

# Quality indicators for paediatric palliative care

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**OBJECTIVES:** To apply quality indicators for paediatric palliative care and evaluate performance in one service provision area.

**METHODS:** After institutional review board approval, medical records were abstracted for well-defined and measurable quality indicators for children with chronic complex conditions (CCCs) between January 2006 and December 2011 (n=50) at a university medical centre.

**RESULTS:** Of the 50 children with a CCC (mean age 64 months, 48% female), 39 (78%) died in hospital, 11 (22%) died at home and 13 (26%) were <1 month of age. In the final month of their life, 10 patients (20%) required an unplanned visit to the emergency department and seven (14%) were admitted. Only four patients (8%) were admitted for >14 days in their final month of life. Goals of care were addressed in a timely manner 60% of the time. An invasive procedure was performed in the final month of life in 27 (44%) patients. Bereavement follow-up was offered to 25 (50%) families. A palliative care consultant was involved with 17 (34%) patients. Palliative care was associated with less frequent invasive procedures in the final month of life and more frequent documentation of the preferred place of death.

**CONCLUSION:** Performance on these particular quality indicators was unsatisfactory across a diverse group of children with CCCs, indicating important opportunities for improvement. Methods used to improve the quality of other aspects of paediatric care, including emphasis on efficient work systems, practical tools and interdisciplinary teamwork, should be used for ensuring delivery of high-quality palliative care.

**Key Words:** Child; Chronic complex condition; Paediatric palliative care; Quality indicators

The death of a child is the most difficult experience for a parent (1). Because it occurs infrequently and represents a considerable emotional burden for families, offering support for those families through a paediatric palliative care approach is important.

In the Eastern Townships (Quebec), between 1997 and 2001, 219 children <20 years of age died. Of these, 106 died from trauma, 29 from perinatal complications, 11 from sudden infant death syndrome (SIDS), 52 from chronic complex conditions (CCCs) and 21 from other causes (2). Unfortunately, most acute conditions, such as trauma, do not lend themselves to palliative care intervention, in contrast to CCCs. High-quality care for children with CCCs and their families includes palliative care (2,3). Paediatric palliative care consultation, hospitalization and home visits by the members of a multidisciplinary team have been available since 1998.

Defining the goals of care, and developing appropriate and feasible quality indicators are essential steps in improving the quality of end-of-life care and in convincing institutions of the necessity of paediatric palliative care (4). Quality indicators are explicitly defined and measurable standards referring to outcomes, processes or structure of care that are required for a particular type of patient

## Les indicateurs de qualité en soins palliatifs pédiatriques

**OBJECTIFS :** Mettre en application des indicateurs de qualité en soins palliatifs pédiatriques et en évaluer l'exécution dans une région de prestation des services.

**MÉTHODOLOGIE :** Après avoir obtenu l'approbation du conseil de révision de l'établissement, les chercheurs ont résumé les dossiers médicaux d'un centre de santé universitaire de janvier 2006 à décembre 2011. Ils visaient ainsi établir des indicateurs de qualité bien définis et mesurables auprès d'enfants ayant des problèmes de santé complexes et chroniques (PSCC; n=50).

**RÉSULTATS :** Sur les 50 enfants ayant des PSCC (âge moyen de 64 mois, 48 % de filles), 39 (78 %) sont décédés à l'hôpital, 11 (22 %) sont décédés à la maison et 13 (26 %) avaient moins d'un mois. Au cours du dernier mois de leur vie, dix patients (20 %) ont dû se rendre à la salle d'urgence sans l'avoir planifié et sept (14 %) ont été hospitalisés. Seulement quatre patients (8 %) ont été hospitalisés plus de 14 jours pendant le dernier mois de leur vie. Dans 60 % des cas, les objectifs des soins ont été abordés dans un délai convenable. Au cours du dernier mois de leur vie, 27 patients (44 %) ont subi une intervention invasive. Par ailleurs, 25 familles (50 %) se sont fait offrir un suivi du deuil, et un consultant en soins palliatifs est intervenu auprès de 17 patients (34 %). Les soins palliatifs favorisaient la diminution du nombre d'interventions invasives pendant le dernier mois de vie et l'augmentation de la consignation du lieu privilégié pour mourir.

