Introduction

Parents play a key role in the daily support and care of a child with cancer and are recognized as one of the main sources of emotional support [1]. When a child is diagnosed with cancer, the entire family is affected by the demand of the illness and its treatment [2, 3]. It brings about significant changes in family dynamics and social relationships [4,5]. The stress reaction of caregiving and social relationship intervention have become pertinent topics in pediatric oncology research [6,7].

It is well established that families experience stress that leaves them at risk of developing long-term physical, emotional and psychological problems [4]. Studies have consistently shown severe stress reactions with elevated levels of anxiety and depression in parents after the disclosure of diagnosis, taking several years to return to levels prior to diagnosis [8-10]. On occasion, the families of children with cancer fail to adjust to the disease, treatment and survival, even after several years [10,11]. The presence or absence of a robust form of social support is held to be a key variable in the development of pathological distress in families undergoing this experience. [11-14]. Indeed, a lack of social support for parents has been linked to a greater risk of ongoing difficulties, in some cases even six years post diagnosis [1,15]. The death of a child remains the ultimate trauma in the childhood cancer experience [16]. In addition to higher total psychosocial distress and adjustment issues, a higher probability of psychiatric dysfunction in families after the death of a child has been attributed to decreased social support [14,17]. Social support has been shown to greatly diminish in these circumstances due to the immediate disengagement of parents from the healthcare system as well an observed general trend toward reduced participation in social activities[18,19].

Families dealing with childhood cancer often require intense and enduring social support [11,17]. The potential for long term support and its associated benefits is challenging given the problems involved in obtaining ongoing assistance from any specific part of a person’s social network. The danger of “burning out” valuable sources of support is very real [20]. While social support may initially be quite high for pediatric cancer patients and their families, it may slowly dissipate over months or years, even though the need remains[17]. High level support is often unsustainable through lengthy treatment protocols or during the periods of uncertainty that follow post-treatment [7]. Clearly, an ongoing attention to the psychosocial needs of parents following a child cancer diagnosis is required [1].

Community based support groups have developed to address, in part, the family's needs for emotional and spiritual support not provided by health care
professionals [21,22]. These groups often focus on both parents, unlike clinical interventions that focus on the parent who is present in the medical setting. The focus on both parents may assist with marital functioning [9,18]. The benefit of parent mutual support is the founding philosophy of the Candlelighters Childhood Foundation formed in 1976, the largest international network of over 200 support groups of parents of children with cancer [20]. Arguably, the group format of support programs addresses a need for access to a rich source of information on every day coping and emotional wellbeing techniques. Group meetings give parents an outlet to discuss feelings and topics not usually approached at a child’s bedside [18, 21]. Additionally, they provide the opportunity for deep holistic understanding based on mutual experience where people are able to be with each other without the constraints of traditional expert/patient relationships [23-26]. Self-help through group participation improves parents’ coping capabilities and increases their sense of empowerment as they care and advocate for their children in an increasingly complex healthcare system [20].

This paper aims to explore therapeutic camping programs as another possible avenue for providing social support for parents affected by childhood cancer. Research has established residential camps as providing invaluable social/peer support for both children with cancer and their siblings, leading to greater self esteem and coping abilities [7, 27, 28]. Kramar in 2002 wrote about the merit of non-residential weekend retreats as a valuable tool for helping families get support and respite from the strains of caregiving for an individual with chronic illness as well as aiding them in coping through the bereavement process [22]. Arnaert in 2010 noted that non-residential retreats provide enduring effects, and contribute to the ongoing healing processes of parents in addition to providing them with strategies for coping in their roles as caregivers [29]. In spite of this evidence there is a specific knowledge gap pertaining to parental benefits obtained by participation at residential camps, and research on their efficacy as an intervention for parents remains scant outside of informal appraisals [28-31].

One of the world’s largest recreational camp programs is offered by The Trillium Childhood Cancer Support Centre Camp Trillium, based in Ontario, Canada. Camp Trillium promotes recreational experiences designed to bring children with cancer and their families together, providing an environment that normalises relationships and experiences with the aim of helping children and their families in the healing process and thereby enhancing their quality of life [23,32]. Operating at two sites in Ontario - Oddfellow and Rebekah Island, formerly Garratt’s Island (since 1989), in Picton, and Rainbow Lake (since 1998) in Waterford - Camp Trillium has experienced phenomenal growth since its inception and remains one of only a handful of camps that cater to the needs of the entire family [32]. The family programs offered at Camp Trillium include day programs, weekend programs as well as the more traditional five day residential programs, that are inclusive of parents and caregivers. The family programs offer respite at all stages of the cancer journey including bereavement [23, 32].

