

## Original Article

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# Palliative team involvement in end-of-life care for Jewish and Muslim children in Jerusalem: A unique clinical and cultural context

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**Abstract**

**Objectives.** Pediatric palliative care services improve the quality of life for children with life-limiting and life-threatening diseases, although little has been published about variation based on cultural and religious factors. This article sets out to describe clinical and cultural characteristics of pediatric end-of-life patients in a majority Jewish and Muslim country with religious and legal constraints around end-of-life care.

**Methods.** We conducted a retrospective chart review of 78 pediatric patients who died during a 5-year period and could potentially have utilized pediatric palliative care services.

**Results.** Patients reflected a range of primary diagnoses, most commonly oncologic diseases and multisystem genetic disorders. Patients followed by the pediatric palliative care team had less invasive therapies, more pain management and advance directives, and more psychosocial support. Patients from different cultural and religious backgrounds had similar levels of pediatric palliative care team follow-up but certain differences in end-of-life care.

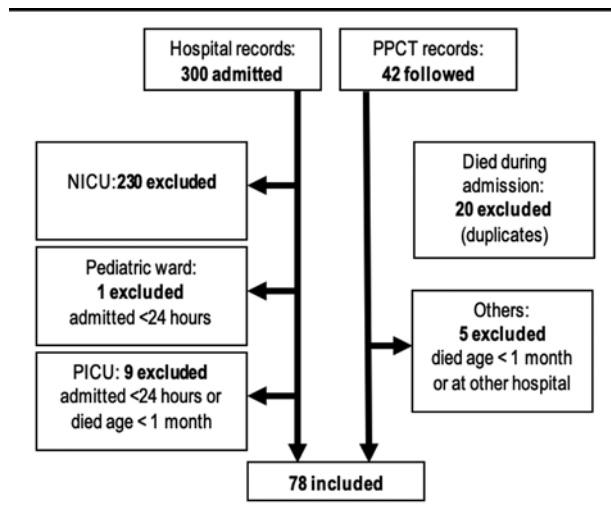
**Significance of results.** In a culturally and religiously conservative context that poses constraints on decision-making around end-of-life care, pediatric palliative care services are a feasible and important means of maximizing symptom relief, as well as emotional and spiritual support, for children at the end of life and their families.

**Introduction**

Pediatric palliative care (PPC) aims to provide the best possible quality of life for children with life-limiting or life-threatening diseases and their families, according to their values and preferences (World Health Organization 1998). Beyond medical symptom management, this also includes support for families making difficult decisions incorporating clinical factors as well as cultural and spiritual conventions (Dreesens et al. 2019; Streuli et al. 2019). The literature describes access to PPC services, suggesting significant variation in end-of-life (EOL) care based not only on diverse medical conditions and health system factors (American Academy of Pediatrics 2013; Ananth et al. 2015; Curlin et al. 2006; Feudtner et al. 2003, 2011; Gibson-Smith et al. 2020; Hoell et al. 2019; Wiener et al. 2013) but also on local cultural norms (Håkanson et al. 2017; Ntantana et al. 2017). Most of the available data on PPC and EOL care comes from North American and Western European centers; there is a paucity of data regarding care of dying children from non-majority cultures and religions (Curlin et al. 2006; Håkanson et al. 2017; Ntantana et al. 2017; Wiener et al. 2013).

In Israel, approximately 1000 children die every year (Israel Central Bureau of Statistics 2017). Unique medical and legal norms partially based on Jewish religious law (*halacha*), as well as patients' and clinicians' religious identity, influence clinicians' input and families' decision-making around EOL care (Soudry et al. 2003).

Most residents of Israel are of either Jewish (75%) or Arab Muslim (18%) ethnicity, and a significant proportion defines themselves as religious: 92% of Muslims and 55% of Jews, among whom approximately one-quarter identify as *haredi* (ultra-Orthodox, typically more strictly observant) (Israel Central Bureau of Statistics 2018; Weiss 2022). In Jerusalem specifically, the Jewish population is more religious overall (approximately two-thirds identify as religious, of whom half identify as *haredi*) (Yaniv et al. 2022). While there is significant diversity among different groups of religious and *haredi* Jews, their approach to EOL care is similar as it is based on established principles in *halacha* (Kaye 2009).



