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Title: Discursive constructions of youth cancer: findings from creative methods research with healthy young people

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Abstract:

Purpose: As part of work to understand the experiences of young people who had cancer we were keen to examine the perspectives of peers who share their social worlds. Our study aimed to examine how cancer in young people, young people with cancer, and young cancer survivors are represented through language, metaphor, and performance.

Methods: We generated data using creative activities and focus group discussions with three high school drama classes, and used Foucauldian discourses analysis to identify the discursive constructions of youth cancer.

Results: Our analysis identified two prevailing discursive constructions: youth cancer as an inevitable decline towards death and as overwhelming personhood by reducing the young person with cancer to ‘cancer victim’.

Conclusions: If we are to understand life after cancer treatment and how to support young people who have been treated for cancer, we need a sophisticated understanding of the social contexts they return to. Discourses shape the way young people talk and think about youth cancer; cancer as an inevitable decline towards death and as overwhelming personhood are key discursive constructions that young people draw on when a friend discloses cancer.

Implications for cancer survivors: The way cancer is constructed shapes how friends react to and relate to a young person with cancer. These constructions are likely to shape challenging social dynamics, such as bullying, that many young cancer survivors experience. Awareness of these discursive constructions can better equip young cancer survivors, their family and health professionals, negotiate life after cancer.

Discursive constructions of youth cancer

Keywords: cancer; survivorship; return to school; young people; representations; discourse analysis; creative methods

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Cancer in young adults

Cancer in adolescents and young adults aged 15 – 29 years is relatively rare, accounting for just under 2% of all new cases diagnosed in Australia between 2003 and 2007 [1]. A small proportion of these young people (approximately 11%) died from their cancer [1]. It is most likely, therefore, that young people diagnosed with cancer will be cured following treatment and will survive long-term. Survivorship brings new physical effects [2, 3, 4], and psychosocial challenges.

Young people undergoing cancer treatment can spend considerable periods of time away from their usual social world as a consequence of recurrent hospitalisations, outpatient care and convalescence at home. Returning to school, university, sporting teams and other peer groups can represent a unique set of challenges. In particular, young survivors experience social dislocation, a sense that they have less in common with their peers or that they have ‘stagnated’ while their friends have moved on to new phases of life [5]. Cancer survivors often miss considerable periods of formal schooling, a range of experiences of daily life and rites of passage associated with adolescence [6,7]. They may become out of step in other ways; for example, gaining an unusual level of maturity through facing serious illness and the real prospect of death [3]. These social disruptions are especially problematic for young people who were school students at the time of their diagnosis - when peer-relationships are at their most intense [6]. School is a highly normative, regulated environment and we know young cancer survivors are sometimes reluctant to disclose their diagnosis for fear of being stigmatised and bullied [8, 9, 10].

Our recent work with young people with cancer has focused on the relational aspects of growing up with cancer (<http://sydney.edu.au/GUWC>). Our findings indicate that cancer illness and treatment profoundly changes relationships between young people and their peers, and can shape the way young people establish and develop new friendships and intimate relationships. The ways cancer experiences changed relationships varied but for all of the young people in our study, cancer marked them as “different”; different to the person they were before diagnosis and different to their peers [11]. To better understand the experiences of young people with cancer we were keen to examine the perspectives of peers who share their social worlds. We know for example that ‘School re-entry and social interactions with peers are among the key factors that influence children’s academic

advancement and achievement of normal psychosocial maturation'. Yet we know little about the perspectives of these peers.

Our aim was to identify the discourses (or discursive constructions) about cancer and young people that peers draw on when they encounter cancer in people of their own age. We are drawing here on a Foucauldian discourse analysis approach – a methodology that is “concerned with language and its role in the construction of social and psychological life” [12, pg112]. A discourse is a set of coherent statements or knowledges that construct youth cancer in specific ways, makes available particular ways of talking about and experiencing youth cancer, and provides positions from which individuals can experience themselves or perceive others [13, 14, 12]. In this case we were interested in identifying the specific knowledges available to and used by young people who are peers of Australian young people with cancer.