This paper seeks to explore if Camp Trillium, as an informal therapeutic intervention, reduces the psychosocial stress of parents of children with cancer
through the mechanism of social support. In addition, we examine the ways in which the camp setting, through which parents have the opportunity to share their common experience, has managed to improve the coping mechanisms and adjustment of parents of children with cancer. These objectives are best suited to the qualitative research paradigm, as we fundamentally seek to obtain personal accounts of parents’ feelings, thoughts and experience at Camp Trillium [3, 33].

**Methods**

**Design and Main Outcome Measures**

Mixed methods research was conducted using questionnaires, semi structured interviews and observation. One hundred and eighty-three families attending Camp Trillium’s summer program between June 26th and August 31st 2012 were invited to participate in the study. Eighty-five of these families completed a questionnaire consisting of 21 close-ended questions and three open-ended questions. Semi-structured interviews were then conducted with a subsample of parents. Fifty-eight participants self-selected to partake in the follow-up interviews that used the following guiding questions:

1. Why did you decide to come to camp?
2. What were your expectations in coming to camp?
3. Were those expectations met? If not, how has your experience differed from what you were expecting?
4. How has the camp experience affected your understanding of your child’s illness?
5. What were the impacts of interacting with other parents at camp?
6. Did you enjoy the parents’ activities? Why or why not?
7. What differences do you see in your child(ren) as a result of attending camp?
8. What differences do you see in yourself as a result of attending camp?
9. What differences do you see in your spouse as a result of attending camp? How has the camp experience impacted your relationship?
10. How has the camp experience impacted your family functioning/dynamic?
11. What, for you individually, has been the number one most important benefit of coming to camp?
12. Will you come back to camp next year? Why or why not?
13. How could the camp experience be adapted to better support your family?
14. Do you have any other comments about the camp experience?

Thirty-four mothers, 23 fathers and one grandmother were interviewed. In Eleven of these interviews participants attended as a couple. The majority of interviews took place face-to-face on site, with seven interviews taking place over the telephone. Interviews were audio-recorded with the exception of ten interviews where consent was not provided by the participant due to lack of comfort around a recording device. In this instance, interviews were thoroughly documented and notes were reviewed at the end of the interview with the participant, to determine that their views had been portrayed accurately. In addition, researchers examined interactions between parents, and between parents and staff, drawing upon 222 hours of on-site observation across the two campsites generating detailed field notes and providing an external view of group dynamics in operation at Camp Trillium.

**Ethical Approval**
Approval was received by the Research Ethics Board of McMaster University, Ontario, Canada and by the Board of Directors of Camp Trillium, Ontario, Canada. Participant consent was obtained prior to commencement of questionnaires and interview recording. Quotations have been anonymised and pseudonyms used to protect the identities of participants.

Analysis
Data from the questionnaire established participant characteristics such as (a) family status (b) treatment status (c) method of referral to camp (d) number of times attending camp and (e) attendance at camp as a family. Percentages were used to capture the proportion of participants who shared key responses on questions relating to their (f) reason for attending camp, (g) benefit of attendance and (h) benefits of meeting other parents.

Data obtained from the semi-structured interviews and on-site observation were categorized using thematic analysis [33]. Interviews ran from 15 to 60 minutes in length and those recorded were transcribed. Each transcript was analysed and any keywords, phrases, and patterns in the data distinguishing central issues were noted. The transcripts were revised again and divided into themes and given a code, which reflected the content of the theme. These themes were then grouped into similar topics to provide overarching thematic essence referred to as super ordinate themes. This method was repeated for both documented interviews and field notes.

Through the coding process the authors met to clarify code and themes, crosschecking for verification. All codes were subject to a consensual process involving at least two of the authors and verification of the final key themes sought consensus of the entire research team, including two senior researchers. Such collaboration allows for reflection in the analytical process and strengthens the credibility of identified themes [33]. Phrases or quotations that most accurately illustrate themes are identified.

Results
Participant Characteristics
The respondents to the questionnaire were 87% two-parent families and 13% single parent or separated families. Sixty-five percent of families had a child who was off treatment, 26% had a child who was still on treatment and 9% of families were bereaved.

