

Hopework*
Stories of Survival from the C.O.U.R.A.G.E. Program
Families of Children Diagnosed with Cancer

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ABSTRACT

Most parents would never dream of having a child with cancer. When that happens it most often feels like a nightmare. Community narrative therapy practices provide many possibilities to help turn this nightmare into a 'hopedream'. Families in Montreal, Canada are doing a great deal of 'hopework' in order to find their special achievements, knowledges and resources and voice them through 'stories of survival', stories of mastery and coping. To do this we developed a bi-lingual group (English and French) called C.O.U.R.A.G.E. This paper documents details of their experiences and the narrative practices used. Examples of their words, collective documents and pictures are included to facilitate understanding.

Keywords: community, narrative practices, culture, children, families

INTRODUCTION

Never in their wildest dreams would most parents think they would have a child diagnosed with a life threatening illness such as a cancer. Then, when it happens it seems like their greatest nightmare. Even when the percentages regarding chances of getting into a remission from the disease are good, the news that their child will have to go through years of chemotherapy, always surgery, sometimes radiotherapy and often hospitalization is very hard to hear and when it happens even harder to bear. And all this treatment, they are told by physicians, is for a remission, never a cure. They are told that remission might last for a long normal life but there is never a certainty. There are always worries about a relapse or other cancers and/or long term secondary effects coming from the chemotherapy or radiation. These are always a possibility. Some of the secondary effects include very debilitating physical handicaps, learning problems, sterility and unfortunately, even death. Their child will often feel sick, will lose his/her hair, will have to stop going to school and often can only see one, very well friend, at a time. Nearly all family 'get togethers' have to stop. The child cannot be taken to community activities such as church or school concerts. There can be no swimming. This is because the chemotherapy kills not only the bad cells (using the language used to explain things to the children) but also the cells that protect them from illness. There are so many changes for children and families. Often one parent has to quit work or reduce

working hours, the other children in the family will get much less parent time than previously and finances go down (for a fictional understanding, which from stories I have heard quite appropriately describes the lives of some of these families, you could read *My Sister's Keeper* by Picoult, 2004).

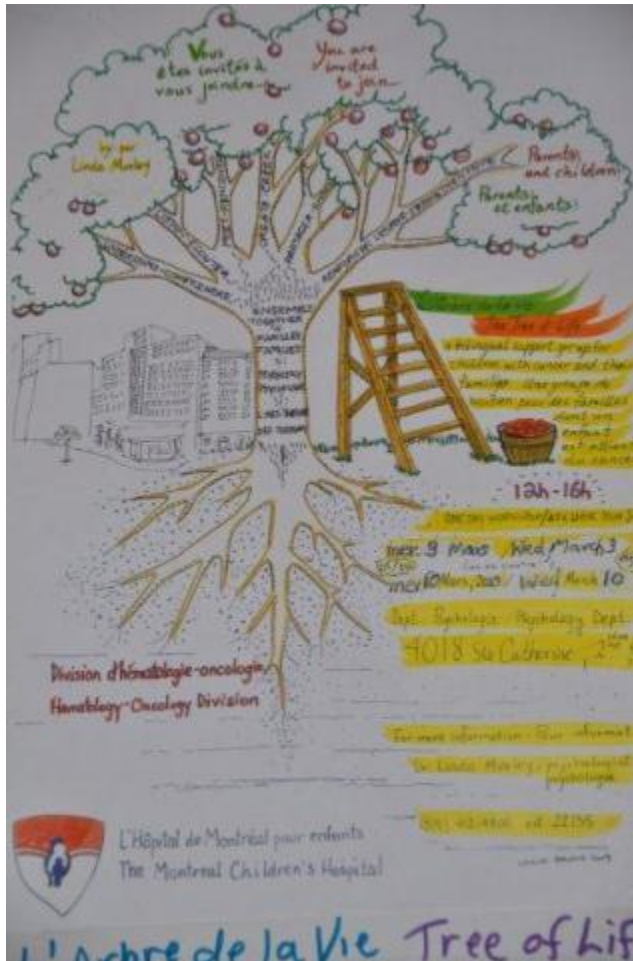
Thus when one has a child with cancer it may be necessary to participate in a lot of 'hopework'. A group of parents at The Montreal Children's Hospital in Canada, decided to take control of this nightmare and try to make some sense of it by turning what seemed like a bad dream into a hope-dream. This paper documents the 'hopework' or 'hope-dreams' carried out by parents and their children in the haematology/oncology service from 2008 to the present. This project aimed at gathering together 'hope' stories or as they were sometimes called, "stories of survival". Survival is a tricky word for the parents since they all stated that their biggest fear was that their child would not survive. Thus thinking and writing about their own "stories of survival", using the term survival in a different way, seemed to have great meaning to them. Stories came from the children relating to their experiences in surviving the significant changes in their lives as a result of having cancer, from the parents relating to their special knowledges realized as part of the process of having a child with cancer and more recently, from the siblings relating to their experience of having a brother or sister with cancer. The members have named this bi-lingual (French and English) programme C.O.U.R.A.G.E. C.O.U.R.A.G.E means using Cancer as an Oppportunity to Unite and share Resources in an Amicable Group setting that provides Encouragement. (COURAGE is also a French word, which translates perfectly into a French anagram with similar meaning).

When parents approached me to ask for a support group, I began to think about how I could do this and not end up **only** with stories of suffering (the problem saturated story). I asked myself how we could find stories of mastery and coping. How could we find ways that achievements, knowledges, and resources could be voiced? Narrative practice helps people move away from the reality of the problem stories into other realities which are also there but relatively unavailable (Michael White, 2004, 2005). The 'hopework' followed the narrative practice of searching for 'double stories, (White, 2007a) which would acknowledge not only the struggles faced after a diagnosis and treatment of cancer for families and children but also the skills, abilities, and special knowledges that could be discovered using narrative practices. We used many metaphors in the process of searching for these 'double stories'. I thought, first of the Tree of Life metaphor (Denborough, 2008; Ncube, 2006) which helps us acknowledge and identify our resources. I wondered if this might be a helpful metaphor for these families.

