

Differences in service utilization between pediatric and adult palliative care services in a single center

Original Article

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Abstract

Objectives. Current recommendations do not separate adult and pediatric palliative care (PC) in terms of the personnel needed, or the distribution of care between community and hospital-based services. We evaluated the differences in the utilization of pediatric and adult hospital PC services for non-oncological patients.

Methods. Retrospective study. Parameters included demographics, underlying diagnoses, number of consultations per patient, duration of PC involvement, and follow-up. All non-oncology patients seen by the adult or pediatric PC teams between June 2021 and July 2023 at a single tertiary hospital.

Results. A total of 445 adults and 48 children were seen by the adult and pediatric palliative teams, respectively. Adults were primarily seen in the terminal stages of common chronic diseases, with a high mortality rate. Children were mainly seen at a very young age with rare and complicated diseases. Children needed longer duration of follow-up (114 vs. 5 days, $p < 0.001$), more consultations (8.5 vs. 4, $p < 0.001$), and died less while hospitalized (25% of patients vs. 61.6%, $p < 0.001$).

Significance of results. Adult patients had relatively common diseases, seen and treated often by primary care practitioners, whereas children had rare life-limiting diseases, which primary care pediatricians may have limited experience with, and which require involvement of multiple specialized hospital-based services. Future healthcare PC planning should consider these factors in planning the primary setting for PC teams, specifically more training of adult general practitioners in PC skills, and earlier referral of pediatric patients to hospital-based PC.

Introduction

Palliative care (PC), in its current form, is a relatively new field. It was only recognized by the World Health Organization (WHO) as a distinct specialty in 1990 (New England Journal of Medicine Resident 2020), and is still evolving today. Adult PC has only recently derived benchmarks for hospital PC teams (Joint Commission Resources 2015; Henderson et al. 2019). While the published benchmarks were published by adult PC specialists, they did suggest that these benchmarks may be applicable to pediatric teams as well. Pediatric PC has no standards for team make-up, or the number of personnel per number of patients, and teams vary widely between hospitals (Feudtner et al. 2013). The WHO did publish a document in 2018 outlining pediatric PC, but as the document suggests, their recommendations are not clinical guidelines, and are the “minimum palliative care and symptom relief that should be accessible by any child in any setting” (World Health Organization 2018).

While adult and pediatric PC have similar treatment aims (Scholten et al. 2016; Boyden et al. 2018; Mitchell et al. 2021), there are likely differences in the management of adult and pediatric patients, due to different diseases, projected life spans, and the specific medical knowledge of primary and hospital-based teams. These may require a separate design of adult and pediatric PC services, both in-hospital and in community healthcare settings.

In Israel, PC is a budding profession. Only in 2009 did the Israeli Ministry of Health (MOH) require the development and implementation of PC services in hospitals and community health services (Livneh 2011). In 2016, the Israeli MOH, in cooperation with the American Jewish Joint Distribution Committee, published recommendations for a national plan for palliative and end-of-life care. These recommendations did not separate adult and pediatric PC in terms of the type of care, the personnel needed, or the distribution of care between community and hospital-based services (Israeli Ministry of Health 2016).

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The Israeli healthcare insurance system includes universal health coverage for all citizens, delivered through 1 of 4 competing non-profit providers known as health plans (HPs). HPs provide various in-house medical services such as primary and specialist care for their members, in addition to covering costs of third-party care provider services included in the Ministry of Health's "Health basket," such as hospital care, oncology outpatient services, and more. Home PC services are included in the "Health basket" and usually provided by third-party providers. Inpatient PC consultations are included in hospital services while inpatient hospice care entails pre-approval by the HP.

Our hospital has both an adult palliative care service (APCS), which was established in 1994, and a pediatric palliative care service (PPCS), which was established in 2017. Each service has developed under separate management and clinical teams, seeking to answer the needs of patients as they arise. Both the APCS and PPCS are one of the first to develop in the country. The aim of the study was to show the differences between the utilization of the APCS and PPCS. These data are important for tailoring PC services more effectively to each group's specific needs.

Methods

PC setting

The SZMC is a 1000-bed tertiary hospital affiliated with the Hebrew University School of Medicine. The medical center serves the population of the greater Jerusalem area, including 1,147,000 residents, 43% of whom are children. The population is religiously and culturally diverse; 62% are Jewish and 38% are Muslim (Israeli Central Bureau of Statistics 2018).