Representations of cancer

Research exploring the symbolic meanings of cancer has looked to representations of cancer in the mass media [15], pharmaceutical advertising [16], and film [17]. Analyses like this have made cultural representations of cancer obvious, and in particular the way metaphor is used to make sense of cancer [15]. An analysis of the British press, for example, found ‘cancer is war’ the most common metaphor [18]. This way of conceiving of cancer typically features heroes (the patient), enemies (cancer), allies (medical and allied health staff), and weapons (chemotherapy) [15, 16, 19, 18]. There are battle casualties - those who do not survive - and miraculous survivors who are represented as heroes in media good news stories [20]. Sporting metaphors, where cancer is described as being like climbing a mountain or running a marathon, are less common [21]. Cancer is also represented as a journey a patient takes on a path to enlightenment (or some other advanced destination) with ‘trials’ and ‘road blocks’ and the need for ‘U-Turns’ [16].

Discursive constructions have consequences for people. They make available subject positions for the people drawing on them [22-24]. Lupton has argued that the battle metaphor instils fear and disempowers women with breast cancer [15]. Reisfield [16] notes that this metaphor suggests winning the battle is simply a matter of fighting hard enough; a position that leaves those who lose their battle positioned as failures. The cancer ‘fear’ or ‘enemy’ metaphor also seems to be (paradoxically) detrimental in motivating prevention practices. A recent experimental study found framing cancer as ‘enemy’ reduced the likelihood of people spontaneously listing – or

having an intention to engage in – prevention practices that involved limiting their behaviour (reducing alcohol, high fat and red meat intake) [25]. The authors argue this is because self-limiting behaviour does not sit well with the action orientation of the war metaphor. Although encouraging people to ‘fight’ cancer seems a good way to increase their likelihood of imagining or intending to engage in pro-active prevention practices (such as eating fruits and vegetables, eating foods high in fibre, eating foods made of whole grains), it had no effect.

Despite a growing literature on cultural representations of cancer and work demonstrating the framing of cancer has consequences for experience and behaviour, we know very little about discursive constructions of cancer in adolescents and young adults. This is the motivation for the analysis we present in this paper.

Methods

Participants

We conducted focus groups with three high school drama classes: 15 x 12 to 14-year-olds (high school year 7 and 8), 15 x 14 and 15-year-olds (high school year 9) and 12 x 16 to 18-year-olds (high school year 12).

Participants were students at a non-denominational co-educational Christian school that teaches preschool to year 12 (final year of high school). It is a moderately sized school with around 500 enrolments and 50 teaching staff, located in the western suburbs of Sydney, Australia.

This school was selected for a number of reasons. First, a member of the research team had an existing relationship with a drama teacher at the school - making it more likely that we could achieve effective engagement with students, parents and school administration. Second, we knew the planned research activity was consistent with creative activities usually undertaken in this school’s drama classes – making it less likely that students would be daunted by the creative process. And finally, there was no methodological justification to prefer recruitment of students from a government school over students from an independent high school, or from different geographical regions.

Data collection

A focus group method for data generation was an appropriate choice as we were interested in cultural representations of youth cancer. However, we had several concerns about the utility of focus groups for researching this topic. Group discussions might simply produce platitudes, or make it difficult for young people

to express socially unacceptable notions about youth cancer. More pragmatically, young people with no personal experience of youth cancer might not find the topic engaging. Finally, we were concerned that school-teachers and administrators would not see any value in supporting focus groups being conducted with their students. We addressed these concerns by integrating creative methods into the focus group strategy [26]. We have previously used creative methods in conjunction with interviews to encourage young people to represent their experiences of growing up and having cancer [[11]; see also <http://sydney.edu.au/GUWC>]. The use of creative methods allowed us to make discursive constructions of cancer more relevant to the school curriculum – and so more interesting to both students and teachers/administrators. In both the creative methods and focus groups we were inviting young people to imagine the life of a young person their age with cancer. The creative activities sought to reveal already circulating ideas about youth cancer, while the focus groups allowed us to explore with young people what they thought about these representations.

