

See discussions, stats, and author profiles for this publication at: <https://www.researchgate.net/publication/277252317>

Supporting young people living with cancer to tell their stories in ways that make them stronger: The Beads of Life approach

Article in *Clinical Child Psychology and Psychiatry* · May 2015

DOI: 10.1177/1359104515586467 · Source: PubMed

CITATIONS

23

READS

3,016

3 authors:



Sara Portnoy

The Whittington Hospital NHS Trust

21 PUBLICATIONS 371 CITATIONS

SEE PROFILE



Isabella Girling

University of East London

3 PUBLICATIONS 34 CITATIONS

SEE PROFILE



Glenda Fredman

University of Hertfordshire

47 PUBLICATIONS 729 CITATIONS

SEE PROFILE

Supporting young people living with cancer to tell their stories in ways that make them stronger: The Beads of Life approach

Clinical Child Psychology

and Psychiatry

1–13

© The Author(s) 2015

Reprints and permissions:

sagepub.co.uk/journalsPermissions.nav

DOI: 10.1177/1359104515586467

ccp.sagepub.com



Sara Portnoy¹, Isabella Girling² and
Glenda Fredman³

¹Child and Adolescent Psychological Services, University College London Hospitals NHS Foundation Trust, UK

²University of East London, UK

³Department of Psychology, Camden and Islington NHS Mental Health Trust, Hunter Street Health Centre, UK

Abstract

This article describes the ‘Beads of Life’ approach – a five-part methodology informed by narrative therapy to enable children and young people to make sense of their cancer journey in ways that make them stronger. Young people are invited to use beads as prompts to tell preferred stories of their identity to create a safe place to stand from which to story their cancer journey. The approach positions young people as experts in their lives. It aims to change their relationship with cancer to reduce its negative impact on life by lessening isolation. By enabling medical staff to get to know the young person apart from the cancer, this approach aims to create hope for the future and improve quality of care.

Keywords

Adolescents, trauma, tree of life, narrative therapy, cancer, children and young people, young people with cancer

Ravi was 16. He lived at home with his parents and his younger brother and sister. He had a passion for football, was an avid Arsenal supporter, played mid-field for his local club and had aspirations to trial for Leighton Orient. One evening Ravi noticed a lump in his neck when he was washing his hair and showed it to his mother who took him to their doctor ‘just to be sure’. After several consultations with the general practitioner (GP), Ravi was referred to his local hospital for scans, blood tests and a biopsy. A week later, the consultant oncologist gave him a diagnosis of Hodgkin’s lymphoma, a form of cancer, and recommended a specialist unit where the doctors were ‘experts at working with teenagers with cancer’.

Corresponding author:

Sara Portnoy, Child and Adolescent Psychological Services, University College London Hospitals NHS Foundation Trust, 6th Floor Central, 250 Euston Road, London NW1 2PG, UK.

Email: sara.portnoy@uclh.nhs.uk

Within a couple of days, Ravi found himself opening the doors to the 'Teenage Cancer Unit'. A nurse, Serena, introduced herself, showed him to his bed and told him a lot about what would happen over the next couple of days, when chemotherapy would start, who would look after him, how to get to the day room, the pool table and so much more. Ravi recalls listening to everything

Serena said but remembering almost nothing once she had gone. He remembers sitting on his bed staring at the boy in the bed opposite, thinking, 'One thing we have in common is cancer' while his mother unpacked his belongings, talking incessantly. Ravi wished she would 'just stop talking' and then through the fog of his thoughts and her chattering, realised 'she is as worried as me'.

When the nurse returned, Ravi did not feel able to ask her questions since she had 'already told me . . . I didn't listen properly . . . she was very busy'. Within a couple of days, he was having a bad reaction to chemotherapy which made him 'the sickest I have been in my whole life' so that all he wanted was to sleep as much as possible. Although the doctors had given him anti-sickness medication, it took a while before it started to make a difference. Every day the unit staff invited Ravi to join activities with the other young people like eating pizza, playing on the Wii and attending school, but he did not want to talk to anyone except his mother, could not 'be bothered' and wanted to be left alone. Concerned that his reaction was 'abnormal', staff asked his parents, 'Is he always so quiet and withdrawn?'

When Cancer¹ walks into a young person's life, it takes centre stage as hospitals and medical treatments take over. As Ravi describes, 'everything happens so quickly'. Within a short space of time, a young person can go from engaging fully in teenage life and feeling strong and healthy to undergoing a myriad of invasive procedures and treatments, witnessing or participating in incomprehensible conversations and feeling 'the sickest I have been in my life'.