THE TREE OF LIFE WORKSHOPS

When I first started talking about the parents wish for a support group, the Art therapist on our Oncology-Haematology team, Sarah Brodie, thought she could have an art therapy group for the children diagnosed with cancer and their siblings at the same time as I would hold the parent group. However, when I started talking about the Tree of Life metaphor we came up with the idea of beginning our 'hopework' by holding two half-day workshops that would include any family members who wished to attend.

Montreal is a multi-lingual city with its inhabitants speaking either French or English as at least a second language. Many parents are bilingual or multilingual and most of the children have one or the other as preferred language or second language. We decided to hold our group as a bilingual group, French and English, just like our hospital, which is bilingual. We designed an invitation to portray our haematology/oncology team also using the tree metaphor:



Picture 1: Our invitation

In our introduction, which was presented in both French and English with a paper copy given to the group members, we talked of privacy, trying to use child friendly language. The ideas in the introduction were discussed together. We asked what brought the families together and their answer was the experience of the diagnosis and treatment of cancer. We suggested that our plan was to design the day to approach darkness with light. We were hoping that the struggle of childhood cancer could be helped with the solace of community, creativity, caring and sharing. We stated that we would be creating on that day and that we hoped no one would be working to create a masterpiece (although many masterpieces were created – see picture 2 below) but rather working to create a metaphor. We hoped that all discussions would follow this non-judgmental attitude, for our trees (especially our own), for our language (bilingual French and English), and for our ideas and comments. The possible experience of pain in the process was

acknowledged and the possibility of strong emotions coming out in the sharing was discussed. We discussed ways that this might be managed.



Picture 2

We acknowledged that each person would have varying degrees of comfort in the two languages but that by repeating ourselves in two languages we hoped to have the advantage of truly clarifying what we wanted to say and how we understood it. It was our goal to use our bilingual group to every person's advantage and we asked everyone to exercise tolerance of errors, pauses, and miscommunications, stating that together we would find a way.

We stated in that introduction that we had come to understand from them that one of the most painful aspects of cancer was how meaningless it is. We can ask the WHY of so many things but that for this; we are told by parents and even by the kids themselves, there is no answer. We suggested that one of the ways that narrative therapy and art therapy might be helpful is to promote family members finding some meaning in their experiences and in their lives through more understanding of themselves and their families. We talked about the idea that we understood that children often make meaning out of their experience through play. So in this workshop we would play together using the Tree of Life as our special metaphor, our symbol that we would use to introduce each family to each other but also to help each family to see itself, hopefully from a different perspective. We said that we thought this was a particularly appropriate metaphor for Canadians because our national symbol, with even the leaf on our flag, is the maple tree. The Quebec symbol is the Fleur de Lys (not a tree but a lily flower which can also have similar parts as a tree).

Non-self judgment was not always easy with different age groups as could be seen with one little three-year-old boy (Picture 3¹). Even when others encouraged him with hugs and positive comments on his and his mother's tree, he still said (translated from French),

“Everyone is trying so hard to help me feel good about my tree but it is just not working. I don’t know what to do”. However he did finish the tree and participated in the Forest of Life discussions.



Picture 3

We felt that the introduction was the first step of trying to create a safe place for these families and hopefully to create an environment of sharing and telling stories that would honour their knowledges, values, and skills. Michael White called this process creating islands of safety (from Ncube, 2006). That is, helping the child and family stand in a different space in relationship to the problem. He would say, it is then and only then that we can pass on to the problem story (White, 2005, 2007b).

We started with a short questionnaire that I adapted from one I had used at the Hinks Delcrest Centre in Toronto and using some of the narrative words (Johnson, 1994).

1. What is your reason for attending this workshop?
2. On a scale of 1-10 how important would you rate this reason?
3. Please identify the strengths that your family has that have helped to sustain your family through hard times?
4. At the end of this workshop, how will you know it has been helpful?

Some of the responses were: “For support; camaraderie”; “To find ideas to manage life”; “To find hope”; “For mental support”; “To support each other”; “To understand my family’s dynamics”; “For comfort”; “To share feelings, questions, concerns”.

They rated the importance of their reasons for attending the workshop at 8 to 10.

Examples of family strengths were: “Supporting each other”; “Expressing our feelings to each other”; “Priorizing and sticking to these priorities”; “Accepting the inevitable, whatever that is” (this inevitably was the possibility of death or handicap).

Some answers to how will they would know this workshop was helpful were: “I will have a big smile on my face and feel content”; “I will feel that I am not alone in my thinking and emotions”; “My heart will feel lighter and I will see my son participating”; “I will have new knowledges, (this is honestly the exact word that this mother wrote, Michael White, 1995, began using this word early in his workshops and writings and for this mother, this word, with the s was also an appropriate word), new tricks, ‘I will know I am not the only vulnerable one’”.

I appreciated the open telling of stories that occurred. I would like to acknowledge the seven families who agreed to share with us their stories, their trees and their pictures. (For a better understanding of the Tree of Life metaphor, please refer to Ncube, 2006 and Denborough, 2008). For our workshop, we put bilingual instructions on both side of the room. We asked the families to think of the roots as their culture and heritage and the people who formed that for their family. We suggested including songs or traditions that were important for each family. The ground was where each family was living and what they were doing right now. There were many stories about the hospital and the chemotherapy treatments. For the trunk we asked family members to think of strengths and resources available to the family. (I now ask them for their values for the trunk of the tree). For the branches, the families were to think of hopes, dreams and aspirations. The leaves were the people in their lives and the fruits were the gifts they had received. We suggested certain questions adapted from those of Nazelo Ncube’s(2006) (see the appendix) to help them develop ideas that were not necessarily concrete but more abstract, which sometimes can be difficult for children.

