



## Consulting young people about living with cancer

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### *Abstract*

This article draws on the narrative therapy concept of 'consulting your consultants', and documents the skills and knowledges of young people who are living with cancer. The young people offer their ideas about how to think about aspects of cancer in externalised ways; ways of focusing on living, rather than dying; the life lessons and skills they have learnt from family members; and how their skills and knowledges might be helpful for others.

**Key words:** *cancer, young people, narrative therapy, externalising conversations, re-authoring conversations, therapeutic documents, re-membering conversations*

In Singapore, approximately 140 children and young people are diagnosed with childhood cancer every year. Over the past six years, I have personally journeyed with children and young people who have been diagnosed with cancer and given a poor prognosis. I am always amazed with their ways of responding to this adversity in life. The medical settings these children find themselves in are often dominated by adults and medical professionals and, in this context, I have attempted to re-centre the voices, skills and knowledges of the young people I am working with, using a 'consulting your consultants' approach (Epston & White, 1992). This paper documents some of these conversations with young people, especially two young women – Nas, 23, had been diagnosed with chronic myeloid leukemia and experienced a relapse, and Natalie, 18, who was diagnosed with osteosarcoma and experienced four relapses. This work involved the use of many maps of narrative practice, including externalising conversations, re-authoring conversations, using therapeutic documents, and re-remembering conversations (see White, 2007). Rather than attempting to summarise all of the background and steps in each of these maps, I focus in this paper more on the contexts of the lives of young people with cancer, as well as some details from the conversations I had with young people, so as to let their ideas shine a little brighter.

### *Challenging totalising notions about cancer*

When young people are diagnosed with cancer, they usually immediately enter a medicalised world, not only of diagnosis and prognosis, but medication, management plans, check-ups, and case notes. Throughout this process, the dominant discourse is often about the negative impacts of cancer on the children, and they are clearly placed in a position of being 'the patient', which can run the risk of, as David Epston and Michael White wrote, 'stupifying patienthood' (1992, p. 24). Adopting a 'consulting your consultants' approach helped me to not reinforce this position – and showed me some unexpected and delightful ways that young people approached living with cancer that might otherwise have been 'invisible' to the broader medical system they found themselves in.

For example, while the general discourse perceives cancer as something 'bad', children and young people may actually experience constructive changes in the process that alter their attitudes and beliefs in life (Patenaude & Kupst, 2005), as well as enriching their life stories. One of the young people I worked with, Natalie, shared that the idea of being 'affected' by cancer implied a kind of negativity that did not fit with her life philosophy. Instead, she preferred to use the word 'change' – and she perceived cancer as changing her life for the better, as

she was 'seeing life in a clearer sight' ever since her diagnosis. When Natalie shared this with me, it reminded me that – without denying the challenges that a diagnosis of cancer can present – not all children and young people are badly affected by cancer and do not necessarily feel disabled and helpless thereafter. In other words, I need to be mindful of the powerful influence of the dominant discourses about cancer, and instead let children and young people articulate what roles cancer plays in their lives. Otherwise, I may run the risk of further 'stupefying patienthood'.

By adopting the concept of 'consulting your consultants' (Epston & White, 1992) in this way, I learnt to listen to the young people from a de-centred position (White, 1997). This opened up space for wider range of possibilities and multiple perspectives to look at their lives. While it prompted me to remain curious and track their life stories more closely in our conversations, I'd like to acknowledge that it took a lot of mindfulness and self-discipline to withhold my pre-existing knowledge and assumptions. As the positions the young people took and the words they used to express these were often very nuanced, this also increased the requirements for me to listen very closely and pay particular attention to what they were saying.