Fifty-four percent of parents were referred to Camp Trillium by health care staff from their hospital and 31% heard about Camp Trillium from other parents attending their clinic. Three percent learnt about it from their community and 12% of parents were referred to camp through other sources such as social workers, fellow Candlelighter members and pamphlet displays in their hospitals.

Forty-six percent had attended camp four or more times, 41% had attended two or three times and 13% of participants were attending camp for the first time. Eighty-seven percent of participants attended as a whole family, 7% without their spouse/partner only and 6% without one of their children.
**Shared Responses**

Questionnaire data identified 58% of parents’ primary reason for attending camp was for their children, followed by 24% who had heard good things about the camp. Nine percent attended camp as a chance to escape daily routine, 6% attended to meet other families, and 3% for other reasons. All parents reported the primary benefit of attending camp was the satisfaction of seeing children having fun. However on further exploration parents went on to identify personal benefits: 68% of parents reported a break from everyday routine was the key secondary benefit, followed by 28% who cited meeting other parents as a key secondary benefit. The realisation of parental benefits from attending camp beyond those attained for seeing their children have fun was reported by several parents:

"After the first day I realised how much I needed the **** camp. It was unbelievable! I thought it was all for her, but no!"

"In some ways I would say maybe the parents are helped more [at camp] than the kids. I dare say, in a lot of ways because the parents are really worrying about it, the kids who are under treatment, I don’t think they are worried. I think they are going through hell, I know they are going through hell, but worry is not the big thing. The parents are worried to death. You see your child, it’s like somebody has a loaded gun pointed to their head at all times, and you can’t do anything about it. How do you deal with that, all the time? Any day something could happen, and they could go. So it’s just getting past that kind of nonsense, just that sheer horror."

"Being part of Camp Trillium is just as important as medical treatments. Kids, parents need this – for any outcome... If they pass away -lifetime memories, if they relapse – support. If they move beyond – building happy and healthy foundations to move forward in life."

The particular benefits derived from meeting other parents included: the ability to talk about anything and not be worried (41%), talking about their cancer journey with others (20%), comparing cancer diagnosis and treatments (15%), learning about camp (11%) and 13% cited other benefits, including learning ways to cope, and tips and tricks to help deal with treatment and tests.

From the qualitative interviews, six distinct themes were explicated: (a) A sense of normalcy; (b) Reconnecting as a family (c) Valuable interactions; (d) Group tensions (e) Information sharing and (f) Choice of participation. The themes identified were mirrored by the observations by both researchers on site.

**A Sense of Normality**

**Acceptance and Understanding**

Many parents enjoyed the sense of camaraderie, remarking that Camp Trillium allows both parents and children to be themselves, without judgment or teasing or questioning.
“What’s really great is that there’s a kid here with a gastro tube taped to his nose, but nobody really even looks at him twice. If there’s a kid with a prosthetic limb, nobody really cares. Because here nobody cares what the issue is here, you’re just a kid and you’re just a mom or a sibling.”

“I think it’s nice to come to camp, even if your kid is having a temper tantrum, everybody knows that there is the possibility of steroids and knows what they have been through, it is not a normal situation...it is the tolerance of these different behaviours, and that there is a reason behind it, that you just don’t get in the general population. So I think that is enough of the support network, that we need. Just that understanding.”

An Escape from Cancer
Parents emphasized that attendance at camp is a quintessential part of the Canadian childhood. As a result of this emphasis, the researchers interpreted that attendance at camp became a return to a pre-cancer, normal state of childhood. In particular, parents whose kids are still on treatment discussed the opportunity camp provided for families to step away from everyday stress and concerns.

“That is at least one thing here with all the families, nobody is different. Everybody has had different health problems but the normalization is good. I don’t think we would have come if it was some big cancer workshop kind of thing”

“You come here to escape what’s happening there so they’ve created that escape they’ve given us that week of no worries about treatment... its our own little utopia where the kids can be normal the parents can be normal and not worry about what’s said to them.”

“It [cancer] creates turmoil for the first year and a half, everything you think is normal is not normal anymore, it’s just not ever the same. So to come here this creates this sense that there is life beyond this kind of thing and you can have a normal life again”

“Here is just like going back to where we used to be before this happened.”

Redefining Normalcy
It was observed that the setting of camp provided a healthy comparison of normality. Whilst some parents commented on comparisons between families, more common was a sense of social solidarity and a glossing over of difference rather than dwelling on it. The connection with peers seemed to assist parents to re-define what is “normal” in their world.