We engaged with a local high school drama teacher and developed a performance task that mirrored a format students were familiar with: scripting a short performance to a brief and then reflecting on their performances. Our data collection sessions were constrained to two hours by the length of the usual drama class, and scheduled for the end of the academic year. At each session we put students into four groups and asked them to prepare a 2-3 minute television news story about a young person of their age who had had cancer. We encouraged them to be creative in their performances and gave them examples: a segment about a young person triumphing over their illness by succeeding in sport, having a baby, or going to university; a celebrity interview with an actor or pop star who had had cancer when they were younger; or an exposé on a young person experiencing school bullying after returning to school. We gave them explicit permission to make the performance serious, silly, sad, funny or outrageous. They had 20mins to develop the performances; the drama teacher and researchers circulated during this time to provide guidance. The drama classroom had minimal props available for the students to use. The groups performed their piece in front of their class; performances were generally to time and all were digitally videoed.

After the performances we conducted a single focus group discussion with each class group, that is, with 12 to 15 students. These discussions were audio-recorded and lasted 30-45 minutes. Focus groups began with a reflection on the performances, what they told us about the different ways of depicting young people with cancer and how they made participants feel. We also asked participants to tell us how much like the real life of

young people with cancer they thought the representations were. After the focus groups we spent a short time debriefing about the 'reality' of cancer in young people, in particular diagnosis and survival rates.

Ethics

We secured ethical approval from the University of Sydney Human Research Ethics Committee and permission from the school principal. In advance of data collection we provided information letters to the school for students to take home to parents/guardians, and a separate letter for the students themselves. To participate in the study, students had to provide signed consent from themselves and their parent/guardian to their drama teacher prior to the relevant drama class. A few students (or their parents) declined to consent; their drama teacher organised alternative activities for these students.

Analysis

We began by making detailed descriptions of the content of the performances, paying particular attention to the setting, characters, mood, and action. We captured verbatim language where it seemed particularly salient. We also made interpretative notes about what we thought was going on in the performance. Our Foucauldian discourse analysis followed the steps set out by Willig [12]; identifying how youth cancer and young people with cancer were constructed; exploring differences between constructions; considering the subject positions various constructions make available - the opportunities for action they open up or close down; and finally, describing the consequences for our participants' subjective experiences. Given our broader focus we also examined the implications of these constructions for young people affected by cancer.

We analysed the performance data first and then the focus group data. We asked the same questions of each: how are cancer, young people with cancer, cancer survivors being talked about or represented; what metaphors and language are participants using; what 'objects' and 'subjects' [13] do the language, metaphors and stories produce. In our analysis we were interested in exploring how young people can and do make sense of youth cancer, rather than seeking to make claims about how common these ways of representing young cancer survivors were. Through this process we identified three initial constructions of youth cancer: cancer as a trajectory towards inevitable decline; cancer as overwhelming; cancer as emotional disconnection. Through further close reading of the two data sets together and refining these constructions we identified the two central constructions of cancer examined below.

Results

There was a relatively limited range of characters across the 12 performances; all but one featured an actor playing a young person who had cancer. Ten included a TV interviewer, personality or celebrity; the others were narrated by parents and one was a reality TV show in the style of the American courtroom show *Judge Judy*. Nine performances featured immediate family members, usually a parent, and they were usually the character doing the talking. Five performances featured a clinician of some kind, usually a doctor. Other characters included a school bully, a friend of a young person with cancer, a 'do-gooder', and a TV production crew.

One discursive construction of youth cancer dominated the performances and the focus group discussions: cancer overwhelms all aspects of the life of a young person affected by cancer. Within this, cancer was represented as an *inevitable decline towards death* and as *overwhelming personhood* by reducing the young person with cancer to 'cancer victim'.

Cancer as an inevitable decline towards death

Ten out of the 12 performances followed a 'script' of cancer diagnosis, upheaval, and deterioration. This linear trajectory was occasionally interrupted when a young person rallied, giving hope for improvement to parents and clinicians, before returning to a seemingly inevitable decline. In this script cancer physically overwhelmed the bodies of young people. In performances they were shown crying or silent, holding on to a parent or sitting at their feet, and physically small or squashed, as though the cancer was overwhelming their very existence. In focus groups, participants spoke of cancer bodies as thin, pale or '*fragile*'.

