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End of life care in children and adolescents with cancer: perspectives from a French pediatric oncology care network

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1 Original study

2 **End of life care in children and adolescents with cancer:**
3 **perspectives from a French pediatric oncology care network**

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33 **Abbreviations key table**:

34	CNS:	Central nervous system
35	DNRO:	Do-not-resuscitate orders
36	HM:	hematological malignancies
37	IDF:	Île-de-France area
38	IV:	intravenous
39	ST:	solid tumors
40		

41 **ABSTRACT**

42 **Background:** In developed countries, cancer remains the leading cause of pediatric death from
43 illness, after the neonatal period. **Methods:** The objective of this study is to describe the end-
44 of-life care characteristics of children and adolescents with solid tumors (ST) or hematological
45 malignancies (HM) who died from tumor progression, in the Île-de-France area.

46 This is a regional, multicentric, retrospective review of medical files of all children and
47 adolescents with cancer who died over a one-year period. Extensive data from the last three
48 months of life was collected. **Results:** A total of 99 eligible patients died at a median age of 9.8
49 years (range 0.3-24 years). Most frequent terminal symptoms were pain (n=86), fatigue (n=84),
50 dyspnea (n=49) and anorexia (n=41). Median number of medications per patient was 8 (range,
51 3-18). Patients required administration of opioids (n=91), oxygen (n=36) and/or sedation
52 (n=61). Decision for palliative care was present in all medical records and do-not-resuscitate
53 orders in 90/99 cases. Symptom prevalence was comparable between children and adolescents
54 with ST and HM. A wish regarding the place of death had been expressed for 64 patients and
55 could be respected in 42 cases. Death occurred in hospital for 75. **Conclusions:** This study
56 represents a large and informative cohort, illustrating current pediatric palliative care
57 approaches in pediatric oncology. End-of-life remains an active period of care requiring
58 coordination of multiple care teams.

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66 **Introduction**

67 Each year, over 500 children and adolescents are treated for malignancies in pediatric hemato-
68 oncology departments in *Île-de-France* (IDF), the area encompassing Paris, France and its
69 surroundings (12.2 million inhabitants in 2019, including 3.13 million under 20 years old).
70 Although the five-year overall survival rate is 82% for children, adolescents and young adults
71 aged 0 to 24 years with cancer in western European countries, cancers remain the leading
72 cause of death from illness, after the neonatal period. The majority of patients die from tumor
73 progression^{1,2}. Palliative care in pediatrics is an elaborate practice of medicine, as each
74 situation is unique and complex³. A seminal study in pediatric palliative care in oncology by
75 Wolfe et *al.* has shown that it is a period rich in burdensome symptoms, such as pain,
76 weakness, dyspnea, and anorexia⁴. Several studies have described the care provided to
77 children with cancer in the palliative setting, showing that most of these dying children
78 receive intensive treatments during the terminal phase⁴⁻⁸. Two previous mono or multi-centric
79 studies have already analyzed palliative care trajectories for children and adolescents with
80 cancer in the IDF area^{9,10}, describing that children mostly died in hospital (67-78% of cases).
81 In addition, these studies highlighted the need for optimal coordination between outpatient
82 and inpatient care as well as the need for age-appropriate structures such as ones dedicated to
83 adolescents and young adults. All authors underlie the need for a multidisciplinary team to
84 support patients and their families during this complex palliative phase^{6,7}. These care teams
85 need to be trained in palliative medicine and should ideally be assisted by a resource team.
86 For the IDF area, such a resource team was created in 2010 and was called *PALIPED*. In the
87 IDF area, children and adolescents can receive care in one of five tertiary specialized pediatric
88 oncology centers and one of 24 satellite centers, supported by a healthcare network called
89 RIFHOP (*Réseau Île-de-France hémato oncologie pédiatrique*)¹¹. The RIFHOP is the IDF
90 hematology and oncology pediatric network, launched in 2007. This multidisciplinary care

91 network aims to improve the quality of care for all children and adolescents with cancer and
92 support their families.

93 The primary objective of this study was to describe the end-of-life care characteristics of
94 children and adolescents who died from tumor progression in IDF during a 12-month period.
95 Secondary objectives were to compare the care provided at the end of life of various subgroups:
96 children versus adolescents, patients with solid tumors (ST group, including CNS tumors)
97 versus those with hematological malignancies (HM group).

