Employment and financial challenges faced by adolescent and young adult (AYA) cancer survivors: A qualitative study

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Introduction

• Cancer is a life-disrupting experience for AYA cancer patients (16 to 39 years old)

• Critical juncture in life with multiple milestones, including:
  – Completing education
  – Embarking on a career
  – Starting a family
Aims

• To evaluate the impact of employment and financial challenges on cancer survivorship among AYAs

• Include both AYA cancer survivors and healthcare professionals caring for AYA patients
Methods: Study design

- Qualitative study employing focus group discussions
- Recruitment between July 2017 and October 2018
- Ethics approval obtained from SingHealth CIRB
- Written informed consent sought from all participants
# Methods: Study population

## AYA survivors

**Inclusion criteria**
- Diagnosed between 16 and 39 years
- In disease remission for 6 months to 4 years
- Singaporean citizen or permanent resident

**Exclusion criteria**
- Severe comorbidities

## Healthcare professionals

**Inclusion criteria**
- Involved in the care of AYA cancer patients
Methods: Focus group sessions

- Number of focus groups: 8 (AYA survivors), 3 (HCPs)
- 2 to 6 participants per group
- Facilitated by a research pharmacist
  - No professional relationship with participants
  - Not involved with recruitment
- Thematic content analysis using a deductive approach
Results: Participant characteristics

• Recruited 23 AYA survivors
  – Majority (65.2%) were currently employed
  – Survivors from a range of malignancies, including lymphoma, sarcoma, germ cell tumor and breast cancer

• Recruited 18 HCPs
  – Physicians, nurses, medical social workers, allied health therapists and patient navigator
  – Most (61.1%) had more than 10 years of healthcare experience
Results: Returning to work

- Concerns of inability to keep up with expectations

- Disclosure of cancer history when looking for jobs

- Counterexample: leveraging on experience with cancer as an advantage

“My work is very, actually very stressful. I just worry that if I go back to my work, can I cope with the work, the daily load I used to have?”

AYA #13
(30 years old)
Results: Issues faced at work

• Residual complications from cancer and antineoplastic treatment
  – Cognitive impairment
  – Fatigue

• Restrictions imposed due to identity as cancer survivors
  – Taking on duties with less burden or more “regular hours”
  – Unable to pursue area of interest due to presence of “more first-hand germs”

“[She] slowed down, [she] changed jobs, and then she didn’t know what to do, because [she] hated her job... she was a high-flyer... she wanted to just get going.”

HCP #17 (Psychologist)
Results: Complexity of work-related issues

- Work-related challenges among AYA cancer survivors are complex and multifaceted
- Varied nature of problems and attitude of survivors
- Return-to-work services must avoid one-size-fit-all approach
- Future research in this area should carefully consider outcomes
Results: Misinformed perceptions

- Common perception: AYAs with history of cancer unable to return to previous work levels

**AYA Survivors**

Consequences:
- Lack of confidence in seeking/changing jobs

Reality:
- With assistance?
- Experience leveraged upon as advantage

**Employers**

Consequences:
- Work restrictions imposed on survivors

Reality:
- Restrictions unnecessary
- Career advancement may be impeded
Results: Access to insurance

- Insurance coverage during and after cancer treatment
- Adequate coverage alleviates financial burden during treatment
- Lack of access post treatment leads to insecurity
- Contrary to expectations, given local healthcare landscape

"... when [the] doctor said ‘you are diagnosed with cancer,’ I quickly... quickly go and check...”

AYA #2
(39 years old)
Results: Information needs

• Unmet information need – echoes finding of previous study

• Sources of information

• Key uncertainties: embargo period, coverage of previous cancers, impact on children

Conclusion

• AYA survivors face difficulties at work and in obtaining insurance coverage

• Imperative to incorporate return-to-work programs and financial counselling in survivorship services
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