The PPCS includes 2 physicians, 2 nurses, 2 social workers, a psychologist, an occupational therapist, a dietician, and a child life team, including teachers and therapists of the hospital's school. The APCS includes 2 physicians, 2 palliative medicine trainees, and 5 PC nurse specialists. The team collaborates with social workers and the occupational and physical therapy teams of the department. Both teams collaborate with a spiritual care team.

Patients may be referred to the APCS or PPCS by any staff member in any of the hospital's departments. The referring team may ask for a single consultation (e.g., symptom management) or long-term follow-up for patients with a life-limiting or life-threatening condition with frequent hospitalizations or uncontrolled symptoms.

Both services provide inpatient consultation services and outpatient clinics. The PPCS also provides a home hospice service.

Study cohort

For this retrospective cohort study, the SZMC electronic records were searched for all non-oncological patients referred to the APCS and PPCS between June 2021 and July 2023. All patients treated by the teams were included in the study. The following data were extracted for each patient: age at the first consultation, sex, underlying diagnoses, number of PC consultations, total duration of PC team involvement, and outcome (i.e., death or recovery).

The SZMC institutional ethics committee approved this study, and waived informed consent, as this is a retrospective study.

Statistical analysis

The median (range) was used to describe continuous variables. For nominal data, we reported the absolute and relative frequencies.

The Kruskal–Wallis H test was used to determine statistically significant differences between 2 groups of an independent variable on a continuous dependent variable. A 2-sided significance level of $\alpha = 0.05$ was considered significant.

Results

Study cohort

During the study period, 445 adults and 48 children with non-oncological diseases were cared for by the APCS and PPCS, respectively (Table 1). Adults, most at an elderly age (>70 years), had a high frequency of highly prevalent chronic diseases, mostly organ failures. Most children were diagnosed with a rare disease, i.e., a disease with a prevalence of less than 1:1500, and enrolled in the PPCS at a very young age (<6 months of age).

A significantly higher rate of adults, 274 (62%), died while being followed by the PC service compared to children, 12 (25%) (Table 1).

The utilization of the PC service was different between adults and children. Children required a significantly longer duration of follow-up and had twice as many consultations as their adult counterparts (Table 1). Age at enrollment to palliative service was not associated with follow-up time among children or adult PC patients.

In adults, there was no difference in the median number of consultations and median follow-up time between those who died and those who survived (4 vs. 4 consultations and 5 vs. 6 days, respectively). In comparison, children who died had a non-significant trend toward a lower median number of consultations and shorter median follow-up time compared to children who survived (4 vs. 10 consultations and 54 vs. 125 days, respectively).

Discussion

Our study reveals differences in the characteristics and utilization of non-oncological PC services between children and adults. The APCS saw a large volume of patients, mostly in the terminal stages of common chronic diseases, with a high mortality rate and shorter and less frequent consultations. The PPCS saw a relatively small number of children at a very young age, most of whom had complex, rare conditions, needing frequent consultations over a considerably extended follow-up period.

To our knowledge, this is the first study comparing the utilization of APCS and PPCS at all, and specifically in the same institution. While it may seem obvious that adult and pediatric palliative patients will have different diseases and require different services, published guidelines specifying team make-up and settings of care do not differentiate between the 2 populations (Israeli Ministry of Health 2016; Henderson et al. 2019). We decided to compare the 2 populations in 1 hospital, because cultural, religious, and spiritual characteristics of patients play a big role in the care of PC patients, and it is important that these characteristics are similar.

As in other countries, there is a severe shortage of PC physicians in Israel (Israeli Ministry of Health 2016; Care CtAP 2022). There are 48 certified APCS physicians (18 in primary health-care, 30 hospital-based) and 3 certified PPCS physicians in Israel (Israeli Ministry of Health Data Base 2024), for a population of 9 million people (Israeli Central Bureau of Statistics 2023). Ideally, community-based multidisciplinary PC teams would allow best practice care of patients, and the most efficient utilization of the

Table 1. Characteristics of adults and children followed by the palliative care team

	Adults	Children	p value	
Total	445	48		
Female (%)	239 (53%)	23 (47%)	0.83	
Age in first consultation, years ^a	75 (18.5 – 103)	0.43 (0.17 – 17.3)	–	
Underlying diseases (%) ^b				
	Heart failure	118 (26%)	Metabolic/neurodegenerative	24 (50%)
	Neurological deterioration ^c	109 (24%)	Perinatal	16 (33%)
	Renal insufficiency	62 (14%)	Inborn malformations	3 (6.25%)
	COPD	36 (8%)	Chromosomal disorders	2(4%)
	Liver failure	39 (9%)	Trauma	2 (4%)
Died during study period (%)	274 (61.6%)	12 (25%)	<0.001	
Duration of follow-up, days ^a	5 (1 – 718)	114.5 (1 – 761)	<0.001	
Duration > 60 days (%)	28 (6%)	31 (64%)	<0.001	
Number of consultations ^a	4 (2 – 23)	8.5 (1 – 41)	<0.001	
Less than 4 consultations (%)	202 (44%)	9 (12%)	0.001	

^aMedian (range).