98

99 **Methods**

100 We performed a non-interventional retrospective study with review of anonymized medical
101 records that were in compliance with the reference methodology MR-004 from the
102 *Commission Nationale de l'Informatique et des Libertés* (CNIL). Institutional review board
103 approval was obtained for the study. Patients were identified through the RIFHOP patient
104 database and by patient lists provided by each pediatric oncology tertiary center. Patients were
105 eligible for the study if they (a) had a cytologically or histologically/histological proven HM
106 or ST malignancy, (b) were younger than 18 years old at the diagnosis of their malignancy,
107 (c) were treated in one of the tertiary pediatric and adolescent hematology and oncology
108 centers in IDF and (d) died as a result of a progressive malignancy between January 1st and
109 December 31st, 2016. “Children” were defined as patients aged 0 to 14 years old and
110 “adolescents” as patients aged 15 years or older at the time of death.

111 Data was collected by one pediatrician on a standardized case report form, after medical
112 records review. We collected data about clinical history and cancer treatment, care provided
113 during the three last months of life and specifically the last week of life, patterns of physical
114 symptoms (\geq grade 3 CTCAE version 4.0, Common Terminology Criteria for Adverse

115 Events¹²), treatments received during the last week of life, cause and place of death. We
116 collected data of all treatments included antibiotic prophylaxis.

117 Data were analyzed with the *BiostaTGV* software. All data was analyzed using descriptive
118 statistical methods and the proportion of patients within each group was compared using the
119 chi-squared or Fisher's exact test, when appropriate. For univariate analysis, a p-value less
120 than 0.05 was considered statistically significant.

121

122 **Results**

123 Patient selection is detailed in Figure 1. Ten patients were excluded because they did not die
124 from progressive disease, five of which died from treatment-related toxicity. Patients'
125 characteristics and total burden of cancer-directed therapies during initial phases of treatment
126 is described in Table I. In summary, among the 99 patients selected, 79 had a ST diagnosis
127 and 20 were treated for a HM. There were 78 children and 21 adolescents. More than half of
128 deceased patients had a CNS malignancy or a sarcoma diagnosis. Median delay from cancer
129 diagnosis to death was 19 months [range, 1-190] and with a median age at death of 9.8 years
130 [range, 0.3-24]. Ten patients in the adolescent group were over 18 years of age when they
131 died.

132 Patients displayed frequent severe and/or refractory symptoms during the last week of life that
133 required active interventions, such as pain (n=86), fatigue (n=84), dyspnea (n=49) and
134 anorexia (n=41) (Figure 2). Almost half of patients (48/99) received oral or intravenous
135 chemotherapy during the last month of life (Table II), and 7% of patients were included in an
136 experimental phase I-II clinical trials during this month. Median number of concurrent
137 medications per patient was 8 [range, 3-18]) during the last week of life, with a median
138 number of intravenous drugs of 4 [range, 0-11]. Patients needed administration of opioids

139 (n=91), antibiotics (n=35) and oxygen (n=36) (Table II). Overall, 23% of patients received
140 nutritional support by enteral, parenteral nutrition or both. 40% of patients received a
141 transfusion in the last week of life. For 61 patients (information available for n=94), end-of-
142 life sedation was required (any form of sedation and not only terminal sedation), mainly for
143 refractory pain or severe uncontrollable dyspnea. The drug used was intravenous (IV)
144 midazolam in all instances, combined with IV ketamine in 5 cases. The palliative care context
145 was notified in the medical chart for 100% (99/99) of patients. Do-not-resuscitate orders
146 (DNRO) were found in 90/99 medical records. The intervention of a specific palliative care
147 team had been requested for 24/99 patients at a median time of 21 days before death (range:
148 2–455 days). Almost two-thirds of the patients (63/99) were cared for in collaboration with a
149 satellite center. In addition, 8 patients were hospitalized or seen as out-patients in follow-up
150 care and rehabilitation centers. Home care nursing was involved for 45/99 patients.

151 Among the 99 patients, 75 died in hospital, mostly in the tertiary pediatric oncology centers
152 (Figure 3). No patient died in an intensive care unit. Home was the place of death for 24/99
153 patients. Patients or families had expressed a specific wish regarding the place of death in
154 65% of cases (children, 63%; adolescents, 71%). Envisioned place of death was most often
155 home (children 80%; adolescents 53%). Those wishes were always fulfilled when the place of
156 death was hospital (n=15). For those who had opted for death to happen at home, only 51% of
157 patients (24/47) saw their wish fulfilled. This last proportion was comparable for the children
158 group (51%) and the adolescent group (50%).