In the student performances only two young people with cancer were cured and survived. In the others, four young people were dead or dying, four were alive but their prognosis was ambiguous, and two were on the road to recovery but survival was not assured. The following insight from a year 12 focus group participant demonstrates the power of this particular discursive construction of cancer, whereby a cancer diagnosis in a piece of fiction is symbolically saturated by death:

...like [cancer's] kind of like a doomed thing, that's why you can implement [it] in many fictional pieces because it's kind of like, soap operas, because it's kind of signalling a death

(Year 12 focus group; 16 to 18-year-olds)

We saw the same construction of cancer as an inevitable decline towards death in the focus group discussions. Cancer was talked about as a frightening and sudden diagnosis producing uncertainty and insecurity about the present and the future, followed by death. The following extract demonstrates this – the uncertainty here is around when, and not if, young people with cancer die.

Participant: And sometimes with cancer, it's like you're waiting for them to die.

Participant: Yeah.

Participant: Yeah.

Participant: Yeah.

Participant: It feels like there's no hope because it's pretty hard to stop.

(Year 9 focus group; 14 and 15-year-olds)

Cancer could also overwhelm life by extinguishing the desire to live. Participants in one focus group spent considerable time talking about this, about young people being '*completely broken*' by cancer:

Participant: Yeah. I don't think I could - actually I don't think I could deal with having cancer because I just would just – because - - -

Participant: You just - - -

Participant: It's just something, you know it would just be – it'd be like having something so heavy dropped on you. It'd be like I would not

Participant: It changes everything. Absolutely everything.

Participant: I would just give up.

(Year 9 focus group; 14 and 15-year-olds)

As part of our analysis we consider how discursive constructions open up or close down particular ways of seeing the world or opportunities for action [12]. The consequence of this construction of youth cancer was that it rendered giving up an entirely understandable reaction. This is a striking antithesis of the discourse of positivity/positive thinking that usually infuses talk about cancer [27]. Even more strikingly, the unequivocal

expressions of ‘defeat’ and giving up, like suicide – an especially transgressive act for a group of students at a religious school – became not only comprehensible but a possibility that students would consider supporting:

Like if they say, ‘go and get me this medicine because I want to kill myself now’, like are you going to do that because that’s what they want you to do?

(Year 9 focus group; 14 and 15-year-olds)

When talking about ‘cancer as an inevitable decline towards death’, participants were acutely aware of its significance for young people; their futures had moved from undefined to certain death.

...even if you’re 15 you don’t think you’re like going to die soon. You think you’ve got a solid like 60 years or something left in me. Like I’m not going to worry about that stuff. So to find out that that was – that whole kind of branch of unknown things and the rest of your life has just been completely closed off. That would be pretty awful to just know that like your future – well I mean you don’t know but it would be really hard to swallow I reckon.

(Year 9 focus group; 14 and 15-year-olds)

The discursive construction of cancer as inevitable decline towards death made a particular ‘subject position’ available to young people with cancer, their families and their health care providers in very particular ways [12]. In most performances young people and their families were portrayed as powerless to resist the inevitable decline that cancer rendered. In the focus groups this tended to be talked about as the lack of control over cancer. In both data sources, there was a proliferation of the familiar battle metaphors and allusions to ‘fighting’ the disease. Typical ways of heroically striving to resist (the inevitable) decline portrayed in the performances included remaining positive, having religious faith, persevering throughout the struggle and turning away from or supplementing traditional mainstream medicine.

There was a sense here that cancer pushed both people (young people and their families) and modern medicine to its limits; this discursive construction opened up an opportunity for action [12]. Specifically, it made understandable when young people (their family or health care providers) took seemingly ridiculous actions such in one performance where they placed hope in a ‘miracle cure’ for cancer derived from a Blue Ringed

Octopus. Even when these actions bordered on harsh they were rendered understandable within this discursive construction; as one focus group participant reflected after a performance: *'Yeah, awful maybe, but I'm thinking if my daughter had cancer and I thought beetroot juice could help, I would force it down her throat'*(year 12 focus group; 16 to 18-year-olds). The 'extreme' actions portrayed in the performances were rarely successful, making these stories of heroic failure. The 'last resort' in the face of cancer for some students was not medicine but the will of God; perhaps unsurprising given this was a sample of students from a religious school.

