

Patient experiences and treatment access with pediatric rhabdomyosarcoma

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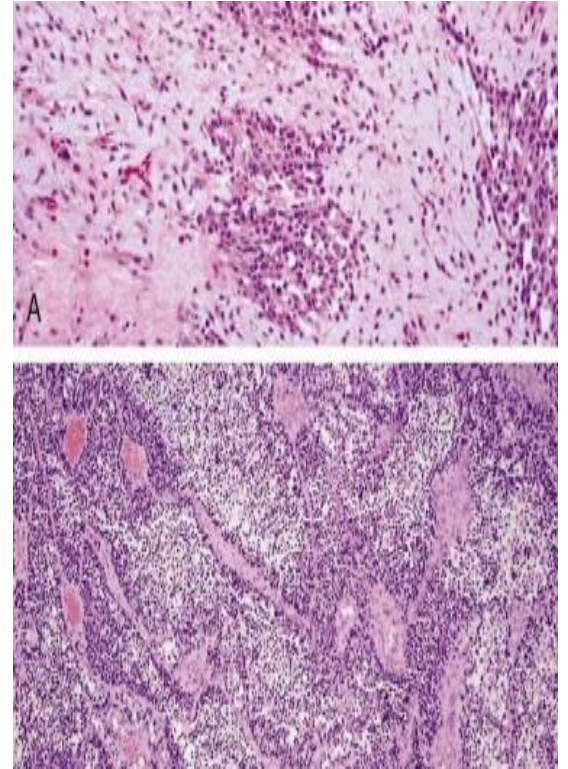


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Pediatric Rhabdomyosarcoma

Background

- Incidence: ~350 cases per year¹
 - 15-20% arise in the GU
- Treatment: Radiation + chemotherapy with goal of bladder preservation
- Overall 5-year survival is ~84%²
- Rare disease that leads to unique challenges faced by patients and their families



Methods



39-question online survey



Members of two online support groups invited to participate

One group for parents of children living with rhabdomyosarcoma

One group for parents of deceased children from rhabdomyosarcoma



Inclusion:

All respondents with RMS age 18 and younger

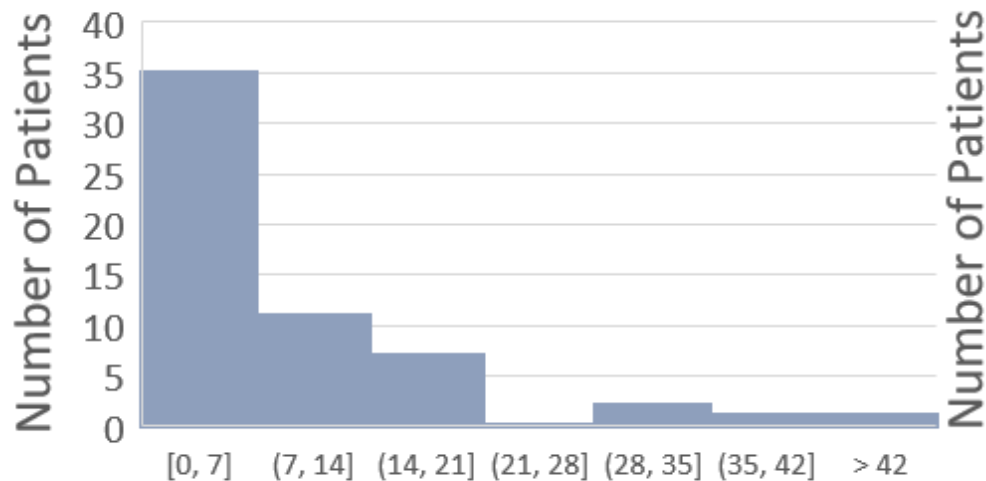
Excluded multiple responses from same IP address

Demographics

DEMOGRAPHIC	VALUE	NUM. PATIENTS	PERCENTAGE
Sex			
	Male	41	56%
	Female	32	44%
Age			
	0-4 years	30	41%
	4-8 years	18	25%
	12-16 years	8	11%
	16+	10	14%
Histology			
	Embryonal	51	70%
	Alveolar	14	19%
	Undifferentiated	8	11%
Status			
	Living	66	90%
	Deceased	7	10%

