

Pediatric Palliative Care Program at KHCC

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KING HUSSEIN CANCER CENTER



مركز الحسين للسرطان

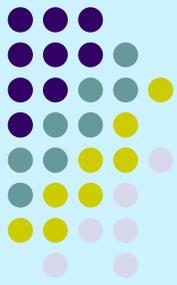


مركز الحسين للسرطان

No	Name	Age (Y)	Diagnosis	dead/alive
1	AN	3	NBL	Yes
2	RA	2	JMML	Yes
3	SB	4	NBL	Yes
4	OS	9	BT	Yes
5	MA	18	ST (DT)	Yes
6	KA	7	BT	Yes
7	SA	22	OS	Yes
8	RN		OS	Yes
9	AH	3	BT	Yes
10	RC	9	BBL	Yes
11	FH	7	BT	Yes
12	FA	14	RMS	Yes
13	BJ	3	BT	Yes
14	ZA	8	BT	No
15	OA	6	AML	Yes
16	EA	7	NBL	Yes
17	RH	12	BT	Yes
18	BQ	8	NBL	Yes
19	AAR	13	BT	No
20	AK	20	ACC	Yes

No	Name	Age (Y)	Diagnosis	dead/alive
21	NA	11	BT	Yes
22	MA	18	HD	Yes
23	ZH	15	BT	Yes
24	HA	11	BT	Yes
25	HA	16	AML	Yes
26	LSS	2	NBL	Yes
27	SAA	20	ALL	Yes
28	RJ	13	AML	Yes
29	MQ	0.3	AML	Yes
30	SZ	8	ST(Rt0)	Yes
31	OM	13	Wilms	Yes
32	RA	14	ALL	Yes
33	EH	8	OS	Yes
34	HY	2	RMS	No
35	TH	7	NBL	No
36	AAD	4	NBL	Yes
37	AF	6	NBL	No
38	AAA	9	AML	Hospice
39	RQ	18	OS	Hospice
40	AA	11	PNET	Yes

No	Name	Age (Y)	diagnosis	dead/alive
41	MS	12	ES	Yes
42	MK	9	PNET	Hospice
43	TA	14	BT	No
44	AS	19	GCT	Yes
45	SB	8	BL	Hospice
46	HA	16	NPC	No
47	NR	15	HD	Yes
48	HA	17	BT	Yes
49	HH	20	BT	Yes
50	HA	18	DLBL	Yes
51	AM	13	AML	Yes
52	MK	3	BT	Yes
53	HA	3	BT	Hospice
54	OAR	20	HD	Hospice
55	AA	5	BMT/SAA	Floor
56	SA	13	BT	Yes
57	LA	10	ES	No
58	MS	5	AML	No
59	GA	14	O.S	No
60	RAS	13	ALL	No
61	MN	10	HCC	YES

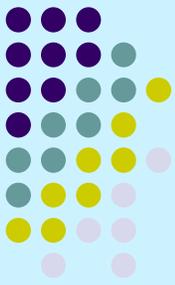


Demographics

Total patients	61
Solid tumors	26
Brain tumors	16
Leukemia-lymphoma	19
Alive (follow-up)	11
Died	50
Age range	0.3-22 years
Sex	23 females and 38 males

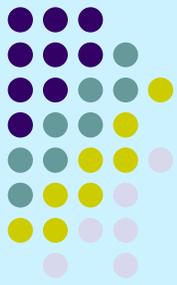
R.Q.

- 18 years old
- Pregnant 3rd trimester
- Osteosarcoma of right chest wall May 2005
- Biopsy done: brachial plexus injury, leading to neuropathic pain
- Pain management team

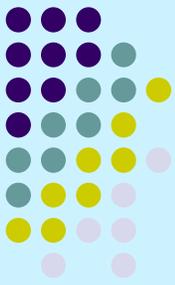


R.Q.

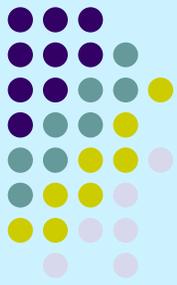
- Chemotherapy after delivery
- Surgical resection, February 2006
- Recurrence of tumor, May 2006, resected
- More chemotherapy, no response
- Developed metastasis to lungs and bone.
- Referred to palliative care August 2006



R.Q

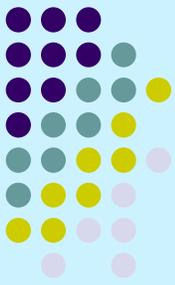


- Problems at referral
 - Neuropathic pain
 - Bony pain
 - Enlarging mass
 - Pleural effusion
 - Respiratory distress with progression
 - Depression
 - Major Psychosocial problems