159 Symptom type and incidence, along with administered treatments were comparable in the two
160 age-defined groups. Adolescents were less likely to carry a central venous line or naso-gastric
161 tube at time of death ($p=0.001$ and $p=0.037$, respectively). Some specificities could be
162 highlighted with regards to end-of-life care characteristics of adolescents versus those of
163 younger patients: 29% of adolescents (versus 4% in children, $p=0.003$) had no device at the

164 time of death and 20% died in an adult palliative centers (versus 0%, $p= 0.001$). End of life
165 characteristics were mostly comparable in the two disease-defined groups, even if patients
166 with HM received significantly more blood products ($p<0.001$) and IV antibiotics ($p=0.023$)
167 than those with ST (Table III).

168

169 **Discussion**

170 This study described the end-of-life care provided to close to a hundred children and
171 adolescents who died from tumor progression over a year, in the large Ile de France area. We
172 analyzed that for this population, a decision to transition to best supportive/palliative care was
173 documented with precision in the medical records for all patients. The decision not to perform
174 invasive resuscitation measures was documented in 90% of medical records. Even if this data
175 had not been collected in the other historical studies in IDF, this rate is higher than the one
176 reported in the Northern American context by Bradshaw *et al.*^{13,14}. In consequences,
177 anticipation and planning of the expected end-of-life situations makes it possible to avoid
178 transfers to the intensive care unit and eliminate the risk for irrelevant invasive acts when
179 symptoms worsen¹⁵.

180 Symptoms experienced by patients during the last week of life are numerous and remain
181 burdensome despite multiple attempts at treating. Similar symptom prevalence has been
182 reported in previous different studies^{3,4,9,10}. Refractory pain is still predominant in this patient
183 population despite the frequent use of opioids (95% of patients in our cohort)^{4,7,16,17}. The
184 multiplication of symptomatic treatments may actually impact quality of life and very few
185 pediatric studies show evidence-based benefit from these therapies in advanced end-of-life
186 situations^{3,18,19}.

187 Sedation was often a necessary measure and was prescribed in two-thirds of the cases, during
188 the terminal phase for severe refractory symptoms. These results were in line with other French

189 experiences regarding sedation in the context of severe unbearable symptoms that could not be
190 relieved with supportive therapies in a palliative situation^{2,20}. The retrospective nature of this
191 work, performed by medical chart review, did not allow us to accurately collect and evaluate
192 psychological symptoms, which has to be acknowledged as a main limitation of our work.

193 In this report, the hospital remains the most frequent place of death (75% of patients). This
194 proportion has remained stable since 2002 in Ile-de-France, as demonstrated in previous
195 retrospective studies^{9,10}. We were able to document that wishes regarding the place of death
196 were respected in the majority of cases, but not in a constant manner. Occurrence of severe
197 symptoms, such as respiratory distress, seizures or refractory pain might have led families or
198 patients to change their mind from the initial wish. Even if talking about of the possible place
199 of death may be difficult conversation, advance planning allows better fulfilment of the
200 family and patient's wishes^{21,22}. Along the same lines, and in probable relation with this
201 planning step, we did not record any deaths in intensive care units within this cohort^{9,10,16,23}.

202 In France, despite the deep implication healthcare networks and the frequent presence of
203 home care in the household, the majority of deaths in pediatric oncology occur in hospital.
204 This is different from what is observed in some other developed countries: 61 to 88% of
205 children dying at home in countries such as The Netherlands, United States of America, and
206 Australia^{7,21,24}. This can be explained by a different societal vision and is highly dependent on
207 the local mapping of healthcare and home care support networks. In addition, this should be
208 analyzed by comparing the variation in the rate of death at home according to the some other
209 French areas²⁰. In the Lyon area, the rate of home death is higher for pediatric oncology
210 patients (65%), possibly in relation with a very dedicated and mobile pediatric palliative care
211 team, a single tertiary center and a lower population density²⁵. In IDF, a similar organization
212 is not currently possible due to the greater population density, a multiplicity of care centers
213 and perhaps the absence of a dedicated pediatric hospice.

