adolescents whose future is uncertain, the need to play or go to school can sometimes be overlooked or underestimated [16, 42, 43, 120].

### *End-of-Life Care*

Support at the end of life allows children and adolescents to say what they need to say and do what they need to do before they die. Health professionals must ensure that children and adolescents at the end of life have access to the care they need twenty-four hours a day, seven days a week, so they can die at home if they or their parents so choose.

#### *6.1.1.2. Needs of the Family*

Of the needs they identified, the working group retained the following family needs:

- support for parents
- respite
- family cohesiveness
- end-of-life care
- bereavement support

### *Support for Parents*

Parents need psychosocial support, as well as support to deal with the reactions and judgments of friends and family over the choices they must make. They also need to be well-informed so that they can deal with their child's growing problems. In addition, they must be given information on the resources and services available to them. These include home support, e.g. cleaning and meal preparation, and financial support through services that can provide compensation for their numerous leaves without pay, loss of employment in some cases, and the inherent costs of caring for their child.

### *Respite*

For families whose child requires palliative care at home, respite is vital. Respite services must be provided to help them regain their physical, emotional, psychological, social or spiritual strength, and deal with their challenging situations.

### *Family Cohesiveness*

In families affected by the illness of a child, family cohesiveness is often at risk. Siblings may feel neglected or disregarded, which may have serious consequences on their emotional, social and academic life. Furthermore, the role of parent may supplant the role of spouse and cause tension within the couple. The many significant changes in family dynamics can further increase tensions that already exist within the

family. The right intervention may help the family adapt to the changes and encourage the extended family, particularly grandparents, to provide much-needed support. The complexity of today's family (i.e. blended families) and of its value system increases the challenge family members must face to maintain cohesiveness. Such complexity makes support all the more important.

### *End-of-Life Care*

Healthcare providers must provide families with end-of-life care. They must anticipate the various stages families will go through and the changes they will face when their child reaches the end of life. To be able to discuss death with their dying child and with any other children in the family, parents need support. Providing families with practical information at the moment of death may be very helpful. The treatment team must also be sensitive to the child's and family's wishes regarding where he or she will die.

### *Bereavement Support*

Bereavement support is a part of palliative care [12, 25, 33, 34, 171-178]. Because each family member may experience grief differently, bereavement support must be adapted to their individual needs. Whatever the cause of death, the family is going through a period of mourning. Bereavement support may be helpful for any family that has lost a child to chronic disease, trauma, sudden death or perinatal death (fetal death, stillbirth or neonatal death). The grief associated with the death of a child may have serious and long-term consequences on the whole family. Whenever possible, bereavement support should be provided by a person known to the family. This does not mean that normal coping processes of bereaved families should be treated as a pathology. However, difficulties that may have a negative impact on the family or one of its members should be identified early.

#### *6.1.1.3. Needs Assessment*

A proper and complete needs assessment is an important component of pediatric palliative care. A clear and objective assessment should identify the comprehensive needs of both the child and the family. It should be individualized and take into account each child's and family's uniqueness. At different stages of development (perinatal period, childhood or adolescence), different interventions will be required to meet the needs of children and their families. The specific characteristics of adolescents [19, 179-181] and young adults must be acknowledged as they gradually gain independence, break away from their parents and discover their sexuality. Individual needs vary with the child's illness and as the illness progresses. The needs of families with physically or cognitively disabled children will differ from those whose children are not disabled. Needs also vary according to the family environment and the resources to which the family has access. The assessment must therefore be made by healthcare providers who fully understand the child's development and can interact appropriately with the child and family. A good assessment will identify the priority needs of both the child and family. The assessment of needs allows professionals to interact with the child and family, inform them of the situation they face and focus on finding solutions together. Because needs evolve as children and their families traverse the various stages of the illness, the needs must be reassessed regularly.

According to the ACT, a proper needs assessment should:

- be comprehensive and be conducted by properly trained professionals using a multidisciplinary approach

- be developed in collaboration with the child and the family to achieve an individualized assessment that takes into account their unique situations
- include parents, siblings and any other child- or family-designated persons
- recognize each family member’s individuality
- be conducted in plain language that is easily understood by the child and family
- be conducted in a confidential manner
- be assured of with parental consent every time information concerning the child is shared with others
- be an on-going process, updated on a regular basis as the child’s condition changes [182]

Using specially designed tools to assess pediatric palliative care needs would help systemize the assessment, ensure that all aspects of the needs are covered, update relevant data in the child’s file, facilitate the sharing of information by team members, improve communication between children, families and healthcare providers, prevent members of the interdisciplinary team from needlessly asking the same questions, and facilitate the training and integration of new team members. Assessment tools must be adapted to the child’s stage of development and have been validated [12, 34]. They must also assess the family dynamics and how they function [183, 184].

An effective needs assessment is essential to developing a relevant and feasible intervention and service plan.<sup>VII</sup> A comprehensive assessment will ensure proper service planning, foresee future needs and prevent crisis situations. The intervention and service plan identifies all the interventions (either medical, psychological, social or spiritual) required to meet the needs of children and their families. The plan also includes the practical support and respite services provided to families, and addresses all the stages that patients and their families must go through, including bereavement support. The intervention and service plan, which includes the objectives to be met, must be prepared in collaboration with the child and family. It must respect their cultural background, values and belief system [185, 186]. Taking a family’s cultural background into account involves taking into consideration their values, traditions and beliefs, as well as their environment and the ethnic and religious community in which they live, even when this may conflict with what we, as individuals or institutions, consider “good medicine.”

---

<sup>VII</sup> According to Section 102 of the *Loi sur les services de santé et les services sociaux* (Québec Health and Social Services Act), an institution must develop an intervention plan for a class of users defined by regulation in accordance with Section 505, Subsection 27 of the Act, to the extent provided therein, in order to identify their needs, set the objectives and how to reach them, and determine the length of time during which services must be provided to the users. The intervention plan must provide for the coordination of the services provided to users by the various health care providers involved. When, for a certain length of time, a user must receive health and social services involving more than one institution, the institution providing the bulk of the services or most of the designated health care providers must prepare a service plan tailored to the individual as soon as possible.

#### 6.1.1.4. Standards of Practice: Meeting the Child's and Family's Needs

**Standard A:** *Health care providers conduct a complete assessment of the child's and family's needs. The family includes the mother, father, siblings, grandparents and any other person who has a significant bond with the child or parents.*

**Criteria A:** A-1 – The six groups of children and families representing the population in need of palliative care <sup>VIII</sup> have access to it.

A-2 – The treatment teams define the criteria used to identify children and families in need of palliative care.

A-3 – Family members are identified by name and relationship. This information is recorded in the child's file.

A-4 – The needs assessment includes the needs of both the child and the family. The specific needs of adolescents and the different phases of illness, e.g. the end-of-life phase, are taken into consideration.

A-5 – An assessment process is implemented so that health care providers can avoid needlessly asking the same questions or performing the same clinical tests.

A-6 – A comprehensive list of the child's and family's needs is included in the child's file. The list addresses all physical, psychological, social, spiritual, cultural and developmental needs.

A-7 – Health care providers use proven and standardized tools to assess the various needs when such tools exist.

A-8 – Pain is considered to be the fifth vital sign; pain is assessed using standardized tools and documented in the child's file.

A-9 – Needs are reassessed regularly and the list of needs updated when necessary.

---

VIII See section 3.2: Target Population.

**Standard B:** *An intervention and service plan is developed to meet all the needs of the child and family.*

**Criteria B:** B-1 – Health care providers take the necessary action to meet each need and then document this action in the child’s file.

B-2 – Respite services in the home or in some other appropriate setting are provided to children and families in need.

B-3 – The family members are given the information and support that they need to care for the child. This information is described in the intervention and service plan.

B-4 – Health care providers monitor their actions on an ongoing basis by consulting the intervention and service plan. When necessary, the intervention and service plan is revised.

B-5 – The revised version of the intervention and service plan is communicated to the relevant health care providers and organizations.

**Standard C:** *Bereavement support is described in the intervention and service plan.*

**Criteria C:** C-1 –As the child nears death, health care providers conduct a systematic assessment of the family’s needs and compile a list of resources required to meet these needs.

C-2 – Bereavement support is accessible to all families after the death of a child, regardless of the cause; this includes an external cause\* (car accident, drowning, overdose, suicide, etc.) or perinatal loss (abortion, stillbirth, perinatal death).

\*ICD 10: V01-Y98 External causes of morbidity and mortality

### 6.1.2. Communication and Participation in Decision-making

Good communication is the foundation of strong child-family-health care provider relationships [28, 34, 181, 185, 187-196]. Through good communication, health care providers are able to: gain a better understanding of the child’s and family’s perspective; put their actions into context; and take the child’s and family’s values and preferences into account. Information about the child and family must be treated confidentially, and health care providers must first consult the child and family before disclosing any of this information. Given the importance of communication in pediatric palliative care and the inherent difficulties associated with it, communication-skills training is essential for all interdisciplinary team members, as has been demonstrated [191].

Communication skills are particularly critical during discussions regarding the diagnosis and prognosis of a potentially life-threatening illness. However, health care providers must also pay special attention to how they communicate when they conduct needs assessments, make important decisions or provide parents with information to help them in their role as family caregivers.

The announcement of the diagnosis and prognosis of a potentially fatal illness is a critical moment. [66]. Parents must be fully informed of their child’s diagnosis and prognosis during a private, face-to-face discussion. The information must be accurate, complete, clear and timely, and be disclosed to the parents with honesty, sensitivity and respect. Because strong communication skills are critical when breaking potentially distressing news to a child and his or her family, only a properly trained and experienced individual should exercise this responsibility [42, 197]. Interdisciplinary pediatric palliative care teams can

help provide communication-skills training to treatment teams and other palliative care teams, as well as help them maintain their competencies.

To the extent that their age and maturity level allow, children should be able to participate in decisions that concern them and have a say in the recommended treatment. Their participation in decision-making can be achieved in numerous ways: they can be given information or consulted, their opinion can be taken into consideration or they can be the main decision-makers [33]. The right of children to express themselves and participate in decisions that concern them is well recognized, as described in Article 12 of the *Convention on the Rights of the Child*.

*“States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.”*

[198]

Communication with children poses challenges unlike those associated with adults. This is particularly true for very young children, though it also applies to adolescents. The communication strategies used to reach children will therefore vary according to their age and level of comprehension. Because verbal communication with children is often insufficient, health care providers must also use age-appropriate techniques and strategies such as games, drawing or story-telling to communicate with the children they treat.

Even the youngest children can participate in the dynamics of communication. In a British consultation process on cancer services, children as young as two were consulted [191]. All children, whatever their age were able to express opinions on various subjects, such as access to health services, treatment and care provided by the hospital, the need for information from their families, communication, health care providers, community and home care, and family support.

Parents, whose role it is to protect their child, manage the information the child receives [195]. They therefore have a clear influence on any communication with the child as well as the child's participation in decision-making. Evidence shows that some children would clearly like to be involved in making the decisions that concern them [190, 196]. However, raising the subject of illness and death with their child is difficult for parents. Interdisciplinary care teams must therefore support parents in this matter and respect the way in which they broach the subject with their child.

Decision-making involving many individuals is difficult to manage and can lead to conflicts between parents, between parents and children, or between the family and the interdisciplinary team. Blended families with more than two parents pose a particularly special challenge. When the individual concerned is a child rather than an adult, participation in decision-making and obtaining consent for certain treatments can raise distinct and often more complex interpersonal, ethical and legal issues [33, 34].

Children and their families must be provided information on palliative care and on the practical services available to them [199, 200]. Such information can address topics such as the assessment and management of pain and symptoms, participation in decision-making, practical ways to making the child more comfortable, the services that can be provided by the interdisciplinary team, home care services, assistance with household tasks, financial aid programs, transportation and respite services. Armed with this information, parents gain some control over what is happening to their child and know to whom they can turn when problem situations arise. Information on palliative care and the available services must be conveyed in plain language by means of an appropriate vehicle. *The Lighthouse, Children and Families*, a non-profit organization, has produced such a resource guide [201].

### 6.1.2.1. Standards of Practice: Communication and Participation in Decision-making

**Standard D:** *Health care providers are able to convey accurate information to children and families in a clear and sensitive manner. Communication with children or adolescents is age-appropriate and suited to their level of comprehension.*

**Criteria D:**

D-1 – Health care providers have received communication skills training on how to deliver bad news to children and their parents.

D-2 – Health care providers are able to use a range of verbal, nonverbal and symbol-based communication strategies to communicate with children and adolescents.

D-3 – Interpreters are made available to children and families who do not speak the same language as the health care providers.

**Standard E:** *When health care providers deliver bad news to the child and family or discuss important decisions with them, they do so in an appropriate setting, in complete confidentiality and in a respectful and honest manner.*

**Criteria E:**

E-1 – Meetings involving breaking bad news<sup>IX</sup> or discussing important decisions<sup>X</sup> are planned.

E-2 – These meetings are held in private, face-to-face discussions with both parents, simultaneously if possible, and in an appropriate setting. Relevant information and the names of those in attendance are recorded in the child's file.

E-3 – Health care providers review the details of the meetings to ensure that the information conveyed has been well understood. The minutes of these meetings are added to the child's file.

---

IX Special attention is needed from health care providers conveying information about the diagnosis of a potentially fatal illness or when discussing the child's prognosis.

X Important decisions include the decision to cease certain treatments or not use them, advanced care directives, the decision to not resuscitate the child, organ donation, end-of-life sedation and the place of death.

<b>Standard F:</b>	<i>The interdisciplinary team involves parents in decisions throughout all stages of their child's care and treatment. Children and adolescents are kept informed of the situation and participate in decisions that concern their care and treatment plan to the extent that is suitable for their age, level of maturity and preferences.</i>
<b>Criteria F:</b>	<p>F-1 – Children's and adolescents' ability to participate in decisions that concern them is assessed on a regular basis. The assessments are recorded in their file.</p> <p>F-2 – The interdisciplinary team consults with the child and family when important decisions must be made. These decisions are recorded in the child's file. The child's and parents' values and preferences are clearly noted.</p> <p>F-3 – The interdisciplinary team and the family can consult an ethics committee when faced with complex situations.</p>
<b>Standard G:</b>	<i>Children and families have access to appropriate and free information on palliative care and on the services provided.</i>
<b>Criteria G:</b>	<p>G-1 – Children and their families are provided with documentation on palliative care. This documentation includes information on the physical, psychological, social and spiritual aspects of care.</p> <p>G-2 – The interdisciplinary team provides children and their families with a wide range of information, including information on the services they provide, support groups and community organizations, home care and household services that are available.</p> <p>G-3 – The interdisciplinary team provides the family with documentation on financial aid programs, such as government programs, support foundations, tax exemptions, employment insurance, and reimbursement of drug costs.</p> <p>G-4 – When providing children and families with information material, the interdisciplinary team takes their age, level of education and language spoken into account.</p> <p>G-5 – The information material is reviewed on a regular basis.</p>

### 6.1.3. Continuity of Care

Continuity of care is considered achieved when children and families feel they have received consistent care throughout the illness and bereavement period. Continuity of service delivery prevents fragmentation of care and therefore minimizes the feelings of abandonment that children and their families may experience. Continuity of care also leads to a more efficient use of resources and eliminates the burden placed on children and parents who are made to undergo the same tests or answer the same questions. In addition, it is all the more critical to provide continuity of care during transitional periods: from curative to palliative care, from palliative to end-of-life care, from end-of-life care to bereavement, or from pediatric palliative care to adult palliative care.

Continuity of care is said to have been achieved when: information regarding the child and family is systematically relayed between the various health care providers and is used consistently (informational continuity); the relationship between the child, family and health care providers is continuous (relational

continuity ); and when the management of care is coordinated effectively (management continuity ) [38, 202-204].