When you've got people like Annabel and their parents, they concentrate so hard they change her entire diet, and doing this and doing that and like just so she can get better, but in the end she still died. And I think no matter what you do, you don't have any control. It's just based on faith. Yeah.

(Year 12 focus group; 16 to 18-year-olds)

As expected, young participants talked openly about the physical changes that cancer illness and treatment can cause, in particular hair loss. But we saw an interesting reaction against the usual positioning of hair loss as an understandable source of distress. In one year 12 performance, a soap opera couple argued: Leticia was distressed about how her lover would react to her cancer: *'will you still love me when all my hair's gone?'*

Participants reflected on this in the discussion afterwards:

Participant: Kind of shallow - people who care about their appearance more than anything else really.

Participant: But I suppose for example, you see bald men, I'm not sure how often you see bald women. So I guess that if you were a woman or even both sexes, if you did get cancer I guess, one of the things that you could worry about, which is kind of sad, like one of the first things you could worry about is, maybe I'm going to lose my hair.

Participant: I guess it comes back to what we were kind of talking about before, like they understood that it was a problem, but really what they were focusing on there was the physical kind of losing of the hair. So there was this big massive, big hype about this big kind of thing about cancer is bad, but really, what they were kind of drawing on was that it's - - -

Participant: It's like there was more fear in treatment rather than the cancer itself.

Participant: Yeah, but just kind of like a lack of understanding of where the problem really lies, even though it is a problem where everything is - the real problem is that Leticia could - - -

(Year 12 focus group; 16 to 18-year-olds)

This criticism of distress at hair loss can be understood simply as a kind of unsympathetic misunderstanding of why young women (in this case) might be distressed about changes in their appearance following cancer. But a Foucauldian discourse analysis asks us to trace the consequences of discursive constructions [12]. The silent ‘die’ at the end of this utterance ‘*the real problem is that Leticia could - - -*’ suggests a more compelling reading within the construction of cancer as an inevitable decline towards death: if death is inevitable then worrying about your appearance does seem to be shallow, sad, the ‘wrong’ thing to worry about. It’s not the “real problem”. While worrying about your appearance would be understandable within a discourse of youth, for example, here it was rendered incomprehensible.

Counter constructions to decline and death were rare. Indeed, this construction was so taken for granted that stories of people who had survived cancer – what one year 12 focus group participant called a ‘*shining story of cancer*’ – were positioned as miracles – ‘*It’s a pretty big miracle*’ (year 9 focus group; 14 and 15-year-olds), and their protagonists as heroes:

...I guess the reason why it’s seen as such a huge thing is because like people who say that they’ve overcome cancer and all that are seen as heroes because there’s not really much of a cure or anything like that. A survivor is sort of seen as somebody who’s overcome this great big mysterious like fatal disease

(Year 12 focus group; 16 to 18-year-olds)

Cancer overwhelming personhood

The most surprising feature of the 12 performances was that despite being given a brief to tell a story about young people with cancer, these protagonists were often silent or absent. Five of the 13 young people with cancer featured never spoke. One performance featured no young people with cancer at all. And in the performances we repeatedly saw examples of young people whose value was entirely as symbols of cancer, ‘props’ for stories about youth cancer. The subject position available within the discourse to young people with

cancer granted them few opportunities to speak or act [12]. Our participants were sensitive to this reduction of individuals with cancer to ‘cancer victim’.

One year 12 performance was an excellent example – and commentary – on this: a TV director making a program about a young man with cancer says: ‘*we need something schmaltzy so we’ve gone for the old surviving cancer*’. A reporter is shown physically moving the program’s subject (a young cancer survivor) around, complaining about how happy and well he looks, and repeatedly getting his name wrong. The reporter admonishes himself to use his serious face, cries when filming starts, and ceases crying when filming stops. The young man with cancer never speaks and is never directly engaged by any of the crew. In the subsequent focus group discussion, the participants talked about the young man’s reduction to ‘cancer patient’, a useful prop for the story:

Participant: It’s all the same. The reporter and the director, it was kind of like not even really treating Jeremy as a person.