During the story sharing of the Forest of Life we heard several stories of culture. We encouraged the children to come up to the front and share their family tree with the others (Picture 4¹). We asked the witnesses to make notes of encouragement to tell the children after. We asked the families to see if they could find any connections of their own story with the others. We then talked of the storms of life. This gave the families a chance to think in a collective way about the difficult times that have confronted them in their life. Then we thought of skills and abilities they have used to overcome storms and shared them with the others. Some of these stories you will read in the collective document. We used four questions proposed by David Denborough (2007, 2008). Since the first Tree of Life workshop there have been many other stories of overcoming storms from the C.O.U.R.A.G.E. programme and some of them have been included in the collective document. I would also like to thank all those whose ‘hopewords’ are documented here.



Picture 4

The Overcoming the Storms of Life metaphor that was discussed at the end of our workshop seemed to be particularly meaningful for the families and produced the idea of writing up ‘stories of survival’. Also I agreed to work on a collective document and explained what that was. It seemed important to these families to acknowledge the difficulties of receiving the diagnosis of cancer in a child for all concerned. We talked together about what some of the special storms of childhood cancer are. We worked on a document coming from the children’s perspective and another document from the adults’ perspective. In the first year of the C.O.U.R.A.G.E. programme we had over 29 families participating at different times. Here is some of their *Words of COURAGE*. The document was written in both English and French and is now placed in a living document book (for a better understanding of the term living document please see Newman, 2008) and on our virtual group e-mail communication.

WORDS OF COURAGE

The Children’s Document

We have not always found it easy having cancer. This has caused lots of storms for us. Many of the storms produce stormy feelings.

Feelings

As children with cancer, some of us were too embarrassed to visit with our friends or tell them we had cancer. We feared ridicule because we would lose our hair and our bodies would change because steroids often make us gain weight and our faces get round. We thought we might be less likeable and we saw that the chemotherapy and other things often made us feel angry and act angry, feel sad, and act sad, and there were lots of

changes in our emotions. Sometimes we were very afraid and saddened by what we were going through so that we didn't want to face our friends who were sometimes frightened and sad too. Sometimes we noticed that our family members were frightened and sad and this made us more fearful. Sometimes we were angry and would find it unfair.

These things were often hard to bear but we often talk to family members. We call this coping trick; family.

Family

Many of us found it helpful to talk to family members about the worries, fears, angers, embarrassment and sadness.

“I did not want those in my school to know that I had cancer and then my older brother came home from school one day and I overheard him tell my parents that they had been lying to him. One of his classmates had come to him and said, ‘I heard your sister has only a month to live.’ I was really frightened then, because I thought my parents were lying to me too. But my mom noticed I was listening and she got us all together to talk about my cancer. She told me my cancer was the best of a worst thing that can happen to someone. That she had been told by the doctors that the chemotherapy would kill the cancer cells and our life together as a family would go on. I felt better. But I still felt the anger because people at school knew what was happening to me.”

Sometimes guilt entered our lives and we wondered what we had done to deserve this.

“I used to have temper tantrums. One night I dreamed that I would get cancer. Then I did. I thought that I caused this. I told my dad. He helped me see that my tempers and my dreams could not cause cancer. He actually said, maybe this experience would help me understand better other kids because I always planned to be a teacher. I was really thankful to have my dad to talk to.”

There seems almost always to be some family member with whom we can talk. We have sometimes worried about all these feelings but we also have found ways to overcome these feelings by talking to others. We called this coping trick, ‘Others Who Understand’.

Others Who Understand

We think that it is important to have a chance to talk about our experiences and we are glad that our parents asked to have the C.O.U.R.A.G.E. group. We can talk to other kids who understand and other parents too.

COURAGE means using Cancer as an Oppportunity to Unite and share Resources in an Amicable Group setting that provides Encouragement. Our parents worked out that name. Some of these words are big but we know what courage is and we can just think of it as a Find Bravery Group. Talking to others who understand helps us Find Bravery.

“I find that talking to the others who come to the COURAGE group really helps me. I like drawing and making things also helps.”

“I really got upset when the doctor told me I would gain weight and lose my hair with the chemotherapy. I love my parents but I really could not talk to them. I stopped eating and started obsessing about calories and such. Then my parents went to see a psychologist and found another one for me to talk to and that really helped me.”

Sometimes we need to talk with someone who is not in our family. Maybe it is to other kids with cancer and maybe it is our friends, maybe a relative and maybe it is a professional.

Some of us find it hard to talk about cancer and about the worries but we can still get help from other things. We read, we take our values from songs, books, and movies. We call this coping trick, ‘Using What We Have Around Us to Find Inspiration and Values

Using What We Have Around Us to Find Inspiration and Values.

Using things that we have read or seen has helped us find inspiration and values. This comes from such things as music, poetry, movies or books.

“I read Japanese Mangas. They often have stories of really strong women in them. There was one girl named Shinca, whose mother had died and she had to live with her grandfather whom she did not know. She was having a harder time than I am having and she could be strong. Her mother had taught her lots of values, like don’t waste food and appreciate what you have. She helps me to appreciate what I have.”

“I love music and I find that there are so many hopeful lyrics, I love to sing and singing a hopeful song helps me. One song by the Cowboy Fringant group is called, Holding Your Head High. There was a boy with cancer who went to a concert and the Cowboys Fringants Group invited him up on stage. They later wrote a song about him. Such songs help me feel less ashamed and maybe even a bit proud when I go out.”