To achieve continuity of information and provide care suited to the patient's situation, the patient's case history must be taken into account to make current care appropriate. This information must therefore be exchanged among health care providers and between care teams. In addition, relevant information must flow between the patient's various care sites. Effective communication, combined with optimal use of information technologies, can greatly facilitate continuity of care.

In order to develop a strong, stable relationship with the patient and family, it is important to get to know them personally. When the relationship between a patient and caregiver is stable, continuity of care can be established, and the patient's transition between the different phases of the illness can be a smooth one. The fact that Québec, other Canadian provinces and many other jurisdictions are currently focusing on the role of the nurse navigator or care navigator aptly reflects the need to provide relational continuity in our complex healthcare systems.

Management continuity is based on the proper coordination of care and ensures that the various health care providers can provide consistent care. The intervention and service plan promotes coordination of care because it addresses the range of hospital and community services required to meet the needs of children and their families. A consensus on the definition of the roles, responsibilities and rights of the various teams, regardless of where they provide services, also facilitates the coordination of care. Care navigators play a major role in ensuring continuity of care, and in coordinating and developing the intervention and service plan [43, 205, 206]. They maintain contact with the child and family and assess their needs. They establish ties with other health care providers who work in the same care facility and with health care providers who work in other care facilities or in the community. The National Health Services of England describes the responsibilities of the care navigator (*key worker*) as follows: to provide information and advise; to identify the needs of the patient; to improve access to services; to improve coordination of services; to provide emotional support to the patient and family and act as the patient, family and team spokesperson [16]. This description is similar to how the MSSS describes the responsibilities of the nurse navigator [207]. The nurse navigator acts as a stable resource-person for the family, provides coordination and continuity of care, answers patients' and family members' questions, and supports and helps them through the various stages of the care process. The nurse navigator is a specialized nurse whose position requires advanced knowledge and analytical skills that can only be obtained through a bachelor's degree in nursing.

#### 6.1.3.1. *Standards of Practice: Continuity of Care*

**Standard H:** *The information required in order to provide continuity of care is described in the intervention and service plan.*

**Criteria H:** H-1 – The various health care providers, services, institutions and community resources (including schools) that will contribute to meeting the needs of children and their families are identified in the intervention and service plan.

H-2 – The role and responsibilities of the various health care providers and organizations are described in the intervention and service plan.

H-3 – Health care providers and organizations are informed of any changes to the intervention and service plan.

<b>Standard I:</b>	<i>Continuity of care for the child and family is maintained when the child is transferred from one institution to another or when the child returns home.</i>
<b>Criteria I:</b>	<p>I-1 – When the child is transferred from one institution to another, from an institution to the child’s home, or from the child’s home to an institution, the intervention and service plan is reviewed with the health care providers who will be providing care to the child and family; the intervention and service plan is communicated to the relevant individuals.</p> <p>I-2 – A member of the interdisciplinary team ensures that the personnel, equipment and medication required to provide the child with comfort and security are available wherever the child is transferred.</p> <p>I-3 – The methods used to maintain communication between the care team and the individuals who provide care in the setting into which the child is transferred are described in the child’s file.</p>
<b>Standard J:</b>	<i>Continuity of care is provided to the child and family when they are being treated by more than one team or during transitions between different kinds of care.</i>
<b>Criteria J:</b>	<p>J-1 – The various care teams consult each other to define their roles and responsibilities.</p> <p>J-2 – For children who survive into adulthood, the transition from pediatric palliative care to adult palliative care is organized in such a way as to ensure that it takes place in a timely and progressive manner.</p> <p>J-3 – The intervention and service plan describes the bereavement support resources that are provided to parents, siblings and other family members.</p>
<b>Standard K:</b>	<i>A nurse navigator or care navigator is assigned to each child and family. This individual ensures that the child’s and the family’s needs are met and that care is coordinated.</i>
<b>Criteria K:</b>	K-1 – Regardless of the care-delivery site, the child and family always know who their nurse or care navigator is.
<b>Standard L:</b>	<i>The child and family have access to medical and nursing care services.</i>
<b>Criteria L:</b>	<p>L-1 The child and family have access to on-call medical services 24 hours a day, 7 days a week, regardless of the service-delivery setting.</p> <p>L-2 The child and family have access to on-call nursing care at home, 24 hours a day, 7 days a week.</p>

## 6.2. FOCUS AREA II: Interdisciplinarity

Because children and families have multifaceted needs, pediatric palliative care requires a multidisciplinary team of health care providers and volunteers. Although they may work independently, health care providers working in interdisciplinary teams are better able to meet the child's and family's needs, Interdisciplinarity aims to maximize a concerted approach among healthcare providers.

Interdisciplinarity is defined as health care providers from various disciplines working toward a comprehensive, common and unified understanding of an individual's state of health, through a concerted intervention approach based on sharing complementary expertise and skills [208, 209]. Whereas multidisciplinary requires that health care providers from several disciplines work together to study a common subject, interdisciplinarity requires that health care providers also synthesize and harmonize their views to find common ground that is both consistent and coordinated. Interdisciplinarity is important whether the team in question is a treatment team, a palliative care team, or a team combining both treatment and palliative care teams.

Interdisciplinarity allows health care providers to pool their efforts and optimize their complementary expertise. Whether from the perspective of the patient, the family, the health care providers or the healthcare network, the advantages of interdisciplinarity are numerous. Interdisciplinarity involves attending interdisciplinary meetings and sharing information [209], ensuring consistent interventions, and providing proper care in a timely and continuous manner. As a result, the patient receives care that is both holistic and more comprehensive, and child and family satisfaction increases.

Working as part of a team, particularly an interdisciplinary team, is an enriching yet demanding experience. Institutional support is therefore critical in minimizing the burden that these demands can place on health care providers and in ensuring the success of this model of care.

Often, meeting the needs of the child and family will require the involvement of several teams. In these cases, the treatment and palliative care teams will work in close collaboration to provide comprehensive and continuous care.

### 6.2.1. Members of the Interdisciplinary Team

The makeup of an interdisciplinary pediatric palliative care team relies on the expertise required to support the treatment teams and provide quality care [12, 33, 34, 210, 211]. To meet the child's physical needs, a pediatric palliative care team must include physicians and nurses. To meet the psychosocial needs of the child and family and to support the family during bereavement, the team must also include social workers and psychologists. To attend to spiritual needs, pastoral services are required. Pharmaceutical care is required for optimal pain and symptoms management. The pharmacist's expertise is particularly valuable in adjusting or tailoring an individual's treatment plan, preventing adverse reactions to drugs, or increasing the effectiveness of drugs according to the reality of the child, family and home environment. In addition, physiotherapists, occupational therapists and dieticians play a major role in maintaining the child's physical abilities as long as possible. Lastly, a child-life professional can support the efforts of all team members through games and expression, e.g. story-telling, which are essential when caring for children and adolescents [212].

Although the literature on pediatric palliative care clearly states that a team consisting of members of the various disciplines mentioned above contributes to the quality of pediatric palliative care, there is no clear consensus on the roles that the various professional health care providers should play. However, the sources consulted agree that all health care providers in a pediatric palliative care team must have training in the treatment of children in palliative care.

The members of a pediatric palliative care team are often part of various treatment teams. However, they are unique in that they have acquired expertise in pediatric palliative care and wish to dedicate at least some of their time to working with a team that specializes in such care.

The role of volunteers in pediatric palliative care is becoming increasingly recognized [213]. Volunteers who choose to work with a pediatric palliative care team must be trained in the tasks they are likely to be assigned, regardless of the setting in which they may find themselves. As part of their home respite program, *The Lighthouse, Children and families*, a non-profit organization, has developed a training module for volunteers, which could be used as a guide to train pediatric palliative care volunteers [214]. In addition, volunteers must have the support of institutional structures, in collaboration with parent or community organizations, and be guided by a code of ethics. Although intended for volunteers in adult palliative care, *Recrutement et évaluation des bénévoles en soins palliatifs*, a document on the recruitment and assessment of volunteers in adult palliative care, could serve as a guide to recruit volunteers in pediatric palliative care. The guide is published by the *Réseau de soins palliatifs du Québec* (Québec network of palliative care) [215].

#### 6.2.1.1. Standards of Practice: Interdisciplinary Teams

**Standard M:** *Interdisciplinary team members have the necessary skills to meet the needs of children who require palliative care and those of their families.*

**Criteria M:** M-1 – The interdisciplinary pediatric palliative care teams at UPCs include physicians, nurses, pharmacists, social workers, psychologists, physiotherapists, occupational therapists, dieticians, pastoral counsellors, child-life professional and any other health care provider whose skills are required to meet children’s and families’ needs; such health care providers may work exclusively in pediatric palliative care or divide their time with other care teams.

M-2 – The interdisciplinary pediatric palliative care teams at UPCs have the necessary skills to support both the care teams working within their institution and those working at institutions located within their RUIS areas by providing information, advice, and consultations.

M-3 – Other interdisciplinary care teams providing pediatric palliative care must either include the health care providers required to meet the needs of children and their families or have access to those health care providers.

#### 6.2.2. How an Interdisciplinary Team Works

A pediatric palliative care team can operate according to different models. Currently, interdisciplinarity represents the model most likely to meet the needs of children and their families. How an interdisciplinary team operates is defined by the structures and processes implemented by the team [209]. These structures and processes help team members understand the perspectives of other disciplines and integrate them into their own practice; minimize any lack of understanding between members of different disciplines, prevent disagreements between team members, address any gaps in care and promote continuity in care delivery; and foster productive relationships between health care providers from various disciplines to improve interdisciplinary practice. By working in an interdisciplinary team, health care providers from different disciplines can coordinate their skills and provide care and services to a clearly defined population.

The structures and processes of interdisciplinary teams have been well described. Making structures work requires strong leadership, clearly defined roles and responsibilities, and effective information-sharing and decision-making [209].

Team leadership is essential to the well-being of the team and to the quality of their work. Interdisciplinary teams usually include a medical director and clinical administrative coordinator [209]. The director and coordinator are responsible for motivating the team, assigning tasks and guiding the team's efforts. They work with team members to set objectives and formulate strategies to achieve them.

The roles and responsibilities of each team member, e.g. their professional contribution to the team's overall efforts, must be made clear [208]. As professionals, team members must be at the leading edge in their respective fields of expertise. They must continually upgrade their skills and inform the other team members of any new developments, initiatives and discoveries in their field. As members of a team, they must attend clinical and administrative meetings, contribute to discussions and abide by collective decisions. The decisions they adopt may have a direct impact on practice, i.e., care plans, the most effective practices agreed upon, the tools used, data collection and care policies. Interdisciplinarity therefore promotes a sense of team membership and of belonging. Continuous quality improvement activities, such as training, evidence-based practice, and research and evaluation is also integral to the roles and responsibilities of team members.

#### 6.2.2.1. *Standards of Practice: Interdisciplinary Team Processes*

**Standard N:** *The teams adopt an interdisciplinary model of care to coordinate the work they carry out with children and families.*

**Criteria N:** N-1 – The team's approach to pediatric palliative care, their objectives and the strategies they will pursue to achieve their objectives are documented. This document will serve to guide the team's work and will be reviewed annually.

N-2 – A director and coordinator are appointed to the interdisciplinary team.

N-3 – The interdisciplinary team holds clinical meetings on a regular basis to plan, review and assess the care provided to children and families. Decisions made during these meetings are noted in the child's file.

N-4 – Administrative meetings are held by the interdisciplinary team regularly to discuss and decide how they will proceed in their work. The decisions made during these meetings, and any related information on previous decisions, are noted in writing.

#### 6.2.3. **Supporting the Interdisciplinary Team**

Interdisciplinarity means setting time aside to participate in discussions and decision-making. Because the demands made on health care providers are already considerable, finding time to participate in team activities can be challenging. Support is therefore required to help the teams meet these demands.

Interdisciplinarity is based on the exchange of ideas, views and opinions to make decisions collectively. If such exchanges are to be positive, productive and non-confrontational, team members must respect each other and their colleagues' expertise, have confidence in working as a team and be flexible. How well meetings are facilitated will have an impact on consensus-reaching in team decisions, on the atmosphere during and in between meetings, on the time required to make decisions, and on the results achieved. The team director and clinical and administrative coordinator should therefore be trained in facilitation.

To deal with the emotional and psychological demands of working with children in pediatric palliative care, the interdisciplinary team must hold group support meetings or find other ways of providing psychological support to its members [33, 34, 216, 217].

Institutional support contributes significantly to the interdisciplinary team's success. When an institution chooses interdisciplinarity as part of its main strategic orientations, the institution can harness its available resources to promote the interdisciplinary model. The institution must recognize the team's legitimacy and provide support through human resources planning by: allocating time for interdisciplinary team activities; providing training; encouraging participation at conferences or meetings; and supporting members' interest in serving as experts on various committees. The institution must also provide practical assistance by contributing administrative support services and equipment (photocopiers, computers, internet access, and documentation centres).

#### **6.2.3.1. Standards of Practice: Interdisciplinary Team Support**

**Standard O:** *Interdisciplinary team members are concerned with the demands of working as a team and the emotional and psychological demands of working with children in pediatric palliative care and their families.*

**Criteria O:** O-1 – The director or coordinator of the interdisciplinary team acquires the necessary skills to act as an effective team facilitator.

O-2 – Members of the interdisciplinary team have access to psychological support.

**Standard P:** *The institution supports the interdisciplinary care team(s) that provide pediatric palliative care*

**Criteria P:** P-1 – The institution formally recognizes the roles and responsibilities of the care team and its members that provide pediatric palliative care.

P-2 – The institution allocates time in its human resources planning for interdisciplinarity.

P-3 – The institution encourages members of the interdisciplinary team to maintain their skills by providing opportunities to attend courses or participate in conferences.

P-4 – The institution provides practical assistance by giving access to administrative support services and equipment.

### 6.3. FOCUS AREA III: Continuous Quality Improvement

To effectively meet the needs of children in palliative care and their families, care providers require specialized knowledge, qualifications and skills, whether they are part of a treatment or palliative care team. They must also maintain their competencies.

Although the required expertise is, in part, similar to that of adult palliative care, many of the necessary skills, knowledge and qualifications are specific to pediatrics. Pediatric palliative interventions must take into account the child's development, the key role that parents play, consequences of the child's illness on siblings, and the fact that pathologies vary within this age group. Compared to adults, the number of deaths among children is relatively low. As a result, acquiring or maintaining skills in pediatric palliative care poses a significant challenge for health care providers and care teams.

Through training, health care providers can acquire and maintain the skills they need to provide pediatric palliative care. Health care providers can maintain and upgrade their skills by keeping abreast of recent developments in the field, by engaging in a continuous quality improvement program that includes practice and service organization evaluation, and by participating in research activities [218]. Skills can therefore be acquired and maintained through:

- basic training and continuing education;
- knowledge of the most effective practices;
- evaluation and research activities.

#### 6.3.1. Training

Although some progress has been made, more extensive training is required for health care providers who work with children requiring palliative care, with the families of these children or with bereaved families. All too often, and to the detriment of children and their families, health care providers learn through trial and error. As a result of this lack of training, the consequences on children and their families should never be underestimated [61, 62].

Training lays the foundation for quality pediatric palliative care [34, 220-231]. According to the Institute of Medicine, training must cover: 1) scientific and technical knowledge; 2) interpersonal and technical skills; 3) professional ethics and principles; and 4) organizational skills, to help patients and their families navigate the health care system [12]. Sound training provides health care providers with a better understanding of the feelings and emotions that children and their families experience during a very difficult time in their lives; acknowledges the emotional burden placed on health care providers who provide care to children and to the families of children whose lives are at risk, thereby lowering the risk of professional burnout [33, 34, 216]. Training helps health care providers recognize and assess pain and symptoms and provide the appropriate pain- and symptom-management interventions. It also helps them assess what information should be given to children and their families. Training provides health care providers with the basis for delivering proper and consistent care and teaches them to show compassion during the palliative phase, the end-of-life phase and the bereavement phase.