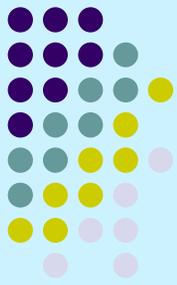


Psychosocial problems

- Poor socioeconomic class
- Married against family wish, abandoned
- Pregnant, delivered baby girl
- Husband is unloving, unsupportive, **abusive**, and he abandoned her
- Her family more supportive after diagnosis
- Caring for a growing child

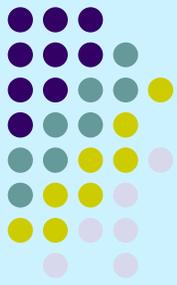


*R. Q. died at the age of 19
her daughter was 1 year old*



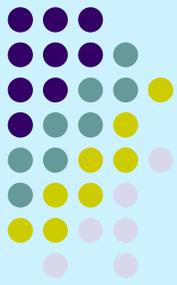
The Program

- The service of PPCP at KHCC started in August-2005 as a program of the Department of Pediatrics.
- It provides care to children and young adults up to 18 years (*but we follow up all our pediatric patients until death regardless of age*)
- It was integrated with the adult KHCC palliative care program



KHCC Team

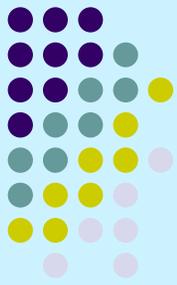
- The service is run by multidisciplinary team, composed of:
 - Pediatric Oncology Consultant
 - General Pediatrician
 - Nurse coordinator
 - Psychologist (when possible)
 - Social workers (when possible)
 - **Parents**



In-patient Service:

- Two beds are available for pediatric patients in the hospice, in addition to using beds in the pediatric floor if needed.
- Patient admitted for:
 - symptom management and stabilization
 - Discharge planning
 - Terminal care

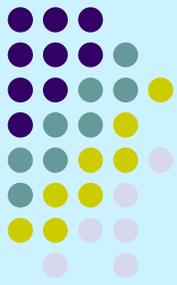
Out-patient Care

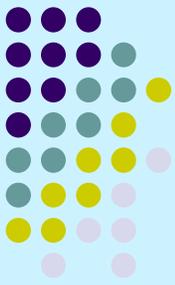


- Clinics
 - Three clinics are open for outpatient care
 - Regular follow-up
 - Symptom management
 - Psychological support

Home care

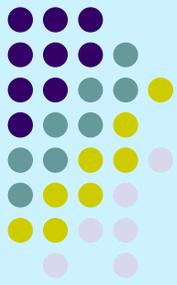
- Home visits
 - Pediatric team is not available
 - Adult nurses currently cover this service
 - Nurses uncomfortable with children.
 - Limited are of coverage





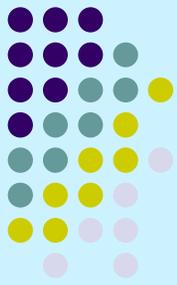
Home care services

- Can provide Telephone follow-up service
- Pediatric nurse coordinator calls the family daily for follow-up
- parents can call the nurse coordinator any time .



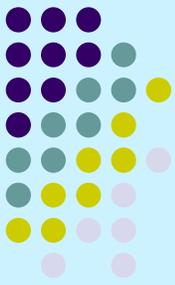
physicians and Nurse:

- Delayed referral
- Physician denial
- Physician and nurse attitudes and understanding of palliative care
- Uncomfortable caring for a terminal patient
- Difficulty in discussing change of goals of treatment and referral to palliative care.
- Patients demanding, need extra care and time consuming



Family and patient:

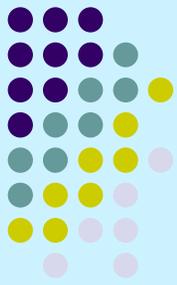
- Feeling of alienation and isolation
- Neglected by primary team
- Family unrealistic expectations
- Social situation
- Level of education
- Child neglect



Hospice :

- Families refuse admission to hospice
 - Place of death
 - Isolated
- Unfriendly hospice environment for children and family
- No pediatric hospice, adult nurses uncomfortable caring for a child
- Shortage of beds

Home care

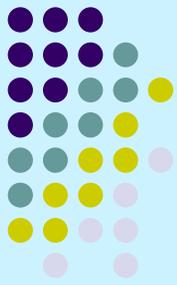


- No pediatric, home care nurses, adult nurses uncomfortable caring of a child
- Limited area of coverage
- Lack of resources for home care
- The Stigma of having a child with cancer



BURNOUT





Thank You!