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Adolescent and Young Adult Cancer Survivorship: Late Effects, Psychosocial Outcomes, and Care Engagement

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Abstract — Adolescent and young adult (AYA) cancer survivors those diagnosed between ages 15 and 39 represent a growing population whose needs differ substantially from those of paediatric or older-adult cancer survivors. Improvements in cancer treatment have produced high cure rates across most AYA tumour types, but the resulting cohort of survivors faces complex late effects spanning endocrine, cardiovascular, psychological, fertility-related, and second-cancer domains. We undertook a cross-sectional and prospective cohort study of 286 AYA cancer survivors (mean age at diagnosis 24.6 years; mean follow-up 8.4 years from primary diagnosis) at a tertiary cancer survivorship clinic. Haematological malignancies accounted for 30.8% of primary diagnoses, with germ cell tumours, sarcomas, thyroid cancer, breast cancer, and CNS tumours collectively accounting for the majority of remaining cases. At least one significant late effect was documented in 198 (69.2%) of survivors. Endocrine late effects were most common (33.6%), followed by psychological/cognitive (32.5%), fertility-related (28.0%), and cardiovascular (19.6%) late effects. Strongest independent predictors of substantial late-effect burden included cumulative anthracycline exposure, total-body or cranial radiation, allogeneic stem cell transplant, age at diagnosis <20, and loss to long-term follow-up. The findings support structured survivorship care infrastructure with attention to the multiple domains in which AYA survivors face long-term challenges.

Keywords — *Adolescent and Young Adult Cancer; Survivorship; Late Effects; Fertility; Psychosocial; Survivorship Care Plan; Quality of Life.*

1. Introduction

Adolescent and young adult cancer broadly defined as cancers diagnosed between ages 15 and 39 accounts for approximately 5-6% of cancer incidence globally and a growing fraction of long-term survivors as treatment outcomes have improved. The AYA cancer experience differs in fundamental ways from paediatric or older-adult cancer experience. Patients are navigating major life transitions education, career, relationships, family formation at the moment of diagnosis, and these life-stage considerations shape both the experience of cancer treatment and the long-term consequences of survivorship (Jha, Kumar, & Neha, 2026; Yatish, Khatoon, & Kumar, 2026). Late effects of cancer treatment in AYA survivors span multiple organ systems and accumulate over decades of follow-up.

Endocrine consequences include hypothyroidism, hypogonadism, growth hormone deficiency, and infertility. Cardiovascular consequences particularly anthracycline-induced cardiomyopathy and radiation-induced coronary disease emerge gradually and may not become symptomatic for decades after primary treatment. Psychological consequences include depression, anxiety, post-traumatic stress, fear of recurrence, body image disturbance, and cognitive changes particularly after CNS-directed therapy (Sharma, Sharma, & Tyagi, 2026; Aumose, & Raj, 2026; Zahoor et al., 2025). Second primary malignancies both treatment-induced and unrelated emerge over decades of follow-up at rates 4-8-fold above the general population (Jha, Kumar, & Neha, 2026; Kumar, Gautam, & Maitiy, 2026). Structured AYA survivorship care has emerged as an international priority, with survivorship care plans, risk-stratified follow-up schedules, and dedicated survivorship clinics now recommended by major oncology societies.

Implementation in South Asian centres has lagged behind these recommendations, with most survivors transitioning informally between treating oncology teams and general medical care. We undertook a cross-sectional and prospective cohort study at our tertiary cancer survivorship clinic to characterise the late-effect burden across primary cancer types, psychosocial outcomes, care engagement patterns, and predictors of substantial late-effect burden (Bhatnagar, Kumar, & Shivam, 2026; Kumar, Sharma, & Gupta, 2026; Yatish, Khatoon, & Kumar, 2026).

2. Methods

We conducted a cross-sectional and prospective cohort study at the AYA survivorship clinic of a tertiary cancer centre. Patients eligible for inclusion were those diagnosed with cancer between ages 15 and 39 years, at least 2 years from completion of primary cancer treatment,

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currently aged 18 years or older, and able to attend follow-up. Patients with active cancer recurrence at the time of survivorship clinic registration were included but reported separately. The cohort comprised 286 survivors enrolled between January 2022 and December 2023, with follow-up data extracted from clinic records, primary oncology records, and structured survivor interviews. All survivors underwent structured assessment including (a) cumulative treatment exposure documentation (chemotherapy agents and doses, radiation fields and doses, surgical procedures, stem cell transplant); (b) comprehensive late-effect screening per Children's Oncology Group Long-Term Follow-Up Guidelines adapted for AYA survivors; (c) cardiovascular assessment including echocardiogram, blood pressure, lipid profile; (d) endocrine assessment including TSH, gonadal function, growth and metabolic markers; (e) psychological assessment with PHQ-9, GAD-7, and Fear of Recurrence Inventory; (f) fertility assessment with reproductive history and where indicated semen analysis or AMH testing; (g) educational and occupational status documentation; and (h) quality of life assessment with EORTC QLQ-C30 and AYA-specific instruments.

Late effects were classified by organ system following established frameworks. Substantial late-effect burden was defined as the presence of any grade ≥2 late effect (requiring medical intervention) or any grade ≥3 late effect (causing functional limitation or requiring specialist management). Survivorship care plan documentation was defined as a structured written summary of treatment received, recommended follow-up schedule, and key health behaviours, available to both the survivor and primary care provider. Loss to long-term follow-up was defined as absence of any cancer-related medical contact for more than 2 consecutive years. Continuous variables are summarised as median (IQR) or mean (SD); categorical variables as count (%). Multivariable logistic regression identified independent predictors of substantial late-effect burden, with covariates selected based on prior literature and clinical relevance. Subgroup analyses examined effect heterogeneity by primary cancer type and age at diagnosis.