Treatment and palliative care teams must possess basic training and pursue continuing education. Because self-training is demanding, it must be encouraged, facilitated and recognized by the work environment. Training must also be tailored to the health care providers' specific roles and responsibilities.

Basic training and continuing education must be provided through experienced trainers. Pediatric palliative care teams working in UPCs play a major role in training the health care providers who are part of the

integrated university health network (RUIS). New information technologies, including teletraining for distance education, will simplify their role as trainers. Pediatric palliative care teams at UPCs must participate in the development of university courses for pediatric and palliative care programs. University programs in pediatrics and palliative care should include a pediatric palliative care component, taken either before or after graduation. Continuing education programs should offer the same.

In addition to helping health care providers who are part of the healthcare network, teaching helps members of the pediatric palliative care team stay up to date in their knowledge and gain recognition through their role as trainers. Members of treatment teams, particularly those who work in UPCs, must participate in pediatric palliative care training.

### 6.3.1.1. Standards of Practice: Training

**Standard Q:** *Members of the interdisciplinary team, including volunteers, have the necessary training to provide care to children and to the families of children in palliative care.*

**Criteria Q:** Q-1 – Health care providers who work as part of pediatric palliative care teams at UPCs have in-depth training in pediatric palliative care and pursue continuing education.

Q-2 – Health care providers who work with other interdisciplinary teams establish the structures necessary to acquire and maintain knowledge in pediatric palliative care.

Q-3 – Volunteers receive training in pediatric palliative care through a recognized organization.

**Standard R:** *Interdisciplinary teams working in pediatric palliative care at university pediatric centres help interdisciplinary health care providers—from their institution and from their RUIS region—acquire the training they need to provide care to children in palliative care and meet the needs of their families.*

**Criteria R :** R-1 – Interdisciplinary pediatric palliative care teams working in UPCs provide practicums in various pediatric palliative disciplines, including family medicine.

R-2 – Interdisciplinary pediatric palliative care teams in UPCs work with their RUIS to ensure that a pediatric component is included in palliative care training and that a palliative care component is included in pediatric training programs.

R-3 – Interdisciplinary pediatric palliative care teams working in UPCs support the continuing education efforts of pediatric palliative health care providers in their region. The activities in which they participate are included in their annual report.

**Standard S:** *Interdisciplinary teams contribute to raising institutional and public awareness on pediatric palliative care issues.*

**Criteria S:** S-1 – Interdisciplinary teams possess documentation, e.g., brochures and videos, that describes pediatric palliative care, as well as the services that can be provided and how to access them.

S-2 – Interdisciplinary teams possess pedagogical material to develop public awareness on pediatric palliative care issues. They also participate in information sessions on how to raise public awareness.

### 6.3.2. Evidence-based Practice

Evidence-based practice promotes continuous quality improvement in care and services. Interdisciplinary teams support continuous improvement in health care practices by developing, reviewing, and implementing clinical practice guides, guidelines, procedures and care pathways. However, keeping abreast of the latest developments in evidence-based practice can be challenging in a field with scarce resources [232].

Pediatric palliative care teams working in UPCs could collaborate to develop, review and implement clinical practice guides, guidelines, procedures and care pathways by combining their expertise and efforts, addressing all important aspects of care, and ensuring the continuity and dissemination of proven initiatives.

They could also collaborate with other partners, such as local and regional palliative care teams and community organizations.

#### *6.3.2.1. Standards of Practice: Evidence-based Practice*

**Standard T:** *Interdisciplinary teams providing pediatric palliative care engage in evidence-based interventions and apply them consistently.*

**Criteria T:** T-1 – Interdisciplinary teams make use of evidence-based written procedures, guidelines, and assessment and care coordination tools, such as care pathways.

T-2 – Interdisciplinary teams hold scientific meetings and training sessions. They maintain a list of the subjects addressed during these meetings.

**Standard U:** *Pediatric palliative care teams working in university pediatric centers (UPC) make recommendations on best practices in pediatric palliative care.*

**Criterion U:** U-1 – Interdisciplinary pediatric palliative care teams working in UPCs collaborate to develop guidelines, protocols and procedures, encourage their dissemination and appropriation by health care teams in Quebec.

### 6.3.3. Evaluation and Research

#### *6.3.3.1. Evaluation*

Evaluation of standards can address any clinical and organizational aspect of care and services [34]. Reasons for conducting evaluation include: to take a critical look at how teams operate; to identify any variation between the practices that are used and those that should be used; and to adopt measures that address these variations as soon as they are identified.

Evaluation must be conducted regularly to determine the extent to which health care teams have achieved their objectives. As such, teams must first have defined their general and specific objectives. They must develop a way to measure each objective and, possibly, establish indicators to measure the progress they have made in achieving the objective. The evaluation will be enhanced if results can be compared to those of other teams working in Quebec, in the rest of Canada or in other countries.

Evaluation can be conducted in various care locations and can take on various forms: 1) periodic reviews on specific subjects, such as how to treat symptoms, continuity of care and children's and families' satisfaction; 2) case reviews; 3) consistent measurement and monitoring of key indicators through database analysis.

#### *6.3.3.2. Research*

Healthcare teams that undertake or participate in research not only contribute to the advancement of knowledge, but acquire strong skills in interpreting scientific data and in transferring these skills to their daily practice [12, 34, 233-238]. In addition, participation in joint research projects promotes networking and speeds access to new data.

All healthcare teams can participate in research. Palliative care teams working in UPCs play a key role in advancing research in pediatric palliative care. They fulfil this role by conducting their own studies, participating in joint studies or promoting project development within well-established research groups.

### 6.3.3.3. *Standards of Practice: Evaluation and Research Standards*

**Standard V:** *Interdisciplinary teams assess their practices and find ways to improve them consistently.*

**Criteria V:** V-1 – Interdisciplinary teams identify their objectives in pediatric palliative care and define expected results. They identify the indicators they will use to determine the extent to which the results have been achieved.

V-2 – Interdisciplinary teams regularly conduct evaluation activities, discuss their results and implement measures to improve palliative care and services.

V-3 – Interdisciplinary teams prepare an annual report that describes their activities and progress.

V-4 – Interdisciplinary teams maintain a clinical database that helps them know their patients and assess their performance.

**Standard W:** *Interdisciplinary teams undertake or participate in research projects.*

**Criterion W:** W-1 – Interdisciplinary teams document the research projects they implement or those in which their members participate.

## 6.4. FOCUS AREA: Clinical Governance

Clinical governance is, first and foremost, a framework for continuous improvement in the quality of care. Governance is the responsibility of not only administrators, but also of clinicians. The standard for clinical governance applies to any institution that delivers palliative care services to children and their families, and is based on a consensus between administrators and health care providers on the objectives to achieve. A partnership between clinicians and administrators makes resources, structures and processes available for the provision of quality care. Clinical governance creates an organizational climate that promotes excellence in care and services and stresses each person's responsibility (administrators and healthcare providers) in providing quality clinical work [239-242]. Sound clinical governance in pediatric palliative care must recognize the unique health needs of children and their families [243]. Institutions, HSSAs and the MSSS must demonstrate this recognition concretely through the decisions they make.

Institutions, HSSAs and the MSSS must also recognize that palliative care is part of the continuum of care in pediatrics. They must also have in-depth knowledge of the six categories of children and families that constitute the target population described in Chapter 3. This population receives care from various services and departments including intensive care, emergency, obstetrics and neonatology, pediatrics, pediatric specialities and home-care services. Institutions must develop policies that ensure fair access to pediatric palliative care for all children and their families, regardless of where they live. Implementing an institutional pediatric palliative care program may help mobilize all those who are involved in pediatric palliative care.

The environment and institutional regulations must also be tailored to the needs of children who receive pediatric palliative care and those of their families. For example, a private room must be provided to children and their families during the end-of-life stage; parents must be able to remain with their child 24 hours a day; dedicated rooms must be available when health care providers deliver bad news; and siblings and friends must be allowed to visit the child at any time during the terminal phase. The family's need for respite must also be recognized.

Establishing parent committees and appointing family representatives to various advisory boards or working groups can help focus action on the child and family.

Institutions must support pediatric palliative care teams in developing, consolidating and maintaining their skills. The long-term stability of a pediatric palliative care team relies on material and physical resource planning and staff retention and recruitment. The responsibilities of team members must be compatible with interdisciplinarity. To acquire and maintain their skills, care teams must have access to training and continuing education.

Administrators must facilitate continuity of services in pediatric palliative care. Many institutions are involved in providing pediatric palliative care. In order to provide good, timely service as close as possible to the child's and family's living environment, these institutions must share responsibilities. When institutions and health care providers have well-defined roles and responsibilities, they are better able to fulfil these roles and meet their responsibilities. Institutions must negotiate agreements to improve service coordination and continuity of care.

Pediatric palliative care poses a complex set of problems. Parents and health care providers may have differing opinions on what is in the child's best interest and on the child's participation in decision-making. Often, difficult decisions must be made regarding cessation or non-administration of treatment, sedation at the end-of-life, end-of-life instructions, non-resuscitation and the child's and family's participation in research. Institutions must therefore ensure that health care providers have access to an ethics committee with substantial experience in pediatric palliative care issues.

Accreditation through a recognized accrediting body is mandatory for all institutions within Québec's health network. Accreditation must include an evaluation based on AIM palliative care standards if it is conducted by the CCHSA; if accreditation is conducted by another agency, the evaluation must be based on equivalent standards.

#### 6.4.1. Standards of Practice: Clinical Governance

**Standard X:** *Institutions (UMCs, UAMCs, university institutes, regional medical centres, palliative care hospices and HSSCs) develop policies tailored to pediatric palliative care, and make resources and structures available to improve the quality of care and services they provide.*

**Criteria X:** X-1 – The institution identifies the children and families in their reference population that are likely to benefit from pediatric palliative care.

X-2 – The institution ensures that children and their families have access to palliative care services, including respite services.

X-3 – The institution establishes a parent committee to support the institution in its decisions regarding pediatric palliative care.

X-4 – The institution provides a physical environment tailored to the needs of children who receive pediatric palliative care and their families.

X-5 – The institution adapts its policies to the needs of children receiving pediatric palliative care and to the needs of their families, e.g. visitation policies regarding siblings and friends.

X-6 – The institution ensures that the members of the interdisciplinary team providing palliative care have the expertise required to provide quality care in all the fields needed; the institution ensures that its members have the time and resources to deliver quality services.

X-7 – The institution establishes indicators to describe the target population and evaluate the services it provides in pediatric palliative care.

X-8 – The institution provides access to an ethics committee with substantial experience in addressing pediatric palliative care issues.

X-9 – A special policy is established to provide quality palliative care when a child is admitted through the Emergency department or when a child dies in Emergency.

X-10 – The institution is accredited in accordance with CCHSA or equivalent palliative care standards.

X-11 – UPCs develop a pediatric palliative care program that includes bereavement support.

## 7. Dissemination and Knowledge-Sharing

The working group identified the strengths and opportunities that would help to disseminate the standards and share knowledge on best practices. The group also noted the weaknesses, obstacles and challenges that would have a negative impact on dissemination and knowledge-sharing. They concluded that, for the most part, Quebec has the infrastructures and tools needed to disseminate the pediatric palliative care standards and oversee their adoption.

In fact, one could say that dissemination of the standards is already underway, as their development was largely dependent on the involvement of provincial healthcare providers. Throughout the process, the working group observed a high level of enthusiasm and receptiveness to the proposed standards. However, the dissemination and adoption of standards requires more than the commitment of individuals. It also requires the mobilization of many institutions and establishments that provide pediatric palliative care.

## Conclusion

The proposed standards can foster continued improvement in the quality of pediatric palliative care provided through the various care-delivery sites across Québec. Because the proposed standards were developed following a thorough review of the literature, they are founded on recognized best practices in the field of pediatric palliative care. The group also consulted with a wide range of people from across the province, including parents, treatment teams, administrators and community organizations. As a result, these standards benefit from a broad range of perspectives and are in-line with the Québec reality. Moreover, the parents who were consulted during the process felt that the standards could effectively bridge the observed gaps in care and services.

The potential benefits of these standards will be even greater if the spirit in which they are being proposed is well understood. The working group sees these standards as goals to strive for and pursue and as benchmarks to guide action in a way that is realistic for the field of pediatric palliative care. The idea is for each care-delivery site to assess the current situation, compare it with the objectives set out in the standards, and determine how to work progressively towards achieving these goals.

Thanks to the recent adoption of the Québec End-of-Life Palliative Care Policy, and the efforts of many pediatric, pediatric palliative care and adult palliative care professionals, the province is currently in a favourable period for continuous improvement in pediatric palliative care. By providing more precise directions and objectives, the standards, if implemented, would no doubt support the efforts being made to improve quality of care. Pediatric palliative care teams of the UPCs, administrators of The Lighthouse, Children and Families organization and many other partners have expressed a desire to formally consolidate their efforts. This would help achieve common projects and share information about what is working and what needs improvement. In order for all of this to come to fruition, the immediate goal is to ensure that these standards are adopted and that mechanisms are put in place to foster their application.

## References

### General References

In addition to the references cited in the body of the text, two works were particularly useful in writing this report since they addressed all aspects of pediatric palliative care. The working group therefore referred to the works in their entirety, which vastly improved the quality of this document. They are:

- Humbert, N. (2004). *Les soins palliatifs pédiatriques*. Collection Intervenir, Hôpital Sainte-Justine, 656 p.
- Goldman, A., Hain, R., Liben, S. (2006). *Oxford Textbook of Palliative Care for Children*, 576 p.

Several internet sites were also consulted:

- Association for Children with Life-threatening or Terminal Conditions and their Families (<http://www.act.org.uk>)
- Initiative for Pediatric Palliative Care (<http://www.ippcweb.org/>)
- Pédiadol ([http://www.pediadol.org/rubrique.php3?id\\_rubrique=110](http://www.pediadol.org/rubrique.php3?id_rubrique=110))
- Pediatric Pain – Science Helping Children (<http://pediatric-pain.ca/pedpain.html>)
- The National Center of Medical Home Initiatives for Children with Special Needs ([http://www.medicalhomeinfo.org/publications/palliative\\_pro.html](http://www.medicalhomeinfo.org/publications/palliative_pro.html))
- Canadian Network of Palliative Care for Children (<http://www.cnpsc.ca/>)
- Réseau francophone de soins palliatifs pédiatriques (<http://www.hsj.qc.ca/RFSPPL/>)

### Other References

1. Côté-Brisson, L., et al., *Projet de programme de soins palliatifs pédiatriques au Centre mère-enfant du CHUQ*. Québec (Québec). 2004: 66 p.
2. Ministère de la Santé et des Services sociaux, *Quebec End-of-Life Palliative Care Policy* [http://www.chpca.net/public\\_policy\\_advocacy/Quebec\\_policy.pdf](http://www.chpca.net/public_policy_advocacy/Quebec_policy.pdf), the original source French language version was consulted online on August 30, 2005. 2004: 98 p.
3. International Society for Quality in Health Care, *International Principles for Healthcare Standards*. Second edition. <http://www.isqua.org/isquaPages/Accreditation/ISQualAPPPrinciplesV2.pdf>, consulted online on December 10, 2004.
4. Canadian Council on Health Services Accreditation, *Literature review and environmental scan for cancer specific standards*. Submitted to the CSCC Standards Action Group. 2004.
5. Bédard, C., et al., *Soins palliatifs de fin de vie au Québec: définition et mesure d'indicateurs*. Institut national de santé publique du Québec. Québec. 2006: 160 p.
6. Sepulveda, C., et al., *Palliative Care: the World Health Organization's global perspective*. *J Pain Symptom Manage*, 2002. 24(2): 91-96.
7. Canadian Hospice Palliative Care Association and Canadian Network of Palliative Care for Children, *Pediatric Hospice Palliative Care: Guiding Principles and Norms of Practice*. [http://www.chpca.net/marketplace/pediatric\\_norms/pediatric\\_norms.htm](http://www.chpca.net/marketplace/pediatric_norms/pediatric_norms.htm), consulted online on September 9, 2005. 2004: 66 p.

