

ONTARIO PARENTS ADVOCATING FOR CHILDREN WITH CANCER Development of a Weekly Support Program for Parents of Children with Cancer at HSC

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Introduction

- Having a child diagnosed with cancer is a stressful life event.
- 2009 HSC survey on parent support indicated that in excess of 70% of parents or caregivers of children with cancer wanted education and peer support to help ease the impact of cancer diagnosis and treatment procedures.
- Ontario Parents Advocating for Children with Cancer (OPACC) was established in 1995 as a parent led organization to develop additional resources and supports for families of children with cancer.
- Since 2010 a regular informal drop-in parent support group has been established at the Hospital for Sick Children (HSC) facilitated by a Parent Liaison with the co-operation of the hematology/oncology program at HSC.



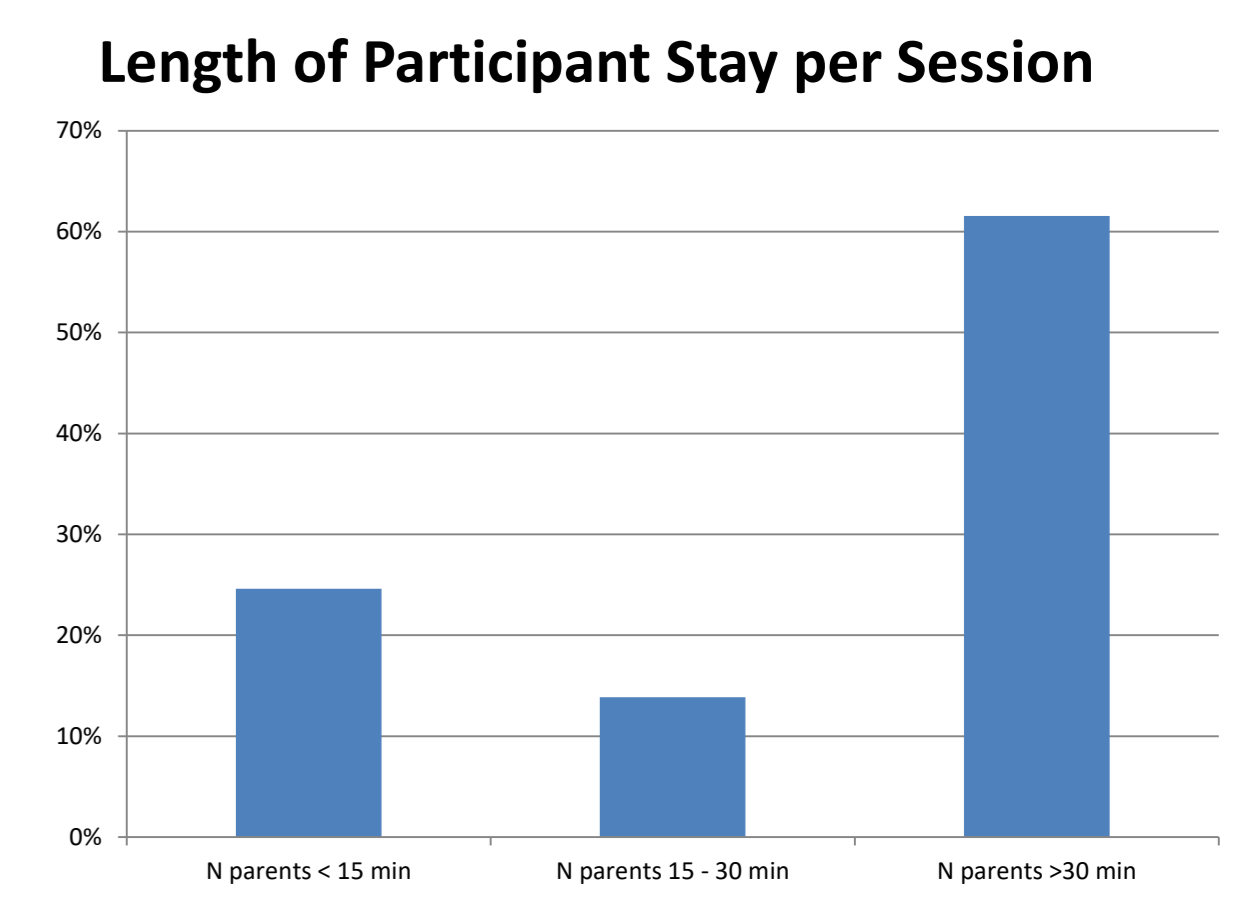
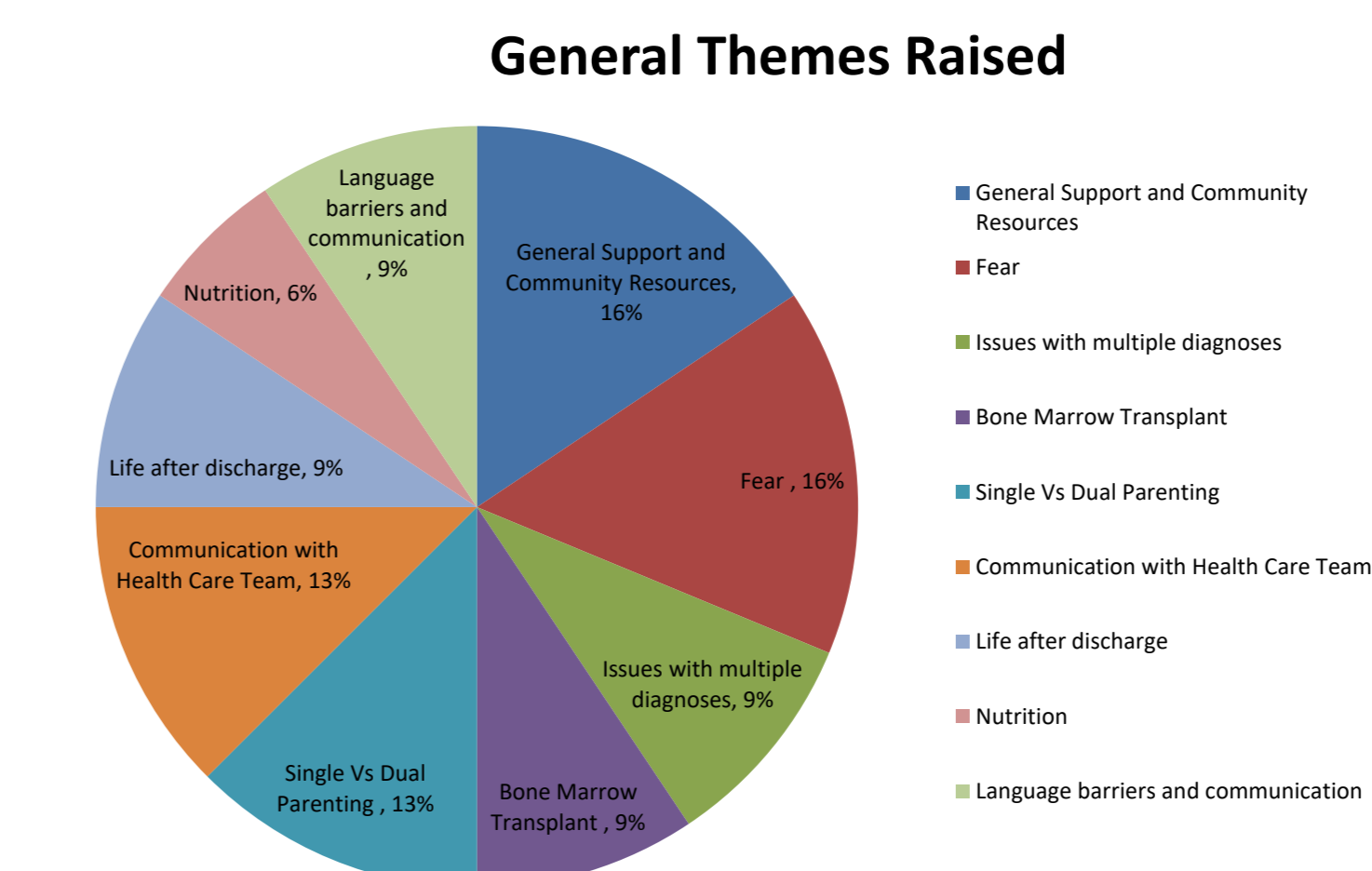
What is a Parent Drop-In?