214 The majority of our population was of pediatric age (0-14) and was treated for a solid tumor.
215 Still, the relative presence of an adolescent group, along with a group with hematological
216 malignancies allowed us to compare various aspects of end-of-life care and to show that these
217 populations' characteristics were mostly similar. The fact that adolescents died less frequently
218 in satellite centers in our study can be explained by the complexity of adolescents and young
219 adults end of life management in a general pediatrics unit, without a specific unit and without
220 staff trained to care for this population^{10,26}. This stresses the importance of having units and
221 staff dedicated to adolescents and young adults, including in end-of-life situations^{27,28}.

222 This study represents a large and informative cohort, illustrating our current harmonized
223 palliative care approaches in pediatric hematology and oncology in Ile de France. The
224 strength of this study is its regional scope and exhaustive approach. Indeed, we had access to
225 detailed data thanks to our strong care network, even though we can regret that this study is a
226 retrospective and regional study, as are most studies in pediatric palliative care²⁹. An
227 important innovative point of the study is the description and the comparison of between
228 different subgroups. An important limitation is that the data in relation to care received in the
229 home was limited in some charts, and we might not have had a completely accurate view of
230 this aspect. Due to the importance of remaining uncontrolled severe symptoms, prospective
231 comparative studies, even on supportive care, including at the end of life, seem necessary to
232 better help patients and families.

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239 **Conflicts of Interest:** The authors have no conflict of interest to disclose for this work.

240 **Authors' contributions:** SB collected the data and performed the statistical analysis
241 displayed in this study. SB, SCG and DO designed the study, wrote and edited the
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340

341 **LEGENDS**

342 **1) Figures titles**

343 Figure 1. Flow chart

344 Figure 2. Physical symptoms during the last week of life (n=99)

345 Figure 3. Place of death

346

347 **2) Tables titles**

348

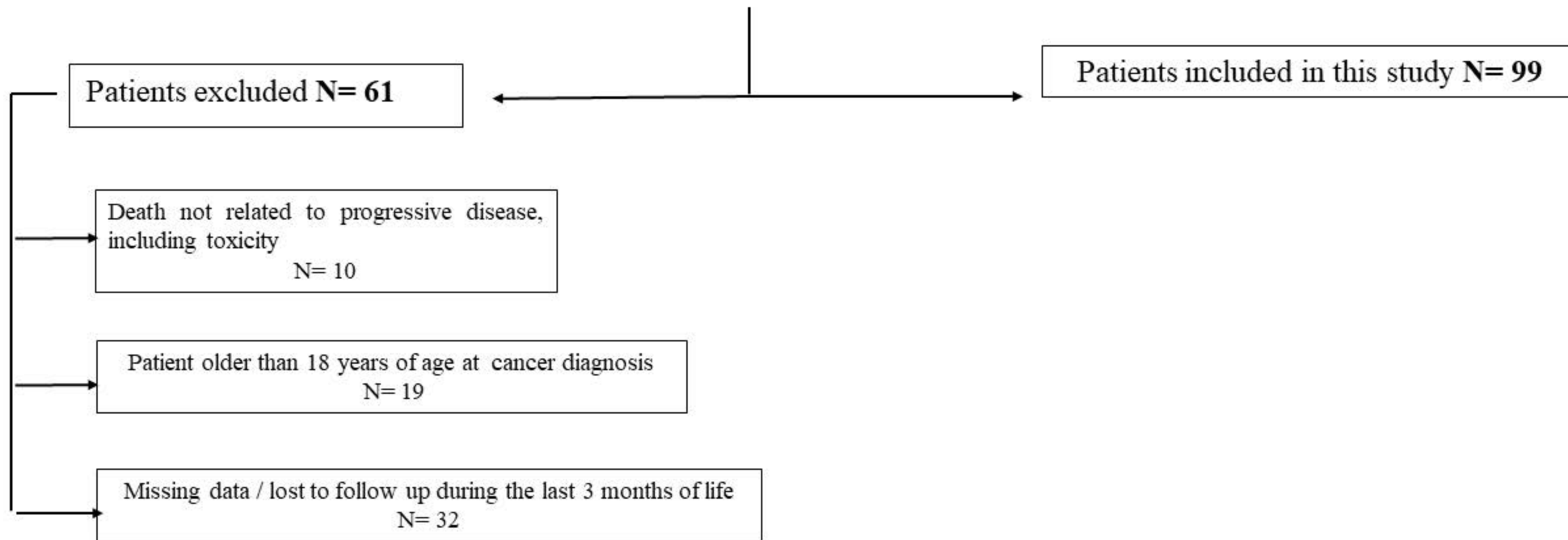
349 Table I. Characteristics of the study population (n=99)

350 Table II. Supportive care characteristics during the last week of life. Data regarding cancer-
351 directed therapy was collected during the last month of life.