Participant: They were treating him as a cancer patient. And that’s the kind of melodrama that’s developed.

Participant: Actually it’s a prop.

Participant: Yeah, yeah, yeah.

Participant: It was you that worked in tears yourself. You didn’t actually engage with the person to work up your tears.

(Year 12 focus group; 16 to 18-year-olds)

The performer of another piece described it as the story of ‘*little Annabel Harvey and her fight with cancer*’. This featured Annabel’s parents, siblings and teacher talking about Annabel, or at least about her cancer, while Annabel herself was physically present (curled up in a ball on the floor, never engaging with the camera) but entirely silent. In the subsequent focus group discussion, participants reflected on this loss of personhood:

And even in ours, when I was sitting next to them, and it was kind of like I was hushed and I was told to be quiet and I was in the background out there, they were still talking about me as though I was this non-existent sort of like person that’s voice doesn’t - - -

(Year 12 focus group; 16 to 18-year-olds)

Only in four performances did a young person with cancer play a central role and talk about their experience. Here they were depicted by the actors as doing something brave or inspirational - such as raising money for cancer research or fighting to bring a charlatan doctor to justice. In one year 7/8 performance, a young woman narrated her own journey from diagnosis to her eventual death 'live' on TV. Even in these performances, therefore, young people were only of note – they could only be recognised – because of their cancer. The discursive construction of 'cancer victim' or 'cancer survivor' became their central or defining experience and had major consequences for their subjective experience [12]. The year 12 focus group participants in particular were very tuned in to the loss of self to cancer; it came up in multiple performances and during their post-performance reflections:

... so you're not having, actually being able to separate the difference between a person and cancer, you know what I mean. So rather in that particular story, that the mother was going over the top kind of way of showing that all she saw was the cancer in her daughter.

(Year 12 focus group; 16 to 18-year-olds)

...so it's just kind of like even if you've recovered, it's like you are cancer. You were cancer once and so it's kind of I guess it would be difficult to kind of return to just a normal kind of life like ours because everybody has that kind of media push idea of you have/had/cancer.

(Year 12 focus group; 16 to 18-year-olds)

We see this discursive construction acting in similar ways during the year 9 focus group discussion. Even as the young participants imagined that they would need their friends if they themselves had cancer, they were weighing up whether they would disclose cancer to them: *'But I wouldn't want to tell my friends, because what if they start treating me different'* (year 9 focus group; 14 and 15-year-olds). That is, they worried that their friendships would become organised around cancer. This led to a discussion about how to behave towards a friend with cancer:

Participant: It would also change the way like people acted if someone got cancer. You wouldn't want - if you were a mum and your daughter got cancer, and you guys used to fight all the time, you wouldn't want your last conversation to be about how you hate each other or something like that.

[...]

Participant: Not just your families. Like you have a massive fight with your friend, but then you discovered they had cancer, you'd want to make up and be friends with them before they die.

Participant: Definitely.

Participant: But you don't want everyone to be like, you've got cancer I'm not going to give you my opinions. Or I'm not going to argue with you. And I'm just going to let you have your own way.

Participant: Yeah.

Participant: No way.

Participant: It's kind of a bit of a balance of - - -

Participant: Yeah.

Participant: - - - what you say and what you don't say. I think.

Participant: But if you only makeup with them because they have cancer - - -

Participant: Yeah.

Participant: - - - that's not really a good reason to make up with them.

Participant: What I'm talking about – what I'm talking about is you'd want to watch the way you acted around them. So that you wouldn't like hate them when they died or anything. But I'm not saying that you'd just give them everything they want. You'd just be careful about what you said.

(Year 9 focus group; 14 and 15-year-olds)

There are a few things to note in this interaction. Although they imagined not wanting to be treated differently themselves, the participants were doing exactly this to the imagined other in this interaction. This imagined friend was no longer someone with whom they have a history or established ways of relating to. They became simply someone who has cancer, and as we have already seen, young people with cancer die. This rendered

friends morally obliged to be nice to them. This is an example of the way the two discursive constructions of cancer we have presented acted to shape the “psychological realities” of the young participants [12].

