Children's Cancer Foundation

THE SCOPE

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WELCOME TO THE FIRST ISSUE!

We are excited to present to you, two of our latest qualitative studies. Take a peek into the lives of the children, hear their challenges and understand how they cope in their journeys. Before that, let's understand more about what's qualitative research!

Qualitative studies give voice to the participants. They allow researchers to have a deeper understanding and insights on how certain issues are being perceived or experienced by the participants.

What is Qualitative Research?

> **WHILE QUANTITATIVE RESEARCH SEEKS TO ASK "WHAT", QUALITATIVE RESEARCH IS CURIOUS TO KNOW "WHY" & "HOW"**

Qualitative research are commonly done through interviews, focus group discussions, observations, review of documents and examination of artefacts. In CCF, qualitative studies are usually conducted through semi-structured interviews or focus group discussions.

How do we decide – semi-structured individual interviews or focus groups?

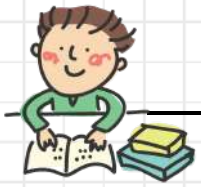
Semi-structured individual interviews are usually conducted when the study seeks to understand in depth the personal experiences directly from the participants. Unlike structured interviews, the order of questions in semi-structured individual interviews flow according to participant's narration of events while allowing for probing of details. Hence, it is less directive but yet allows the interview to remain focused.

Focus group discussions are conducted when we want to find out the perception of a specific topic from certain groups and when we believe the group format can stimulate more discussion and bring out aspects of the topic that may not emerge in individual interviews. Participants will be grouped according to certain attributes - eg. age, occupation etc. The researcher will be present to facilitate the discussions. It is less time-consuming as compared to individual interviews.

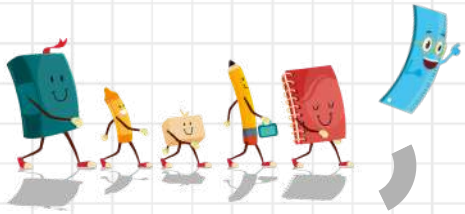
Needs of Children with Cancer Who Have Returned to Mainstream School

by Khoon Chai Wee

What are some of the challenges the children face after returning to school?



When a child is first diagnosed with cancer, he/she may have to miss school for a period of time to undergo treatment. We've conducted semi-structured individual interviews with **16 parents and 4 teenagers** to understand more about their challenges after returning to school.



Being away from school for a considerable period of time has implications on the child's **social network and academic progress,** particularly when the child returns to school.

"...people would feel awkward, I think.... I can sense. Some people I knew before, I walked past them in the corridor, they don't dare to look at me in the eye... I think they are scared to look at me or scared to talk to me." (Teen 3)

In addition, when the child is returning to school, there are also emotional and physical adjustments that the child has to make.

Physical and health-related challenges such as short-term and long-term side effects of treatment (hair loss, physical impairment, neurocognitive changes etc) compounded the challenges that children with cancer faced after their return to school.

"...He cannot "tahan" (endure) the whole day (of schooling). He's like a battery, after recess he will be low batt. The beginning part is okay, the second part, he will not be able to." (Parent A2)

"...people start to ask, "eh, why you wearing a cap." ...the school is so big and she is the only one wearing this cap because her hair was either bald or short. So a lot of people started to ask..." (Parent A6)

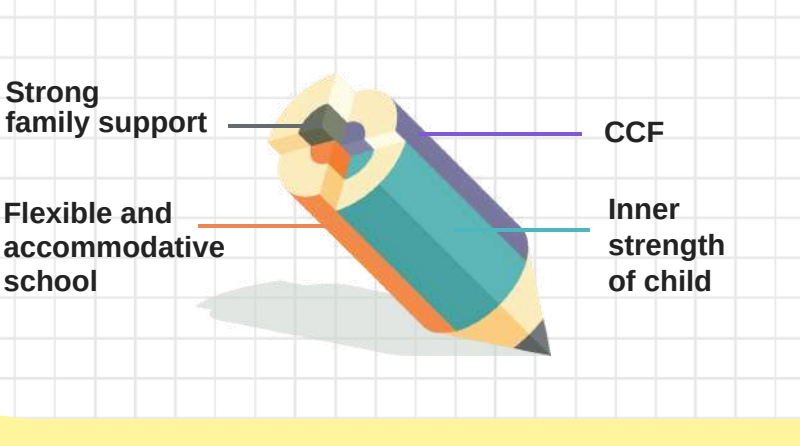
"...I remember for biology we were doing something about bio-ethics. Then my teacher actually came up and asked me if I was comfortable enough to come and sit in in this debate because it was about cancer...So that kind of thing, it's just they are very sensitive, to my needs..." (Teen 3)