“There is a gentleman over there and his family, It was nice to see him outside of the hospital, it’s nice to see his kids outside not having a tube shoved in them and its nice to be able to next time when I see them laying in that bed recovering from surgery to be like oh, I just saw her a couple of weeks ago playing and stuff, it puts a level of normality”.
“Our cabin mate had lost his lower leg to cancer, in the cabin he’d slide around on his bum, my son said to him “Jason get off your bum and walk the floor is dirty” My son had never noticed the missing leg and Jason just laughed as said “I can’t buddy I have no leg!” God bless him and my son for looking at each other as normal kids with no ailments. Eight years later we are still good friends”

“I would get so angry at my husband he would just bottle it up, we were not able to console each other, we were both too busy being afraid in our own corners we could not reach out to each other but at camp I realized that it was ok for my husband to deal with it differently to me. It was ok we didn’t say exactly the right thing at the right time, I stopped feeling mad and stopped feeling different”

Reconnecting as a Family
Many parents discussed the impact cancer has had on the relationships within the family. Moreover they commented on the opportunity camp provides to reconnect and rebuild relationships, and to make up for time lost due to the demanding nature of their child’s treatment schedule.

“I remember one of the charge nurses when we first got told the news, of course you are devastated, she pulled us aside and I’ll never forget what she said- she said ‘this can either make a family or break a family’ so we chose carefully how we wanted to pursue this...”

Family Time
Parents for the most part enjoyed the flexibility that the camp format currently provides. They can choose to spend a lot of time with their kids, or just a little. They can use the time at camp to reconnect with their kids, or to reconnect with their spouse or take some time for themselves:

“We had to do an obstacle course and you had to put on all these clothes and run around it. There is my husband putting on all these clothes and I remember when he was doing it I was laughing so hard I was going to pee my pants, so I ran to the bathroom and I remember sitting there and then as I was walking back I remember seeing them doing this and I was like ‘wow we’re having fun again’ and you know that’s when I realised its been months since I’ve laughed or enjoyed time with the family really because... sorry I’m starting to tear up, but when Josh was sick we didn’t do anything we didn’t have fun and laugh so it was just so nice to enjoy and have fun.”

“In our family, what tends to happen is if daddy is not stressed, nobody is stressed. So when Dean gets a chance to just relax, and be who he wants to be, everybody is happier. So I can definitely see where it allows his relationship with the girls to grow, because he has the presence of mind to focus on them, and to really be involved in what they are doing, as opposed to what he has to get done before his mind explodes for that day. And for us too, for he and I, it is good for the same reasons.”

“This is probably the only time in the year where we sit down and all have dinner together, or a meal together as a family, for four days in a row.”
“I think that it gives us all something to look forward to. It is time together, it is time to do things together, it is memories that we are making of doing happy things together. And even though we are at Camp Trillium, which is a cancer camp, you don’t think about it. It gives you a chance to forget about your troubles.”

“We are very lucky to have Trillium, this is the most important part of our treatment in the journey of fighting cancer....medicine may have saved my child but Camp Trillium saved our family”

Spousal Relationships
Parents commonly identified the strain cancer has placed on their relationship. Some went on to discuss how their interaction with other parents at camp played a role in changing their perspective on the importance of their relationship with their spouse:

“You have to seek out most of the help you get. The social workers at the hospital aren’t going ‘hey come here and sign up for this 10 quick steps to make sure your marriage survives the cancer journey’ you know there isn’t anything like that. So many parents wake up on the other side of their journey and go ‘who are you and why are we together?’ you totally disconnect as couples.”

“One week at camp maybe our second summer here we had people in our cabin, the mum and I were talking and she’d said how they’d had a relapse scare and she realised she hadn’t put enough time into fixing their marriage from the first time and it really struck me. As mums especially you have tunnel vision, my child is sick I have to help fix my child and its my child, my child and your partner doesn’t matter as much as your child does because your child needs you. So I think that interaction for me was key in [the decision that] I need to spend more time worrying about fixing my marriage and making sure its stronger and I remember at one point saying to Marc, ‘you know if Lucy were to have a turn for the worst and she was to pass’, one of our friends had just lost their child, I said ‘our marriage wouldn’t make it, I know that right now it wouldn’t make it’. So we took steps to get that back on track.”

Many parents commented how camp provided necessary time to reconnect with one’s spouse:

“My wife and I were out in two kayaks on the lake and we floated side by side and stopped to look at each other and never would I have thought that we would be here after everything I just looked at her and asked ‘how are you honey?’ I can’t remember the last time I did that!”