**CONCLUSION :** L'exécution de ces indicateurs de qualité était insatisfaisante dans un groupe diversifié de patients ayant des PSCC, ce qui est indicateur d'importantes possibilités d'amélioration. Il faudrait recourir aux méthodes utilisées pour améliorer la qualité d'autres aspects des soins pédiatriques, en s'attardant à des systèmes de travail, des outils pratiques et un travail d'équipe interdisciplinaire efficaces, pour assurer la prestation de soins palliatifs de qualité.

or clinical circumstance (5). Unfortunately, there are few studies describing the standards of care, and those that exist in the literature are mostly descriptive and qualitative (6,7).

The objectives of the present study are to use quality indicators in paediatric palliative care for patients with CCCs. The quality indicators used in the present study were previously established by the Health Ministry of Quebec in 2009 (8).

## METHOD

Following approval from the institutional review board, medical records of children who died from CCC between January 2006 and December 2011 (n=50) at the *Centre Hospitalier Universitaire de Sherbrooke* (CHUS, Sherbrooke, Quebec) were reviewed for well-defined and measurable quality indicators.

The medical records were identified within the hospital database and the list of patients of specific paediatric clinics that followed children with CCCs. Once identified, these charts were reviewed.

The quality indicators used were the number of emergency department visits, unplanned and planned hospitalizations,

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**TABLE 1**  
**General characteristics of patients (n=50)**

Characteristic	n (%)
Age	
0 to <1 month	13 (26)
1 month to <1 year	7 (14)
1 to <12 years	18 (36)
12 to 18 years	12 (24)
Sex	
Male	26 (52)
Female	24 (48)
Siblings	28 (56)
Palliative care consultation	
Yes	17 (34)
No	33 (66)
Place of death	
Acute care hospital	39 (78)
General paediatric ward	15 (39)
Emergency room	4 (10)
Neonatal intensive care unit	2 (5)
Paediatric intensive care unit	9 (23)
Maternity ward	9 (23)
Home	6 (12)
Unknown	5 (10)

hospitalizations >14 days and invasive procedures, all in the final month of life. A planned hospitalization was defined as respite care or hospitalization planned >24 h before admission. Additional analyzed variables were the number of clinically significant symptoms (pain, irritability, fatigue, dyspnea, laboured breathing, seizure, constipation, nausea, vomiting, diarrhea) during the final month of life and the bereavement follow-up offered to the family. Finally, regarding the preferred place of death, whether a discussion occurred and whether the family's wishes were respected (ie, the actual place of death) were assessed.

#### Data analysis

Descriptive statistics were used to report the data. Fisher's exact test was used to compare categorical variables;  $P < 0.05$  was considered to be statistically significant.

#### Results

A total of 161 medical records were identified, which included 61 deaths caused by perinatal complications, 19 traumas, four cases of SIDS, 27 cases of acute illness or unknown causes of death, and 50 CCCs. Of these 50 cases of CCC, 17 were associated with neurological disease, 10 with hemato-oncological disease, 11 with cardiac disease, 11 with genetic disorders, two with nephrological disease and one with gastroenterological disease. The general characteristics of these patients are presented in Table 1. With regard to the number of clinically significant symptoms during the final hospitalization or the final month of life, 32% of the children had no symptoms, 14% had one symptom, 20% had two symptoms, 16% had three symptoms, 16% had four symptoms and 2% had up to five symptoms.

The level of achieving the quality indicators is presented in Table 2. The majority of children did not undergo an invasive procedure (mechanical ventilation, cardiopulmonary resuscitation, surgery and/or admission to intensive care unit) during their final month of life. However, 34% of children underwent one to six invasive procedures. Although the longest hospitalization lasted 365 days, unplanned hospitalizations during the final month of life lasted a median of four days.