"...the other form teacher, she was always, so scared. At one point of time, it was too much...we were boarding the bus for our learning journey... she was like carrying me. I was (telling her), no, don't do that, I want to do it (board the bus) myself but then she doesn't want to listen..." (Teen 1)

From the experiences shared by the teenagers, **behaving sensitively** to the needs of children with cancer but **not imposing what adults think is the best** for the teenagers is something that is appreciated.

How did the children cope with the challenges?

Children with cancer received support from different sources to help them cope with the challenges upon returning to school.



The impacts of childhood cancer on the child's education are present throughout the child's illness trajectory. They do not cease after the child has completed treatment. Therefore, there is a need for continued collaborative effort among the medical system, school system, CCF and the family to support the return of children with cancer to school.

The Aftermath of Losing A Caregiver to Cancer

by Dr Carolyn Ng

“After [father’s] death, my life is turned upside down… I’m just a child. I still have a whole life [ahead], but without [him].” (Child N)

Having a parent being diagnosed with cancer, witnessing his/her deterioration and dying, and eventually losing him/her to death is never a natural and anticipated life experience from a child’s perspective. Such journey can understandably be overwhelming, leaving devastating effects on the child’s life. Ironically, at the time when children are in need of the greatest support, the adults, on whom they normally rely to shepherd them through life adversities, are the least available, as they get entangled with their own struggles over the illness, the resulted stressors, as well as the impending loss and grief.

Listen to some of the voices of 13 children and adolescents, aged 7-16, as they generously invited us into their worlds and revealed their journeys that not many know…

Be it pre- or post-death period, all of them experienced some form of emotional impacts and practical disruptions in daily life.

Yet, all of them had their own coping strategies, primarily by engaging themselves with some forms of activities (behaviourally) and distracting themselves from the resulted distress (cognitively).

“I think the challenging part was seeing your mom being really sick… my school friends completely had no idea… a lot of things happened in a short period of time… you would have a bad feeling even though you don’t know anything.” (Child F)

“I was the one who washed the plates for my mother… washed the clothes… I needed to feed her… at night I slept with her, in case she fell down.” (Child L)

What are some risk and protective factors that influence the impacts on these children?

They tend to experience more stress when diagnosis / critical deterioration / death happened around the time when they're at a developmental transition (e.g. in between P6 and Sec 1), or certain challenging circumstances (e.g. exams period), or when their knowledge of the sick parent's condition is unclear.

"I felt that I had to take care of my dad more… I felt stressed… when exam was coming, that was the most stressful part [because] it's very rush during exam time… I didn't know what to do." (Child H)

RISK FACTORS VS PROTECTIVE FACTORS

"I think it's unnecessary [to be secretive, hiding and lying]… I think the children will suffer more." (Child F)

"Sometimes my dad would just take us aside and talk to us, or when he is driving us somewhere, he would just casually ask us about stuff. I think that's good as well. He would also share how he is feeling, which is quite rare… it was nice to know that you're not alone in feeling how you're feeling." (Child F)

"Sometimes, they (school friends) would come to my house to check me out and [ask] me how I feel. If [my teacher] sees me, he would stop me and ask me how I am." (Child K)

Their primary sources of support came from school teachers and/or schoolmates and their nuclear families through visiting and/or talking to them, engaging them with some activities and being understanding and encouraging.

The above are merely snapshots of these children and adolescents' lived experiences in the face of their parent's cancer and eventual death. Yet, they have also shown incredible tenacity in sailing through the seas of grief and loss and soaring above the adversities in their lives.

Greetings from the research team

Hope you've enjoyed our first issue and had a better understanding about qualitative research.
The Scope will be published bi-annually, to share exclusive insights of our latest research studies in a digestible format. We hope that you will be able to have a better understanding of our research through the narration of our participants. Listen to their voices and let them lead you through their journey.

If you are interested to read about our studies in greater detail, you may contact anyone of us in the research team for the full report or should you have any enquiries.

Thank you!

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