“I think each year we have taken different things away from camp the first year was like ‘oh my goodness you’re my husband, I forgot who you were’ and the second year was probably a little bit of that too.”
“Camp allows you that time to rekindle the romance, to take her away, sometimes we even look at each other and I can tell we are thinking the same thing, sneaking off to one of the tepee’s, not that she ever would!”

Valuable Interactions
Parents commented on the support they received from other parents and staff as being a powerful part of their experience at camp.

Staff Trust and Support
At Camp Trillium families are assigned specific staff members that are designated to entertain and provide support to the children of that family. These staff members are affectionately referred to as ‘special friends’.

“[The staff] are so well chosen. For all of the right qualities. It just blows you away, what they do every day for you. I don’t even know if they totally realize what they are doing, I don’t know if they realize the impact it has on us. They might be told that, but I think until you are sitting in the situation that we are in, you don’t really understand it. So I do think they feel the appreciation, because you do build relationships with these people, and even run into a lot of them from my city, I will run into them there, and they always remember my name. I don’t know how! We still run into them, and ones that have been with your kids four years ago still have that really close connection with them. You show up, and it doesn’t really matter where you see them, and there are always hugs going around, and hellos, and all that.”

“ The special friends let us paint them, dress them up, throw them in the lake and they do it all for my kids. They work from 7am-11pm with a smile painted on their face... that’s some kind of blessing to have people like that in the world, it fills you with hope.”

“Here they have people that dote on the kids and just love them so I feel like I can actually step back and someone is still giving my kids what I can’t give right now. I’m tired and I want to be able to do it but I need somebody else to step in there, I’m exhausted and the relationship [with the staff] does support that”

“ We also get treated at camp, one special friend asked if I would like a cup of tea or coffee in the morning and brought it to me on the porch, all I had to do was sit there. I can’t remember the last time I had a cup of coffee made for me especially as a single parent.”

A Fostered Sense of Community
The celebration of milestones such as the ‘no more chemo cakes’ (presented to children upon completion of their most recent round of treatment) fosters a bond within this community that is hard to replicate with others who have not gone through the same experience. Many parents mentioned the benefit of talking with other parents with a child with cancer and indicated that individuals outside of the cancer community have difficulty truly understanding, even if they are sympathetic.
“Not to devalue the support you get from your family and friends, but there is really a limit of their understanding of what you have been through...and coming here is almost another support group. It's not like we sit around bitching about the treatment and woe is me and all of that but you do sort of get that kinship”

“I think for those very reasons that camp exists, the value in the short term is for distraction, is for that camaraderie, we are all sort of in the same boat. Or maybe I have moved to a different boat, but I have been in your boat. It is just knowing that there are people there who have walked the road ahead of you and have stories, even if their stories turned out really differently than yours, good or bad, you have been there.”

“The friendships I have forged here I have kept, when Trish calls me she really asks me how I am doing, not the sugar-coated version. She pushes when I say I'm fine, she'll say I know you have just been watching your kid vomit blood don’t tell me you’re fine! She will listen to me cry and understand.”

Looking Out for One Another
The acculturation of new members into Camp Trillium was observed as being handled most sensitively. Parents were seen to assess newcomers’ feelings and reactions to the camp situation and parents discussed how veteran campers support newcomers by affirming feelings and reactions and by helping them interpret and respond to their situation.

“I just like to see everybody's good nature. It just recharges you to see how nice people can be to each other. That really just makes the whole experience for me. How everybody here just takes a real interest, and emotional investment, in everyone else. And they aren’t faking it, you can tell that. For me that is powerful, just to come and be a part of it.”

“There is a family here that both Jo and I picked up on from day one, independent of each other, we didn’t talk to each other about what we were thinking. We both really picked up on the attitude, or something. They just stood out to us, let’s put it that way. And it looked like there was either a lot of fear, or a lot of anger, about their son’s situation, and we both independently thought “we just want to get to know them, to see how we can help.” And then we ended up talking about it with each other. We had both been really struck with how difficult it seems to be for them, and so we have been really making an effort to talk to them a lot, to include them in the activities. And even in two days, we have seen them just open up a lot more. So yeah, I can see the value in having families at each stage of the journey in one space.”

Some parents did say that they felt closer with the families they met at their clinic, since they see them continuously over an extended period of time, whereas the families they meet at camp they may not see again if they are coming from a different part of the province, creating a sort of “temporary intimacy” between families.
“I love interacting with them [other parents] here, I think they’re all wonderful, I haven’t met a family yet that I don’t like the parents. I’d like to sit down and chat with all of them. But I find, for me anyways, it’s very short term.”