^bA patient may have more than 1 diagnosis.

^cDementia or cerebral vascular accident.

PC, palliative care; COPD, chronic obstructive pulmonary disease; CVA, cerebral vascular accident.

workforce available. This requires training of more medical and non-medical PC community-based healthcare providers. However, in Israel, in the community setting this is rarely the case – general practitioners (GPs) and pediatricians work alone with the patient, except in the case of hospice. While there is room to consider whether a more multi-disciplinary approach to community-based practice would be more beneficial to patients, a full discussion of this is beyond the scope of this article.

One possible solution for the shortage of adult PC specialists, which was also offered by the Israeli MOH recommendations for PC (Israeli Ministry of Health 2016), is deeper involvement of GPs in care of palliative patients. As seen in our study, and in keeping with published data (Taylor et al. 2023), adult patients have relatively common diseases and are treated for a range of symptoms seen often by GPs, allowing them to act as the patient's primary PC teams. Studies show that training of GPs to recognize early and care for patients requiring PC is feasible (Thoonsen et al. 2016a, 2016b). This means that the training of GPs in Israel should include more palliative training. In addition, society at large should be more involved in promoting PC training and practice.

In contrast, we found that most children had rare life-limiting diseases. Many primary care pediatricians have limited experience and feel uncomfortable with treatment of these patients, in particular PC (Michelson et al. 2009; Sanderson et al. 2016). They also had long duration of PC follow-up and more consultations. Furthermore, these diseases often cause multi-organ symptoms requiring involvement of multiple specialized hospital-based services (e.g., metabolic disease specialists, neurologists, pulmonologists, etc.). Our findings are similar to those published previously (Brouwer et al. 2020; Feudtner et al. 2021; Mitchell et al. 2021). The fracturing of healthcare for medically complex patients is a difficult problem. In general, in Israel, when pediatric patients are medically complex, follow-up is mostly done by specialists who are hospital-based. This means that in pediatrics, rather than a community health-care based approach, a dedicated hospital-based

multidisciplinary PC team which attends to the child and his/her family along the course of disease, irrespective of the site of care (inpatient admissions, outpatient clinics, and home visits), will help prevent a splintered medical team. Ideally, the patient is introduced to the PPCS close to the diagnosis of the life-threatening condition to provide this holistic care throughout the course of the disease. In considering these factors, future training in pediatrics in Israel should include recognition of palliative patients, to facilitate early referral to a specialist in-hospital PC team. In addition, training of more pediatric in-hospital PC specialists should be considered.

There are a few limitations to the study. The first is its retrospective design, which did not allow us to look more closely at the patients chosen for PC consults and follow-up. In addition, this study summarizes a single institution's experience in a relatively high-income country. The findings are reflections of the available hospital manpower resource allocation, health care structure, referral patterns, and the prevailing culture of care. However, our data of follow-up duration and number of consultations are similar to that reported in the literature for APCS and PPCS (Bösch et al. 2018; Nogueira et al. 2023 for adults; Kwong et al. 2023; Peláez-Cantero et al. 2023 for pediatrics). While our findings are specific to our Israeli-based hospital, they may be applicable to other countries with a shortage of PC practitioners. An additional limitation is the smaller number of children than adults in our study. The smaller pediatric group provides less data, resulting in wider confidence intervals and reduced certainty about the findings. Moreover, the characteristics of the smaller pediatric group may not reflect the diversity and variability of a larger population. However, since pediatric PC cases are significantly rarer than adult cases, and since we included all available cases, we could not control this size discrepancy.

In conclusion, the experience of the SZMC adult and pediatric PC teams illustrates differences in the pattern of service utilization between pediatric and adult PC services. In considering future Israeli palliative healthcare planning guidelines, we suggest that it

would be reasonable for adult PC services to be more heavily provided in a primary care setting, with consultations by community-based PC specialists, and only the most complex patients be treated by the hospital-based PC services. In contrast, we would suggest that pediatric PC services be hospital-based, with training given to primary pediatricians for early recognition and referral to a specialized hospital-based pediatric PC team.

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