**Fig. 1.** Inclusion of cases in the study.

**Table 1.** Demographic characteristics of patients included in the study

Category	<i>n</i>	%
Age at death		
Under 1 year	26	33.3
1–5 years	34	43.6
6–11 years	11	14.1
12 years and up	7	9.0
Gender		
Female	39	50.0
Ethnicity		
Jewish	50	59.5
Arab/Other	34	40.5
Religion		
Jewish – orthodox	33	42.3
Jewish – secular or unspecified	12	13.4
Muslim	26	33.3
Christian/other	7	9.0
Residence		
West Jerusalem	25	32.1
East Jerusalem	23	29.5
Outside of Jerusalem	30	38.5
Living arrangement		
Home	74	94.9
Long-term care facility	4	5.1

In this paper, we describe the medical and psychosocial EOL care of pediatric patients who were treated at the Wilf Children's Hospital at Shaare Zedek Medical Center (SZMC) in Jerusalem, a large tertiary-care hospital serving approximately one million residents of the greater Jerusalem area. PPC is a relatively new field in Israel, where availability of PPC services is limited

**Table 2.** Clinical characteristics of pediatric EOL patients prior to final admission

	Followed by PPCT					
	All ( <i>N</i> = 78)		Yes ( <i>N</i> = 36)		No ( <i>N</i> = 42)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Primary diagnosis category						
Chromosomal	14	17.9	7	19.4	7	16.7
Malignancy	18	23.1	16	44.4	2	4.8
Trauma	12	15.4	0	0.0	12	28.6
Sepsis/immune deficiency	8	10.3	3	8.3	5	11.9
Chronic kidney	7	9.0	1	2.8	6	14.3
Neurologic	6	7.7	2	5.6	4	9.5
Metabolic	5	6.4	2	5.6	3	7.1
Perinatal	2	2.6	2	5.6	0	0.0
Cardiac anomaly	2	2.6	2	5.6	0	0.0
Other	4	5.1	1	2.8	3	7.1
Device dependence <sup>a</sup>						
Any	51	65.4	19	52.8	32	76.2
Number of medications at home						
Any	51	65.4	31	86.1	9	21.4
Median	3		4		0	
IQR	7		5.3		5.8	

<sup>a</sup>Device dependence includes noninvasive respiratory support, tracheostomy, gastrostomy, nephrostomy, ventriculo-peritoneal shunt, or central venous line.

(Bentur et al. 2015; Golan et al. 2008; Laronne et al. 2021a, 2021b; Shaulov et al. 2019; Silbermann et al. 2012). A multidisciplinary PPC team established at SZMC in 2018 operates in inpatient, outpatient, and home hospice settings. The PPC team includes 2 senior physicians (a pediatric oncologist and a pediatric intensivist with palliative care training), 2 nurses with oncology and palliative care training, 2 social workers, allied health professionals, a psychologist, and child-life specialists. Children with life-threatening or life-limiting conditions and medical or psychosocial complexity are referred from inpatient and outpatient services. The PPC team is presented as assisting children with complex or life-limiting conditions and their families, with symptom management, decision-making, and psychosocial support.

We conducted this study to better characterize EOL care of children who died in the past 5 years at SZMC, comparing those followed by the PPC team and those not followed and comparing between groups based on religious affiliation.

## Methods

We conducted a retrospective chart review of electronic medical records for all pediatric patients (aged 0 to 18 years) who died while admitted to inpatient units at SZMC, as well as those who died in home hospice while followed by the PPC team, during the period between January 1, 2017, and December 31, 2021. We excluded patients who died in the neonatal intensive care unit (NICU) and those who died before 1 month of age; this is because the Israeli law guiding care of terminally ill patients (Steinberg and Sprung 2007)

**Table 3.** Care during final admission prior to death

	All (N = 78)		Followed by PPCT			
			Yes (N = 36)		No (N = 42)	
	n	%	n	%	n	%
<i>Action documented in chart during final admission prior to death</i>						
Advance care directives						
On admission (DNR/DNI)	21	26.9	19	52.7	2	4.8
Multidisciplinary support (any)	61	78.2	27	75.0	34	81.0
Social work	49	62.8	18	50.0	31	73.8
Occupational therapy	13	16.7	8	22.2	5	11.9
Physical therapy	25	32.1	13	36.1	12	29.0
Psychologist	7	9.0	6	16.7	1	2.4
Spiritual care	4	5.1	4	11.1	0	0.0
Alternative medicine	2	2.6	2	5.6	0	0.0
Advanced radiology <sup>a</sup>	45	57.7	13	36.1	32	76.2
Invasive procedures <sup>b</sup>	47	60.3	10	27.8	37	88.1
Surgery	10	12.8	10	27.8	0	0.0
Hemodialysis	8	10.3	0	0.0	8	19.0
Opioid analgesia	30	38.5	16	44.4	14	33.3
Non-opioid analgesia	42	53.8	24	66.7	18	42.9
Sedative medication	32	41.0	17	47.2	15	35.7
CPR	18	23.1	4	11.1	14	38.9
<i>Duration of final admission (days)</i>						
Median	8		7		12	
IQR	23.3		29		18.8	
<i>Days in PICU during final admission</i>						
Any	44	56.4	8	22.2	36	85.7
Median	1.5		0		5.5	
IQR	6		0		16.5	

