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

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Conflict of interest disclosure

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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

"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)



Counterexample: leveraging on experience with cancer as an advantage

Results: Issues faced at work

- Residual complications from cancer and antineoplastic treatment
 - Cognitive impairment
 - Fatigue

 Restrictions imposed due to identity as cancer survivors "[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)

- Taking on duties with less burden or more "regular hours"
- Unable to pursue area of interest due to presence of "more first-hand germs"



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 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



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Results: Access to insurance

- Insurance coverage during and after cancer treatment
- Adequate coverage alleviates financial burden during treatment

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

AYA #2 (39 years old)



- Lack of access post treatment leads to insecurity
- Contrary to expectations, given local healthcare landscape

Results: Information needs

- Unmet information need echoes finding of previous study¹
- 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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