







# Understanding the experience of cancer survivorship among adolescent cancer survivors and their parents through camera lenses: A Photovoice study

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## Introduction

- ❖ Although the relative survival rate of childhood cancer has increased substantially in recent years, the pursuit of successful outcomes is often accompanied by negative impacts on adolescent cancer survivors and their parents' physical and psychosocial wellbeing.¹
- ❖ Little is known about childhood cancer survivors and their parents' experiences during the cancer survivorship period.

# Aims of the study

The present study, using a Photovoice approach, aims to explore the experiences of cancer survivorship among adolescent cancer survivors and their parents.

## Methods

- A descriptive qualitative design using Photovoice approach to explore the participants' experience through photos, narratives, and interviews.
- Paediatrics/adolescent survivors of childhood cancer and their parents were recruited from an outpatient clinic of a local hospital.
- ❖ Participants were invited to take about 10 photos reflecting the cancer survivorship experience in the coming four weeks.²
- Interview was conducted with survivors and their parents after they had taken the photos.

## Findings

- ❖ 17 CCS aged 9-18 and one of their parents participated in this study from Sept 2022 to March 2023.
- Thematic analysis was performed on 217 photographs submitted with 5 themes emerged.

#### Theme 1: Indelible marks

This theme described the lasting impact of painful memories and ongoing emotional trauma experienced primarily by parents, particularly during their children's diagnosis and treatment phase.



P12: It feels like it was a long time ago, but sometimes these emotions pop up. I always think back to the days when I was sitting in a hospital chair in despair.

#### Theme 2: Struggling with late effects

This theme underscored the struggle with late effects of cancer and its treatments.

P9: I used to worry that I wouldn't grow taller after chemotherapy.



#### Theme 3: Striving to return to normalcy

This theme described how adolescent cancer survivors and their parents strived to establish a sense of normalcy and live a normal life after completing treatments.



S13: After recovering, I continue to engage in fitness activities to live my life just like any other person.

#### Theme 4: The strength of support

This theme highlighted support that participants received from various sources, including religious communities.

S5: We pray and choose to place our trust in Him and follow Him through the darkness as He leads us to explore!



#### Theme 5: Living in the moment and hope for the future



This theme described despite concerns about cancer recurrence, participants enjoyed living in the moment and were filled with hope for the future.

P10: My little boy has transformed into a young man. I hope he can take off with his sports dream!

# Conclusions and Implications

- Findings highlighted how survivors and their parents experience the cancer journey and how family and spirituality influence their well-being.
- Photovoice presents a powerful opportunity to be used as a therapeutic strategy for survivors and their parents which demands further research.

#### References

- 1. Kwak M, Zebrack BJ, Meeske KA, et al. Trajectories of psychological distress in adolescent and young adult patients with cancer: a 1-year longitudinal study. J Clin Oncol. 2013;31(17):2160-2166.
- 2. Wang C, Burris MA. Photovoice: concept, methodology, and use for participatory needs assessment. Health Educ Behav. 1997;24(3):369-387.