- Facilitated by a Parent Liaison (PL) and trained volunteer parent (a minimum of one year post treatment who have experienced the difficulties of having a child with cancer and therefore have a firsthand understanding of the complexities of a cancer diagnosis and its impacts), in collaboration with HSC.
- Sessions are advertised through the OPACC website, flyers in the wards and by word of mouth. Refreshments are provided and parents are encouraged to discuss any issues, questions or concerns they may have.
- Offered weekly on an ongoing basis and open to all parents and caregivers, individuals are welcome to stop by for as little or as long a time as they choose within the 2 hour session timeframe.
- Supports offered include educational materials, OPACC Parent Resource Binders, laundry detergent, community resource information, refreshments and an array of items intended as take-a-ways.
- Offered in a comfortable setting that provides a safe place for parents to share any thoughts and feelings they may have toward their child's cancer diagnosis, personal issues or other topics.
- Parent attendees see themselves in the parent facilitators and that "normal" will again exist for them as well.
- The PL and Facilitators provide an opportunity for parents to talk to someone who has "been there" and can validate their experiences. They provide information on available services and direct parents to local support groups that may exist in their communities.
- Additionally the PL is available to parents in the hematology/oncology clinic and on the ward at Sick Kids on a regular basis or as arranged to suit an individual's needs.



Evaluation & Results

- The informal drop-in sessions were evaluated over a 10 week period. A total of 67 parents attended. The PL kept detailed observation notes of each session. The PL and the parent facilitators tabulated and coded the data regarding attendance, demographics, topics discussed including concerns for self, concerns about the child and family as well as practical concerns and information around resources in the community. Staff from HSC provided assistance in the evaluation process.



Conclusions

- This study substantiates the importance of peer support for parents and other family members of children with cancer.
- Parents open up to other parents and feel well-supported as parents having other experienced parents as facilitators.
- Parents and families are better engaged with OPACC and the PL as well as creating linkages within HSC

Acknowledgements

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