Using things around us like music and books can give us inspiration and help us find our values.

Some of us have been brought up in certain religions and this gives us hope and help. We call this coping trick, ‘Beliefs’.

Beliefs

Remembering that we have beliefs can give some of us strength.

“I have been brought up as a Hindu. When I first got out of hospital we went into a store of a friend of my mother’s. This woman did not know I had cancer because we decided

that we would only tell people we were sure would give us positive energy. This woman said to my mother, 'I do not know what happened to you but I can tell you are suffering'. She told my mother that she participated in a meditation group and she suggested that my mother try it. My mother thought about it and in a few weeks she went, and then she persuaded my dad and me to come. The meditation is really helping me find peace even in a time of trouble".

"My great aunt brought back holy water from France. Every day before going for my chemotherapy my mom gives me a sip and we pray. Something about that really gives me hope."

Beliefs can give some of us strength and hope.

Some of us can no longer participate in the sports that really helped us before now. We do not have the energy and we cannot go into crowds or groups of people. But there are lots of things to learn about sports and some of us learn values from sports. We call this coping trick: 'What we can learn from sports'.

What we can learn from sports.

"I used to play soccer and now I can't. I love soccer. I can always think about when I will play again. I can watch soccer too. They work in good teamwork and if they don't play as a good team then they won't win any games. I have to be part of a different team now, the hematology/oncology team. This team includes my family, all the medical people and me. We are all working together for my cure and the cure of my friends. Knowing about teamwork helps me work better with this team."

Some of us get help from sports. We can learn to cope from so many different things and for some of us thinking of sports helps.

Some of us felt that the experience of having cancer has taught us a lot. We called this coping trick: What we can learn from having cancer.

What we can learn from having cancer.

"I decided that health and my body are very important. I now think about how I can take care of myself. I think of the foods I eat and what I put into my body. I'm not sure I would have learned this without the experience of being ill".

"I learned to not let the little pains bother me. I now know the difference between big pain and little pain."

"I learned to appreciate school more and how to be useful to others. When sitting in the hospital I felt useless and missed the learning from school. Now I think of how to be useful and how to appreciate".

Some of us have learned a lot because we were sick.

We all have been suffering a lot but we found that we also have lots of coping tricks. We talk to family, we talk to others who understand, we can use what we have around us like music, books or movies and we can use our religion and sports and we realized that the experience taught us a lot. All these things can help us keep strong.

The parents also created a document that went into the COURAGE book (along with documents and pictures from the children and youth) and this book is now placed in the Oncology-Haematology clinic waiting room and the kitchen on the ward, to provide ‘hopestories’ for other parents and their children. The parents and children were thinking that this book might be helpful for parents and the children with new diagnoses.

The Parents’ Collective Document on ‘Hopework’ from the C.O.U.R.A.G.E. Group

Sharing

We wanted to know what sustains us, particularly during the storm of having a child diagnosed and treated for a life threatening illness. We shared experiences free of storms. We talk with each other of hope and positive energy.

Survival strategies

As parents of a child with cancer we worry a lot. Our biggest fear is that our child will die. Even when the statistics for survival are good it is hard to forget that fear, and not think, ‘what if my child is in the 20% of those who do not survive’ instead of thinking, ‘my child has an 80% chance of survival’. Also, we meet parents of children who have relapsed, even after 11 years and we know parents whose children have died. We wonder sometimes how we can keep our hope alive.

When we talked together we realized that many of us are getting lots of help from spirituality.

Keeping spirituality strong

We keep spiritually strong be it by religion or another way.

“I pray the Novena prayer. Every day for 9 days, I pray. I remembered doing this in the past for my father-in-law. He was so sick they said he was dying. We did the Novena prayer and he became strong. He said that he saw an angel sitting and watching. So now we have twice done the Novena prayers for my daughter. As long as I do not lose my faith, never blame Him and continue my responsibility to Him, I will manage.”

“I do meditation to a living Hindu God. My daughter had finished her chemotherapy but she was hospitalized with a fever that would not go away. The doctors did an imaging test of her lungs and saw many dark spots in her lungs. This was not good news. She was to have a biopsy in four days and they talked of a year of antibiotics. My community and I prayed very hard to our living God. He accepted the prayers and when she had her biopsy HER LUNGS WERE CLEAR. The doctors did not understand but I did.”

For some of us spirituality is really helpful.

Keeping in mind the importance for our child to keep hope alive.

Remembering the positives.

We all can find positives and some of that can come from the statistics about our child's illness and for some of us that can be helpful and for others we have to learn how to feel hope from the statistics.

“I looked up on the internet statistics for leukemia. These are varied but the highest survival rate mentioned was 89%. I keep that number in my mind every time I begin to get doubts.”

“My child relapsed and the number I was told was 40% survival now. My mind kept saying that means 60% no survival. Then I told myself, how can I keep hope alive in my child if I don't concentrate on the idea that survival can still happen. I must keep that in mind.”

“When I was first told about my daughter's tumour they said there was a certain percentage of a 5-year survival. At first I thought what happens after 5 years. Does that mean she dies then? I stewed for a while and then I got the nerve to ask and found out that if she lives for five years the chances are very good that she will have a normal life. The five years will be hard and long but every day she survives is bringing us closer to that five year date.”

We have decided that it is only the positive statistics we should keep in mind.

Some of us are so fortunate to have family close by during these difficult times and some of us have to find ways to bring our family closer even if it is in our memories or imagining what family members might say to us.

Family

We all feel very alone but even if family does not live nearby we can usually get support from some family member. We find it important to think of that.

“When my mind goes the direction of fearing my daughter will die, I call my mom. She was so there for me when my little girl was first diagnosed. She is a baby nurse and that

reassured me. We took turns sleeping at the hospital for the 21 days she was in hospital after the diagnosis.”