8. Association for Children with Life-threatening or Terminal Conditions and their Families and Royal College of Paediatrics and Child Health, *A guide to the development of children's palliative care services*. Second Edition. [www.act.org.uk/pdffdocuments/ACTChildPallServGuide.pdf](http://www.act.org.uk/pdffdocuments/ACTChildPallServGuide.pdf), consulted online on September 9, 2005. 2003: 51 p.
9. Ministère de la Santé et des Services sociaux, *Projet de politique en soins palliatifs de fin de vie*. <http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2004/04-828-02W.pdf>, consulted online on August 30, 2005. 2004: 164 p.
10. Steele, R.G., *Experiences of families in which a child has a prolonged terminal illness: modifying factors*. International Journal of Palliative Nursing, 2002. 8(9): 418-434.
11. Carnevale, F.A., et al., *Daily living with distress and enrichment: the moral experience of families with ventilator-assisted children at home*. Pediatrics, 2006. 117(1): e48-e60.
12. Field, M.J. and R.E. Behrman, *When children die: Improving palliative and end of life care for children and their families*. [www.nap.edu/catalog/10390.html](http://www.nap.edu/catalog/10390.html), consulted online on December 15, 2005. 2003.
13. Liben, S. and B. Mongodin, *La notion de répit pour les familles d'enfants atteints de maladies à issue fatale: une évaluation des réseaux disponibles et des stratégies courantes, perspectives d'amélioration*. The Lighthouse, Children and Families. 2000.
14. Mount, B. and L. McHarg, *The Montreal Children's Hospital palliative care assessment committee report*. 1987.
15. Cyr, C., *Le deuil des grands-parents*. Bulletin du réseau de soins palliatifs du Québec, 2005. 13(3): 16-17.
16. Department of Health and Department for Education and Skills from the Government of United Kingdom, *Commissioning children and young people's palliative care services: a practical guide for the NHS*. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4123874](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4123874), consulted online on December 15, 2005. 2005.
17. Sieben-Hein, D. and E.A. Steinmiller, *Working with complex care patients*. J Pediatr Nurs, 2005. 20(5): 389-395.
18. Ernoult, A. and D. Davous, *Attentes et besoins des parents ayant un enfant en soins palliatifs*. Info Kara, 2003. 18: 94-96.
19. Thornes, R. and (on behalf of the Joint Working Party on Palliative Care for Adolescents and Young Adults), *Palliative care for young adults aged 13-24*. Association for Children with Life-threatening or Terminal Conditions and their Families (ACT). [www.act.org.uk/documentation/documentation.asp](http://www.act.org.uk/documentation/documentation.asp), consulted online on December 15, 2005. 2001.
20. Association for Children with Life - Threatening or Terminal Conditions and their families (ACT). *Voices for Change Current perceptions of services for children with palliative care needs*. [http://www.act.org.uk/component/option,com\\_docman/task,cat\\_view/gid,15/Itemid,26/](http://www.act.org.uk/component/option,com_docman/task,cat_view/gid,15/Itemid,26/), consulted online on December 21, 2005. 2003.
21. Hinds, P.S., et al., *Key factors affecting dying children and their families*. J Palliat Med, 2005. 8 Suppl 1: S70-S78.
22. Himmelstein, B.P., *Palliative care for infants, children, adolescents, and their families*. J Palliat Med, 2006. 9(1): 163-181.
23. Hynson, J.L. and S.M. Sawyer, *Paediatric palliative care: distinctive needs and emerging issues*. J Paediatr Child Health, 2001. 37(4): 323-325.
24. Kane, J.R. and M. Primomo, *Alleviating the suffering of seriously ill children*. Am J Hosp Palliat Care, 2001. 18(3): 161-169.
25. Kang, T., et al., *Pediatric palliative, end-of-life, and bereavement care*. Pediatr Clin North Am, 2005. 52(4): 1029-1046, viii.

26. Whittam, E.H., *Terminal care of the dying child: Psychosocial implications of care*. *Cancer*, 1993. 71(10 Suppl): 3450-3462.
27. Davies, B., et al., *Addressing spirituality in pediatric hospice and palliative care*. *J Palliat Care*, 2002. 18(1): 59-67.
28. Kane, J.R., M.B. Hellsten, and A. Coldsmith, *Human suffering: the need for relationship-based research in pediatric end-of-life care*. *Journal of Pediatric Oncology Nursing*, 2004. 21(3): 180-185.
29. Raina, P., et al., *The health and well-being of caregivers of children with cerebral palsy*. *Pediatrics*, 2005. 115(6): e626-e636.
30. Drake, R., J. Frost, and J.J. Collins, *The symptoms of dying children*. *Journal of Pain Symptom Management*, 2003. 26(1): 594-603.
31. Feudtner, C., J. Haney, and M.A. Dimmers, *Spiritual care needs of hospitalized children and their families: a national survey of pastoral care providers' perceptions*. *Pediatrics*, 2003. 111(1): e67-e72.
32. Wolfe, J., et al., *Symptoms and suffering at the end of life in children with cancer*. *N Engl J Med*, 2000. 342(5): 326-333.
33. Humbert, N., *Les soins palliatifs pédiatriques. INTERVENIR Series*. 2004: 656 p.
34. Goldman, A., R. Hain, and S. Liben, *Oxford textbook of palliative care for children*. 2006: 576 p.
35. Hilden, J.H., et al., *End-of-life care: special issues in pediatric oncology*. *Improving palliative care for cancer*, ed. K.M. Foley and H. Gelband. 2002, Washington D.C.: National Academy Press. 161-198.
36. Davies, B., et al., *The impact on families of respite care in a children's hospice program*. *Journal of Palliative Care*, 2004. 20(4): 277-286.
37. Donnelly, J.P., et al., *The needs of children with life-limiting conditions: a healthcare-provider-based model*. *Am J Hosp Palliat Med*, 2005. 22(4): p. 259-267.
38. Heller, K.S., M.Z. Solomon, and the Initiative for Pediatric Palliative Care (IPPC) Investigator Team, *Continuity of care and caring: what matters to parents of children with life-threatening conditions*. *Journal of Pediatric Nursing*, 2005. 20(5): 335-346.
39. Maunder, E.Z., *The challenge of transitional care for young people with life-limiting illness*. *British Journal of Nursing*, 2004. 13(10): 594-596.
40. Nolbris, M. and A.L. Hellstrom, *Siblings' Needs and issues when a brothers or sister dies of cancer*. *J Paediatr Oncol Nurs*, 2005. 22(4): 227-233.
41. Hain, R.D., *Paediatric palliative medicine: a unique challenge*. *Pediatr Rehabil*, 2004. 7(2): 79-84.
42. National Institute for Health and Clinical Excellence, *Guidance on cancer services. Improving outcomes in children and young people with cancer. The manual*. <http://www.nice.org.uk/nicemedia/pdf/C&YPMManual.pdf>, consulted online on September 9, 2005: 194 p.
43. Department of Health and Children, The Irish Hospice Foundation, and the Faculty of Paediatrics at the Royal College of Physicians of Ireland, *Report on a Research Study of the Palliative Care Needs of Children in Ireland*. [http://hospicefoundation.biznetserver.com/up\\_documents/2005\\_Childrens\\_Palliative\\_Care\\_Needs\\_Assessment.pdf](http://hospicefoundation.biznetserver.com/up_documents/2005_Childrens_Palliative_Care_Needs_Assessment.pdf), consulted online on December 10, 2005. 2005: 215 p.
44. Department of Health and Children and The Irish Hospice Foundation, *A Palliative Care Needs Assessment for Children*. [http://www.dohc.ie/publications/pdf/needs\\_assessment\\_palliative.pdf?direct=1](http://www.dohc.ie/publications/pdf/needs_assessment_palliative.pdf?direct=1), consulted online on December 2005. 2005: 56 p.
45. Norfolk Children and Young People's Palliative Care Group, *Norfolk Palliative Care Strategy For Children and Young People*. [http://www.cancernw.com/content/palliative\\_care/palliative\\_care.php](http://www.cancernw.com/content/palliative_care/palliative_care.php), consulted online on December 10, 2005. 2002.

46. Department of Health and Ageing from the Australian Government, *The National Palliative care program. Paediatric Palliative care Service Model Review Final Report*. [http://www.health.gov.au/internet/wcms/publishing.nsf/Content/465D773A8A4DEDFECA25700D001A1883/\\$File/rptcover.pdf](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/465D773A8A4DEDFECA25700D001A1883/$File/rptcover.pdf), consulted online on December 10, 2004.
47. Monterosso, L., et al., *Paediatric Palliative and Supportive Care. Caring for Life: The needs of children and families in Western Australia*. <http://www.health.wa.gov.au/HRIT/publications/docs/Paediatric%20Palliative%20Care%20Report.pdf>, consulted online on October 25, 2005. 2005: 58 p.
48. Association for Children with Life-threatening or Terminal Conditions and their Families, *The ACT charter for children with life-threatening or terminal conditions and their families*. <http://www.act.org.uk/content/view/37/130/>, consulted online on September 9, 2005. 1998.
49. Freeman, K., C. O'Dell, and C. Meola, *Childhood brain tumours: children's and siblings' concerns regarding the diagnosis and phase of illness*. *J Pediatr Oncol Nurs*, 2003. 20(3): 133-140.
50. Li, J., et al., *Hospitalization for mental illness among parents after the death of a child*. *N Engl J Med*, 2005. 352(12): 1190-1196.
51. Li, J., et al., *Mortality in parents after death of a child in Denmark: a nationwide follow-up study*. *Lancet*, 2003. 361(9355): 363-367.
52. Kreicbergs, U., et al., *Care-Related Distress: A Nationwide Study of Parents Who Lost Their Child to Cancer*. *J Clin Oncol*, 2005. 23(36).
53. Kreicbergs, U., et al., *Anxiety and depression in parents 4-9 years after the loss of a child owing to a malignancy: a population-based follow-up*. *Psychol Med*, 2004. 34(8): 1431-1441.
54. Seecharan, G.A., et al., *Parents' assessment of quality of care and grief following a child's death*. *Arch Pediatr Adolesc Med*, 2004. 158(6): 515-520.
55. Andresen, E.M., G.A. Seecharan, and S.S. Toce, *Provider perceptions of child deaths*. *Arch Pediatr Adolesc Med*, 2004. 158(5): 430-435.
56. Meyer, E.C., et al., *Parental perspectives on end-of-life care in the pediatric intensive care unit*. *Crit Care Med*, 2002. 30(1): 226-231.
57. Widger, K.A. and K. Wilkins, *What are the key components of quality perinatal and pediatric end-of-life care? A literature review*. *J Palliat Care*, 2004. 20(2): 105-112.
58. National Consensus Project for Quality Palliative Care, *Clinical practice guidelines for quality palliative care*. <http://www.nationalconsensusproject.org/Guideline.pdf>, consulted online on September 9, 2005. 2004: 68 p.
59. Dokken, D., *Quality domains, goals of care and indicators for family-centered care of children living with life-threatening conditions developed by The initiative for Pediatric Palliative care (IPPC)*. [http://www.ippcweb.org/login.asp?from=display.asp?filename=domains\\_eap.pdf&type=pdf](http://www.ippcweb.org/login.asp?from=display.asp?filename=domains_eap.pdf&type=pdf), consulted online on December 10, 2005. 2001.
60. Tadmor, C.S., et al., *Policies designed to enhance the quality of life of children with cancer at the end-of-life*. *Pediatr Hematol Oncol*, 2003. 20(1): 43-54.
61. Contro, N., et al., *Family perspectives on the quality of pediatric palliative care*. *Arch Pediatr Adolesc Med*, 2002. 156(1): 14-19.
62. Contro, N.A., et al., *Hospital staff and family perspectives regarding quality of pediatric palliative care*. *Pediatrics*, 2004. 114(5): 1248-1252.
63. Mack, J.W., et al., *Parent and Physician Perspectives on Quality of Care at the End of Life in Children with Cancer*. *J Clin Oncol*, 2005. 23(36): 9155-9161.
64. Feudtner, C., *Perspectives on quality at the end of life*. *Arch Pediatr Adolesc Med*, 2004. 158(5): 415-418.
65. Bradshaw, G., et al., *Cancer-related deaths in children and adolescents*. *J Palliat Med*, 2005. 8(1): 86-95.

66. Association for Children with Life - Threatening or Terminal Conditions and their Families (ACT), *A framework for the development of integrated multi-agency care pathways for children with a life - threatening and life-limiting conditions.*
67. Department of Health and Department for Education and Skills from the Government of United Kingdom, *Care pathway for the discharge and support of children requiring long term ventilation in the community.*  
[http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4115098&chk=YjeYr6](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4115098&chk=YjeYr6), consulted online on December 15, 2005. 2005.
68. Steele, R.G., *Trajectory of certain death at an unknown time: children with neurodegenerative life-threatening illnesses.* Can J Nurs Res, 2000. 32(3): 49-67.
69. Carter, B.S., et al., *Circumstances surrounding the deaths of hospitalized children: opportunities for pediatric palliative care.* Pediatrics, 2004. 114(3): e361-e366.
70. Robinson, W.M., et al., *End-of-life care in cystic fibrosis.* Pediatrics, 1997. 100(2 Pt 1): 205-209.
71. Graham, R.J. and W.M. Robinson, *Integrating palliative care into chronic care for children with severe neurodevelopmental disabilities.* J Dev Behav Pediatr, 2005. 26(5): 361-365.
72. De Graves, S. and S. Aranda, *When a child cannot be cured - reflections of health professionals.* Eur J Cancer Care (Engl), 2005. 14(2): 132-140.
73. Feudtner, C., et al., *Characteristics of deaths occurring in children's hospitals: implications for supportive care services.* Pediatrics, 2002. 109(5): 887-893.
74. Parker, D., I. Maddocks, and L.M. Stern, *The role of palliative care in advanced muscular dystrophy and spinal muscular atrophy.* J Paediatr Child Health, 1999. 35(3): 245-250.
75. Weidner, N.J., *Developing an interdisciplinary palliative care plan for the patient with muscular dystrophy.* Pediatr Ann, 2005. 34(7): 546-552.
76. Widger, K. *Who receives pediatric palliative care in Canada?* in *International Pediatric Palliative Care Rounds.* 2005. Hospital For Sick Children, Toronto (Ontario).
77. Wilson, D., *Final report integrated end-of-life care: A Health Canada Synthesis Research Project funded by Health Canada (project #6795-15-2002/478004). Appendices. Literature Review Report: Pediatric End-of-life Care.* 2003.
78. Children's International Project on Palliative / Hospice Services (ChIPPS), *A call for change: Recommendations to improve the care of children living with life-threatening conditions.*  
[www.nhpco.org/i4a/pages/index.cfm?pageid=3409](http://www.nhpco.org/i4a/pages/index.cfm?pageid=3409), consulted online on December 15, 2005. 2001.
79. Victoria Paediatric Palliative Care Program, *Caring for the dying child: Challenges for paediatrics, challenges for palliative care. Inaugural report.* 2002.
80. Joshi, D.D., *"Virtual" pediatric palliative care: a novel concept for small pediatric programs.* J Palliat Med, 2005. 8(6): 1089-1090.
81. Canouï, P., *Les soins palliatifs pédiatriques.*  
<http://www.sante.gouv.fr/htm/actu/hennezel/annexe13.pdf>, consulted online on December 15, 2005. 2003.
82. Craig, F. and A. Goldman, *Home management of the dying NICU patient.* Semin Neonatol, 2003. 8(2): 177-183.
83. Leuthner, S.R., A.M. Boldt, and R.S. Kirby, *Where infants die: examination of place of death and hospice/home health care options in the state of Wisconsin.* J Palliat Med, 2004. 7(2): 269-277.
84. Bélanger, S. and N. Humbert, *La mise en place d'une équipe de soins palliatifs dans un hôpital universitaire... un parcours pas à pas. L'expérience du CHU mère-enfant Sainte-Justine Montréal.* Info Kara, 2003. 18: 67-69.
85. Dangel, T., *The status of pediatric palliative care in Europe.* J Pain Symptom Manage, 2002. 24(2): 160-165.

