





'It Could Have Been Me':

An Interpretive Phenomenological Analysis of Health Care Professionals' Experiences Caring for Adolescents and Young Adults (AYAs) with Terminal Cancer

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**AYAs
with
Cancer**

Caring for AYAs with Terminal Cancer


- Therapeutic alliance is protective for AYAs with terminal cancer¹
- Grief in health care professionals (HCPs) is common²
 - Younger patients
 - Identification with patients
- Caring for AYAs patients may differentially impact HCPs




¹Trevino et al 2013 *J Clin Oncol*
²Graneek et al 2017 *Psychooncology*

Study Objective

To understand HCPs' experiences caring for AYAs with terminal cancer



Tutelman et al. (accepted)



Methods

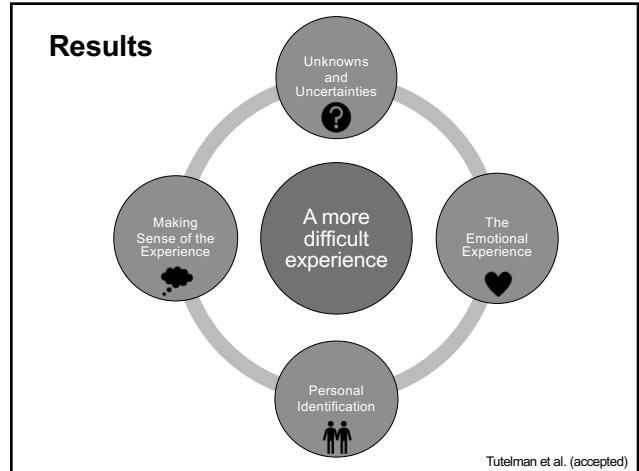

Design: In-depth interviews

Setting: Atlantic Canada

Participants: 9 HCPs who cared for at least one AYA with terminal cancer in the past 3 years, purposively sampled

Analysis: Interpretive Phenomenological Analysis

Tutelman et al. (accepted)

- Many unknowns and uncertainties related to caring for AYAs with terminal cancer including:
 - Complexities of AYA developmental stage
 - Minimal training
 - Scarcity of research

Tutelman et al. (accepted)



“...You know, they’re in transformation ... And then you’re getting this bad news of, you know, they’re likely going to die of the cancer at the same time. So it’s this kind of murky...murky world of where are they at ... And really trying to figure them out as human beings is more difficult.”

Tutelman et al. (accepted)



- Caring for AYAs with terminal cancer is emotionally difficult than caring for other populations due to the:
 - Unexpectedness of the circumstance
 - Degree of grief experienced by family members
 - Increased tendency to ruminate

Tutelman et al. (accepted)



“...Every time I'd lay down, you know, lay in bed, I'd think did I miss anything? ...We were trained to leave work behind. And for the most part I'm able to do that. But with those two [AYA] patients, it was easier said than done because of their age ...”

Tutelman et al. (accepted)



- Personal identification with AYAs with terminal cancer and their families:
 - Described “seeing themselves” within the patients and families
 - Elicited a sense of vulnerability

Tutelman et al. (accepted)



“... [we were] only a few years [apart]. And his kids, he had two daughters very close to my kids' ages. So I couldn't help but think, it could have been me. I think that's what makes it the hardest.”

Tutelman et al. (accepted)



“...you can see yourself in the situation, right? And you think like, oh my word, like what would I do if that were me, and it was my kid...? You want ... to swoop in and fix it. And you can't ... it sometimes can be very frustrating that you can't fix it for them.”

Tutelman et al. (accepted)



- Attempts to rationalize a young person's shortened life
- Thwarted by feelings of injustice and unfairness
- Comparison to older adults and young children

Tutelman et al. (accepted)



“... Somehow I'm able to philosophize that the little kid dying was never meant to be. But you're seeing the manifestation of the personality by the AYA age (...) they're kind of bringing the consciousness of, 'Oh, this is what my life could have been.' Little kids don't understand that ... they haven't had enough life experience to ... mourn the loss...”

Tutelman et al. (accepted)

Conclusions

- Caring for AYAs with terminal cancer is more challenging (logistically and emotionally) than caring for other populations
- These results parallel AYAs' self-reported healthcare experiences¹
- Additional training and support for clinicians providing this care is needed

¹Figueroa Gray et al 2018 J Adolesc Young Adult Oncol

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