### *Externalising conversations as enabling nuance*

Bringing this kind of nuanced listening to externalising conversations has also helped in my work. For instance, in one of my externalising conversations with Natalie, she named the potential of dying of cancer as 'the possibility': on the one hand, she acknowledged the poor prognosis, especially given that she had multiple relapses but, on the other hand, she preserved the hope that she might prove the doctors wrong and survive in the end. As I invited her to elaborate further on 'the possibility', she shared about how she usually 'stalled' it at the back of her mind. Her choice of words here was particular; she did not use the more usual expression of 'keeping' something at the back of her mind. Instead, the idea of 'stalling' evoked the idea that she was actively able to impede 'the possibility's' movement, while knowing that it might re-gather momentum at times. She also went on to tell me about how she handled 'the possibility' when it did somehow sneak out to the front to her consciousness. In this conversation, I noticed that she started to describe her interactions with 'the possibility' in a playful manner and with occasional laughter. This converted a supposedly heavy topic to something more entertaining and injected a degree of humour.

Externalising conversations can also create a context for children and young people to redefine their identities

and experience their lives anew. For example, in one of my externalising conversations with Nas, she named her awareness about dying as 'the crush'. Initially, she positioned herself as the victim of 'the crush' and shared about how 'the crush' would overwhelm her to the extent that she would have 'no life'. As I gradually invited her to reflect on how she was able to handle 'the crush', she generated a substantive list of skills she had in handling visits by 'the crush'. In one of our later conversations, Nas shared that somehow 'the crush' had not visited her recently, and that she was eating well, enjoying herself, and smiling most of the time, while also being able to concentrate on her studies.

## *On the politics of metaphor*

In view of its life-threatening nature, one prevalent discourse perceives cancer as a 'battle' for people to 'fight' and 'conquer'. While, to some extent, this notion can reflect the nature of children and young people's relationship with cancer, it does make me wonder about how we should look at those who eventually die. Having witnessed children and young people's incredible perseverance and courage in the face of tough struggles, as well as their hope and even smiles in the midst of pain and suffering, the last thought that I want to have is to perceive them not as good-enough 'fighters', or imply that they 'failed' or 'lost the battle'. Such notions not only narrowly describe children and young people's journeys with cancer and inevitably neglect their other encounters (Russell & Carey, 2004), but also do an injustice to them. Imposing these metaphors can reduce our ability to hear far more poetic, hopeful, and nuanced understandings of life.

For instance, in our conversations, Natalie preferred to describe her journey with cancer as 'roller-coaster rides', because there are ups and downs in the journey and she is also attending to radically different things at different points of time (for example, the impact of the cancer cells upon relapse, and scoring well upon returning to school). Similarly, another young person shared about how he learnt to 'live with' cancer and, over time, even 'make friends' with the two chest tubes inserted in his lungs for symptom management. Through externalising conversations, he further elaborated on how he could be at peace with cancer and continue with his daily routines together with his two 'friends'. This short recounting includes three quite profound notions: first, that the young man was focusing on 'living with' cancer, rather than constantly being under the threat of his own death; second, he was able to avoid being a 'stupified patient', and actively re-purposed medical equipment as being more in his realm of life; and third, that he took his cancer, and the medical equipment 'along' with him, in a sense, in his daily life, rather than having his daily life be seen as interrupted by these elements.

## *'Whatever you can do, just do it!'*

In pediatric medical settings, children and young people are usually known as 'patients' who are sick. With such labels, we tend to see people only from the medical lens and perceive them as weak, needing care, and so on. Consequently, we forget that they have a lot of other events and experiences happening outside of the hospital. This runs the risk of us missing out many other identities and other aspects of their lives that can be potentially significant, yet out of phase with their dominant storylines (White, 2007). On top of that, adults can sometimes forget that these children and young people are children 'first', and not just their illness. Even when they are gravely ill, many children continue to want to live, play, and experience life until the end of their lives (Cincotta, 2004; Scheier & Carver, 2001). These other territories of life and identity can be brought to the fore through re-authoring conversations (White, 2007).