86. Hain, R.D., *Palliative care in children in Wales: a study of provision and need*. Palliat Med, 2005. 19(2): 137-142.
87. Price, J., P. McNeilly, and M. McFarlane, *Paediatric palliative care in the UK: past, present and future*. Int J Palliat Nurs, 2005. 11(3): 124-126.
88. Jennings, P.D., *Providing pediatric palliative care through a pediatric supportive care team*. Pediatr Nurs, 2005. 31(3): 195-200.
89. Feudtner, C., et al., *Deaths attributed to pediatric complex chronic conditions: national trends and implications for supportive care services*. Pediatrics, 2001. 107(6): E99.
90. Frager, G., *Pediatric palliative care: building the model, bridging the gaps*. J Palliat Care, 1996. 12(3): 9-12.
91. Goldman, A. and K.S. Heller, *Integrating palliative and curative approaches in the care of children with life-threatening illnesses*. J Palliat Med, 2000. 3(3): 353-359.
92. Toce, S. and M.A. Collins, *The FOOTPRINTS model of pediatric palliative care*. J Palliat Med, 2003. 6(6): 989-1000.
93. Rushton, C.H., *A framework for integrated pediatric palliative care: being with dying*. J Pediatr Nurs, 2005. 20(5): 311-325.
94. Hoeldtke, N.J. and B.C. Calhoun, *Perinatal hospice*. Am J Obstet Gynecol, 2001. 185(3): 525-529.
95. Ramer-Chrastek, J. and M.V. Thygeson, *A perinatal hospice for an unborn child with a life-limiting condition*. Int J Palliat Nurs, 2005. 11(6): 274-276.
96. Milstein, J., *A paradigm of integrative care: healing with curing throughout life, "being with" and "doing to"*. J Perinatol, 2005. 25(9): 563-568.
97. Jones, R., et al., *The need for paediatric palliative care in New Zealand*. N Z Med J, 2002. 115(1163): U198.
98. Hudson, P.L., S. Aranda, and L.J. Kristjanson, *Meeting the supportive needs of family caregivers in palliative care: challenges for health professionals*. J Palliat Med, 2004. 7(1): 19-25.
99. Ellershaw, J.E. and D. Murphy, *The Liverpool Care Pathway (LCP) influencing the UK national agenda on care of the dying*. Int J Palliat Nurs, 2005. 11(3): 132-134.
100. Heyland, D.K., et al., *End-of-life care in acute care hospitals in Canada: a quality finish?* J Palliat Care, 2005. 21(3): 142-150.
101. Howell, D. and K. Brazil, *Reaching common ground: a patient-family-based conceptual framework of quality EOL care*. J Palliat Care, 2005. 21(1): 19-26.
102. Glare, P.A., et al., *The interface between palliative medicine and specialists in acute-care hospitals: boundaries, bridges and challenges*. Med J Aust, 2003. 179(6 Suppl): S29-S31.
103. Palliative Care Expert Working Group NZ, *Palliative care for Children. Palliative care report of the Palliative Care Expert Working Group to the Cancer Control Steering Group*. <http://www.cancercontrol.org.nz/pdf/ewg5.pdf>, consulted online on December 15, 2005. 2003. 20 p.
104. Ahmedzai, S.H., et al., *A new international framework for palliative care*. Eur J Cancer, 2004. 40(15): 2192-2200.
105. Strasser, F., P. Walker, and E. Bruera, *Palliative pain management: when both pain and suffering hurt*. J Palliat Care, 2005. 21(2): 69-79.
106. Bookbinder, M., et al., *Improving end-of-life care: development and pilot-test of a clinical pathway*. J Pain Symptom Manage, 2005. 29(6): 529-543.
107. Clarke, E.B., et al., *Quality indicators for end-of-life care in the intensive care unit*. Crit Care Med, 2003. 31(9): 2255-2262.
108. Palliative Care Australia, *A guide to palliative care service development: A population based approach*. <http://www.pallcare.org.au/Portals/9/docs/publications/PCA%20Service%20Provisions.pdf>, consulted online on September 9, 2005. 2005: 48 p.

109. National Comprehensive Cancer Network, *Palliative care guidelines*. [http://www.nccn.org/professionals/physician\\_gls/PDF/palliative.pdf](http://www.nccn.org/professionals/physician_gls/PDF/palliative.pdf), consulted online on December 15, 2005. 2002.
110. Center to Advance Palliative Care, *Crosswalk of JCAHO standards and palliative care – with PC policies, procedures and assessment tools. Reflects a review of the 2005 current updates for the Comprehensive Accreditation Manuals for Hospitals*. [http://www.capc.org/support-from-capc/capc\\_publications/JCAHO-crosswalk.pdf](http://www.capc.org/support-from-capc/capc_publications/JCAHO-crosswalk.pdf), consulted online on September 9, 2005. 2004: 66 p.
111. Children's Hospice International Scientific Review Board, *CHI standards of hospice care for children*. <http://www.chionline.org/resources/standards.php>, consulted online on September 9, 2005. 1993.
112. Department of Health and Department for Education and Skills from the Government of United Kingdom, *National service framework for children, young people and maternity services: core standards*. [http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4089099&chk=VBBAQJ](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4089099&chk=VBBAQJ), consulted online on June 14, 2006. 2005.
113. Department of Health and Department for Education and Skills from the Government of United Kingdom, *National service framework for children, young people and maternity services: children and young people who are ill*. [http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/ChildrenServicesInformation/ChildrenServicesInformationArticle/fs/en?CONTENT\\_ID=4089111&chk=U8Ecln](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/ChildrenServicesInformation/ChildrenServicesInformationArticle/fs/en?CONTENT_ID=4089111&chk=U8Ecln), consulted online on June 14, 2006. 2004.
114. Department of Health from the Government of United Kingdom, *Evidence to inform the National Service Framework for Children, Young People and Maternity Services*. [http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4112403&chk=YAJDnt](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4112403&chk=YAJDnt), consulted online on June 14, 2006. 2005.
115. NHS Scotland and Clinical Standards Board for Scotland, *Clinical standards: specialist palliative care*. <http://www.palliativecarescotland.org.uk/publications/palliative.pdf>, consulted online on December 10, 2002. 63 p.
116. NHS and Department of Health from the Government of United Kingdom, *Manual for cancer services*. [http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4090081&chk=hq28gu](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4090081&chk=hq28gu), consulted online on December 15, 2005. 2004.
117. NHS Cancer Services Co-ordinating Group, *National standards for specialist palliative care cancer services*. [http://www.wales.nhs.uk/documents/SpecialistPallCare\\_Eng.pdf](http://www.wales.nhs.uk/documents/SpecialistPallCare_Eng.pdf), consulted online on November 23, 2005. 2005: 28 p.
118. Department of Health and Department for Education and Skills from the Government of United Kingdom, *National service framework for children, young people and maternity services: disabled children and young people and those with complex health needs*. <http://www.dh.gov.uk/assetRoot/04/09/05/56/04090556.pdf>, consulted online on September 9, 2005. 2004: 44 p.
119. Welsh Assembly Government, *A strategic direction for palliative care services in Wales*. <http://www.wales.nhs.uk/documents/pall-care-final-e.pdf>, consulted online on September 9, 2005. 2003: 18 p.

120. ACT NOW, *The NSF: focus on children's palliative care*.  
[http://www.act.org.uk/component/option,com\\_docman/task,cat\\_view/gid,16/Itemid,26/](http://www.act.org.uk/component/option,com_docman/task,cat_view/gid,16/Itemid,26/), Issue 35  
 consulted online on September 9, 2005. 2004: 8 p.
121. Little Company of Mary Health Care and Commonwealth Department of Health and Aging in  
 Australia, *National Palliative Care Plan Initiative. Final Report*.  
[http://www.health.gov.au/internet/wcms/publishing.nsf/Content/palliativecare-pubs-serv-init-  
 pdf.htm/\\$FILE/NPCPIrpt.pdf](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/palliativecare-pubs-serv-init-pdf.htm/$FILE/NPCPIrpt.pdf), consulted online on December 10, 2005. 2003: 267 p.
122. Palliative Care Australia, *Standards for providing quality palliative care for all Australians*.  
<http://www.pallcare.org.au/Portals/9/docs/publications/FINAL%20STANDARDS%20230505.pdf>,  
 consulted online on September 9, 2005. 2005: 41 p.
123. Palliative Care Australia, *Standards for Palliative Care Provision. Third edition*.  
<http://www.capc.org/tools-for-palliative-care-programs/guidelines/au-standards-99.pdf>, consulted  
 online on December 10, 1999: 28 p.
124. Ministry of Health from the government of New Zealand, *The New Zealand palliative care strategy*.  
[http://www.moh.govt.nz/moh.nsf/0/65C53A08E9801444CC256E62000AAD80/\\$File/palliativecarestr  
 ategy.pdf](http://www.moh.govt.nz/moh.nsf/0/65C53A08E9801444CC256E62000AAD80/$File/palliativecarestrategy.pdf), consulted online on September 9, 2005. 2001: 57 p.
125. Agence nationale d'accréditation et d'évaluation en santé, *L'accompagnement des personnes en  
 fin de vie et de leurs proches. Conférence de consensus. Faculté Xavier-Bichat, Paris*.  
[http://www.has-sante.fr/portail/upload/docs/application/pdf/Accompagnement\\_long.pdf](http://www.has-sante.fr/portail/upload/docs/application/pdf/Accompagnement_long.pdf), consulted  
 online on June 15, 2006. 2004. 54 p.
126. Comité de suivi soins palliatifs et accompagnement (committee on palliative care and support),  
*Guide de bonnes pratiques d'une démarche palliative en établissements. Ministère de la Santé et  
 de la Protection sociale, Direction de l'hospitalisation et de l'organisation des soins*.  
[http://www.sante.gouv.fr/htm/dossiers/palliatif/guide\\_demarche.pdf](http://www.sante.gouv.fr/htm/dossiers/palliatif/guide_demarche.pdf), consulted online on June 14,  
 2006. 2004.
127. Provincial Palliative Care Network, *Norms of practice. Hospice palliative care document. Manitoba*.  
 2005.
128. Canadian Council on Health Services Accreditation. *Hospice Palliative and End-of-Life Care. Aim  
 Program* (in progress). 2004.
129. Réseau québécois de soins palliatifs, *Standards de pratique en soins palliatifs*. Bulletin de  
 l'Association québécoise de soins palliatifs, 2001. 9: 5-15.
130. Canadian Hospice Palliative Care Association, *A Model to Guide Hospice Palliative Care: Based on  
 National Principles and Norms of Practice*.  
[http://www.chpca.net/marketplace/national\\_norms/A+Model+to+Guide+Hospice+Palliative+Care+2  
 002-URLUpdate-August2005.pdf](http://www.chpca.net/marketplace/national_norms/A+Model+to+Guide+Hospice+Palliative+Care+2002-URLUpdate-August2005.pdf), consulted online on September 9, 2005. 2002: 105 p.
131. Giovanola, J., *Sibling involvement at the end of life*. J Pediatr Oncol Nurs, 2005. 22(4): 222-226.
132. Spinetta, J.J., et al., *Guidelines for assistance to siblings of children with cancer: report of the SIOP  
 Working Committee on Psychosocial Issues in Pediatric Oncology*. Med Pediatr Oncol, 1999. 33(4):  
 395-398.
133. Von Essen, L. and K.G.B. Eskär, *Important aspects of care and assistance for siblings of children  
 treated for cancer: A parent and nurse perspective*. Cancer Nurs, 2003. 26(3): 203-210.
134. O.-d'Avignon, M., *Identification des besoins de la fratrie d'enfants en fin de vie*. Masters Thesis in  
 Social Service. Université Laval. 2006.
135. O.-d'Avignon, M., *Les besoins de la fratrie en contexte de soins palliatifs pédiatriques*. 16<sup>e</sup> congrès  
 du Réseau de soins palliatifs du Québec (16<sup>th</sup> conference of the palliative care network of Québec),  
 Québec, Canada. 2006.
136. Mongeau, S., et al., *Au delà du répit et des activités un message de solidarité. Évaluation du  
 programme « Répit à domicile »*. The Lighthouse, Children and Families, phase II. 2004.

137. Mongeau, S., M.C. Laurendeau, and P. Carignan, *Un soutien qui fait une différence. Évaluation de la phase pilote du programme « Répit à domicile »*. The Lighthouse, Children and Families. 2001.
138. Canadian Association for Community Care, *Best Practices in Respite Services for Children. A Guide for Families, Policy Makers, Program Developers*. [http://www.cfc-efc.ca/docs/cacc/00001\\_en.htm](http://www.cfc-efc.ca/docs/cacc/00001_en.htm), consulted online on September 9, 2005. 1996.
139. Ingleton, C., et al., *Respite in palliative care: a review and discussion of the literature*. *Palliat Med*, 2003. 17(7): 567-575.
140. ARCH National Resource Center for Respite and Crisis Care Services and National Respite Network, *Respite for children with disabilities and chronic or terminal illnesses*. <http://www.archrespite.org/fs2.pdf>, consulted online on September 12, 2005. ARCH Factsheet, 1992(2).
141. Horsburgh, M., A. Trenholme, and T. Huckle, *Paediatric respite care: a literature review from New Zealand*. *Palliat Med*, 2002. 16(2): 99-105.
142. Scal, P. and M. Ireland, *Addressing transition to adult health care for adolescents with special health care needs*. *Pediatrics*, 2005. 115(6): 1607-1612.
143. American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine, *A consensus statement on health care transitions for young adults with special health care needs*. *Pediatrics*, 2002. 110(6 Pt 2): 1304-1306.
144. Pediatric Oncology Group of Ontario, *POGO pediatric palliative care expert contact information*. <http://www.pogo.ca/care/expert.contacts.aspx>, consulted online on June 14, 2006. 2005.
145. Hagen, C.M. and T.W. Hansen, *Deaths in a neonatal intensive care unit: a 10-year perspective*. *Pediatr Crit Care Med*, 2004. 5(5): 463-468.
146. Catlin, A., *State of the art. Creation of a neonatal end-of-life palliative care protocol*. *J Perinatol*, 2002. 22: 184-195.
147. Kavanaugh, K., et al., *Life support decisions for extremely premature infants: report of a pilot study*. *J Pediatr Nurs*, 2005. 20(5): 347-359.
148. Carter, B.S. and S.R. Leuthner, *Decision making in the NICU--strategies, statistics, and "satisficing"*. *Bioethics Forum*, 2002. 18(3-4): 7-15.
149. Carter, B.S. and S.R. Leuthner, *The ethics of withholding/withdrawing nutrition in the newborn*. *Semin Perinatol*, 2003. 27(6): 480-487.
150. Comité consultatif national d'éthique pour les sciences de la vie et de la santé, *Réflexions éthiques autour de la réanimation néonatale*. Avis N°65. <http://www.ccne-ethique.fr/docs/fr/avis065.pdf>, consulted online on December 8, 2005. 2000.
151. Leuthner, S.R. and R. Pierucci, *Experience with neonatal palliative care consultation at the Medical College of Wisconsin-Children's Hospital of Wisconsin*. *J Palliat Med*, 2001. 4(1): 39-47.
152. Leuthner, S.R., *Fetal palliative care*. *Clin Perinatol*, 2004. 31(3): 649-665.
153. Leuthner, S.R., *Palliative care of the infant with lethal anomalies*. *Pediatr Clin North Am*, 2004. 51(3): 747-759, xi.
154. American Academy of Pediatrics, *Death of a child in the emergency department: Joint statement by the American Academy of Pediatrics and the American College of Emergency Physicians*. *Pediatrics*, 2002. 110: 839-840.
155. Knazik, S.R., et al., *The death of a child in the emergency department*. *Ann Emerg Med*, 2003. 42(4): 519-529.
156. Feudtner, C., M.J. Silveira, and D.A. Christakis, *Where do children with complex chronic conditions die? Patterns in Washington State, 1980-1998*. *Pediatrics*, 2002. 109(4): 656-660.
157. van der Wal, M.E., et al., *Circumstances of dying in hospitalized children*. *Eur J Pediatr*, 1999. 158(7): 560-565.