Group Tensions
Engaging with Others
Whilst there appears to be a respect of boundaries between parents to identify those who want to talk vs. those who do not wish too, some parent spoke of the complications arising from engaging with parents at different stages in their cancer journey. This was of notable difficulty for bereaved parents, who described feeling like outsiders and talking about their experience as taboo.

“Part of me feels that I can see this person, ok her son’s died, she’s still walking, talking, functioning, living, sleeping, doing all the things that are necessary, I can make it through but at the same time you sort of feel that you don’t want to go near that person because they represent a place where I don’t want to be.”

“A friend of mine said [at camp this morning], I can support you up until this point because my kids have gone through all of that but I can’t go on this journey with you any further the way you’re going because my child hasn’t died”

“This is the first year where I haven’t had to watch how peoples’ reactions are and that really sucks as a bereaved parent because you do that all the time and you’re the one that has suffered the loss, it’s my child that died but I have to wait and see how people are going to react, it’s challenging!”

“It would fulfilling to have a quite place to go to honor or remember out children who lost their battle, a garden or benches, etc. while at camp. At times it feels like we can’t talk about that “stuff” at camp because we are the parents that no one wants to be. However realistically, it’s all part of the journey.”

Length of Attendance
Many parents commented on their awareness of the shortage of places at camp and their disappointment when waitlisted. Others felt it was importance to give up their place in order for others to experience it when they need it most (in the early stages of treatment). Some parents voiced disapproval of other families staying at camp for longer than they viewed as necessary.

“If it was just up to us, and the enjoyment that we get out of it, we could come the rest of our lives, and still love it every time. But we are really mindful of the fact that it costs a lot of money to bring us here,…we don’t want to keep any other family from experiencing it, so we would not want to come if somebody else was being left home because of it. “

“There are families that have been off treatment for 10-15 years right and its great that they can still accommodate them but I wouldn’t want to see new families that have just been diagnosed, one or two years into it being put on a waiting list... [if it
were] me, I would prefer to give up my spot after so many years knowing that a
new family would be able to enjoy it."

**Information sharing**

A sentiment that was echoed throughout the interviews with parents was the
benefits of sharing information with other parents. An overwhelming majority of
participants in the study expressed their desire to maintain contact with “cancer
world” and continue their education even long after treatment has finished.
Sharing stories and knowledge about diagnosis, treatment, and post-treatment
was viewed as expanding the parents’ knowledge base and provided a different
perspective from that offered by the healthcare system.

“And the older families that were here, you talk to them a little bit, you tell your
story, and it’s amazing how well it matches up with what others have gone
through. And there are things that you are worried about, and you raise those
issues, and they say “yeah, we did that, don’t worry about it, it will be fine”.
"

“I got a lot of good advice, that doctors don’t give you. When the chemo and
radiation is over, you are on your own. And when you talk to other people, they tell
you different remedies of what they did, and what worked, what didn’t work. So
then you take that, and go with it, and you try the best too. So I think it is good.”

Parents mentioned the evolution of their support role as the years at camp go by.
Initially the parents receive support, but they often tended to offer it more in
later years.

“And now that we’ve been here for years, there are new parents coming in, and you
can see the same look in their faces as you know that you had when you came here.
And you talk to them, and they say “oh, this is going on, and that is going on.” And
you say “yeah, yeah, oh boy” and you share that, and they look at your kids, and
they see how well they are doing, and a look of relief comes across their faces. You
can tell they are really happy they had that chat with you. And I totally enjoy
sharing it with them.

“As the years go by your role changes to support those that are new and listen to
their stories. You can see the relief on their faces after they realize how much we all
have in common.”

“It would be a shame for me to get all of this out of this experience, and not be able
to share it with someone else, and help someone else. So that is what I do,
absolutely. You see them when they’re talking, and you go over, sit down with them,
and just chat, and sooner or later it comes out. You know they want to talk about it,
you know they have to talk about it. And then you just listen, don’t say a thing, just
listen! And then they say ”well, what do you do in this situation?”, or whatever, and
you say ”well, this is what we did.” You know, you cannot say ”this is the right way
to do it, or the wrong way,” you just give them the support that they need.”

**Empowerment**
A number of parents highlighted feelings of dis-empowerment in the hospital setting and their difficulties in sourcing support from the healthcare system. They spoke of the hope that camp brought to their lives empowering them throughout their journey.