“My Italian in-laws and their community kept us supplied with home cooked meals during the first ‘21 Terrible Days of Steroids’ when we spent over a month in hospital after my son’s leukemia diagnosis. I became so much closer to that side of my family after.” “My sister-in-law has now become my best friend. She had a miscarriage after waiting for many years to get pregnant. She understands my situation”.

We all agree that family is important. Some of us have conversations imagining what important family members would say to us even if they are not around.

When we need more than family many of us have found what we have learned to call positive energy friends. We keep those friends around us and we keep a distance from the negative energy friends.

Friends

“I decided that I would not tell anyone about my son’s illness but they found out anyway. I soon learned that there were some who were really going to be helpful and others were not. I made a decision that I would only answer the phone when it was a positive energy friend. I could do this because I have call display. I kept others up to date with a web page and thus did not have to talk to those I did not want to talk to.”

Many of us have found out who are really our friends, those are the ones with positive energy and we stick close to them.

Some of us are pretty alone here in Montreal since we have come from other countries. We have found help from other helpers.

Other helpers

Many of us worry about our other children. How will they manage when we have to be at the hospital so often with our children with cancer? There are lots of feelings of guilt. Did we choose the wrong neighbourhood to live in, the wrong house with too many toxins, too close to electricity lines? Some of us talk to professionals to help us with these worries.

“For ages I was furious with my husband because he stored IKEA wood in my baby’s room. The doctors told me that this wood was not the reason for my child’s condition but it really took lots of trips to talk to the minister of my church and talks with other church members for me to feel less guilty and less angry. My minister helped me a lot.”

“Did I bring my child to hospital soon enough? Maybe if I had noticed sooner the tumour would have been smaller? Through conversations with the psychologist and with other parents, I realized that I actually had been quite vigilant and would not take the

family doctors reassurance that it was probably the flu. I came to emergency with my daughter. The community of haematology/oncology was really helpful for me.”

“At first, I wondered why all these professionals were coming to meet with me. I met physicians, nurses, child life specialists, a social worker, the psychologist, and an art therapist. I thought they must think that my child will die to be offering so much support. Then my son started the 21 terrible days of steroids. He became so irritable, so fearful, tempers got big, and he hit me. This was not my child! I found out it was the steroids. We met with Linda (the psychologist) and figured out how to find courage against the dragon of fear. He was given a "Tigger" toy to help guide him through the tempers and find his way out from under its shadow. He created the fears and tempers through art with Sarah (the art therapist), and I was thankful for all those visits.”

“I was having trouble getting paid time off work. They did not believe that I really was too anxious, depressed and upset to work. It was not just that I wanted to stay by my child’s side (which I did) but that I really could not work. I got letters from team members, the psychologist and social worker, to support my position and got extended paid time off”.

We have found that we have lots of helpers and this has often been a great relief.

We come from so many different cultures and there are many ways our cultures have been helpful.

Culture:

Many of us have sayings, rituals and cultural values that sustain us. Some of us argue more with our partners because of our stress; our fatigue and our worries and our cultural values have helped get us through this.

“I thought we might get a divorce. But my family really comes from a culture, the Greek Orthodox culture, which does not believe in divorce. My mother helped me to remember my values.”

We all have certain proverbs and sayings that help us through hard times.

“I remembered a saying my mother use to say. Yesterday is History. Tomorrow is Mystery. Today is a gift. That is why they call it Present. This illness of my child has really helped me to remember that.”

Many of us realize more now than ever how helpful our culture can be.

Some of us found that what sustains us is community.

Community

Some of us feel very lonely in this process. We feel that we are the only ones in the world with this problem.

“My wife and I moved to Canada from Pakistan. We drew a maple tree for our flower because that is the symbol of Canada. We drew it to represent the warmth and welcome we felt from Canadians who helped us feel cherished and safe after our daughter’s diagnosis that made surgery and chemotherapy necessary. She became blind in one eye and partially sighted in the other but if this had happened in Pakistan she might have died and would certainly be completely blind. We would never have had the money to pay for her treatments. Our family appreciated the help of the haematology-oncology team. They became our community. The other parents were so helpful too. It made me want to help the other parents so I bring food up to some of them.”

“I feel so lucky to be a French Canadian living in my home province. I have so many friends around me who have been my friends for years. I know who can be helpful and who to keep a bit of distance from and that also is helpful. I have friends who could spell me off when my son was in hospital so I could go home and spend times with my other sons. My friends also helped with the other children when I needed someone to pick them up from school. Thank goodness for such a close friendship community.”

Even with all these other ways of sustenance many of us think the people who can best understand our concerns and difficulties are other parents of children with cancer so we asked Linda, our psychologist, for help to form a group which became the COURAGE group. Linda started our group using the Tree of Life metaphor. That is where we met and shared our stories with other families. We began to realize things about our heritage, our environment, and special traditions, songs and stories of our cultures. We thought together as individual families and as a collective family about what our lives are at present but even more important we began to understand the things that sustain most of us during such hard times. We decided that what sustains us most is community. These communities are cultural, religious, family and the culture of the oncology team and the other oncology families. We feel that we are beginning something that will never end.

After the Tree of Life workshop the parents were questioned about its helpfulness to them. They were asked to rate it on a scale of 1-10. They rated it either a 9 or 10.

It was my hope that this would be the beginning of a spiral with no end. The families and myself began to make plans together. Unfortunately Sarah could not stay with us as the COURAGE group continued because she found it too difficult to plan for the children when one never knew who was coming and what age the children would be. One of the young members who had started back to school because she was in maintenance (the period of time when chemotherapy continues but is not so intensive) agreed to work with me in planning for the children around different metaphors. She needed to get community work credits for one of her high school classes and the school agreed that she could use COURAGE group time for this. She wrote about it in the COURAGE book and another high school student decided that she would do the same.