158. McCallum, D.E., P. Byrne, and E. Bruera, *How children die in hospital*. J Pain Symptom Manage, 2000. 20(6): 417-423.
159. Feudtner, C., D.L. DiGiuseppe, and J.M. Neff, *Hospital care for children and young adults in the last year of life: a population-based study*. BMC Med, 2003. 1: 3.
160. Feudtner, C., D.A. Christakis, and F.A. Connell, *Pediatric deaths attributable to complex chronic conditions: a population-based study of Washington State, 1980-1997*. Pediatrics, 2000. 106(1 Pt 2): 205-209.
161. Canadian Council on Health Services Accreditation, Accreditation Program, (glossary). 2006.
162. Shields, L., *Family-centered care for children in hospital (protocol)*. The Cochrane Collaboration. 2005.
163. Bartell, A.S. and D.W. Kissane, *Issues in pediatric palliative care: understanding families*. J Palliat Care, 2005. 21(3): 165-172.
164. Committee on Hospital Care and American Academy of Pediatrics, *Family-centered care and the pediatrician's role*. Pediatrics, 2003. 112(3 Pt 1): 691-697.
165. Last Acts Palliative Task Force, *Precepts of palliative care for children/adolescents and their families*. [http://www.apon.org/files/public/last\\_acts\\_precepts.pdf](http://www.apon.org/files/public/last_acts_precepts.pdf), consulted online on June 14, 2006. Last Acts, 2002.
166. Institute for Family-Centered Care and American Hospital Association, *Strategies for leadership: Advancing the practice of patient and family-centered care*. <http://www.familycenteredcare.org/resources/index.html>, consulted online on January 15, 2006. 2005.
167. Wertlieb, D., *Converging trends in family research and pediatrics: recent findings for the American Academy of Pediatrics Task Force on the Family*. Pediatrics, 2003. 111(6 Pt 2): 1572-1587.
168. MacKean, G.L., W.E. Thurston, and C.M. Scott, *Bridging the divide between families and health professionals' perspectives on family-centred care*. Health Expect, 2005. 8(1): 74-85.
169. Schor, E.L. and American Academy of Pediatrics Task Force on the Family, *Family pediatrics: report of the Task Force on the Family*. Pediatrics, 2003. 111(6 Pt 2): 1541-1571.
170. Lehoux, P. and S. Law, *Les technologies de soins à domicile: enjeux de l'organisation et de la prestation des services au Québec*. Agence d'évaluation des technologies et des modes d'intervention en santé. <http://www.aetmis.gouv.qc.ca/site/download.php?96f167dc2b6b4e775cc267cfc455b424>, consulted online on June 14, 2006. 2005.
171. American Academy of Pediatrics, *The pediatrician and childhood bereavement*. Pediatrics, 2000. 105: 445-447.
172. Schut, H. and M. Strobe, *Interventions to enhance adaptation to bereavement*. J Palliat Med, 2006. 8: S140-S147.
173. Lang, A., C. Goulet, and R. Amsel, *Explanatory model of health in bereaved parents post-fetal/infant death*. Int J Nurs Stud, 2004. 41(8): 869-880.
174. Michon, B., S. Balkou, and C. Cyr, *Death of a child: Parental perception of grief intensity – End-of-life and bereavement care*. Paediatrics and Child Health, 2003. 8(6): 363-366.
175. Center for the Advancement of Health, *Report on bereavement and grief research*. <http://www.cfah.org/pdfs/griefreport.pdf>, consulted online on September 9, 2005. 2003: 182 p.
176. Forte, A.L., et al., *Bereavement care interventions: a systematic review*. BMC Palliat Care, 2004. 3(1): 3.
177. de Jong-Berg, M.A. and D. de Vlaming, *Bereavement care for families part 1: a review of a paediatric follow-up programme*. Int J Palliat Nurs, 2005. 11(10): 533-539.
178. Macdonald, M.E., et al., *Parental perspectives on hospital staff members' acts of kindness and commemoration after a child's death*. Pediatrics, 2005. 116(4): 884-890.

179. Freyer, D.R., *Care of the dying adolescent: special considerations*. Pediatrics, 2004. 113(2): 381-388.
180. George, R. and S. Hutton, *Palliative care in adolescents*. Eur J Cancer, 2003. 39(18): 2662-2668.
181. Hinds, P.S., et al., *End-of-life decision making by adolescents, parents, and healthcare providers in pediatric oncology: research to evidence-based practice guidelines*. Cancer Nurs, 2001. 24(2): 122-134.
182. Association for Children with Life - Threatening or Terminal Conditions and their Families (ACT), *Assessment of children with life-limiting conditions and their families. A guide to care planning ACT*. [http://www.act.org.uk/component/option,com\\_docman/task,doc\\_view/gid,29/Itemid,26/](http://www.act.org.uk/component/option,com_docman/task,doc_view/gid,29/Itemid,26/), consulted online on December 21, 2005. 2003.
183. Wright, L.M. and M. Leahey, *L'infirmière et la famille. Guide d'évaluation et d'intervention, 2<sup>nd</sup> edition*. 2001, Ville Saint-Laurent, Québec: Éditions du Renouveau pédagogique.
184. Duhamel, F., *La santé et la famille: une approche systématique en soins infirmiers*. 1995, Montréal, Québec: Gaétan Morin.
185. Browning, D., *To show our humanness. Relational and communicative competence in pediatric palliative care*. Bioethics Forum, 2002. 18: 23-28.
186. Tervalon, M. and J. Murray-Garcia, *Cultural humility versus cultural competence: a critical distinction in defining physician training outcomes in multicultural education*. J Health Care Poor Underserved, 1998. 9(2): 117-125.
187. Buckman, R., *Breaking bad news: why is it still so difficult?* Br Med J (Clin Res Ed), 1984. 288(6430): 1597-1599.
188. Hurwitz, C.A., J. Duncan, and J. Wolfe, *Caring for the child with cancer at the close of life: "there are people who make it, and I'm hoping I'm one of them"*. JAMA, 2004. 292(17): 2141-2149.
189. de Haes, H. and S. Teunissen, *Communication in palliative care: a review of recent literature*. Curr Opin Oncol, 2005. 17(4): 345-350.
190. Young, B., et al., *Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents*. BMJ, 2003. 326(7384): 305.
191. National Institute for Health and Clinical Excellence, *Guidance on cancer services. Improving outcomes in children and young people with cancer. Evidence review*. <http://www.nice.org.uk/guidance/order/publicationslist/pubguidcancserguid.jsp>, consulted online on September 9, 2005. 2005: 467 p.
192. Goldman, A. and D. Christie, *Children with cancer talk about their own death with their families*. Pediatr Hematol Oncol, 1993. 10(3): 223-231.
193. Mack, J.W. and H.E. Grier, *The Day One Talk*. J Clin Oncol, 2004. 22(3): 563-566.
194. Scott, J.T., et al., *Interventions for improving communication with children and adolescents about their cancer*. Cochrane Database Syst Rev, 2003(3): CD002969.
195. Kreicbergs, U., et al., *Talking about death with children who have severe malignant disease*. N Engl J Med, 2004. 351(12): 1175-1186.
196. Hinds, P.S., et al., *End-of-Life Care Preferences of Pediatric Patients With Cancer*. J Clin Oncol, 2005. 23(36).
197. National Institute for Health and Clinical Excellence, *Guidance on cancer services. Improving supportive and palliative care for adults with cancer. Research evidence*. <http://www.nice.org.uk/nicemedia/pdf/csgspmanual.pdf>, consulted online on September 12, 2005. 2004: 204 p.
198. United-Nations, *International Convention of the Rights of Children*. <http://www.unhchr.ch/html/menu3/b/k2crc.htm>, consulted online on June 14, 2006. 1989.
199. Palliative Care Australia, *Journeys – Palliative Care for Children and Teenagers®*. <http://www.pallcare.org.au/Default.aspx?tabid=314>, consulted online on June 14, 2006. 2005.

200. Association for Children with Life - Threatening or Terminal Conditions and their families (ACT) and Royal College of Paediatrics and Child Health, *Information pack for families*. [http://www.act.org.uk/documentation/pdfdocuments/family\\_information\\_pack.pdf](http://www.act.org.uk/documentation/pdfdocuments/family_information_pack.pdf), consulted online on June 14, 2006. 2004.
201. Côté, S., *Vivre au quotidien avec un enfant gravement malade: renseignements pratiques et ressources*. Les Éditions de l'Hôpital Sainte-Justine and The Lighthouse, Children and Families. 2006.
202. Haggerty, J.L., et al., *Continuity of care: a multidisciplinary review*. BMJ, 2003. 327(7425): 1219-1221.
203. Dumont, I., S. Dumont, and J. Turgeon, *Continuity of care for advanced cancer patients*. J Palliat Care, 2005. 21(1): 49-56.
204. Reid, R., J. Haggerty, and R. McKendry, *Defusing the Confusion: Concepts and Measure of Continuity of Care. Final Report*. [http://64.26.159.84/final\\_research/commissioned\\_research/programs/pdf/cr\\_contcare\\_e.pdf](http://64.26.159.84/final_research/commissioned_research/programs/pdf/cr_contcare_e.pdf), consulted online on December 10, 2005. 2002: 50 p.
205. Greco, V. and P. Sloper, *Care co-ordination and key worker schemes for disabled children: results of a UK-wide survey*. Child Care Health Dev, 2004. 30(1): 13-20.
206. Rahi, J.S., et al., *Meeting the needs of parents around the time of diagnosis of disability among their children: evaluation of a novel program for information, support, and liaison by key workers*. Pediatrics, 2004. 114(4): e477-e482.
207. Comité de l'évolution de la pratique infirmière en oncologie (committee on the future of oncology nursing practice). *Pour optimiser la contribution des infirmières à la lutte contre le cancer*. Avis. Québec Centre for Cancer Control. Ministère de la Santé et des Services sociaux. Québec (Québec). 2005. 101 p.
208. Comité de soutien à la qualité du programme québécois du cancer du sein (support committee to the quality of the Québec breast cancer program), *Le fonctionnement interdisciplinaire dans le cadre de l'investigation. Programme québécois du dépistage du cancer du sein*. Ministères de la Santé et des Services sociaux du Québec. Québec (Québec). <http://publications.msss.gouv.qc.ca/acrobat/f/document/2002/02-204-10.pdf>, consulted online on June 14, 2006. 2002.
209. Comité des équipes interdisciplinaires de lutte contre le cancer (interdisciplinary committee on cancer control) (CEILCC), *Les équipes interdisciplinaires en oncologie*. Québec Centre for Cancer Control. Ministère de la Santé et des Services sociaux. Québec (Québec). 2005: 77 p.
210. Association for Children with Life - Threatening or Terminal Conditions and their Families and the Royal College of Paediatrics and Child Health, *A guide to the development of children's palliative care services. Second Edition*. [http://www.act.org.uk/component/option,com\\_frontpage/Itemid,1/](http://www.act.org.uk/component/option,com_frontpage/Itemid,1/), consulted online on September 9, 2005. 2003: 51 p.
211. National Institute for Health and Clinical Excellence, *Guidance on cancer services. Improving supportive and palliative care for adults with cancer. The manual*. 2004: 205 p.
212. Committee on Hospital Care and American Academy of Pediatrics, *Child life services*. Pediatrics, 2000. 106(5): 1156-1159.
213. Champagne, M. and S. Mongeau, *Conditions d'une bonne relation entre le bénévole, l'enfant atteint d'une maladie à issue fatale et sa famille*. Les cahiers de soins palliatifs, 2004: 5-28.
214. Champagne, M., et al., *Formation des bénévoles du programme « Répit à domicile » du Phare, Enfants et Familles*. Manuel des formatrices. Montréal (Québec). The Lighthouse, Children and Families. 2006.
215. Volunteer Committee of the Réseau des soins palliatifs du Québec, *Recrutement et évaluation des bénévoles en soins palliatifs*. 2005.

216. Barnes, K., *Staff stress in the children's hospice: causes, effects and coping strategies*. Int J Palliat Nurs, 2001. 7(5): 248-254.
217. Fillion, L. and L. St-Laurent, *Stressors linked to palliative care nursing: the importance of organizational, professional and emotional support*. Final research report submitted to the CHSRF, Ottawa, Canada. 2003.
218. Canadian Council on Health Services Accreditation, *Planning models for quality accreditation resource tool. Quality improvement plan*. 2005.
219. Hilden, J.M., et al., *Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey*. J Clin Oncol, 2001. 19(1): 205-212.
220. Hain, R. and A. Goldman, *Training in paediatric palliative medicine*. Palliat Med, 2003. 17(3): 229-231.
221. Frager, G. and Y. McConnell, *Decision making in paediatric palliative care. Education module 12. Ian Anderson Continuing Education Program in End-of-Life Care*. <http://www.cme.utoronto.ca/endoflife/Modules.htm>, consulted online on December 15, 2005. 2004.
222. Serwint, J.R., *The use of standardized patients in pediatric residency training in palliative care: anatomy of a standardized patient case scenario*. J Palliat Med, 2002. 5(1): 146-153.
223. Serwint, J.R., L.E. Rutherford, and N. Hutton, *Personal and professional experiences of pediatric residents concerning death*. J Palliat Med, 2006. 9(1): 70-81.
224. Papadatou, D., *Training health professionals in caring for dying children and grieving families*. Death Stud, 1997. 21(6): 575-600.
225. Solomon, M.Z., et al., *New and lingering controversies in pediatric end-of-life care*. Pediatrics, 2005. 116(4): 872-883.
226. Bagatell, R., et al., *When children die: a seminar series for pediatric residents*. Pediatrics, 2002. 110(2 Pt 1): 348-353.
227. Initiative for Pediatric Palliative Care, *The IPPC curriculum modules: engaging with children and families, relieving pain and other symptoms, analyzing ethical challenges in pediatric end-of-life decision making, responding to suffering and bereavement and improving communication and strengthening relationships*. <http://www.ippcweb.org/curriculum.asp>, consulted online on September 12, 2005.
228. Sahler, O.J., et al., *Medical education about end-of-life care in the pediatric setting: principles, challenges, and opportunities*. Pediatrics, 2000. 105(3 Pt 1): 575-584.
229. Browning, D.M., M.Z. Solomon, and the Initiative for Pediatric Palliative Care (IPPC) Investigator Team, *The Initiative for Pediatric Palliative Care: An Interdisciplinary Educational Approach for Healthcare Professionals*. J Pediatr Nurs, 2005. 20(5): 326-334.
230. Roberts, K.E. and L.A. Boyle, *End-of-life education in the pediatric intensive care unit*. Crit Care Nurse, 2005. 25(1): 51-57.
231. Serwint, J.R., et al., *"I learned that no death is routine": description of a death and bereavement seminar for pediatrics residents*. Acad Med, 2002. 77(4): 278-284.
232. Grol, R. and J. Grimshaw, *From best evidence to best practice: effective implementation of change in patients' care*. Lancet, 2003. 362(9391): 1225-1230.
233. Cooper, J. and A. Hewison, *Implementing audit in palliative care: an action research approach*. J Adv Nurs, 2002. 39(4): 360-369.
234. Agency for Healthcare Research and Quality, *End-of-Life Care and Outcomes*. <http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat1a.chapter.77852>, consulted online on December 15, 2005. 2004.
235. Aoun, S.M. and L.J. Kristjanson, *Challenging the framework for evidence in palliative care research*. Palliat Med, 2005. 19(6): 461-465.