In my conversations with Natalie, she shared her wisdom in thinking about the gains instead of the losses in her roller-coaster ride with cancer. She told me how, upon her initial diagnosis and subsequent relapses, she did not dwell in thinking about the 'why' but think about the 'hows': How might she respond to this news? How would she speak with friends and family? How could she continue to do the things she wanted to in life? How might she be able to nurture herself, and her health, during this time? And so on. In this way, Natalie said she was 'determined to live life constructively rather than being inhibited by cancer'. Instead of 'being pampered and becoming dependent' because of the impacts of cancer or side-effects of the treatment, Nas also shared about how she moved on with her daily routine and engaged in meaningful things, such as studying and exercising.

Despite the uncertainty implied by cancer, many children and young people still display motivation and desire to actively experience and engage with life; none of them is a passive recipient of cancer (White, 2006). To me, the question is how we, as therapists, can honour them as active agents in response to cancer. For example, in one of our conversations as I continued to zigzag between the landscapes of identity and the landscape of action (White, 2007), Nas shared with me her value and belief in 'not lazing around in bed waiting for death', as well as her 'determination to be a strong person', and her 'keen desire to help others with sickness' (descriptions in the landscape of identity). Subsequently, we journeyed to the landscape of action, where she started to ponder upon the possibilities of visiting old folk's homes and hospices because she perceived people there as seemingly waiting for death, and she wanted to be an advocate of 'whatever you can still do, just do it!'

## *'Let time chase after you, not you chase after time'*

Another common theme for Natalie and Nas was the strong sense of time and how they wanted to maximise their available time to live a meaningful and fruitful life. For instance, as Natalie shared about her 'bucket list'<sup>1</sup>, she reflected on how time was important because it allowed her to experience life. She also revealed that she wanted to experience life as much as possible because she did not know how much time she would have. Given her strong awareness of 'having a time limit', she showed her 'determination to seize the opportunities and give (her) best shots'. As she put it, 'Let time chase after you, not you chase after time'.

Re-authoring conversations can help bring forward the values, dreams and identities which cancer cannot take away from children and young people. For example, while Natalie experienced the loss of some friends after her diagnosis, she still valued friendship, and came to have a richer sense of it. As she told me, 'Cancer does not make you lose your friends. It just shows you who your friends are'. She also said that, 'Cancer cannot take away the good stuff from me', and 'what remains unchanged is that I still like studying, I still like sports, and I still like to sing'. As our conversations moved on, we re-ignited her dreams and identity about sports despite the loss of her right leg through amputation; she reflected that, 'My sporty identity is not lost yet ... my sports spirit is still there'. Natalie then started formulating a goal to join the National Disabled League where she could take part in sports again; she reckoned that she could become an 'able disabled'.

## *'I didn't realise that my mother left so much for me'*

Re-remembering conversations allow us to trace the histories of qualities, knowledges, and skills. They also let us examine how we contribute to others' lives in return (Russell & Carey, 2004). This second aspect can be important for children and young people who are dying, as it reminds them that they can be helpful and influential to other people, despite being physically weak, or that their number of days may be limited.

For instance, as Nas shared about her skills in handling 'the crush' (the possibility of death) over the past years, I invited her to recall from where she learnt such skills through re-remembering conversations. While she initially thought that those skills 'just popped up in (her) mind' and she 'simply went with trial-and-error', as I asked further, she started to recall moments

when she remembered seeing her late mother doing something similar in times of difficulties. Later, she also vividly recalled certain good advice given by her mother. At the end of this re-remembering conversation, she came to realise that some of her existing skills of coping with the 'crush' were actually inherited from her mother and she deemed such skills as 'a valuable heritage' for her.

Though her mother died from ovarian cancer 10 years before, this conversation helped bring her mother from the background to the foreground of her life, and reconnect the two of them once again through the similar personhoods that they shared in common. Nas summed this up as, 'I didn't realise that my mother left so much for me'. Such conversations also helped her realise that her mother's advice remained vivid and valid in her mind, even though she had temporarily lost the traces of it, and that her mother was no longer beside her physically.

