

# “Little Annabel Harvey and her fight with cancer”

## Healthy young people’s representations of youth cancer



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### Background

Our recent work on the Growing Up with Cancer project showed that a cancer experience profoundly changes relationships between young people (YP) and their peers. YP can experience a sense of social dislocation as peer groups move on, important social markers are missed, or YP develop different life priorities. As part of understanding these experiences we were keen to examine the perspective of the peers who occupy the social worlds that YP return to after cancer treatment.

### Aim

To investigate the cultural discourses or representations about cancer and young people circulating among adolescents.

### Methods

We engaged with a local high school drama teacher and developed a creative task that mirrored a familiar drama class format. We worked across 3 **drama classes** (15 x 12-14 year olds; 15 x 14-15 year olds; 12 x 16-18 year olds). In small groups students prepared a **2-3 minute television news story about a young person of their age who had had cancer**. We gave them examples and permission to be serious, silly, sad, funny or outrageous. Groups performed their piece on front of whole class. In **focus group discussions** we reflected on what performances said about YP with cancer and how much they reflected their real life. We conducted a thematic analyses of videoed performances and focus group transcripts to identify **culturally available discourses of youth cancer**.

#### Cancer as an inevitable decline

- Consistent script of cancer diagnosis, upheaval, and deterioration; occasional false hope when a YP rallied
- Only 2 performances featured unequivocal survival
- Consistent focus group narrative of frightening and sudden diagnosis producing insecurity about present and future, followed by death

A: *and sometimes with cancer, it's like you're waiting for them to die*

A: *Yeah*

A: *Yeah*

A: *Yeah*

A: *It feels like there's no hope because it's pretty hard to stop*

- Decline and death so inevitable that stories of survival were talked about as miracles, and protagonists as heroes

A: *...A survivor is sort of seen as somebody who's overcome this great big mysterious like fatal disease*

#### Cancer consuming young people

- YP portrayed as crying or silent, clinging to parent, physically small; cancer squashing the life out of them
- Cancer repeatedly represented as disrupting all aspects of YP's life: physical, emotional, economic, social

A: *...it'd be like having something so heavy dropped on you. It'd be like I would not...*

A: *It changes everything. Absolutely everything*

A: *I would just give up*

- Performances portrayed cancer as YP's defining experience; focus group participants attuned to identity erasure

A: *Exactly. So it's just kind of like even if you've recovered, it's like you are cancer*

- Focus group participants worried about how cancer would affect relationships

A: *But I wouldn't want to tell my friends, because what if they start treating me different like – what if they like – you have cancer, I'll help you. Like that*

A: *Yeah. I wouldn't want that*

A: *Wouldn't you just want independence*

#### Cancer disrupting others' lives

- Cancer portrayed as consuming and disrupting the lives of parents, siblings, friends, health care providers, teachers

A: *The cancer can be strenuous on the families. So in like Reece's performance we saw that their life had just kind of been torn apart by it*

- Parents repeatedly portrayed as **emotionally** overwhelmed: bereft (crying, alone, inconsolable at daughter's death bed); angry (struggling to keep emotions under control)
- One focus group took very seriously a performance featuring a grieving father being tried for murdering someone who made a joke about cancer
- Cancer caused division in family relationships with parents disconnecting from each other, and siblings angry at the parental attention their ill sibling garnered (participants saw this jealousy as understandable)
- Cancer could also bring people together

A: *...you'd definitely get closer to them through that. And I guess that's kind of good. It's kind of bad*

### Conclusions

Few participants drew on personal knowledge about a young person with cancer; their imagining of youth cancer was based on experiences of cancer in older relatives and through the media (this likely accounts for the perception that cancer inevitably leads to death in young people). Participants showed empathy for the experiences of young cancer survivors, particularly in relation to identity and relationship changes. Young cancer survivors may find these insights useful when returning to school and other peer group settings, while healthcare professionals could harness this support to smooth the young people's transitions across social worlds.