Medical Facility Visits for Teenage & Younger European Children with Sarcomas (S) Attending Barretstown Therapeutic Recreation Camp: 4-year Comparative Study for Quality of Life

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ABSTRACT (1)

PURPOSE:Assess Medical facility visits (MFV) for children with Sarcomas
METHODS: Prospective collection of needs/events over 28, 10-day camps (1998-2001). Campers - a)7-13 yrs, b)>14-17 yrs -Teen Camp. Staff = 2 volunteer physicians, 3-4 nurses/75 campers. Collected data were demographics, reason for visit (disease-related?).
RESULTS: 2246 children ages 7-18, 26 countries, were supported by 836 staff. Median age=12; M/F= 1.3/1. Most common diagnoses: Leukemia =30%, Lymphoma =15%, Sarcoma=13% (283); other =42%. Subgroups: Ewing-S=100; Osteo-S=94; rhabdomyo-S=48; S =13, soft tissue-S=12; synovial-S=4; other=12. Age=13+3. Countries of origin had different distributions than other cancers: Spain, Hungary = highest. Age distributions differed. Total of 3378 MFV for campers & 1785 for staff. Of 283 S pts, 119 were available to assess visit frequency (yrs 2000-2001); S children made 227 visits (range 0-10) x = 1.9. M/F visit freq = 1.0; other diseases=1.5. Most frequent MFV were misc. complaints (50%), pain, headache, cuts/ abdominal pain. 31% MFV were disease/treatment related vs 10% for other cancers.
CONCLUSIONS: 1) With appropriate medical & staff support, Barretstown demonstrated a high safety profile for S pts. 2)Most medical interventions were related to normal camp issues: bee sting, activity-related injury, etc;69% MFV were not disease-related.3) Staff account for 35% total visits.

INTRODUCTION & STUDY DESIGN (2)

Background: Camping as a 'rite of summer" was a North American experience from which many children have benefited. Over 30 years ago, "PE" 's son David,a leukemia patient, was denied summer camp in Los Angeles only because he was receiving chemotherapy. As a result, she founded a camp in Los Angeles for her son and others and helped promote creation of similar camps that now thrive across the USA, Canada, Europe, Middle East and Africa.

Paul Newman, actor and chef, along with his partner AE Hotchner, have done more for the expansion of camps for seriously ill children than anyone else. The Association of Hole in the Wall Gang Camps supports programs around the world, including the namesake facility in Ashford, CT and the Barretstown Gang Camp in Ireland. Many pediatric oncology divisions in the USA, Europe and Canada host their own camp sessions, using their own medical staff. Most camps are offered at no cost.

Introduction to the issues: Children with sarcomas struggle daily to balance maintenance of health against the desire to partake in traditional youth activities. Resuming normal activities is vital to their psychosocial thriving. This return to normality assists in long-term psychosocial adjustment. Specific effects of camp include increased knowledge of the disease, improved adjustment, increased self-esteem, increased daily activity, and improved family interactions. Though parents strive to enroll their teens in activities that will maintain psychosocial happiness, many hesitate with Camp because of basic questions: Is the camp safe for my child? And is my child safe for camp?

MATERIALS & METHODS & MAJOR QUESTIONS (3)

What is & Where is Barretstown?

The Barretstown Gang Camp (BGC) is a residential camp occupying the grounds of a 17th Century Castle in Kildare County, 40 miles south of Dublin Ireland. Camp sessions run 10 days and the children have all transportation and living expenses paid for by voluntary fund raising by the non-profit BGC. Camp activities include horseback riding, fishing, drama, crafts, boating etc.

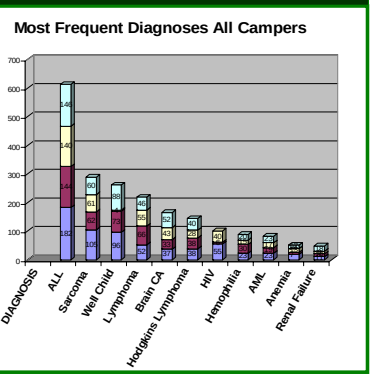
In the eight summer sessions, campers live in 8-10 bed cabins with at least two residential counselors. Overall, counselor- camper ratios are 1:2. Sessions are for 7-13 and 13-18 year olds.