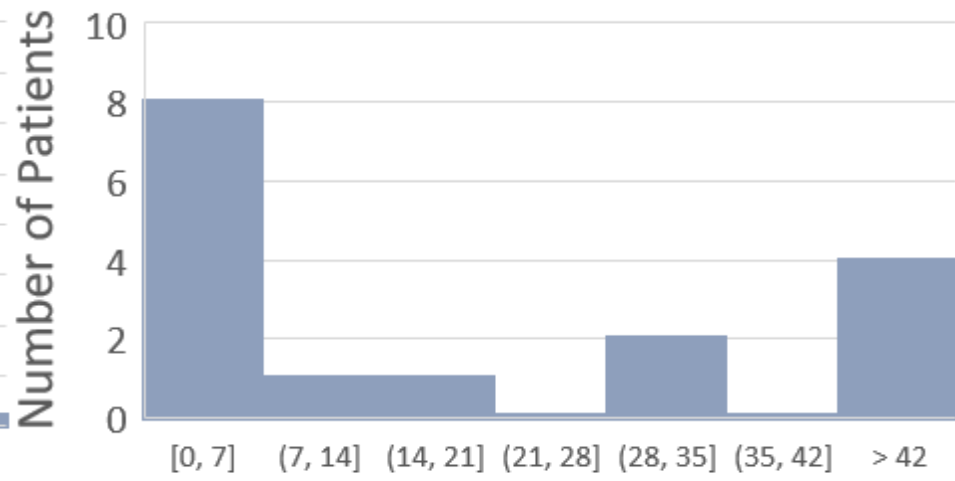
Time-to-Treatment

After Initial Diagnosis



Median = 7.5 days

After Recurrence



Median = 10.4 days

Treatment Access



Travelled > 100 miles for care: 48%

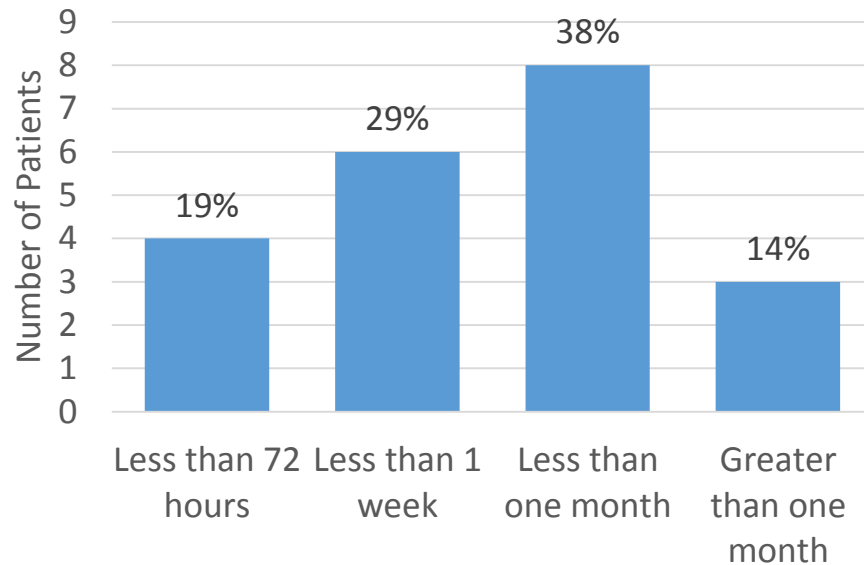


Sought second opinion: 43%



Fertility preservation offered: 23%

Time to Obtain Second Opinion



Limitations/Conclusions

- Limitations
 - Patient reported data
 - Users confined to multiple-choice answers
 - Treatment delays appear to be common among patients with RMS
 - Very few patients are being offered fertility preservation
 - Barriers to expert care include insurance coverage, social situation, and travel expenses
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