“As a senior executive in a multinational company, I am always the person who steps up when no-one else does. When you have a doctor who is telling me I have nothing useful to add when it comes to my own daughter I shut down even though it is my fight. We need to say to the doctors don’t squash our hope, it’s all we have.”

“It is a tremendous opportunity for families to challenge themselves in a positive way in a supportive environment, and not be challenged by a medical condition or a health care system.”

“I saw the chemo cakes and it filled me with hope and I just thought to myself this is not going to get the better of us. We are going to get that ****** chemo cake and we fought for the day that we would be able to taste that cake.”

“I like hearing the success stories. It builds your confidence.”

Many parents were encouraged by the opportunity to try new activities at camp, and spoke of the benefits gained by pushing their limits and learning new things.

“I did the ropes course two years ago, but I’m sure I climbed up the pole to get onto it. And then Rachel said to me this time “no, you can’t do that, you have to pull yourself up the rope.” And I would like “there is no way I can haul myself up that rope, I don’t have the upper body strength.” And she was like “no, you have to, that is how you get up.” And she just told me there was no other way, and so I was like “okay” and so then I started, and it was a whole lot easier than I thought it was going to be, and I actually made it!”

“It gives us an opportunity to do things that we would never really do. Like I would never go on high rope, in my everyday or on vacation. So, I’m doing things here that I don’t normally do, so that’s nice.”

Fathers

Many mothers spoke of the perceived difficulty of being a father and not readily having access to social support. Fathers themselves discussed the important role camp had played in providing the opportunity to interact with other men in a similar situation.

“I could hear gales of laughter coming from the dads especially and it’s so heartwarming to hear as I know dads have a really hard time with it. Mums tend to talk to people and they kind of cope with things but dads sometimes don’t. I think it’s so great they can have that kind of opportunity to laugh and be goofy together”

“It’s nice to see more men getting involved. This isn’t always the same at every camp, women do most of the work, not many men put their hands up to take on the role of main caregiver”
“I was so angry all of the time I could see myself as the guy looking for a fight, just waiting for someone to look at me the wrong way. There is nowhere that helps you deal with that sort of feeling. Then after being in the dark for so long it just clicked for me. I’m still always scared but when I’m here I’m not scared. It’s a safe haven, a rest bay. You leave it [the anger] if you can and if you can’t they help you deal with it here.”

“It’s nice to know you’re not alone, the smart guy, the shy guy, the cool guy and the funny they are all going through the same thing, they are all here. You can talk to other parents and realize you are all dealing with it in different ways, it’s ok to get mad”

**Choice of Participation**
Parents appreciate the informality of the support network at camp. Of note was that only a very few parents seemed interested in the more formal support structures being offered at camp. Having the choice to actively or passively participate in the camp experience was key during their different stages of treatment to gain the most out of the experience.

**Level of Interaction**
“We have worked with a lot of different organisations and social support groups but this is the first place where cancer isn’t shoved in your face...you don’t have to talk about the cancer, you are free to just be you.”

“If they want to, then the opportunities are there for the people who are ready to talk about it. But if you are not, then you don’t have to. Nobody is saying “okay, time to sit down and talk about your cancer journey.” Or whatever. If you are not ready for that, then that would not be a good thing.”

“The parents are very sensitive to each other. I have never had an experience where someone would be saying, “tell me about your experience.” Or anything like that. But it just comes up in conversation... And I have learned a lot, by talking to other parents.”

**Moving on with Life**
Several parents reflected on whether camp will still be important once their child is out of treatment. Some expressed a reluctance to dwell on the cancer once treatment was over and they were through ‘the woods’. Others felt that the cancer experience would always be a part of their lives, even after treatment was done and everything was back to “normal”.

“I want to have camp in this early stage of our journey but I do not see longevity in attendance. I do not want to see camp as a place of commiseration, rather a place of acknowledgement and a place to move forward from. I think it plays an important role in the early stages but becomes a place to dwell and indulge and wallow after time”
“Oh, definitely, we are “lifers”. I dread the day that we cannot come back. Anna is turning 18, and that’s it. Unless she is somehow involved in the camp. And maybe by that time, I will be close to retirement, and I can come in the summers and help out doing maintenance or something.”

Conclusions

Consistent with earlier research, the parents in this study reported significant periods of stress as the caregiver of a child with cancer. They openly discussed how the entire family is affected by the demands of the illness and its treatment regime [2, 3], highlighting the negative impact it has had on relationships with their spouses and the family unit as a whole [4,5].