236. Aoun, S.M. and L.J. Kristjanson, *Evidence in palliative care research: How should it be gathered?* Med J Aust, 2005. 183(5): 264-266.
237. Morrison, R.S., *Palliative care outcomes research: the next steps.* J Palliat Med, 2005. 8(1): 13-16.
238. Nuss, S.L., P.S. Hinds, and D.A. LaFond, *Collaborative clinical research on end-of-life care in pediatric oncology.* Semin Oncol Nurs, 2005. 21(2): 125-144.
239. Berg, M., W. Schellekens, and C. Bergen, *Bridging the quality chasm: integrating professional and organizational approaches to quality.* Int J Qual Health Care, 2005. 17(1): 75-82.
240. Vanu Som, C., *Clinical governance: a fresh look at its definition.* Clinical Governance: An International Journal, 2004. 9(2): 87-90.
241. Denis, J.L., et al., *L'innovation clinico-organisationnelle dans les organisations de santé.* Canadian Health Services Research Foundation. [http://www.chsrf.ca/final\\_research/ogc/pdf/denis\\_final.pdf](http://www.chsrf.ca/final_research/ogc/pdf/denis_final.pdf), consulted online on September 13, 2005. 2001: 22 p.
242. NHS Quality Improvement Scotland, *Clinical Governance and Risk Management: Achieving safe, effective, patient-focused care and services.* National Standards. [http://www.nhshealthquality.org/nhsqis/files/CGRM\\_CSF\\_Oct05.pdf](http://www.nhshealthquality.org/nhsqis/files/CGRM_CSF_Oct05.pdf), consulted online on December 10, 2005. 2005: 36 p.
243. Aynsley-Green, A., et al., *Who is speaking for children and adolescents and for their health at the policy level?* BMJ, 2000. 321(7255): 229-232.

## APPENDIX 1:

### Consultants and Collaborators

Many experts from various organizations were consulted in the writing of this document. We wish to sincerely thank the following people:

*Centre hospitalier universitaire de Québec,  
Centre hospitalier de l'Université Laval (Centre mère-enfant)*

Carmen Allard, Head, pediatric nurse, surgery and cardiology  
Dr. Sylvie Bélanger, neonatologist  
Nicole Blais, clinical nurse specialist  
Marie-Andrée Gignac, nurse educator  
Christine Jandet-Brunet, psychologist  
Alice Leclerc, social worker  
Suzanne Martel, Co-administrator, Family, Youth and Child  
Andrée Rioux, Coordinator, Volunteer Services, Centre hospitalier de l'Université Laval  
Martine Tremblay, pastoral counsellor

*Centre hospitalier universitaire de Sherbrooke, Hôpital Fleurimont*

Dr. Thérèse Côté-Boileau, pediatrician and president of the *Association des pédiatres du Québec* (Québec association of pediatricians)

*Centre hospitalier universitaire Sainte-Justine*

Dr. Mélanie Beaudry, resident in pediatrics  
Marlène Bonneau, pastoral counsellor  
Karine Chalifour, social worker  
Marie-France Côté, nurse  
Sylvie Dion, outpatient palliative care nurse  
Dr. Michel Duval, pediatrician, hematologist and oncologist  
Dr. France Gauvin, intensivist  
Michel Lafontaine, pastoral counsellor  
Nathalie Morin, anthropologist

Dr. Antoine Payot, neonatologist  
Dr. Sanja Stojanovich, pediatrician

*McGill University Health Centre, Montreal Children's Hospital*

Dr. Anne Sophie Carret, hematologist and oncologist  
Pascal Comeau, music therapist  
Annik Otis, clinical palliative care nurse specialist  
Dr. Patricia Riley, neonatologist

Québec End-of-Life Palliative Care Policy, *Follow-up Committee*

Dr. Benoît Deschamps, president, Québec End-of-Life Palliative Care Committee; general practitioner and palliative care educator

*The Lighthouse, Children and Families* (non-profit organization working with sick children and their families)

Michèle Chagnon-Viau, Director  
Sophie Côté, mother  
Annick Gervais, Coordinator, Respite Services Program

*Leucan Québec* (association working on behalf of sick children and their families)

Céline Drouin, Director, Québec City Region  
France Houde, mother  
Unnamed parent

*Saguenay-Lac-Saint-Jean Region*

Dr. Hélène Archibald, palliative care team physician, *Centre de santé et de services sociaux de Chicoutimi* (Chicoutimi health and social services centre)  
Johanne Boudreault, *Centre de santé et de services sociaux de Jonquière* (Jonquière health and social services centre)  
Pierre Boulianne, *Centre de santé et de services sociaux de Chicoutimi* (Chicoutimi health and social services centre)  
Alberte Déry, Director, *Palli-Aide*  
Janick Desbiens, coordinator, Leucan  
Pauline Dufour, *Centre de santé et de services sociaux Cléophas-Claveau* (Cléophas-Claveau health and social services centre)  
Françoise Fortin, *Agence de la santé et des services sociaux du Saguenay-Lac-Saint-Jean* (Saguenay-Lac-Saint-Jean health and social services agency)  
Gaétan Gauthier, *Centre de santé et de services sociaux Maria-Chapdelaine* (Maria-Chapdelaine health and social services centre)  
Isabelle Jean, pharmacist, *Centre de santé et de services sociaux de Lac-Saint-Jean-Est* (Lac-Saint-Jean-Est health and social services centre)  
Jean-Yves Langevin, pharmacist, *Centre de santé et de services sociaux de Chicoutimi* (Chicoutimi health and social services centre)

Édith Simard, *Centre de santé et de services sociaux Domaine-du-Roy* (Domaine-du-Roy health and social services centre)  
Dr. Chantale Tremblay, palliative care team physician, *Centre de santé et de services sociaux de Chicoutimi* (Chicoutimi health and social services centre)  
Marie-Andrée Tremblay, *Centre de santé et de services sociaux de Lac-Saint-Jean-Est* (Lac-Saint-Jean-Est health and social services committee)  
Mona Tremblay, *Agence de la santé et des services sociaux du Saguenay-Lac-Saint-Jean* (Saguenay-Lac-Saint-Jean health and social services agency)

### ***Other Consultants***

Dr. Jacques Brisson, ScD, Epidemiology, Population Health Research Centre, *Université Laval* and *Institut national de santé publique du Québec*  
Floriane Dostie, Medical and Technological Services Branch, *ministère de la Santé et des Services sociaux*  
Serge Dumont, PhD, researcher and social worker, *Université Laval* and *Centre de recherche de la Maison Michel-Sarrazin* (Michel-Sarrazin research centre)  
Marie-Hélène Guertin, Master's student in Epidemiology, *Université Laval*, intern at the *Institut de santé publique du Québec* (Québec institute of public health)  
Marianne O.-d'Avignon, Doctoral candidate, School of Social Work, *Université Laval*  
Dr. Marc Paquet, medical consultant, University Affairs Branch, *ministère de la Santé et des Services sociaux*  
Jean-Marie R. Lance, lead scientific advisor, *Agence d'évaluation des technologies et des modes d'intervention en santé* (Québec agency for health services and technology evaluation)  
Denis Santerre, information scientist, *Agence d'évaluation des technologies et des modes d'intervention en santé*  
Sarah Taber, M.H.A., research and product development specialist, Canadian Council on Health Services Accreditation (CCHSA)

### ***Writing***

Dr. Linda Côté-Brisson, Working Group Chair and Coordinator, pediatric oncologist, palliative care physician, *Centre hospitalier universitaire de Québec, Hôtel-Dieu de Québec*

### ***Writing Assistance***

Dr. Jacques Brisson, ScD, Epidemiology, Population Health Research Centre, *Université Laval* and *Institut national de santé publique du Québec*  
Jocelyn Châteauneuf, Research Officer, Québec Centre for Cancer Control, *ministère de la Santé et des Services sociaux*  
Melanie Kavanagh, Research Officer, Québec Centre for Cancer Control, *ministère de la Santé et des Services sociaux*

### *Administrative Support*

Hélène Mercier, Secretary, Québec Centre for Cancer Control, *ministère de la Santé et des Services sociaux*

### *Supervision*

Brigitte Laflamme, Assistant Director, Québec Centre for Cancer Control, *ministère de la Santé et des Services sociaux*

Dr. Antoine Loutfi, Director, Québec Centre for Cancer Control, *ministère de la Santé et des Services sociaux*

### *English Language Version:*

Administrative Support – Greg Adams, Office Manager, Canadian Hospice Palliative Care Association

Translation – Josephine Versace, Certified Translator, OTTIAQ

Production – Translation and production of the English language version of this document has been supported by a financial contribution from the Ronald McDonald House Charities®

Published by:

La Direction des communications du ministère de la Santé et des Services sociaux

Copy authorized by: Les Publications du Québec

This document was published in French in limited quantity and is now available only in electronic format.

[www.msss.gouv.qc.ca](http://www.msss.gouv.qc.ca); section: Documentation; heading: Publications

The original French document, entitled *Normes en matière de soins palliatifs pédiatriques*, was published by the *Ministère de la Santé et des Services sociaux* (MSSS).

The MSSS declines all liability with respect to this English translation and any damage, loss or prejudice that may be incurred in connection with it. In the event of an inconsistency between the English and French versions of the document, the latter shall prevail.

## APPENDIX 2: Care Pathways

Appendix 2 describes a care pathway model developed by ACT and entitled *A Framework for the Development of Integrated Multi-Agency Care Pathways for Children with Life-threatening and Life-limiting Conditions* (reference 66).

The model outlines the care pathway of children and their families, from the moment the diagnosis of a life-limiting condition is made through to bereavement support, and highlights the major challenges the families face throughout the three main phases:

- 1) the diagnosis or recognition of the child's life-threatening or life-limiting condition;
- 2) the chronicity of the condition, which may be short or span several years; and
- 3) the end of life, including bereavement.

Certain interventions that are considered crucial are recommended to help families face the various challenges of each phase:

- delivery of prognosis or other bad news under the best possible conditions;
- transfer of services and liaison between the hospital and community-based care providers;
- needs assessment and reassessment using a multidisciplinary approach;
- development of an intervention and service plan for the child and family;
- end-of-life care;
- bereavement support.

Basing themselves on the three phases mentioned above and their corresponding interventions, the creators of the model recommend a care pathway framework. The care pathway: focuses on coordination and continuity of care; identifies the various phases of patient care; prevents repetitions and omissions; clarifies roles and responsibilities; allows for interdisciplinary collaboration, the application of common standards of practice and the delivery of patient-centred care; and promotes the continuous improvement of quality of care.

The authors recommend that interdisciplinary teams tailor the care pathway framework to their needs and develop their own care pathway model by basing themselves on the following patient care process:

Phase 1	<ul style="list-style-type: none"> <li>– Compare current practice to evidence-based practice and national standards of care delivery.</li> <li>– Identify gaps between current practice and standards of practice and ways to improve the situation.</li> <li>– Develop a “local” clinical care pathway, which includes targeted objectives; these objectives must be backed by recognized standards.</li> </ul>
Phase 2	<ul style="list-style-type: none"> <li>– Implement a clinical care pathway.</li> <li>– Document results.</li> </ul>
Phase 3	<ul style="list-style-type: none"> <li>– Compare gaps with targeted results.</li> <li>– Take the necessary corrective action and reassess the situation by taking into account that the objective is continuous quality improvement.</li> </ul>

The authors recommend that interdisciplinary teams integrate the results and any observed gaps into their clinical care pathway and that they design this tool in collaboration with the various jurisdictions that provide care and services within and outside hospitals.

## **APPENDIX 3:**

### **Standards of Practice for Pediatric Palliative Care – Monitoring and Evaluation Tool**

An expert working group has established standards of practice for pediatric palliative care (PPC) for Québec. These standards promote a standardized and consistent approach to quality palliative care for children and families, regardless of where they live or receive care.

The standards serve as benchmarks and seek to achieve excellence. They are divided into four areas of focus:

- I) Child- and family-centred care
- II) interdisciplinarity
- III) continuous quality improvement
- IV) clinical governance

Criteria have been developed for each standard so that they can translate into specific measures and concrete actions. Using these criteria, healthcare teams and institutions can assess their performance, focus on areas in need of improvement and find solutions to problems they have identified.

Appendix 3 includes a monitoring and evaluation tool to help interdisciplinary teams implement the standards according to the four focus areas mentioned above. This appendix is a stand-alone document that helps teams monitor how the recommended standards are implemented. Health care providers can assess whether the objectives for each criterion have been achieved using a simple rating scale:

- 1) the objectives have not been achieved and corrective measures are required
- 2) evidence indicates that objectives have been partially achieved, but improvements are required
- 3) evidence indicates that the objectives have been achieved; recommendations must be made to maintain and optimize this result

Space has been allocated in the table for health care providers to record their findings and any potential improvements that can be made to the effectiveness, efficiency and quality of pediatric palliative care.

The appendix is an easy-to-use, flexible and practical monitoring and evaluation tool that encompasses the various facets of pediatric palliative care and is based on the working group's recommendations. It is available in electronic format at [www.chpca.net](http://www.chpca.net).

FOCUS AREA 1: CHILD- AND FAMILY-CENTRED CARE		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
		1	2	3	
<p>A broad consensus exists among pediatric palliative care professionals that a child- and family-centered approach to care, in which the child is the primary concern, should be favoured. The child's quality of life and that of the family are inextricably linked, and maintaining this quality of life constitutes the primary goal of palliative care. The 'family', in this context, includes the mother, father, siblings, grandparents and any other individual who may have a significant bond with the child or parents. A child- and family-centered approach to care helps children and their families reach their physical, psychological, social and spiritual goals.</p> <p>A family is a social and cultural unit with its own set of beliefs and values, which must be taken into account when providing care.</p> <p>In pediatrics, palliative care providers must take into account the fact that children or adolescents are developing physically, psychologically, socially, cognitively and spiritually.</p> <p>The standards of child- and family-centred care are grouped into three different perspectives: 1) the needs of children and their families, 2) communication between all those involved and their participation in decision-making, and 3) continuity of care.</p>					
Standard A	<i>Health care providers conduct a complete assessment of the child's and family's needs. The family includes the mother, father, siblings, grandparents and any other person who has a significant bond with the child or parents.</i>				
Criteria A	A-1 – The six groups of children and families representing the population in need of palliative care have access to it.				
	A-2 – The treatment teams define the criteria used to identify children and families in need of palliative care.				
	A-3 – Family members are identified by name and relationship. This information is recorded in the child's file.				
	A-4 – The needs assessment includes the needs of both the child and the family. The specific needs of adolescents and the different phases of illness, e.g. the end-of-life phase, are taken into consideration.				
	A-5 – An assessment process is implemented so that health care providers can avoid needlessly asking the same questions or performing the same clinical tests.				