OTHER WORKSHOPS:
Coping Tricks from Families of Haematology/Oncology Service.

The second C.O.U.R.A.G.E. group workshop was based on Lunn, 2008's article on Coping Tricks from Sickle Cell Clinic. When parents were asked what was their biggest fear they answered unanimously (writing their answers on a card for anonymity), "That my child will die". The children however answered with fears of needles, fears of losing hair, fears of getting too far behind in school. None expressed the fear of dying. We then began to write out questions of what they would have liked to have known when the diagnosis was first made. Such questions went from the more concrete such as: "How can I get my child to eat when they are nauseous from chemotherapy", to the much more philosophical and abstract; "If there is a God, why would a child get cancer"? I took many different questions several times to our team meetings and the physicians, nurses, social workers, art and music therapists, child life specialists, the dietician, pharmacist and myself, the psychologist, tried to answer them. These answers were put into the COURAGE living document which is now a collection of stories of survival, pictures from the various workshops, the collective narrative documents, helpful hints and many other creations of these parents, the children and siblings.

PROJECTS

The group met, at first, every week for two hours and I came prepared with different ideas and questions. New members often worked on developing answers to what sustains us through hard times. These questions became '*Questions to Keep Hope Alive*'. They are as follows:

1. Please describe something (a particular value, belief, skill or knowledge) that sustains you during hard times. Is there a name for this?
2. Would you share a story about this skill, knowledge or value: a story about a time when this made a difference to you or to others?
3. Please speak of the history of this skill, knowledge or value: a story about a time when this made a difference to you or to others? How did you learn it? Who did you learn it from? Or with whom did you learn it?
4. Is this skill or value linked in some way to any particular group, family, community or cultural histories of which you are part – some collective traditions perhaps? Are there proverbs, sayings, stories, songs, images from your family community and or cultures with which these skills and knowledges are linked?

These questions were developed from personal communication with David Denborough's and adapted later from his book (Denborough, 2008) ... and they are translated also into French.

Another 'hopework' assignment given to new families is called: *If you were to tell a story.*

'If you were to tell a story of some experience in your life which would tell others the most about you, what would this story be? How would this story show your values,

your principles, your hopes and dreams of life and what you really love in life? Who is in this story with you? Are there people who helped you develop these values, principles, hopes and dreams? This story could be something you learned from books, movies, music and other things or from memories in your life.’

For the children we have smaller assignments called ‘*hopetasks*’ that I have developed. Parents and children discussed together the questions which are placed on pictures that can be colored by the child. For example we have been writing prescriptions, not for medications but for keeping happiness alive in times of hardship. (Picture 5), we discuss ideas of putting our best foot forward or what is most helpful from others, and what are the best characteristics of my best friend. We have now developed 50 of these so there can be different one for every week. The group has adapted and changed over now nearly two years. There is now a clinic group where parents and their children complete the idea presented with the picture and discuss it with me if they wish to, then the children and their parents who are hospitalized get a chance to work on the idea and I take my lunch in the parent kitchen and any parent who wants to come and discuss the ideas of the project or anything else, meet with me there. (Most of the children when hospitalized cannot leave their room due to risk of infection). Then the ideas are put together and sent out by e-mail to any parent or child who has ever participated in the C.O.U.R.A.G.E. programme. The group has now become a virtual group as well. There are now 94 families in our virtual group.

Those who have been with us longer have worked on a *journey metaphor* adapted from the article written by McPhie and Chaffey (1998). Michael White wrote more about journey metaphors later (2002). This has now become a monthly journey group.

The questions begin with:

1. Have you started a journey towards dreams of hope?

I introduced the concept of a journey. I say that it was the intention of these questions to encourage people to take a very special journey. In this journey we have as an objective to understand ourselves better than we previously did, perhaps also to understand our child better too. We hoped to create a strong sense of solidarity as parents and children stand up to the effects of having cancer in the family. It was acknowledged that many parents and children struggle with similar issues: isolation, fear, overwhelming sadness, blaming themselves and others. It was also very apparent that they all have much wisdom to offer others. The parents explored the journey metaphor in written documents.

The children were also given the journey idea but used art work more than words. On a very large piece of paper they cut out journey ideas and draw a collective journey on the page. The journey was to be about what it felt like to have a diagnosis of cancer and to think about hopes and fears that happen when one gets such a diagnosis.

(Many of the children made their journey the wish which they would receive when they finish their chemotherapy from the Children's Wish Foundation). The parents discussed such ideas as daring to say hello to dreams, rewriting the book of tricks and lies, trusting their own instincts in the face of confusion and self-doubt, escaping from the clutches of guilt and holding onto hope in the face of fear and terror. These ideas were created through the following questions. (In **bold type** I will include a few responses from one parent which we called 'A Janie Journey'²).

2. What was that starting place like or what do you think it would look like if you have not started yet?
3. What would or did it feel like to envision dreams?
4. Can you name this state? (**Breath of Fresh Air**).
5. Where are you now? (**This journey is a lifetime journey now. I'm more mature. I take time for my son - before I was everywhere for no reason – have to stop at one point, do what I need to, to feel good. This group for example. Stop and play in a nice calm and peaceful way with my child**).
6. What does it feel like to be at this point in the journey?
7. Do you have a name to give this place where you are now? (**La vie – Life should be like this**).
8. Where is this journey taking you, –to the place where you want to be? (**To help other people. This group is very important – I can manage it, it takes me to a place of being a better person for my family**).
9. What does the place look like?
10. What will you be like? (**Proud of myself, more mature**).
11. What will be different about your life? (**The whole family will be more happy, less stressed, less caught on edge, less up and down. My son still hits when not happy. I calm myself, try to really understand. I used to say – what is the day going to be like, thinking it would not be good. Now I say, it is going to be a good day.**)
12. What will it feel like to be where you want to be at last? (**Even lighter, at peace with myself**).
13. How will you get from where you are now to where you want to be?
14. What personal strengths will help you keep moving forward? (**My determination**).
15. What might trip you up? (**I find it hard sometimes to just go for it**).
16. What is it about you that will help you get around obstacles? (**Laughs – turning 40 – maturity comes. My two strong friends from this group help a lot**).
17. A journey is similar to being in a tunnel – the sense that it will never end, that you do not know what is coming next. It may seem as though the tunnel is closing in on you when you have a child with cancer. What will help open up the tunnel? (**Just get closer to my goal and it will not close. My child keeps me focused**).