The practice of our paediatric psychology cancer team is informed by systemic (Fredman, 1997; Fredman, Anderson, & Stott, 2010) and narrative principles (Denborough, 2014; White, 2007). In particular, we aim to take a respectful, non-blaming approach where we view clients as the experts in their own lives (Anderson & Goolishian, 1992). From the start, we view problems as separate from the person and assume clients have many skills, abilities, beliefs and values that could help them change their relationship to the problems in their lives. Therefore, drawing on narrative therapy (NT) principles and practices, we are interested in stories people tell about their lives and their relationships (as well as problems), the effects of these stories and the meanings and contexts within which these stories are formed. Consistent with an NT approach, we have written the article in a story-telling style and have included some of the many stories young people who have participated in 'Beads of Life' have shared with us.

Making sense of the cancer experience: using beads to tell stories

According to Jerome Bruner (1990), we create stories about our lives and ourselves through linking events in a particular sequence across time and 'making meaning' or 'making sense' of our experience. Bruner (1990) identifies key features of a narrative including a sequence of events, actions or states, involving actors or characters connected by a plot giving meaning to the events. He shows us how we use stories to make sense of the unusual or unexpected. Therefore, we started looking for ways to help young people like Ravi tell stories of their experience to make sense of their cancer journey.

The original idea of using beads to help young people tell their stories came from a social worker's teenage son who returned home with a string of beads from a wilderness weekend in Canada. Each bead symbolised an accomplishment; using his beads, he told his mother all about his weekend, the activities he participated in, what he enjoyed and felt proud of, his 'preferred stories'. She worked on a cancer unit for children and introduced the beads to help young people

with cancer tell their own unique story of the challenges they faced while undergoing lengthy medical treatments. She named these challenges 'achievements' (Stutzer & Gove, 2000).

Developed along similar lines, the Beads of Courage Programme (Baruch, 2010) is offered in many cancer units in the United States and United Kingdom to help young people make sense of their cancer treatments. Young people diagnosed with cancer collect a bead each time they undergo a specific medical procedure, for example, seeing the doctor or having a blood test. The beads enable the child to tell the story of their medical journey and thus give meaning to this unexpected episode in their lives when medical treatments dominate and their experiences deviate from the norm.

When we piloted a similar approach to the Beads of Courage Programme, called the Bead Programme, we found that many young people seemed to like the beading activity but did not want to continue telling their cancer story. Some became extremely distressed recounting details of the illness and medical treatments. They chose to stop the activity early on, explained that they found it too upsetting or avoided meeting with the practitioner offering the Bead Programme.

White (2005) describes the risk of 're-traumatising' people when we invite them to tell and retell a 'single-storied' account of their loss or trauma. We realised that by encouraging the young people to retell only their cancer story, we were inviting only a problem-saturated trauma story that gave a 'thin description' of their lives (White, 2005). We had not asked them about their normal daily activities that kept them going or about the important people who had sustained them during their cancer journey, nor about the skills or abilities that they had used to get through hard times.

We recognised that beading appealed to many young people. Some enjoyed the activity of choosing and threading beads; others appreciated the religious or cultural significance of beads in their families or communities. Our challenge, therefore, was to hold on to what was best from the pilot bead programme to enable young people to talk about the difficult experiences in ways that are not re-traumatising.

Creating a safe place to stand

There is a dominant discourse on many cancer wards that people need to express their negative feelings and emotions like anger or distress about their cancer diagnosis and treatments. Naming this the 'no pain no gain' discourse, Yuen (2009) encourages those experiencing the consequences of trauma to consider the alternative notion of 'less pain, more gain' through therapeutic conversations that create a safe place for the person to stand before they talk about their experiences with trauma.

David Denborough (2014) explains that when we are in the middle of the trauma experience, we usually need to put all our efforts into our immediate survival. Therefore, we need to find a way to enable young people to step out of the turmoil of the fast-flowing river full of hazards and dangers and come up onto the riverbank (Kaseke, 2010) where it is safe to stand before they can look down on their life and experiences and hence begin to talk about and make sense of them.