<sup>a</sup>Any of CT, MRI, radiologist-performed ultrasound, or fluoroscopy.

<sup>b</sup>Any of gastrostomy, arterial line, central line, umbilical line, or drain insertion.

explicitly does not discuss EOL care of neonates, and the SZMC NICU has a separate team (physicians, nurses, social worker, and psychologist) who support dying patients and their families. We also excluded patients who died during an admission that lasted under 24 hours, as there was insufficient time for PPC team involvement (except for those who were in home hospice followed by the PPC team and were brought to hospital near the time of death, who remained in the study).

We collected data on the following variables for each patient: demographics (age, sex, ethnic and religious affiliation, area of residence, and living arrangement – home or long-care facility); medical history (primary diagnosis, medical devices, and number of medications at home prior to final hospitalization); advance directives prior to final admission (specifically Do Not Intubate and Do Not Resuscitate orders); whether the patient was followed by the PPC team in hospital and/or in home hospice; clinical information concerning the final admission (diagnosis on admission,

**Table 4.** Patient characteristics and care at the time of death

	All (N = 78)		Followed by PPCT			
			Yes (N = 36)		No (N = 42)	
	n	%	n	%	n	%
<i>Action documented in chart during final 48 hours</i>						
Inotropic medication	17	21.8	3	8.3	14	33.3
Mechanical ventilation	34	43.6	5	13.9	29	69.0
Enteral feeding	32	41.0	19	52.8	13	31.0
Pain scoring	70	89.7	33	91.7	37	88.1
EOL conversation	33	42.3	16	44.4	17	40.5
Palliative team visit	27	34.6	26	72.2	1	2.4
Psychosocial staff visit <sup>a</sup>	27	34.6	12	33.3	15	35.7
Community MD involved	8	10.3	8	22.2	0	0.0
<i>Place of death</i>						
Pediatric ward	26	33.3	13	36.1	13	31.0
PICU	35	44.9	6	16.7	29	69.0
Home	14	18.0	14	38.9	0	0.0
Home – ED	3	3.8	3	8.3	0	0.0
<i>Age at death (months)</i>						
Mean	48		54		43	
St. dev.	53		52		53	

<sup>a</sup>Any of psychologist, social worker, or educational staff.

length of stay in hospital and in the pediatric intensive care unit (PICU), medical and pharmacological interventions, and invasive procedures); and clinical outcomes documented at EOL (during the final 48 hours) including location of death (in hospital or home hospice), whether EOL discussions or visits by psychosocial staff were documented, and whether certain procedures were performed (inotropic medication or mechanical ventilation, pain scoring, and enteral feeding). Patients' families' ethnic and religious identity were determined using information available in the medical record and coded as "unspecified" in the few cases where such determination was not possible. Of note, we classified all Muslim Arabs as religious since the vast majority identify as such (Israel Central Bureau of Statistics 2018; Weiss 2022).

We used descriptive statistics alone to evaluate patient characteristics and compare patients who died with PPC team follow-up versus those without and by religious and cultural identification (due to small cohort size limiting statistical power and thus the meaningfulness of findings of statistical significance).

## Results

We identified a total of 78 cases meeting the criteria for this study (Figure 1). Demographics (age at death, gender, ethnic and religious affiliation, and place of residence) are described in Table 1. The most common categories of primary diagnosis were oncologic diseases (23%) and chromosomal or multisystem genetic disorders (18%) (Table 2). Among patients included in the study, 36 (46%) were followed by the PPC team, of whom 19 (53%) were followed in hospital and 17 (47%) in home hospice (Table 3).