FOCUS AREA 1: CHILD- AND FAMILY-CENTRED CARE		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
		1	2	3	
	A-6 – A comprehensive list of the child’s and family’s needs is included in the child’s file. The list addresses all physical, psychological, social, spiritual, cultural and developmental needs.				
	A-7 – Health care providers use proven and standardized tools to assess the various needs when such tools exist.				
	A-8 – Pain is considered to be the fifth vital sign; pain is assessed using standardized tools and documented in the child’s file.				
	A-9 – Needs are reassessed regularly and the list of needs updated when necessary.				
Standard B	<i>An intervention and service plan is developed to meet all the needs of the child and family.</i>				
Criteria B	B-1 – Health care providers take the necessary action to meet each need and then document this action in the child’s file.				
	B-2 – Respite services in the home or in some other appropriate setting are provided to children and families in need.				
	B-3 – The family members are given the information and support that they need to care for the child. This information is described in the intervention and service plan.				
	B-4 – Health care providers monitor their actions on an ongoing basis by consulting the intervention and service plan. When necessary, the intervention and service plan is revised.				

FOCUS AREA 1: CHILD- AND FAMILY-CENTRED CARE		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
		1	2	3	
	B-5 – The revised version of the intervention and service plan is communicated to the relevant health care providers and organizations.				
Standard C	<i>Bereavement support is described in the intervention and service plan.</i>				
Criteria C	C-1 – As the child nears death, health care providers conduct a systematic assessment of the family’s needs and compile a list of resources required to meet these needs.				
	C-2 – Bereavement support is accessible to all families after the death of a child, regardless of the cause; this includes external cause* (car accident, drowning, overdose, suicide, etc.) or perinatal loss (abortion, stillbirth, perinatal death).  *ICD10:V01-Y98: External causes of morbidity and mortality				
Standard D	<i>Health care providers are able to convey accurate information to children and families in a clear and sensitive manner. Communication with children or adolescents is age-appropriate and suited to their level of comprehension.</i>				
	D-1 – Health care providers have received communication skills training on how to deliver bad news to children and their parents.				
	D-2 – Health care providers are able to use a range of verbal, nonverbal and symbol-based communication strategies to communicate with children and adolescents.				
	D-3 – Interpreters are made available to children and families who do not speak the same language as the health care providers.				

FOCUS AREA 1: CHILD- AND FAMILY-CENTRED CARE		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
		1	2	3	
Standard E	<i>When health care providers deliver bad news to the child and family or discuss important decisions with them, they do so in an appropriate setting, in complete confidentiality and in a respectful and honest manner.</i>				
Criteria E	E-1 – Meetings involving breaking bad news or discussing important decisions are planned.				
	E-2 – These meetings are held in private, face-to-face discussions with both parents, simultaneously if possible, and in an appropriate setting. Relevant information and the names of those in attendance are recorded in the child’s file.				
	E-3 – Health care providers review the details of the meetings to ensure that the information conveyed has been well understood. The minutes of these meetings are added to the child’s file.				
Standard F	<i>The interdisciplinary team involves parents in decisions throughout all stages of their child’s care and treatment. Children and adolescents are kept informed of the situation and participate in decisions that concern their care and treatment plan to the extent that is suitable for their age, level of maturity and preferences.</i>				
Criteria F	F-1 – Children’s and adolescents’ ability to participate in decisions that concern them is assessed on a regular basis. The assessments are recorded in their file.				
	F-2 – The interdisciplinary team consults with the child and family when important decisions must be made. These decisions are recorded in the child’s file. The child’s and parents’ values and preferences are clearly noted.				

FOCUS AREA 1: CHILD- AND FAMILY-CENTRED CARE		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
		1	2	3	
	F-3 – The interdisciplinary team and the family can consult an ethics committee when faced with complex situations.				
Standard G	<i>Children and families have access to appropriate and free information on palliative care and on the services provided.</i>				
Criteria G	G-1 – Children and their families are provided with documentation on palliative care. This documentation includes information on the physical, psychological, social and spiritual aspects of care.				
	G-2 – The interdisciplinary team provides children and their families with a wide range of information, including information on the services they provide, support groups and community organizations, home care and household services that are available.				
	G-3 – The interdisciplinary team provides the family with documentation on financial aid programs, such as government programs, support foundations, tax exemptions, employment insurance, and reimbursement of drug costs.				
	G-4 – When providing children and families with information materials, the interdisciplinary team takes their age, level of education and language spoken into account.				
	G-5 – The information material is reviewed on a regular basis.				
Standard H	<i>The information required in order to provide continuity of care is described in the intervention and service plan.</i>				

FOCUS AREA 1: CHILD- AND FAMILY-CENTRED CARE		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
		1	2	3	
Criteria H	H-1 – The various health care providers, services, institutions and community resources (including schools) that will contribute to meeting the needs of children and their families are identified in the intervention and service plan.				
	H-2 – The role and responsibilities of the various health care providers and organizations are described in the intervention and service plan.				
	H-3 – Health care providers and organizations are informed of any changes to the intervention and service plan.				
Standard I	<i>Continuity of care for the child and family is maintained when the child is transferred from one institution to another or when the child returns home.</i>				
Criteria I	I-1 – When the child is transferred from one institution to another, from an institution to the child’s home, or from the child’s home to an institution, the intervention and service plan is reviewed with the health care providers who will be providing care to the child and family; the intervention and service plan is communicated to the relevant individuals.				
	I-2 – A member of the interdisciplinary team ensures that the personnel, equipment and medication required to provide the child with comfort and security are available wherever the child is transferred.				
	I-3 – The methods used to maintain communication between the care team and the individuals who provide care in the setting into which the child is transferred are described in the child’s file.				

FOCUS AREA 1: CHILD- AND FAMILY-CENTRED CARE		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
		1	2	3	
Standard J	<i>Continuity of care is provided to the child and family when they are being treated by more than one team or during transitions between different kinds of care.</i>				
Criteria J	J-1 – The various care teams consult each other to define their roles and responsibilities.				
	J-2 – For children who survive into adulthood, the transition from pediatric palliative care to adult palliative care is organized in such a way as to ensure that it takes place in a timely and progressive manner.				
	J-3 – The intervention and service plan describes the bereavement support resources that are provided to parents, siblings and other family members.				
Standard K	<i>A nurse navigator or care navigator is assigned to each child and family. This individual ensures that the child's and the family's needs are met and that care is coordinated.</i>				
Criteria K	K-1 – Regardless of the care-delivery site, the child and family always know who their nurse or care navigator is.				
Standard L	<i>The child and family have access to medical and nursing care services.</i>				
Criteria L	L-1 The child and family have access to on-call medical services 24 hours a day, 7 days a week, regardless of the service-delivery setting.				

FOCUS AREA 1: CHILD- AND FAMILY-CENTRED CARE	LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
	1	2	3	
L-2 The child and family have access to on-call nursing care at home, 24 hours a day, 7 days a week.				

FOCUS AREA 2: INTERDISCIPLINARITY		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS	
		1	2	3		
<p>Working as part of an interdisciplinary team allows health care providers to combine efforts and make the best use of their complementary expertise. An interdisciplinary team involves collaboration between health care providers, children and their parents. To meet the needs of children and their families effectively, a pediatric palliative care team calls on the varied expertise of its members. Institutional support is critical to the success of any interdisciplinary team.</p> <p>The standards of interdisciplinarity are grouped into three different perspectives: 1) Composition of an interdisciplinary team 2) how interdisciplinary teams work, and 3) interdisciplinary team support.</p>						
Standard M	<i>Interdisciplinary team members have the necessary skills to meet the needs of children who require palliative care and those of their families.</i>					
	Criteria M	M-1 – The interdisciplinary pediatric palliative care teams at UPCs include physicians, nurses, pharmacists, social workers, psychologists, physiotherapists, occupational therapists, dieticians, pastoral counsellors, child-life professionals and any other health care provider whose skills are required to meet children’s and families’ needs; such health care providers may work exclusively in pediatric palliative care or divide their time with other care teams.				
		M-2 – The interdisciplinary pediatric palliative care teams at UPCs have the necessary skills to support both the care teams working within their institution and those working at institutions located within their RUIS areas by providing information, advice, and consultations.				
		M-3 –Other interdisciplinary care teams providing pediatric palliative care must include the health care providers required to meet the needs of children and their families or have access to those health care providers.				

FOCUS AREA 2: INTERDISCIPLINARITY		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
		1	2	3	
Standard N	<i>The teams adopt an interdisciplinary model of care to coordinate the work they carry out with children and families.</i>				
Criteria N	N-1 – The team’s approach to pediatric palliative care, their objectives and the strategies they will pursue to achieve their objectives are documented. This document will serve to guide the team’s work and will be reviewed annually.				
	N-2 – A director and coordinator are appointed to the interdisciplinary team.				
	N-3 – The interdisciplinary team holds clinical meetings on a regular basis to plan, review and assess the care provided to children and families. Decisions made during these meetings are noted in the child’s file.				
	N-4 – Administrative meetings are held by the interdisciplinary team regularly to discuss and decide how they will proceed in their work. The decisions made during these meetings, and any related information on previous decisions, are noted in writing.				
Standard O	<i>Interdisciplinary team members are concerned with the demands of working as a team and the emotional and psychological demands of working with children in pediatric palliative care and their families.</i>				
Criteria O	O-1 – The director or coordinator of the interdisciplinary team acquires the necessary skills to act as an effective team facilitator.				

FOCUS AREA 2: INTERDISCIPLINARITY		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
		1	2	3	
	O-2 – Members of the interdisciplinary team have access to psychological support.				
Standard P	<i>The institution supports the interdisciplinary care team(s) that provide pediatric palliative care</i>				
Criteria P	P-1 – The institution formally recognizes the roles and responsibilities of the care team and its members that provide pediatric palliative care.				
	P-2 – The institution allocates time in its human resources planning for interdisciplinarity.				
	P-3 – The institution encourages members of the interdisciplinary team to maintain their skills by providing opportunities to attend courses or participate in conferences.				
	P-4 – The institution provides practical assistance by giving access to administrative support services and equipment.				

FOCUS AREA 3: CONTINUOUS QUALITY IMPROVEMENT		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
		1	2	3	
<p>The expertise required to meet the needs of children and their families varies according to each caregiver's and team's role and responsibilities. Health care providers and care teams must maintain their competencies in pediatric palliative care through appropriate training and current evidence-based practice. In addition, a continuous quality improvement program involving an evaluation of practice and service organization, and the participation of the team or some of its members in research should be added. The standards therefore address pediatric palliative care training requirements, evidence-based practice, evaluation, and research.</p> <p>Standards of continuous quality improvement are grouped into three perspectives: 1) training 2) evidence-based practice, 3) evaluation and research.</p>					
Standard Q	<i>Members of the interdisciplinary team, including volunteers, have the necessary training to provide care to children and to the families of children in palliative care.</i>				
Criteria Q	Q-1 – Health care providers who work as part of pediatric palliative care teams at UPCs have in-depth training in pediatric palliative care and pursue continuing education.				
	Q-2 – Health care providers who work with other interdisciplinary teams establish the structures necessary to acquire and maintain knowledge in pediatric palliative care.				
	Q-3 – Volunteers receive training in pediatric palliative care through a recognized organization.				
Standard R	<i>Interdisciplinary teams working in pediatric palliative care at university pediatric centres help interdisciplinary health care providers—from their institution and from their RUIS region—acquire the training they need to provide care to children in palliative care and meet the needs of their families.</i>				
Criteria R	R-1 – Interdisciplinary pediatric palliative care teams working in UPCs provide practicums in various pediatric palliative disciplines, including family medicine.				

FOCUS AREA 3: CONTINUOUS QUALITY IMPROVEMENT		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
		1	2	3	
	R-2 – Interdisciplinary pediatric palliative care teams in UPCs work with their RUIS to ensure that a pediatric component is included in palliative care training and that a palliative care component is included in pediatric training programs.				
	R-3 – Interdisciplinary pediatric palliative care teams working in UPCs support the continuing education efforts of pediatric palliative health care providers in their region. The activities in which they participate are included in their annual report.				
Standard S	<i>Interdisciplinary teams contribute to raising institutional and public awareness on pediatric palliative care issues.</i>				
Criteria S	S-1 –Interdisciplinary teams possess documentation, e.g., brochures and videos, that describes pediatric palliative care, as well as the services that can be provided and how to access them.				
	S-2 – Interdisciplinary teams possess pedagogical material to develop public awareness on pediatric palliative care issues. They also participate in information sessions on how to raise public awareness.				
Standard T	<i>Interdisciplinary teams providing pediatric palliative care engage in evidence-based interventions and apply them consistently.</i>				
Criteria T	T-1 – Interdisciplinary teams make use of evidence-based written procedures, guidelines, and assessment and care coordination tools, such as care pathways.				

FOCUS AREA 3: CONTINUOUS QUALITY IMPROVEMENT		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
		1	2	3	
	T-2 – Interdisciplinary teams hold scientific meetings and training sessions. They maintain a list of the subjects addressed during these meetings.				
Standard U	<i>Pediatric palliative care teams working in UPCs make recommendations on best practices in pediatric palliative care.</i>				
Criterion U	U-1 – Interdisciplinary pediatric palliative care teams working in UPCs collaborate to develop guidelines, protocols and procedures, encourage their dissemination and appropriation by health care teams in Quebec.				
Standard V	<i>Interdisciplinary teams assess their practices and find ways to improve them consistently.</i>				
Criteria V	V-1 –Interdisciplinary teams identify their objectives in pediatric palliative care and define expected results. They identify the indicators they will use to determine the extent to which the results have been achieved.				
	V-2 – Interdisciplinary teams regularly conduct evaluation activities, discuss their results and implement measures to improve palliative care and services.				
	V-3 – Interdisciplinary teams prepare an annual report that describes their activities and progress.				
	V-4 – Interdisciplinary teams maintain a clinical database that helps them know their patients and assess their performance.				

FOCUS AREA 3: CONTINUOUS QUALITY IMPROVEMENT		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
		1	2	3	
Standard W	<i>Interdisciplinary teams undertake or participate in research projects.</i>				
Criterion W	W-1 – Interdisciplinary teams document the research projects they implement or those in which their members participate.				

FOCUS AREA 4: CLINICAL GOVERNANCE		LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
		1	2	3	
<p>Clinical governance is founded on a common vision of the objectives to be achieved. By working together, administrators and clinicians can maximize resources, structures and processes to achieve their quality objectives. Clinical governance creates an organizational climate that is conducive to achieving excellence and promotes quality clinical work. Recognizing the unique health needs of children and their families is a necessary part of sound clinical governance in pediatric palliative care.</p>					
Standard X	<p><i>Institutions (UMCs, UAMCs, university institutes, regional medical centres, palliative care hospices and HSSCs) develop policies tailored to pediatric palliative care, and make resources and structures available to improve the quality of care and services they provide.</i></p>				
	X-1 – The institution identifies the children and families in their reference population that are likely to benefit from pediatric palliative care.				
	X-2 – The institution ensures that children and their families have access to palliative care services, including respite services.				
	X-3 – The institution establishes a parent committee to support the institution in its decisions regarding pediatric palliative care.				
	X-4 – The institution provides a physical environment tailored to the needs of children who receive pediatric palliative care and their families.				
	X-5 – The institution adapts its policies to the needs of children receiving pediatric palliative care and to the needs of their families, e.g. visitation policies regarding siblings and friends.				

FOCUS AREA 4: CLINICAL GOVERNANCE	LEVEL ACHIEVED			RECOMMENDED IMPROVEMENTS
	1	2	3	
X-6 – The institution ensures that the members of the interdisciplinary team providing palliative care have the expertise required to provide quality care in all the fields needed; the institution ensures that its members have the time and resources to deliver quality services.				
X-7 – The institution establishes indicators to describe the target population and evaluate the services it provides in pediatric palliative care.				
X-8 – The institution provides access to an ethics committee with substantial experience in addressing pediatric palliative care issues.				
X-9 – A special policy is established to provide quality palliative care when a child is admitted through the Emergency department or when a child dies in Emergency.				
X-10 – The institution is accredited in accordance with CCHSA or equivalent palliative care standards.				
X-11 – UPCs develop a pediatric palliative care program that includes bereavement support.				