Ncube (2006) faced a similar challenge to ours when she started working with the Tree of Life approach to help children in Africa who had experienced loss and trauma through HIV/AIDS in their families. In the original version of the approach, the children drew trees to symbolise themselves and included fallen leaves to represent important people who had died and bugs to signify problems and challenges in the child's life (Ncube, 2006). The children were engaged by the method, had fun drawing their trees and it helped them tell their stories. However, as in our first efforts with the Bead Programme, in this original version of the Tree of Life, the children often became distressed when recounting events related to the trauma of the fallen leaves and bugs and the counsellors became overwhelmed by the sad stories they heard.

Working with Denborough, Ncube recognised the importance of giving children a 'safe place to stand' and adapted the method using the tree as a metaphor to enable children to tell stories about

their lives and thereby create this sort of 'riverbank position' (Kaseke, 2010). The children were helped to use parts of the tree as prompts to tell their preferred identity stories in terms of the activities of their everyday life (ground); their skills, abilities and values (trunk); their stories of where they come from including their family histories (roots); the important people in their lives (leaves); and their hopes and dreams for the future (branches) (Ncube, 2006).

In retrospect, we recognised that we had not given the young people participating in our pilot bead programme a safe place to stand from which to tell and make meaning of their cancer story. As a result, we took more care to get to know Ravi apart from his cancer experience to enable him to tell his preferred story of self and thereby create a safe place for him to stand from which to tell and make sense of the cancer journey.

Getting to know the young person apart from the cancer

We live our lives according to the stories we tell ourselves and are told by others. The stories shape our lives, influencing what experiences we pay attention to, give meaning to and continue to incorporate into our evolving narratives (White & Epston, 1990). Thus, a narrative is like the thread that weaves together the events we live, forming a story that is constitutive, that forms and informs our sense of who we are and who we can become. When we meet young 'cancer patients' like Ravi, they commonly have a 'thin description', 'single-stranded story' or 'problem-saturated story' of themselves. It was not long before Ravi joined the doctors' and nurses' view of himself as a 'cancer patient' and moved from being a healthy 'football enthusiast' to a 'withdrawn hospital patient' and eventually a 'Hodgkin's lymphoma'. As the 'Cancer' identity slowly edged its way, obscuring Ravi's view of himself, he began to distance from his friends who were playing football, choosing summer music festivals and contemplating transitions to college. The cancer story began to dominate. Noticing this change in their son, Ravi's mother described him as 'a shadow of his former self', and his father kept shaking his head saying 'he is not my boy – he is like someone else'.

Our lives are multi-storied (White, 2005); for Ravi, the cancer is only one strand in the multi-stranded stories of his life. We saw the practice of beading as an opportunity to bring forth rich, meaningful, multi-stranded stories of those aspects of the young people's lives that lie outside of the influence of the illness so that the diagnosis, the symptoms and the effects of treatments do not become the dominant or even sole story of the young person's identity. Therefore, we developed the 'Beads of Life' methodology to 'get to know the child apart from the [illness]' (Freeman, Epston, & Lobovits, 1997), to introduce alternative threads to enable the young people to tell their preferred stories and bring together the rich and varied strands of their lives.

We aimed to provide young people with the opportunity to change their relationship with cancer so that it impacts less negatively on their lives, opening space for them to remember who they are aside from the cancer and develop positive views of themselves. We saw the possibility for this approach to enable young people to share experiences, recognise the people who support them and hence communicate their preferred story of themselves to important people in their network. We thought the approach could offer an antidote to the isolation that the cancer journey leaves in its wake as it interrupts young people's relationships and disconnects them from family and friends. We hoped that the approach could contribute to hope for the future.

'Beads of Life'² methodology

We introduced 'Beads of Life' to Ravi and Catherine, a 15-year-old girl receiving treatment for Ewing's sarcoma, a bone cancer. We explained that

Cancer can easily dominate young people's lives and make you forget about the other parts of your life that were important to you before; 'Beads of Life' gives you an opportunity to get to know other young people on the unit; it can help you remember the things you enjoy doing, and think about your hopes for the future.

Ravi's and Catherine's mothers joined to witness the activity.
The 'Beads of Life' method has five parts.

Part 1: 'Beads of Life'

We provide plates of colourful beads of different shapes and sizes and packs containing an envelope to store beads, twine for threading and colourful sheets to document stories in five sections (Figure 1). The young people choose their 'Life Beads' to represent different aspects of their life including the following:

1. *Daily Lives* and what helps them to keep going (interests and beliefs)
2. *Skills, abilities and values* (what they care about)
3. *Important people*, past and present and the acts of kindness or other gifts they have received from them
4. *Where I come from* (family, customs and culture)
5. *Hopes, wishes and dreams* for the future

To help Ravi and Catherine choose their *Daily Lives* beads, we asked whether they were at school or college, what they liked to do in their spare time and how they had fun. They attached each chosen bead with BlueTac onto the colourful sheet and then wrote next to it what that bead represented. Ravi chose a bead to represent football and another red and white bead for the colours of Arsenal, his football team (see Figure 1 for Ravi's beads).