**Table 5.** Care during final admission prior to death, by religious affiliation

Category	Religious affiliation									
	All patients (N = 78)		Jewish religious (N = 33)		Jewish secular (N = 12)		Arab Muslim (N = 26)		Other (N = 7)	
	n	%	n	%	n	%	n	%	n	%
Followed by PPCT										
Yes	36	46.2	15	45.5	6	50.0	13	50.0	2	28.6
<i>Action documented in chart during final admission prior to death</i>										
Advance care directives										
On admission (DNR/DNI)	21	26.9	9	27.3	4	33.3	7	26.9	1	14.3
Multidisciplinary support (any)	61	78.2	25	75.8	10	83.3	19	73.1	7	100.0
Social work	49	62.8	17	51.5	8	66.7	18	69.2	6	85.7
Occupational therapy	13	16.7	7	21.2	3	25.0	2	7.7	1	14.3
Physical therapy	25	32.1	12	36.4	5	41.7	6	23.1	2	28.6
Psychologist	7	9.0	5	15.2	2	16.7	0	0.0	0	0.0
Spiritual care	4	5.1	1	3.0	2	16.7	1	3.8	0	0.0
Alternative medicine	2	2.6	1	3.0	0	0.0	1	3.8	0	0.0
Advanced radiology <sup>a</sup>	45	57.7	21	63.6	6	50.0	14	53.8	4	57.1
Invasive procedures <sup>b</sup>	47	60.2	19	57.6	6	50.0	17	65.4	5	71.4
Surgery	10	12.8	3	9.1	0	0.0	4	15.4	3	42.9
Hemodialysis	8	10.3	1	3.0	0	0.0	6	23.1	1	14.3
Opioid analgesia	30	38.5	13	39.4	4	33.3	8	30.8	5	71.4
Non-opioid analgesia	42	53.8	17	51.5	6	50.0	17	65.4	2	28.6
Sedative medication	32	41.0	13	39.4	6	50.0	11	42.3	2	28.6
CPR	18	23.1	9	27.3	3	25.0	3	11.5	3	42.9
<i>Action documented in chart during final 48 hours</i>										
Inotropic medication	17	21.8	9	27.3	3	25.0	4	15.4	1	14.3
Mechanical ventilation	34	43.6	15	45.5	6	50.0	9	34.6	4	57.1
Enteral feeding	32	41.0	12	36.4	3	25.0	13	50.0	4	57.1
Pain scoring	70	89.7	30	90.1	12	100.0	21	80.8	7	100.0
EOL conversation	33	42.3	11	33.3	6	50.0	12	46.2	4	57.1
Palliative team visit <sup>c</sup>	27	34.6	11	33.3	6	50.0	8	30.8	2	28.6
Psychosocial staff visit	27	34.6	10	30.3	5	41.7	8	30.8	4	57.1
Community MD involved	8	10.3	3	9.1	4	33.3	1	3.8	0	0.0
<i>Place of death</i>										
Pediatric ward	26	33.3	13	39.4	2	16.7	9	34.6	2	28.6
PICU	35	44.9	14	42.4	6	50.0	12	46.2	3	42.9
Home	14	17.9	6	18.2	4	33.3	3	11.5	1	14.3
Home – ED	3	3.8	0	0.0	0	0.0	2	7.7	1	14.3

<sup>a</sup>Any of CT, MRI, radiologist-performed ultrasound, or fluoroscopy.

<sup>b</sup>Any of gastrostomy, arterial line, central line, umbilical line, or drain insertion.

<sup>c</sup>Any of psychologist, social worker, or educational staff.

On final admission prior to death, a larger percentage of patients followed by the PPC team had advanced care directives than those not followed by the team. During the final admission,

patients followed by the PPC team underwent comparatively fewer diagnostic exams, invasive procedures, and resuscitative measures; received more sedatives and analgesics; received more

psychosocial support (hospital-provided psychologists, spiritual care, or complementary-alternative medicine); spent fewer days in PICU; and fewer died in PICU (Tables 3 and 4).

### Ethnic and religious affiliation

Three-quarters of patients were identified as religious Jewish or Muslim (Table 5). Similar proportions of religious Jews, secular Jews, and Arab Muslims were provided care by the PPC team (46%, 50%, and 50%, accordingly) and had advance directives documented on admission (27%, 33%, and 27%, accordingly). There were differences in medical treatment, communication, and psychosocial support given to each group (detailed in Table 5). Of note, overall fewer religious Jewish patients had an EOL conversation documented in the chart in the final 48 hours of life (33%) compared to secular Jewish (50%) or Muslim (46%) patients.