Every so often I ask the group members to evaluate what we have done so far and I ask every time we have a workshop such as the Tree of Life, Coping Trick or Journey workshop. I ask: If you found this group helpful, how was it so? The answers have been quite positive. Some answers were: "Taking the time to reflect on our family

made me realize how fortunate we are; I have made a beautiful visual of our life (Tree of Life); I really enjoy talking to other parents, sharing our fears, hopes and concerns; it helps to get good ideas on how to cope from other parents who know: these meetings give us the time to reflect on who we are, where we come from and on what is truly important to us and this is good; these questions are useful as a point of departure for things that I think will be really helpful in the future, working with our children and understand each other better is important.”

In answer to a scaling question, so far all the responses have been from 8 or 10 as to how helpful the C.O.U.R.A.G.E. program has been.

MORE RECENT PROJECTS

In summary, the spiral out of the Tree of Life workshop was the workshop on Coping Tricks from Parents and Kids of the oncology service (ideas developed by the article by Lynn, 2008). From this came the plan of writing a newsletter for other parents and this idea transformed into the living document. The first section was pictures from the tree of life workshop and a short article I wrote for the media at their request when a parent told a journalist about the group. There was a section called Helpful Hints and Coping Tricks coming from the second workshop. There was also a section called Questions and Answers. Parents went to clinics and asked many of the waiting parents what questions would they have liked answered at the beginning, which were not clear. Letters of survival take up another part. Instead of a newsletter we have a huge binder with clear envelope pages, which can be added to. New stories and ideas continue to be added at an almost weekly basis. We now have sibling stories, special knowledge stories, pitfalls to avoid stories, prescriptions for keeping happiness alive and many others. I read all stories and work with the authors to help keep in mind the motto of the courage group, which is, ‘Working Through Our Pain by Giving’ and the idea that these would be ‘hopework’ stories. The group has developed a logo of little bald headed children in Tuques with a huge COURAGE smile (see Picture 6). This is constantly being read and from the readings come volunteers for ‘stories of survival’ and other stories.



Picture 6

Meanwhile the children and their parents have been creating in different ways. They decided that there needed to be posters put in the conscious sedation room, which is very dull, and the children must stay for the day in this room receiving chemotherapy. They also decided that it was embarrassing to be told not to eat or drink on Tuesdays, which is when conscious sedation happens (this is a procedure where an anaesthesia is needed). These children have to be fasting and it would be difficult to see others drink or eat and parents and children are told not to eat by the Child Life Specialist. So the children made a poster to be put up on that day. One side of this poster has a road sign with a slash through it – over pictures of “hospital food” – i.e. TNT, glue, porridge, hay and other terrible looking food (see Picture 7). The other side is a picture of a girl with claws out looking at another child eating. It says in both French and English – no food or drink - fasting children may attack. It is evident that even though not stated in the collective document, that humour is also a survival or coping trick. These posters were unfortunately not found acceptable by some of the hospital personnel so could not be used. (Maybe they were not sure that everyone has a sense of humour). However, the children enjoyed making them.

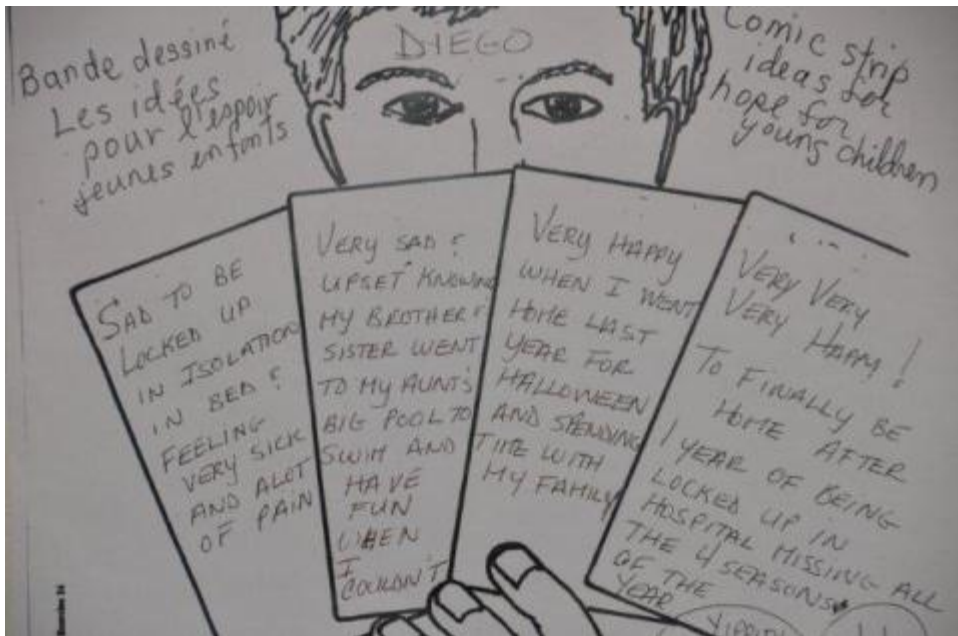


Picture 7

The parents want to start a blog which would also have the current living documents in it and which would be under the Montreal Children`s hospital internet so only could be accessed by Oncology parents and children. The children have started producing a film of their stories of survival for the younger children who cannot read yet or so well. They are now in the process of performing and editing it with my help and the help of a psychology student who is working with me.