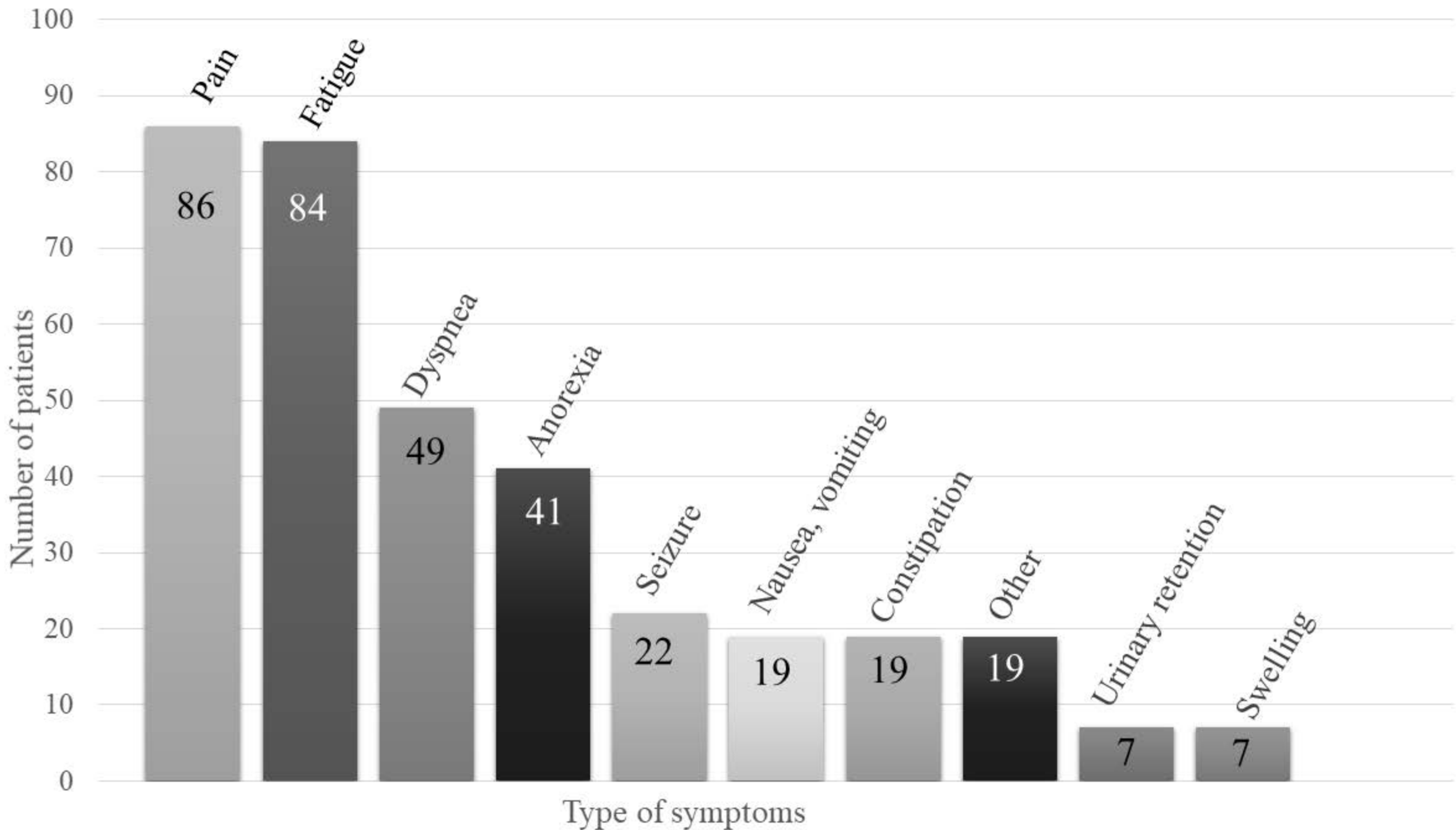
352 Table III. End of life characteristics according to age and disease type

