

SUPER Survivor Profiling ExeRcise

by CCF research team



In May to September 2024, we reached out to over 1000 survivors with the intent to better understand their survivorship experiences. 253 survivors participated in our study, sharing with us how they are doing in their survivorship journey...

Overview of our respondents:



Average age at diagnosis: 8 years old
Ranging from 0 to 18 years old

Diagnosis breakdown



41% were diagnosed with **Leukaemia**



16% were diagnosed with **Brain Tumor/CNS**



11% were diagnosed with **Lymphoma**

Included survivors from various age group:



0 to 6 years old
N=55 (36.4%)



7 to 12 years old
N=32 (12.6%)



13 to 20 years old
N=94 (21.7%)



21 years old & older
N=73 (28.7%)

**Percentage indicated is the percentage of survivors' population who responded*

Quality of Life



Survivors in all age groups were generally doing comparably well to their healthy counterparts, with **the exception of psychological wellbeing**

Survivors **faced different challenges** across their survivorship journey



Survivors who recently completed treatment struggle more with:



Physical wellbeing



Cognitive wellbeing



Long term survivors struggle more with:



Social wellbeing



Psychological wellbeing

Scales used for QoL Measurements:

PedsQL

(0 to 6 years old)

KIDSCREEN

(7 to 17 years old)

WHOQOL-BREF

(18 years old and older)

Domains where childhood cancer survivors were doing poorer than the healthy population^{1,2}

No comparative study for PedsQL



Physical wellbeing



Social acceptance



Psychological wellbeing



Mood and emotions



Psychological wellbeing

Follow up care

91% of the survivors were receiving some form of follow-up care

Discipline of care sought by most survivors:



Oncology



Cardiology



Endocrine

These findings are encouraging as regular medical follow-up care can support our survivors in managing their health and effects of cancer and treatment



Late effects

22% of the survivors **have experienced** late effects

23% of the survivors were **unsure** if they have experienced late effects

Common late effects reported by survivors



Low energy/fatigue

Hearing/vision problems



Emotional problems

Growth problems



Learning/memory problems



Compared with St Jude's Childhood Cancer Survivor study³, where more than 90% of the survivors experience late effects, we are concerned whether there could be a lack of awareness of late effects among survivors

We also looked further to understand their survivorship experiences...

Education

22%

of the survivors experienced a **delay for at least a year** in their education pathways



42%

of the survivors experienced troubles in **social integration**



23%

of the survivors experienced troubles in **academic performance**



Physical Activity

45%

of the survivors **have sufficient exercise** as per HPB's guidelines⁴

On average, Survivors exercised for **2.72 days** per week & **45 minutes** per session



Employment

Most employed survivors indicated that they are in jobs that are **appropriate** to their **education** and **physical conditions**



23%

of the employed survivors faced **difficulties at work** due to **health conditions**.

Common challenges include:

- Physical discomfort
- Memory and attention issues
- Weaker immunity



How does this study support CCF?



Further our understanding of survivors' well-being



Guide our program development & program evaluation



Support our future research on survivors' experiences

References

- Understanding the quality of life of adults with disabilities. (2023). National Council of Social Service. Retrieved December 30, 2024, from <https://www.ncss.gov.sg/research-and-insights/research-and-evaluation/quality-of-life/>
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- Huang, I. C., Brinkman, T. M., Kenzik, K., Gurney, J. G., Ness, K. K., Lancot, J., ... & Krull, K. R. (2013). Association between the prevalence of symptoms and health-related quality of life in adult survivors of childhood cancer: a report from the St Jude Lifetime Cohort study. *Journal of Clinical Oncology*, 31(33), 4242-4251.
- Aim for at least 150 Minutes of Physical Activity Every Week. (2023). HealthHub. Retrieved April 15, 2025, from <https://www.healthhub.sg/live-healthy/150minutes>