To bring forth *Skills, Abilities and Values*, we invited young people to consider what others might appreciate about them, 'What do your friends say you are good at? What does your brother appreciate about you?' Ravi chose beads to represent 'scoring goals', 'cooking' and 'sense of humour'. Inviting young people to name what they 'are good at' often evokes embarrassment or concern about boasting. Therefore, we usually begin by asking them to select beads to represent their values with questions like 'Why do you choose to do [these activities]? What is it about [this activity] that interests you?'

We then asked Ravi and Catherine to choose beads to represent *Important People in their lives or their community* who had supported and sustained them as well as the *Gifts they received or Values* they learnt from these people.

Catherine chose a bead for her sister 'who holds the fort together while I'm in hospital' and one for 'my New Age mother who is always there for me'. When we explained that these important people could be alive or dead, a hero or a pet, Ravi contemplated adding Thierry Henry, his football hero. When invited to choose beads to represent *Where I come from*, Ravi chose beads for Finsbury Park, where he lives; Kerala, where his mother grew up; and a bead for 'Mum's cooking'.

When Cancer enters young people's lives, it can rob them of their hopes and dreams, of daring to think about their future. For teenagers, this comes at a time when all their friends are making decisions about their futures and forging their independence. We therefore ask young people to choose beads to represent their *Hopes, Wishes and Dreams*. This strand is very important as cancer often stops other people asking about the young person's future plans (Penn, 1985). When we ask about hopes for the future, we suggest they think of their future as tomorrow or next week, next month or next year. We may ask what they would like to do when they are older and point out that


















	1. Daily Lives
	Football
	Arsenal
	2. Skills & Abilities
	Scoring goals
	Cooking
	Sense of Humour
	Persistence
	3. Important people & their gifts
	Mum (always there for me)
	Jamie (Loyalty)
	Aisha (sister) keeps everyone smiling
	4. Where I am from
	Finsbury Park
	Kerala
	Mum's Cooking
	5. Hopes, wishes, & dreams
	To be a professional footballer
	Visit my family in America
	Overcome Cancer
	Dinesh (brother) to become a Formula 1 driver
	Arsenal to win the champions league

Figure 1. Ravi's life beads.

this is time for dreaming, not only about hopes for their own lives but also for others like their family, friends or community. Catherine picked beads to represent to 'be a beautician . . . get a tattoo . . . be successful and make my mum proud', and her mother suggested she add 'a clear bead – for your clear view of what you want in the future'.

Part 2: threading and thickening the preferred story

The aim of this part is to bring forth and build a detailed account of an alternative story (White & Epston, 1990) to the problem-saturated illness and medical story, a second preferred storyline of the young person's life that threads together stories of what they give value to, what they stand for, their skills, abilities, hopes, dreams and histories with the significant people in their lives.

Once the young people have selected their life beads, we invite them, one at a time, to take a piece of twine and thread each bead onto the twine. As they thread, we use the beads as a prompt to extend their descriptions into a storyline with questions like 'Can you tell me more about that?' 'How did you do that?' As they put the beads onto the twine, we draw the beads on the colourful sheet so that they have a record of what each bead represents. For example, as Catherine threaded the black and white 'music bead', we invited a thicker description of her story, asking whether she liked listening to or playing music and what kind of music she liked. We learned that Catherine had been lead vocalist in a band for 2 years and loved going to music festivals with her 'New Age' mother.

To further enrich their stories, we invite the young people to make links between the various stories in their lives. We ask about the history of these stories and who else features in them. We ask questions like 'How long have you had this ability/hope? Where does that dream come from? Who taught you that? Whom did you learn it from?' We further thicken their stories by bringing their, skills, values and hopes into relationships by asking

Who notices this skill? Who shares this interest/dream with you? Who else would know what you stand for . . .? Who benefits from this? Who supports you in this now? Who can tell a story about . . .?