Discussion

In this research we were interested in how cancer in young people, young people with cancer, and young cancer survivors are represented through language, metaphor, and performance. This is valuable work; discourses shape the way we talk or think about youth cancer, they provide positions from which to experience the self and others and produce opportunities for action [12-14]. If we are to understand life after cancer treatment and how to best support young people who have been treated for cancer, we need a more sophisticated understanding of the social contexts they return to.

An inevitable decline towards death

One of the most striking things about the ways participants in our study constructed youth cancer was that it inevitably ended in death. This is striking because it simply does not reflect the reality of youth cancer in Australia: young people aged 15 – 29 years diagnosed with cancer have a very high chance of survival, with five-year relative survival rates for this age group increasing from 80% to 88% between 2003 and 2007 [1]. The reasons why this perception of inevitable death was so evident and so strong in our data are unclear. While we have not conducted a historical analysis of the emergence of these discursive constructions, our Foucauldian approach encourages us to consider the resources and wider discourses that these constructions draw on [12].

One explanation is the absence of knowledge - high survival rates may not be well known because cancer in this age group is so uncommon (making up just under 2% of all new cases diagnosed in Australia between 2003 and 2007 [1]). In this regard, it is noteworthy that others have identified the absence of incident and mortality data in news coverage of cancer. A content analysis of 2003 US newspapers finding only one in 20 stories reported mortality data [28]. Similarly, an Australian resource for friends of young people with cancer, where one might expect to find such information made explicit, says only that: “Most cancers can be treated and survival rates are increasing all the time” [29].

None of the participants in our study personally knew a young person who had been treated for cancer. That is, their constructions of youth cancer drew not on personal experience but from cultural sources. In Australia,

representations of youth cancer come through fundraising by youth cancer support organisations and public health promotion, generally around skin cancer prevention, directed at young people. At the time of data collection there had been no recent fictional portrayals of young people with cancer; none of the focus groups mentioned films or television programs about youth cancer. Nor did our participants mention Australia's most well-known youth cancer survivor, pop singer Delta Goodrem. The relative absence of representations of youth cancer and absence of mortality data suggests that young people's construction of cancer as ending in death for young people is derived from discursive resources about *adult* cancer.

This is important because, in contrast to representations of youth cancer, contemporary representations of cancer in adults inevitably link cancer with death. A recent analysis of Hollywood movies that portray cancer showed that cancer was a death sentence; all the characters with cancer died or were about to die [17]. This echoes the observation by one of our participants that in fiction, cancer is used to signal death. The 2014 Hollywood movie about youth cancer, *The Fault in Our Stars* [30], caused some concern among clinicians because of its 'unrealistic' portrayal of the low likelihood of survival [31]. The overrepresentation of death as the outcome of cancer in young people by the entertainment industry, and the relative absence of mortality rates in news reports, underscores the importance of "cultivating accurate illness representations" [28]. This is not a simple matter, however, as the public representation of cancer, particularly in young people, is heavily inscribed with social and political meaning. When Dr Charles Hemenway raised concerns about *The Fault in Our Stars*, it produced a backlash from parents who felt he had downplayed the incidence of childhood cancer and overplayed the likelihood of survival [32]. How one talks about cancer in young people in ways that doesn't create panic, while also acknowledging the devastating experience of cancer for an adolescent or young adult with cancer and their friends and family, is not straightforward.

A Foucauldian analysis asks us not only to identify the constructions of youth cancer circulating, but also to consider the implications of these discursive constructions for subjective experience and for practice [12-14]. If it is these discursive constructions that young people turn to when they seek to make sense of a friend dealing with cancer, what might be the effects of the idea that cancer in young people inevitably leads to death?