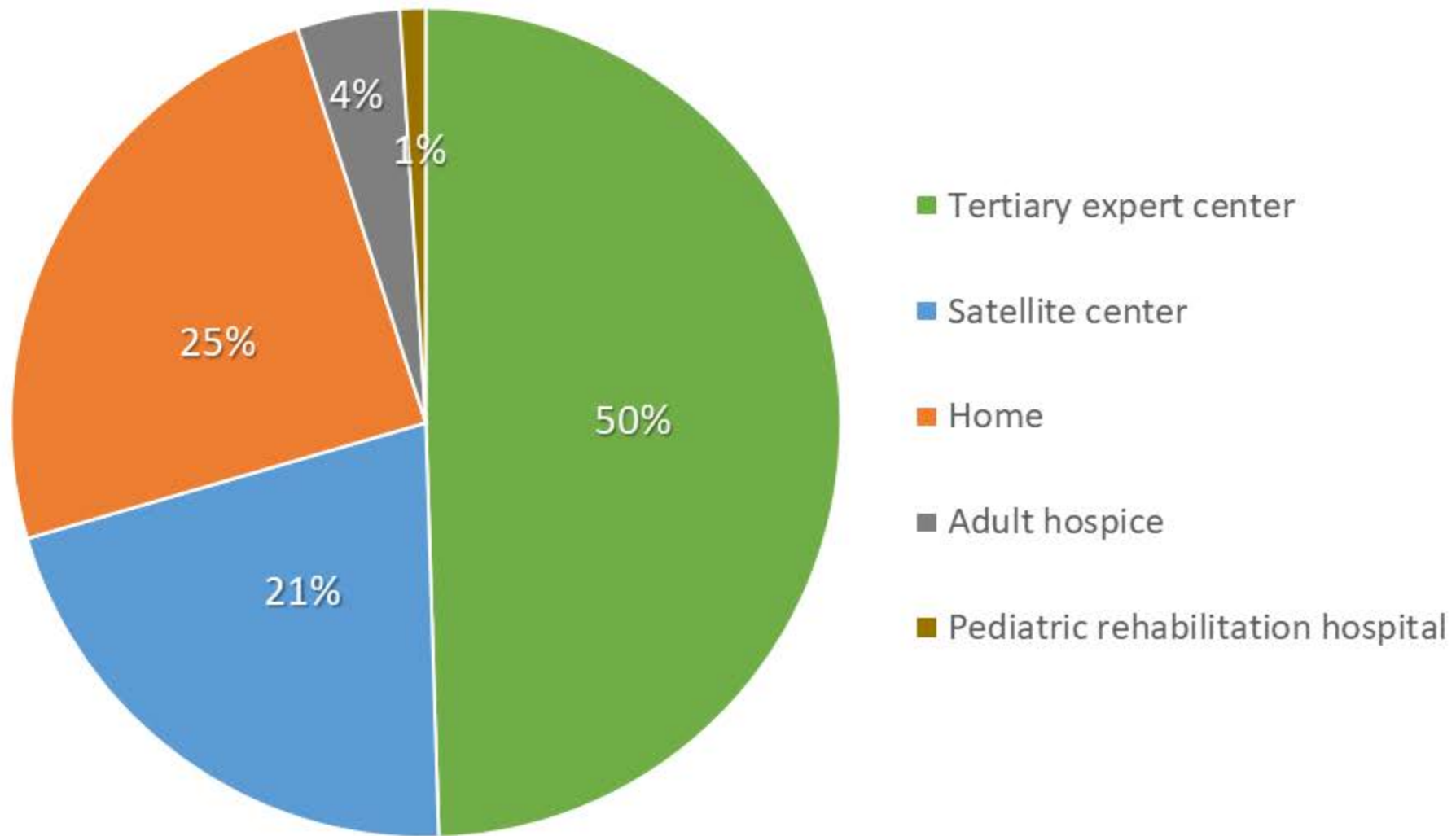
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Patients receiving care in a RIFHOP center
who died between January 1st and December 31, 2016
N= 160