Using these sorts of relationship 'who' questions enables the young people to identify significant figures in their life who hold stories and memories in which they demonstrated specific abilities, knowledge and values. This is intended to redress the individualising and disconnecting effects of a lot of the medical practices, incorporate the contributions of significant people in the life of the young person and identify potentially 'supporting audiences' to draw on later to witness the young person's experience. Summoning the voice of validating people with questions like 'Who would be least surprised at the strength you have shown?' makes it possible for the young person to reconnect with their skills and values that talk to them of the person they were and want to be.

Part 3: witnessing the telling and retellings³

For a story to live and breathe, it needs an audience. Illnesses like cancer often disconnect young people from audiences who might witness the stories they want told about themselves. Those present in the Beads of Life group provide one such audience to appreciate the young people's preferred versions of self. Therefore, we invite all in the group, young people, staff and parents, as witnesses, to identify something the young person said that was important, what they have learnt or valued from listening to their stories. They choose beads as '*Gifts*' to represent this (Carey & Russell, 2003; White, 2005). Catherine's mother gave her a flower bead 'because you are blossoming' and a bead with many parts 'because of all you have already achieved and the things you will achieve in the future'; Ravi's mother gave Catherine an 'A' bead 'because of your amazing attitude . . . you encourage me to carry on'. Hearing an outsider's view of their emerging stories can help the young people see their stories from another perspective and thicken some under-noticed aspects of the stories that they have told (Carey & Russell, 2003). The cancer journey can leave many young people with a sense of very little influence on their own lives, let alone the ability to influence the lives of others. Hearing the impact of their story on others and the contribution their story

makes to others' lives can be a validating experience that opens space for further positive developments of self (White, 2005).

Since the preferred stories that begin to emerge in the process of the Beads of Life are initially witnessed only by those present, they risk remaining fragile. Therefore, to extend the contexts of place and relationships for telling and witnessing, we ask the young person questions like 'Where will you put the beads? To whom do you want to show them? How do you want to use them?' to start the process of 'spreading the news' (Freedman & Combs, 1996). Taking their strands of colourful beads beyond the group has aroused curiosity among staff, other patients and families, thereby inviting the young people to tell and retell their preferred stories using their bead sheets to refer to as documents to further acknowledge the many rich stories of their identity.

Part 4: separating the young person from the cancer

Things happen which are not your fault. Before inviting the young person to tell their medical story, we discuss how problems can happen in any person's life and it is not their fault. We use beads as an analogy – they can be secure on a thread one minute and then suddenly the knots holding them can come undone or threads can snap and the beads fall off and scatter creating fuss and panic for everyone trying to pick up all the pieces. We clarify that this is not the twine's fault; it did not snap itself or ask to be undone. We talk about the Cancer in a similar way – it comes into people's life uninvited and creates problems so that like the beads, some parts of life come apart, get lost or the thread breaks. We emphasise that in the same way as the beads and twine, this is not the person's fault.

Externalising the cancer. Once we have created a safe place to stand for the young person, we ask whether we can talk about what has been happening since 'Cancer came into your life' and invite him or her to externalise and personify (White, 2007) the Cancer with questions like

Does an image or character come to mind that helps you describe the Cancer? Does the Cancer have a shape, colour or a voice? What name do you prefer to call it? If Cancer was sitting on an empty chair in this room, what would it be doing?

Cancer has isolating effects on young people, not only because many of the treatments confine them to isolation in their single cubicle with a limited number of visitors but also because their experiences during treatment differentiate and distance them from those around them. Finding ways to link individual experiences of life to collective experience and collective identity can provide a powerful redress to the isolation cancer creates for the young person (Denborough, 2009). Therefore, where possible, we try to offer this in a group, since we have found that externalising the problem with others facing similar challenges enables the young people to take a position on the problem together and share ideas and helpful responses.

Externalising involves a process of separating persons from problems. Thus, our intention was to help Ravi and Catherine to see the cancer as separate from themselves, thereby not defining of who they are as people. By creating a sense of distance between the Cancer and who they are, our intention was to enable them to see themselves in relationship to the cancer instead of having the illness (she has cancer) or being the problem (she is a cancer patient).

Part 5: 'Just Bead It' the cancer journey

We give each young person a different pot of beads and a new thread with which to tell the medical story as well as a new chart with three sections on it labelled 'Beginning, Where I am now? Where next?' (Figure 2). To position the young people as experts, we usually begin with questions like















1. Beginning	
	Finding a Lump
	Getting a diagnosis
	Anger
	Chemotherapy
	Feeling sick
	Watching lots of episodes of 'Game of Thrones'
F	Facebook
2. Middle	
	Hair Falling out
	Raising £300 in sponsored shave off
	Spending my birthday in hospital
	Susan baking me a cake
3. Where I am now	
	Only 15 days left of Chemo
	Enjoying mums cooking
4. What is next?	
	Less hospital appointments
	Getting on with my life

Figure 2. Ravi's medical beads.