Young people's distress at the bodily changes wrought by cancer and cancer treatment and how this will be perceived by others is widely reported in the literature [33]. A recent Australian study of young people who had

had cancer found nearly half had returned to school bald and half of these respondents felt concerned about this [34]. This degree of concern is unsurprising, not only because of the impact that these physical stigmata of cancer may have on the young person's confidence or self-esteem, but also because hair loss, scars, amputations and other physical markers of cancer or cancer treatment may expose young people to bullying by peers. A Finish study of children who had had cancer found they were three times more likely to have been bullied than students in a control group, or than their siblings [10]. Our analysis provides an explanation for these findings: some participants in our study framed distress around physical appearance as shallow or sad – simply the wrong thing to worry about when death was inevitable. While it is important not to overstate the significance of our results, this does suggest that the construction of cancer as an inevitable decline towards death may be relevant to the creation and maintenance of the social processes around bullying. For school reintegration programs focusing on peers, this may prove a fruitful path for intervention.

Overwhelming personhood

Young people who have had cancer tend to see themselves as more or less the same person as they were before cancer, but as having experienced personal growth or become more 'mature' as a result of their experience [35, 36, 11]. As a consequence, these young people want both the consistency of their identity and the changes they value recognised by others. But relating to a friend who has had cancer as the same person, while acknowledging the ways in which they may also be different, is not an easy undertaking; something our data demonstrates acutely. The young participants in our study were surprisingly sensitive to the ways in which cancer could overwhelm personhood. They embodied through their performances and described in their discussions the various ways in which this functioned – a mother losing sight of her daughter as a person and relating only to her cancer; a news program turning an individual's cancer experience into entertainment. And even when we explicitly requested the participants in our study to make a young person with cancer the central character in their dramatisation, both the imagined young person and our young participants became subject to a discursive construction within which it was hard to even envisage a self beyond cancer. That is, the subject position available to young people with cancer with the youth cancer discourse, grants them few opportunities to speak or act beyond 'cancer victim' or 'cancer survivor'. This finding has major implications both for formal school reintegration programs and for the provision of less formal support for young people returning to their usual social worlds following cancer treatment. Specifically, these results suggest that alternative constructions of young people who have had cancer (counter-discourses [12]), in the media or in support resources, may help

peers imagine ways of relating to young people who have had cancer that do not position them simply as 'victims' of cancer.

Missing discourses?

We do not wish to suggest that all young people think about youth cancer in this way, nor that this is the only way to think about youth cancer. And there is value in attaining a sense of the currency of this discourse. Further research could look for evidence of it in cultural material, but also use survey methods to examine the extent of it across demographic differences. Our argument is simply that the constructions of cancer as an inevitable decline towards death and as overwhelming personhood were the prevailing way that our young participants made sense of youth cancer. There are some notable absences in the performances and the subsequent focus group discussions. Despite reports that young people returning to school face myths that cancer is contagious, we saw no evidence of this in our data. Indeed, none of the performances touched on the causes of youth cancer, perhaps pointing to a perception that, in contrast to adult cancer, cancer in young people is unpredictable and not due to lifestyle.

Just as conspicuous by its absence was the relentless discourse of hope and positivity that is so prominent around adult cancer [16]. Lupton describes the pressure applied by this discourse: "To despair, to lose hope, are frowned upon as strategies of dealing with diseases such as cancer. People with cancer are lauded if they appear to be brave, never allowing themselves to 'give in' to the disease." [15 pg67]. Barbara Ehrenreich's more recent work on breast cancer charts the continued insistence on positivity and positive thinking in the social environment of cancer [27]. In our data, hope was only evident when connected to 'miracle cures' or stories of 'miracle survivors'; death was inevitable in the discourse of youth cancer. Even while the imagined young person with cancer was alive and undergoing treatment, there was an absence of optimism; cancer emotionally overwhelmed young people, extinguished their will to live and would ultimately killed them.

Conclusion

In this paper we examined the perspectives of young people who share the social worlds of young people who have or have had cancer. We identified two prevailing discursive constructions: youth cancer as an inevitable decline towards death and as overwhelming personhood by reducing the young person with cancer to 'cancer victim'. These findings are important because the way cancer is constructed shapes how friends react to and

relate to a young person with cancer. Ultimately, knowledge of these discursive constructions will help young people as they return to school and other social settings following cancer treatment.

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