The results of this study clearly elucidate that residential family camp provides much more than respite and recreational support. Indeed, it provides an invaluable support system that attends to the wider needs of parents dealing with childhood cancer. Parents reported higher levels of perceived social support, hope, and increased ability to cope as a result of attendance at family residential camp. It is evident from their voiced experiences that a “healing culture” of self-help has been obtained through the mobilisation of peers in an informal setting in which parents have the opportunity to share their common experience. The way in which these parents interpret their situation as the parent of a child with cancer can have a profound and diverse effect upon their journey and quality of life through their child’s treatment and well beyond. The camaraderie and peer support at Camp Trillium functions as a surrogate source of intimacy and affirmation and as an expanded social network and intimate community.

Parents discussed the articulation, discovery and elaboration of information and knowledge during their time at camp. The close interaction with other parents allowed them to learn and share their experiences with cancer-their “tricks of the trade” or skills for coping. This type of knowledge diffusion is experiential generating a knowledge base that is both democratic and practical, drawing on experiential encounters rather than technical knowledge provided by doctors such as the special attention and care that is required for the siblings of children with cancer [20]. At camp, the sharing of this unique knowledge between parents was validated as valuable and beneficial.

Affirmation, compassion, empathy, true understanding of another’s situation and identification with a larger social entity provides a relatively stable platform for self healing to occur [4,8]. An environment that was evident at Camp Trillium, parents discussed the reciprocal nature of the healing process. Highlighting the theory of the provision of help itself as serving a therapeutic end; the notion that in seeing one’s self as a helper can be equally as therapeutic as being the recipient of help [23]. The realisation that others may gain from one’s own personal experience and that they may be a useful resource to others has the potential to decrease feelings of helplessness [6,23]. Parents discussed the empowering nature of camp providing them with a much needed boost of strength and hope to see them through the next stage of their journey.
Similar to experiences found in other types of support groups, the issue of group dynamics arose. Whilst this tension did not detract from or disparage the support efforts of other parents, some effort could be made on behalf of Camp Trillium to mitigate the feeling of taboo surrounding bereavement. It was suggested that an openly designated area such as a bench or small garden on the camp sites dedicated to honoring those who have passed would be a subtle yet appropriate way to acknowledge all stages of the cancer journey at camp. An action of this nature may in turn appease the alienation some parents feel around others in their respective stages of treatment or post treatment when they no longer have their child.

A number of parents whose child had completed cancer treatment still expressed pervasive concerns about their child’s future health complications and feared the possibility of relapse in line with previous studies findings [18-20,33,34]. An overwhelming majority of participants in this study expressed a desire to maintain contact with the “cancer world” continuing their education and maintain reciprocal psychosocial support long after treatment has finished. It is, however, not the role of primary health care facilities to provide these types of ongoing services. Rather, this is where Camp Trillium has the potential to provide a sustainable alternative with inherent longevity that caters for all stages of a parent’s journey with childhood cancer.

**Limitations**
There were a greater number of mothers who participated in this study. This is indicative of the fact that it is more likely to be mothers who are the main caregivers. It also highlights fathers’ greater reluctance to talk and share. Interviews that were carried out as couples rather than individually may have contributed to potential positive bias in terms of experiences shared especially in the case of some fathers who indicated their attendance was to appease their partner. In addition the sample used was self-selected and represent a particular demographic and cultural group. Therefore the results may not be reflective of all parents who have a child diagnosed with cancer. Furthermore there was a lack of cultural diversity among the participants.

**Future Directions**
Based on the study, a number of possible areas for further study are suggested. Specifically, more research on the needs of culturally and economically diverse groups – who may have lower levels of social support and difficulties in navigating the health care system for assistance – is appropriate to broaden the reach of such services. Additionally, models on how to tailor appropriate interventions for parents with low levels of social support is worthy of further exploration. Lastly, more quantitative research on therapeutic camping as an intervention to reduce parental stress and increase coping skills would deepen the evidence base and highlight impacts of the program.
In summary, it is clear that Camp Trillium delivers numerous benefits to the families who attend. Though not without opportunities to improve, its successes demand our attention. In the passionate words of one participant

“We are very lucky to have Trillium, this is the most important part of our treatment in the journey of fighting cancer....medicine may have saved my child but Camp Trillium saved our family”

Evidently, approaches to childhood cancer may benefit from a greater emphasis on the broader familial context.
References


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