‘Where does the cancer story start for you?’ or ‘Where do you want to begin this part of the story?’ and go on to ask ‘What happened next?’ We might invite young people to describe the ‘hazards or challenges [they] noticed Cancer can create’ or the ‘effects Cancer has had on [their] lives’.

Ravi began his story at the point he ‘found a lump in my neck’ and included

telling my mother . . . going to the doctor . . . getting antibiotics that did not work, . . . then the doctor said try acupuncture . . . until we had to beg to go to hospital for tests . . . they told me I got cancer.

He said he was ‘angry’ it had taken so long to get a diagnosis and he had to be so ‘persistent before they took me seriously’. I (S.P.) asked which of those parts of the story Ravi wanted to bead; he selected beads for ‘finding the lump’ and ‘getting diagnosis’. Returning to ‘angry’ and ‘persistent’ I asked, ‘Is Anger a good thing? Is it a skill of yours? Does it help?’ Ravi said he did not like ‘Anger’ since it made him ‘hot and bothered and . . . gets me into trouble’. He wanted to include it in his medical beads (rather than add it to his skills) and threaded a red spiky bead for ‘Anger’ on his cancer journey strand. Referring to his ‘Life Beads’ sheet, I noted that Ravi had not previously included ‘Persistence’ as one of his skills and checked whether he wanted to include it. He said he ‘forgot that one’ and chose an elephant bead for ‘Persistence’, threading it on to the strand of his preferred identity story.

Ravi continued to tell his stories of the cancer journey, choosing beads to represent some of the significant moments as he saw them including his first chemotherapy treatment, his hair starting to fall out, raising £300 at his sponsored ‘shave off’, spending his birthday in hospital and the cake a nurse, Susan, baked for him. I (S.P.) invited Ravi to move back-and-forth between the Life Beads (preferred identity) and Medical Beads (cancer journey) strands by asking questions like ‘How have you used your skill of Persistence to help you during [chemotherapy/your hair falling out]? Who taught you that skill?’ thereby weaving the two strands together.

Our ‘Beads of Life’ approach takes care to begin with separating the ‘preferred identity’ strand from the ‘cancer journey’ storyline. In this way, our approach differs from Narrative Exposure Therapy (NET) for post-traumatic stress (Onyut et al., 2005) that is based on the principles of cognitive behavioural exposure therapy. In NET, the child constructs a detailed chronological account of their story of the trauma with the therapist using a single rope to represent their lifeline. They place flowers to mark positive experiences and stones to mark negative and traumatic experiences along the same lifeline. They do not separate positive experiences and negative traumatic experiences or the effects of the trauma from responses to the trauma.

Distinguishing responses from effects

In medical contexts informed by deficit and illness discourses, doctors are trained to look at causes and effects (symptoms) of illnesses. Rarely do they ask about responses (Yuen, 2009), for example, ‘What did you do to make it better, to help, to cope?’ or even ‘What sense or meaning do you make of this?’ Thus, the doctors paid a lot of attention to Ravi’s reaction to the chemotherapy and his symptom of sickness for which they prescribed anti-sickness medication. They did not ask Ravi whether he had found any ways of coping with feeling sick or vomiting. The nurses and activity coordinator talked a lot about Ravi ‘oversleeping’ and passed on concerns about his ‘being withdrawn’ at each meeting; they did not ask how he spent his time when he was awake.

We start from the position that people always respond to adversity and implicit in their responses are skills, abilities and knowledge for which there is a social history (Denborough, 2009). Working from the premise that no young person is a passive recipient of the challenges imposed by the cancer journey and that they will be taking action to minimise their exposure to and the effects of the challenges, we try to tune into the young person’s responses, using ‘double listening’ (White, 2003) so that we can acknowledge and witness the effects of the illness as well as the second storyline, how they responded and the skills and knowledges they used. To help us notice, honour and richly describe people’s responses to challenges along the cancer journey, we ask questions like the following:

- How have you responded to these sorts of problems/challenges? How have you managed when things have been difficult?

- How have you used your skills/values to help you during your medical journey?
- Who has helped you along the way?