## *Therapeutic documentation*

While therapeutic documentation used not to be a part of my usual practice, I started to appreciate its power once I began to use narrative therapy in my clinical work. I found that simple documentation, by listing the children and young people's unique knowledges and skills in handling particular challenges in their lives, could be quite impactful. For instance, over a few conversations with Nas, we externalised 'the crush', explored its impacts on her life, elicited her knowledges and skills in handling it, and traced the history of these knowledges and skills. I was then able to compile all the key points, in her own words, into a document and pass it back to her (this document is reproduced below). Nas was surprised by the long list of knowledges and skills documented – she explained her disbelief because she thought that she could only come up with two or three strategies in handling 'the crush' in previous conversations.

Nas shared with me her desire to pass such knowledges and skills to other children and young people with cancer, as well as her aspiration of 'becoming an encourager and helping others who are in need'. In this context, we have formulated a plan to expand on the documentation, so that it can benefit more people. We intend to record her journey with cancer and her wisdom in handling it and publish it into a book, which can then be circulated among other children and young people with cancer. In fact, Nas expressed her generosity to share her stories with anyone else who may not be diagnosed with cancer but may encounter some other challenges in life. The following document was not intended to be an exhaustive list, or a coherent document created as we went, but was pieced together from my notes after our meetings.

## Nas's knowledge about 'The crush'

### Who/what is 'the crush'?

- I know the truth [about the incurable nature of pulmonary fibrosis]
- I know I'm dying ... I know there's no cure for the lungs... there's no medicine for the lungs, so compared with leukemia, lungs are more frightening because there's a cure for leukemia.

### How does 'the crush' affect you?

- I'll get crushed inside, then I'll cry.
- I'd be very tired and down, just want to sleep, very lethargic, don't like going out or chit-chat with friends, just want to stay home, don't want to go to school.
- If 'the crush' were to take over, then I'd have no life at all... life would be boring... I can't be social or widen my social circle... I'd have no friends and become lonely.

[When asked about her position on these effects (in the externalising conversations map), Nas said, 'That's not what I want ... getting tired, too sleepy, and having no life. I want to wake up and have life, which is something I value more.']

### Knowledge and skills in handling 'the crush'

- Not to brood over it
- Not to suppress it / put it inside
- Not to think negatively, 'cos it'd depress you even more, or even lead to becoming crazy
- Whenever 'the crush' comes, just burst out in tears and let it out
- Talk to someone whom you trust and they can comfort you
- Go out for a walk
- Eat and/or cook comfort food – chicken wings
- Do something that you like (such as shopping)
- Look at something green – nature
- Watch a movie at home

[When asked about her position on these skills and knowledges, Nas said, 'This period without 'the crush' is good. I can eat well ... enjoy myself ... smile most of the time instead of being gloomy ... I'm more awake ... able to concentrate on school stuff more and class'.]

### From where did you learn the above?

1) Just try out and see if it works

2) Mother's positive advice:

- 'Live positively, go on with life, you won't know when you're going to die, so just live, do whatever you want and take whatever risk it is, just continue with life.'
- 'Always think positively. Don't think negatively.'
- 'No matter what, just do it.'
- 'Just keep trying.'
- 'Just climb up all you want.'
- 'Never mind, just let it out.'
- 'Stop brooding over it, just get on with it.'
- 'Let's go for a walk.'

### What do all these things tell you about who you are and what you value?

- I like to try out everything
- I like to have a positive attitude
- I celebrate my passage of life instead of passage of death
- I'm a bit like my mother [in the positive thinking and the above strategies]
- Maybe I can pass this on to somebody else.

## Conclusion

The lives of children and young people diagnosed with cancer are multidimensional and contain many stories, of which illness and death are only one of the chapters, and not the entire story of their lives and identities (Cincotta, 2004; White, 2000). Their rich life stories continue evolving and deserve to be documented and validated by the surrounding adults. In future, I hope to circulate the life stories of the children and young people I work with, and elevate them to play something of an 'expert's' role in sharing their unique knowledges and skills with others (Denborough, 2008). In return, others' responses to their stories would allow them to join the children and young people around shared values and purposes in life.

## Note

- <sup>1</sup> 'Bucket list' is a colloquial term meaning things one wants to do before 'kicking the bucket', that is, dying.

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