### Discussion

We summarize our experience in the care of pediatric patients at the EOL in a medical center with a majority religious Jewish and Muslim population. Most literature on EOL care and preferences of families, particularly in pediatric patients, originate from North America and Europe. While patients' cultural and religious norms are understood to affect patients' and medical teams' approaches to EOL care (Curlin et al. 2006; Ntantana et al. 2017; Soudry et al. 2003; Wenger and Carmel 2004; Wiener et al. 2013), our patients have limited representation in the literature; few studies describe perception of EOL treatment for Muslim (Chakraborty et al. 2017; Choudry et al. 2018; Dabar et al. 2021; Eltaybani et al. 2020; Gustafson and Lazenby 2019; Leong et al. 2016; Muishout et al. 2018) or religious Jewish (Baeke et al. 2011; Blinderman 2007; Choudry et al. 2018; Kinzbrunner 2004; Loike et al. 2010) patients and families.

Religious Jews follow proscribed laws (*halacha*) that govern all aspects of life, including its end; in general, all measures are to be taken to preserve health and find cure to a disease, and it is forbidden to hasten death (Baeke et al. 2011; Choudry et al. 2018; Kaye 2009). On the other hand, most Jewish traditions permit alleviation of pain and suffering, even if this may inadvertently shorten the life of a person who is dying anyway (Choudry et al. 2018; Kaye 2009). Religious Jews will most often look to a *posek* (learned scholar acting as decisor) to provide or assist in decision-making in keeping with *halacha* (Leshem 2009).

In Islam, there are multiple schools of thought with no singular formal guidance on EOL care (Choudry et al. 2018; Muishout et al. 2018). The general belief appears to be that death should not be hastened but that physicians may be in the best position to decide when life-saving therapy should be initiated; it is also believed that if death is inevitable, unnecessary interventions should be avoided (Chakraborty et al. 2017). There are varying beliefs on whether suffering is redemptive (Gustafson and Lazenby 2019) or should be relieved if possible (Leong et al. 2016).

Nuanced religious norms make EOL decision-making and care for Jewish and Muslim patients a craft that requires delicate conversations that account for families' beliefs; their dependence on their rabbi, imam, or other religious leader for guidance; and their wishes for their child to not suffer while also keeping with religious tradition. The existing palliative care literature paints Jewish and Muslim traditions on EOL care in broad strokes, leaving open questions into particulars about withholding treatment, giving terminal sedation, and providing psychosocial and spiritual support.

Our cohort is similar in general demographic makeup to the population of Jerusalem (Israel Central Bureau of Statistics 2018; Yaniv et al. 2022). Our results reflect some of the known beneficial effects of palliative care in a unique cultural context that may constrain some aspects of EOL care. Similar rates of patients were treated by the PPC team across cultural and religious backgrounds; patients followed by the PPC team had better symptom management, more psychological and spiritual support, more advanced care directives, and a supportive framework that facilitated being at home at the time of death if the patient and their family preferred so.

We observed that religious Jewish and Muslim families engaged less in formal EOL counseling and less withholding of invasive care at EOL. However, they were no less likely to seek out and benefit from a palliative framework to maximize their quality of life, in keeping with the mission of palliative medicine to give care according to the patient's values and wishes. Notably, we saw a greater difference in invasive interventions at the EOL between patients with PPC team follow-up versus those without, than between religious and cultural groups.

### Limitations

Although demographically similar, our relatively small cohort may not necessarily reflect the broader population in Jerusalem and in Israel. Small cohort size hindered our ability to meaningfully evaluate the statistical significance of differences or associations between groups. As a retrospective chart review relying on documentation, our data may exclude undocumented but potentially meaningful interactions around EOL, as well as any description of patients' and families' experiences, which are essential to understanding how their cultural and spiritual background influences EOL care and decision-making processes.

Our study is novel in its description of EOL care for pediatric patients from Jewish and Muslim families, since most of the existing literature comes from North American and European countries where these are minority groups. Our findings can benefit palliative care teams who may not be as familiar with these patients' traditions and values. Although EOL care may look different for religious Muslim or Jewish patients (specifically with respect to withdrawal or limitation of life-sustaining therapies), our findings show that these populations are no less likely to utilize PPC services for providing symptom relief, as well as emotional and spiritual support. Palliative care teams could work closely with religious leaders to better adapt EOL care to these patients' cultural and religious values. More studies are required to understand the decision-making processes around EOL care for both patients and medical staff with respect to Jewish and Muslim cultural and religious contexts.

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**Conflicts of interest.** All authors declare that they have no competing interests.

**Ethical approval.** This study was approved by the SZMC institutional review board (0259-20-SZMC).

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