Three new groups began near the end of the first year, one which was called the C.O.U.R.A.G.E. satellite group. This group is used mostly by parents who are back at work and children who are back at school and is held in the evening. This group has had several fundraisers to raise money for such aids as to pay for a person to come and give yoga for parents and hospitalized children on the ward. We (that is one parent and child) had already found a professional yoga teacher who already was interested in helping people with cancer because she provides two free classes a week for people with cancer in her studio. However, she was too expensive so another parent invited a friend who was a yoga teacher and was willing to volunteer. Thus

the group only paid for mats and bolsters (a very economically minded group). Yoga has already begun on the ward and is one of the highlights of the week both for the parents and when possible for me as I get to relax and enjoy the yoga myself sometimes (however, much of the time I spend with a child in the bedroom so the parent can participate). The parents want to provide a yearly membership in a nearby gym for parents of hospitalized children, movie passes, to stock the larder in the ward parent kitchen with staples and to provide one meal a week home cooked by parents at home for the parents and kids in the hospital. The second new group was an adolescent group to help them connect with the other adolescents who have cancer and share their special knowledges and strengths. This group was abandoned and needs to be re-worked because it was interfering with plans of the child-life workers in the clinic. The third group is a children's group to understand the emotions which can come up when one has cancer. These groups were planned with the music therapist and ideas of writing lyrics and songs of survival have developed. From the adolescent group came the idea of drawing comic strips of hope for the younger children. One has four sections of hair loss and the sadness and despair that can come from that, to wearing a nice wig and finally to hair growing back. Several other ideas for comic strips are in the planning and drawing stage (Ideas came from one of the 50 'hopetasks', see picture 8).



Picture 8

I started the cycle again by offering not two but three half-day Tree of Life workshops (the third group was offered due to popular demand) during and after spring break which is the first week of March and I have completed the third cycle. Who knows where this 'hopework' will go from here. With such a creative group it certainly seems to have turned out to be a spiral that has no end. (Picture 9¹ shows some of the founding members). I have just written a grant proposal to try to get funding in order to better evaluate how the families view the various projects and

ideas which have their foundation in community narrative practice. I am very curious to see the outcome of this research.



Picture 9

CHALLENGE

One of the challenges is certainly the bilingual nature. All written documents are presented in the most competent language of the person writing it, either French or English and I have tried to translate most of them (I have had the help of members of the group as well). All ideas in the e-mail edition are translated into either French or English depending on the language of origin by myself. Since English is my first language and French my second, that is time consuming. However, as we had said in our introduction for Tree of Life workshop ‘We want to acknowledge that each person will have varying degrees of comfort with the two languages but we hope that by repeating ourselves in two languages we will have the advantage of truly clarifying what we say and how we understand it. It is our goal to use our bilingual group to every person’s advantage and we asked everyone to exercise tolerance of errors, pauses, and miscommunications. We had confidence that together we would find a way.’”

And we have found a way and I have found it to be a particularly rich experience. The families have certainly been tolerant of my mistakes in written French (and oral French as well), which I am sure there have been many and I certainly have received much from this experience, including, hopefully, improved French abilities.

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I would like to acknowledge all the family members who agreed to have their words and pictures presented in this paper. In particular, I would like to acknowledge the four founding families of the C.O.U.R.A.G.E. group who also allowed their pictures to be part of this paper. Thanks to my son, Carlin, who, as always, helped me edit this paper and to my husband, David who also edits and more importantly supports my many evenings out with the C.O.U.R.A.G.E. group.

NOTES

1. Pictures are included here with the families' written permission. However, it is hoped that any of you who recognizes these people will keep their privacy intact.
2. This mother has given permission for her journey story to be told. However, her name has been changed to protect the family's identity and maintain confidentiality.

*REFLECTION

The term 'hopework' came serendipitously. As mentioned previously, after each group I write up a summary of what we did, sometimes sending the questions or project ideas to parents and children who would not be able to attend (there is a clear agreement that no one attends if there is illness in the household because these children become neutropenic, meaning unable to fight off germs and could get desperately sick if in contact with any of the usually mild illnesses). I, at first called these questions, which I was hoping members of the group would complete and send back to me – homework. One week I accidentally typed 'hopework' and the families loved it and it became hopework from then on. While attending a workshop given by David Epstein in Toronto, I happened to mention this 'accident' and the response was, 'There is the title of your next paper'. And so it was.

Appendix

1. Questions for the tree of life (adapted from those of Ncube, 2006 which were given to me by Karine Parello-Plesner, 2008).

The roots: Where does your family come from? Who has taught you and your family the important things in your life or your family's life? Is there a song or a dance or music from your culture or heritage that means a lot to your family? Does your family name have special significance?

The ground: Where do you live at the moment? What are your daily activities? What are your days like? How are things around you nowadays?

The trunk: What are your special family skills and abilities? From whom did these skills come from? Which skills are used in your family on a daily basis or often? What would a good family friend say about your family? (I am now adding; What are your special family values?)

The branches: What are your hopes, your dreams, your wishes for your future? What direction do you want your family's life to take? What do you hope might happen?

The leaves: Who are the people who are precious in your life (these can be people who are still alive or they might have died)? These could be people from books or music of other places)? These are people you feel have affected your family in a special way.

The fruits: What are the gifts you have received that have special importance for your family (these may be material gifts or things such as love and support which are non-material gifts).

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