Thus, we learned that sleeping helped Ravi cope with feeling sick; watching past episodes of his favourite TV programmes helped distract from the nausea and contacting his friends on Facebook was 'keeping me sane'.

These stories of 'special skills' for getting through hard times are rarely told and may go unnoticed. Therefore, we try to draw attention to these responses to emphasise that negative effects of the cancer do not represent the whole story with questions like the following:

- What is the name of a special skill/knowledge/value that has got you through these hard times?
- What is the story about this skill?
- What is the history of this skill? How did you learn it?

Increasing the young people's awareness of these skills for dealing with hardship makes them more available for use in the future. Thickening these stories enhances their 'personal agency' (White, 2007) so that they experience themselves as people with knowledges not as victims.

The impact of Beads of Life

During 2013, 60 young people (29 boys and 31 girls) between the ages of 7 and 25 participated in Beads of Life on our unit in individual or group sessions. The group size varies between two and eight young people with at least two facilitators. When we explored the experiences and effects of participating in the approach (using questionnaires and semi-structured interviews), many of the young people gave us affirming feedback that the approach gave them a safe place to stand, noting that the 'beads make sessions very relaxed' affording an atmosphere of 'peace and calmness' that is 'therapeutic for the mind'. They also described the activity as 'fun' which helped them 'feel happy to talk about my worries . . . much more easily and naturally'.

They reported that although the facts of their lives did not change (for many the cancer was still present, they still had to endure the noxious treatments and spend inordinate amounts of time in hospital), what could change was which events in their life they emphasised, the meanings they attributed to their experience and the stories they told about themselves, thus influencing what could be possible in the future. For example, they told us that the Beads of Life 'helped me as I was going through treatment', 'made me remember things I did in the past', 'you get to know stuff about yourself that you didn't know before just by questions' and by 'understanding myself through beads . . . it helped me a lot, it made me stronger'. The parents told us that their children 'enjoyed exploring who he is and thinking about his strengths and abilities', 'all the things she did and the skills she developed before being diagnosed with cancer' noting that without 'thinking about achievements in this way, he would not be as strong as he is'.

The young people report that Beads of Life has helped them recognise support. They appreciated the opportunity to 'share things' and to 'remember all the important people – why they are important to me'. It also enabled the parents to see their children as 'blossoming . . . strong . . . still growing and developing ambitions after the cancer'.

Young people told us that storying the medical journey created a sense of 'order in the chaos of cancer'; 'when you look at all the beads connected and you look at what each of them means, you know where you started off and what you've been through'.

Crying and upset are often seen as symptoms of not coping and result in referral by oncology staff to psychological services. However, intensive psychological approaches are not always appropriate, necessary, practical or wanted during cancer treatment. Since the Beads of Life has been running consistently on our unit, the number of individual referrals to the cancer ward psychologist has halved. It seems that working in this way has enabled staff to witness the alternative stories not dominated by cancer so that when a child is 'upset' they begin to see this upset in the context of all the other stories in that young person's life that they are now aware of and thus respond to the young people with reasonable hope (Weingarten, 2010).

Since our practice is to invite the young people we work with to have the last word, we leave you with Ravi's feedback to us:

'Just Bead It' helped me express my feelings. My beads are at home, hanging over Thierry Henry's photo. People ask what it is and I say it is my life story. I explain what each bead means. 'Just Bead It' made me think about things more. Everything I put on the string made me think about all the medical stuff in a different and positive way. I could express how I feel. I don't really talk about things but I did through this. 'It is a helpful way of talking.

Acknowledgements

We thank all the members of staff at University College London Hospital who have embraced this way of working and have run groups in addition to their workload. Without their support, this project would not have flourished.

Ethics and patient consent

The young people mentioned throughout the article have had their names and identifying details altered to protect their anonymity. They have all given consent for their words to be quoted.

Funding

This work was supported by Rays of Sunshine that funded the beads and provided continuous support for the project.

Notes

1. We use a capital letter with 'Cancer' to highlight our intention to separate the Cancer from the person.
2. We named this approach 'Beads of Life' to acknowledge and honour the contribution of the 'Tree of Life' approach and to connect with other projects drawing on this approach, for example, Recipes of Life (Wood, 2012), Kite of Life (Denborough, 2010) and Team of Life (Denborough, 2008). The young people on the unit prefer the name 'Just Bead It' so that is the name we use in our hospital.
3. Witnessing happens at the end of Part 2 after 'Threading and Thickening Preferred Stories' as well as after Part 5, when the young people have beaded their medical stories.