**TABLE 2**  
**Quality indicators**

Quality indicator	n (%)
Emergency room visits*	10 (20)
Unplanned hospitalizations*	10 (20)
Hospitalizations >14 days*	4 (8)
Planned hospitalizations*	3 (6)
Invasive procedures*	17 (34)
Bereavement follow-up	25 (50)
Discussion regarding preferred place of death	30 (60)

\*During the final month of life

Certain quality indicators and other variables of interest were used to compare children who had a palliative care consultation with a specialist in paediatric palliative care with those who did not. The children who benefited from a consultation underwent fewer invasive procedures (24% versus 40%) ( $P > 0.05$ ), more frequently had bereavement follow-up offered to the family (75% versus 41%) ( $P = 0.02$ ), had more discussions regarding preferred place of death (82% versus 48%) ( $P = 0.02$ ) and more frequently used respite care services (31% versus 0%) ( $P = 0.005$ ). The patients experiencing pain or irritability were more frequently referred to a paediatric palliative care specialist (71% versus 9%). The preferred place of death (home versus hospital) was discussed with 30 (60%) families. Of these, 100% of the children passed away in the preferred location.

## DISCUSSION

Measuring the quality of care that is provided enables health care professionals and policy makers to monitor and improve the care that they offer. The quality indicators used were easily measured and objective. In the case of paediatric palliative care, better care implies fewer visits to the emergency department, fewer unplanned hospitalizations and fewer invasive procedures during the final month of life. The health care professionals treating children with a CCC should aim to relieve the child's pain and minimize unnecessary suffering (2,3,5,8).

Most of the quality indicators used focus on the structure or the process of care. Measuring these indicators may be easier and less expensive than measuring outcomes. Whereas outcomes are mainly measured in a prospective manner, the relevant information needed to measure these quality indicators can often be found in medical charts or administrative data. However, we believe that the quality of care analysis should include the subjective evaluation of care by the patients and their families.

The preferred place of death – home or hospital – should be discussed at some point with the child and their family. This discussion is useful as a quality indicator because it reflects the determination of the wishes and respect of the choice of the family. Their choice should be respected as much as possible. If the family are uncomfortable with the child dying at home, then dying at the hospital or in a hospice becomes a good alternative – they can have the support of health care professionals during these difficult times.

Children who were referred to a palliative care specialist have a tendency to use the available services more frequently, particularly respite care service and bereavement follow-up. Not only did they undergo fewer invasive procedures during their final month of life, but they also had more discussions about their preferences regarding the place of death. This tendency can have two explanations: either the primary care provider helped the patient and their family accept the diagnosis and was conscientious enough to refer the patient to a paediatric palliative care specialist, or it is the palliative care specialist who helped the patient and their family to accept the diagnosis.

On the other hand, children experiencing pain or irritability were more frequently referred to a paediatric palliative care specialist. This could indicate that primary care physicians/paediatricians may be more uncomfortable with the management of a child experiencing pain or irritability. This could be addressed by offering tools to the physicians/paediatricians that they could use in these complex clinical situations. Future studies that include physical symptoms, such as pain and dyspnea, in the evaluation of palliative care for children are needed.

The present study had limitations. The retrospective methodology and the use of chart data limit the quality of the information. This methodology did not permit the analysis of the reasons for invasive procedures (intubation, surgery). For example, intubation is an intervention that should be avoided in the final weeks of life. A palliative chest tube for home dyspnea management may be

reasonable in certain situations. Also, the scope and organization of services offered to families and referring physicians is different in our region compared with other regions where hospice care is available. This limits the generalizability of the results.

## CONCLUSION

These results of the measured quality indicators suggest that there truly exists room for improvement in the end-of-life care offered to children with CCCs. The quality indicators used were measurable and objective, and they can be used in other medical settings offering paediatric palliative care to evaluate their end-of-life care. The processes implemented to improve quality of other aspects of paediatric care, such as efficient work systems, practical tools and interdisciplinary teamwork, should also be used to ensure the delivery of high-quality palliative care.

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