RIFHOP: Réseau d'Ile-de-France d'Hématologie Oncologie Pédiatrique, N: number of patients





	Number of patients	
Sex		
Female	44	
Male	55	
Oncological diagnosis		
CNS tumor	36	
Malignant mesenchymal tumor	12	
Acute myeloblastic leukemia	9	
Neuroblastoma	9	
Acute lymphoblastic leukemia	8	
Ewing sarcoma	6	
Osteosarcoma	6	
Malignant germ cell tumor	4	
Wilms tumor	3	
Lymphoma	2	
Other tumors	4	
Shared care in satellite center		
Yes	63	
No	36	
Time between tumor diagnosis and death (months)		
Median	-	19
Range		1-190
Age at death (years)		
Median	-	9.8
Range	-	0.3-24.3
Cancer directed therapies, before last month of life		
Chemotherapy	85	
Median number of lines (range)	-	3 (0-11)
Radiotherapy	64	
High dose chemotherapy with stem cell transplant	27	
Experimental phase I-II clinical trials	50	

Table I. Characteristics of the study population (n=99)

CNS, central nervous system

Delivered therapies	Number of patients	% of patients	Median [range]
<u>During the last month of life</u>			
Palliative chemotherapy	48	48	
Palliative radiotherapy	8	8	
Surgery	4	4	
Inclusion in phase I-II clinical trial	7	7	
<u>During the last week of life</u>			
Total number of drugs	-	-	8 [3-18]
Number of oral drugs			4 [0-10]
Number of intravenous drugs			4 [0-11]
Any subcutaneous treatment	5	5	
Any transcutaneous treatment	28	29	
Opioids	91	95	
Antibiotics	35	37	
Oxygen therapy	36	37	
Nutritional support[#]			
Enteral nutrition	17	18	
Parenteral nutrition	9	9	
Transfusions			
Red blood cells	16	17	
Platelets	22	23	
Sedation	61	65	
Indications*:			
Severe dyspnea	34	55	
Refractory pain	28	46	
Not specified	7	11	

[#]patients could receive both *multiple possible

Table II. Supportive care characteristics during the last week of life. Data regarding cancer-directed therapy was collected during the last month of life.

	Children (n=78)	Adolescents (n=21)	p-value	ST group (n=79)	HM group (n=20)	p-value
Severe main symptoms*(n, %)						
Fatigue	67 (86)	17 (81)	0.73	70 (89)	14 (70)	0.73
Pain	67 (86)	19 (90)	0.73	67 (85)	19 (95)	0.46
Dyspnea	38 (49)	11 (52)	0.96	39 (49)	10 (50)	1
Anorexia	32 (41)	9 (43)	1	36 (46)	5 (25)	0.14
Devices (n, %)						
Central venous access	66 (85)	12 (57)	0.001	64 (81)	14 (70)	0.36
NG or G-tube	16 (20)	0 (0)	0.037	15 (19)	1 (5)	0.29
Received treatments* (n, %)						
Opioids	72 (93)	19 (90)	0.68	71 (91)	20 (100)	0.35
Antibiotics	30 (38)	5 (24)	0.30	20 (25)	15 (75)	0.023
Oxygen	27 (35)	9 (43)	0.66	28 (35)	8 (40)	0.90
Enteral/parenteral nutrition	21 (27)	3 (14)	0.27	19 (24)	5 (25)	1
Red blood cells transfusion	12 (15)	4 (20)	0.74	7 (9)	9 (45)	<0.001
Platelet transfusion	17 (22)	5 (23)	1	5 (6)	17 (85)	<0.001
Sedation	48 (61)	13 (62)	1	47 (63)	14 (70)	0.45
Place of death (n, %)						
Tertiary center	39 (50)	10 (48)	1	39 (50)	10 (50)	1
Satellite hospital	19 (24.5)	2 (9)	0.23	15 (19)	6 (30)	0.36
Home	19 (24.5)	5 (23)	1	20 (20)	4 (20)	0.77
Adult hospice	-	4 (20)	0.001	4 (5)	-	0.58
Pediatric rehabilitation hospital	1 (1)	-	1	1 (1)	-	1

Table III. End of life characteristics according to the age and disease type

Abbreviations: AYA: adolescents and young adults, ST: solid tumors; HM: hematological malignancies n: number of patients. NG: naso-gastric, G: gastric. *during the last week of life