References

- Anderson, H., & Goolishian, H. (1992). The client is the expert: A not-knowing approach to therapy. In S. McNamee & K. Gergen (Eds.), *Therapy as social construction* (pp. 25–39). Newbury Park, CA: SAGE.
- Baruch, J. M. (2010). *The beads of courage program for children coping with cancer* (Dissertation, University of Arizona). Retrieved from https://w3.nursing.arizona.edu/Library/Baruch_Jean_Dissertation.pdf
- Bruner, J. S. (1990). *Acts of meaning*. Cambridge, MA: Harvard University Press.
- Carey, M., & Russell, S. (2003). Outsider-witness practices: Some answers to commonly asked questions. *International Journal of Narrative Therapy & Community Work*, 2003(1), 3–16.

- Denborough, D. (2008). *Collective narrative practice: Responding to individuals, groups, and communities who have experienced trauma*. Adelaide, Australia: Dulwich Centre Publications.
- Denborough, D. (2009). The possibilities of collective narrative practice. *Context, 105*, 40–44.
- Denborough, D. (2010). *Kite of life: From intergenerational conflict to intergenerational alliance*. Adelaide, Australia: Dulwich Centre Publications.
- Denborough, D. (2014). *Retelling the stories of our lives: Everyday narrative therapy to draw inspiration and transform experience*. New York, NY: W.W. Norton & Company.
- Fredman, G. (1997). *Death talk: Conversations with children and families*. London, England: Karnac Books.
- Fredman, G., Anderson, E., & Stott, J. (2010). *Being with older people: A systemic approach* (1st ed.). London, England: Karnac Books.
- Freedman, J., & Combs, G. (1996). *Narrative therapy: The social construction of preferred realities*. New York, NY: W.W. Norton & Company.
- Freeman, J. C., Epston, D., & Lobovits, D. (1997). *Playful approaches to serious problems: Narrative therapy with children and their families*. New York, NY: W.W. Norton & Company.
- Kaseke, S. (2010). 'Standing together on a riverbank': Group conversations about sexual abuse in Zimbabwe. Retrieved from <http://search.informit.com.au/documentSummary;dn=581107456243504;res=IELHEA>
- Ncube, N. (2006). The tree of life project. *International Journal of Narrative Therapy & Community Work, 2006*(1), 3–16.
- Onyut, L. P., Neuner, F., Schauer, E., Ertl, V., Odenwald, M., Schauer, M., & Elbert, T. (2005). Narrative exposure therapy as a treatment for child war survivors with posttraumatic stress disorder: Two case reports and a pilot study in an African refugee settlement. *BMC Psychiatry, 5*(1), 7.
- Penn, P. (1985). Feed-forward: Future questions, future maps. *Family Process, 24*, 299–310.
- Stutzer, C. A., & Gove, S. (2000). Creating meaning: A bead program for children with cancer. *Journal of Pediatric Oncology Nursing, 17*, 100.
- Weingarten, K. (2010). Reasonable hope: Construct, clinical applications, and supports. *Family Process, 49*, 5–25.
- White, M. (2003). Narrative practice and community assignments. *International Journal of Narrative Therapy & Community Work, 2003*(2), 17–55.
- White, M. (2005). Children, trauma and subordinate storyline development. *International Journal of Narrative Therapy & Community Work, 2005*(3/4), 10–22.
- White, M. (2007). *Maps of narrative practice* (1st ed.). New York, NY: W.W. Norton & Company.
- White, M., & Epston, D. (1990). *Narrative means to therapeutic ends* (1st ed.). New York, NY: W.W. Norton & Company.
- Wood, N. R. (2012). Recipes for life. *International Journal of Narrative Therapy & Community Work, 2012*(2), 34–43.
- Yuen, A. (2009). Less pain, more gain: Explorations of responses versus effects when working with the consequences of trauma. *Explorations: An E-Journal of Narrative Practice, 1*, 6–16.

Author biographies

Sara Portnoy is a consultant clinical psychologist at University College London Hospital where she manages the psychologists working with young people with a diagnosis of cancer. She is also the lead psychologist at Life Force, a community paediatric palliative care team.

Isabella Girling is a trainee clinical psychologist at the University of East London. In her previous role at University college London Hospital she supported the development of the Beads of Life project.

Glenda Fredman is a consultant clinical psychologist in systemic psychotherapy and director of systemic training with Camden and Islington Mental Health Trust, London, UK.