The medical facility is a 1500 sq ft clinic with open plan, entry way/ waiting room, four examining rooms, pharmacy stock room, and three 1 bed rooms. Staff include at least one pediatric oncologist, a general or specialty pediatrician, and 2-3 nurses. Depending on their age, medications were either administered to the children by a nurse or the older children visited the Medshed to obtain their own medication.

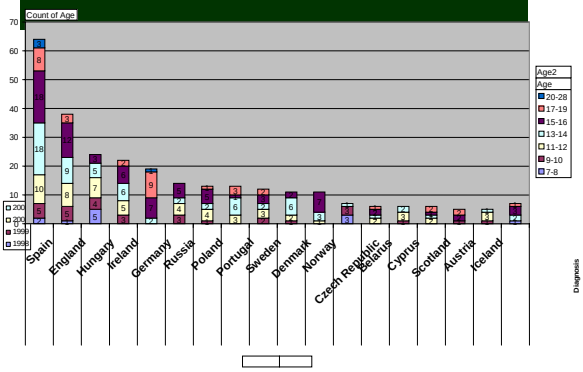
Demographic data were collected for each Camper by mail registration. Since 1998, each "Medshed" visit (MFV) has been recorded by name, reason for visit, main complaint, findings, physician diagnosis, medications given, IV therapies, transfer etc.

The question we sought to address in this report was "Is it safe for these teens to attend camp?" As surrogates we addressed quantitative utilization aspects of the medical care facility at Barretstown Gang Camp: number and reasons for visits, findings, and disposition to address this question.

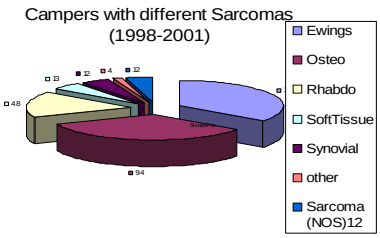
Diagnoses and Ages of Campers 1998-2001 (4)



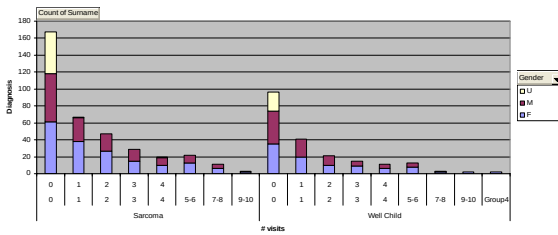
Country of Origin by Age for Sarcoma Campers 1998-2001 (N= 284) (5)



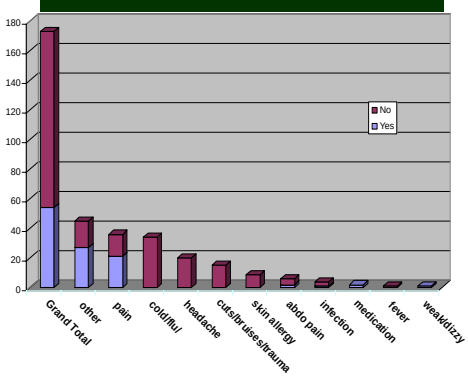
Campers with different Sarcomas (1998-2001)



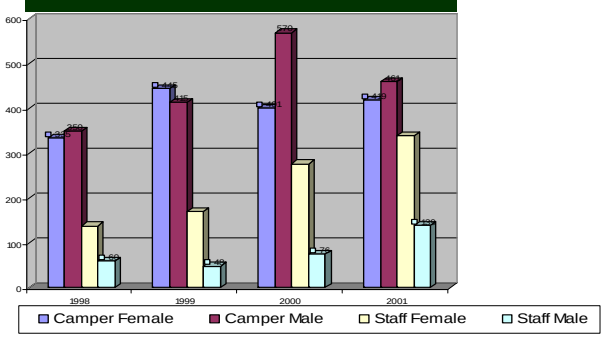
Frequency of MFU Visits by Camper & Gender (6)



MedShed Visits by Complaint for all Sarcoma Campers (8)



All Camper-Staff MFU Visits by Gender 1998-2001 (9)



CONCLUSIONS (10)

1) Previously unrecognized pain required intervention
2) Medical interventions were mostly common camp problems, not disease related.
3) Support staff need for medical care (MFV) was equal to that for campers.
4) No Hospitalizations occurred during camps.
5) Camp for teenagers with sarcomas is a safe experience with adequate professional support