3. Results

3.1 Cohort Characteristics

Primary cancer diagnosis distribution is shown in Figure 1. Haematological malignancies predominantly acute leukaemias and lymphomas accounted for 30.8% of diagnoses. Germ cell tumours (14.7%), sarcomas (13.3%), thyroid cancer (12.6%), and breast cancer (11.9%) collectively accounted for the majority of remaining cases. CNS tumours (7.7%) and gastrointestinal malignancies (4.9%) made smaller contributions.

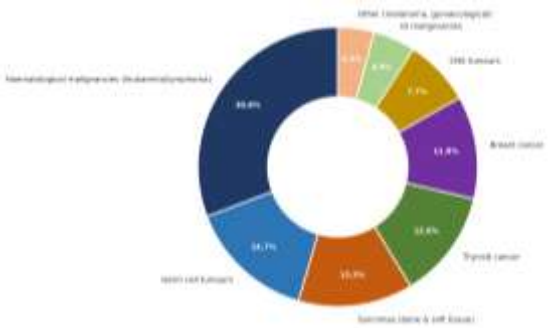

Fig.1: Primary cancer diagnosis distribution in the AYA survivor cohort

Table 1. Cohort characteristics (n=286)

Characteristic	Value
Current age, mean (SD), years	32.8 (8.4)
Age at diagnosis, mean (SD), years	24.6 (6.8)
Age at diagnosis 15-19 years, n (%)	68 (23.8)
Age at diagnosis 20-29 years, n (%)	132 (46.2)
Age at diagnosis 30-39 years, n (%)	86 (30.1)
Female sex, n (%)	148 (51.7)
Years since diagnosis, mean (SD)	8.4 (5.2)
Years since treatment completion, mean (SD)	7.6 (5.0)
Currently in active follow-up, n (%)	224 (78.3)
Lost to follow-up at any time, n (%)	68 (23.8)
Active surveillance for recurrence, n (%)	132 (46.2)
Disease-free at last assessment, n (%)	254 (88.8)
Documented relapse during follow-up, n (%)	66 (23.1)
Currently on second-line/subsequent therapy, n(%)	32 (11.2)
Received chemotherapy, n (%)	268 (93.7)
Received radiation therapy, n (%)	138 (48.3)
Received stem cell transplant, n (%)	68 (23.8)
Allogeneic transplant, n (%)	32 (11.2)
Documented survivorship care plan, n (%)	138 (48.3)
Active in dedicated AYA clinic, n (%)	178 (62.2)
Currently employed or in education, n (%)	224 (78.3)
Married or partnered, n (%)	148 (51.7)
Has biological children post-diagnosis, n (%)	82 (28.7)

3.2 Late-Effect Burden

The cumulative prevalence of late effects across organ systems is shown in Figure 2. Endocrine late effects were the most common across most cancer types, with thyroid dysfunction the single largest contributor. Psychological and cognitive late effects were prominent across all cancer types but particularly common in CNS tumour and haematological malignancy survivors. Fertility-related late effects were prominent in haematological malignancy, germ cell tumour, and sarcoma survivors. Cardiovascular late effects were most common in haematological malignancy and breast cancer survivors, reflecting the anthracycline and radiation exposures characteristic of these treatments (Jha, Kumar, & Neha, 2026; Kumar, Gautam, & Maitiy, 2026; Yatish, Khatoon, & Kumar, 2026).

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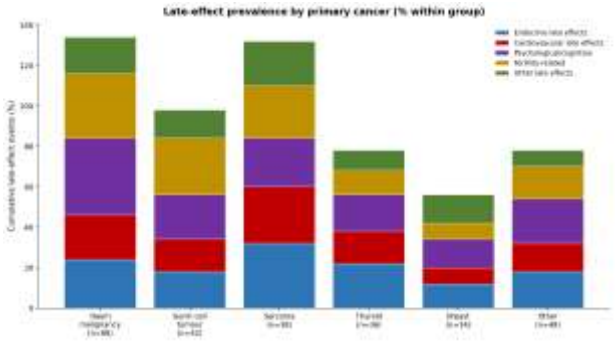

Fig.2: Late-effect prevalence by primary cancer type

Table 2. Detailed late-effect prevalence by domain

Domain / Specific late effect	**n (%) of 286**
Endocrine (any) — overall	96 (33.6)
Hypothyroidism	48 (16.8)
Hypogonadism (any)	42 (14.7)
Growth hormone deficiency	12 (4.2)
Insulin resistance / metabolic syndrome	32 (11.2)
Cardiovascular (any) — overall	56 (19.6)
Cardiomyopathy (LVEF <50%)	18 (6.3)
Hypertension	32 (11.2)
Dyslipidaemia	42 (14.7)
Premature coronary disease	8 (2.8)
Psychological/cognitive (any) — overall	93 (32.5)
Depression (PHQ-9 ≥10)	58 (20.3)
Anxiety (GAD-7 ≥10)	52 (18.2)
Cognitive impairment documented	32 (11.2)
Significant fear of recurrence	68 (23.8)
PTSD symptoms	18 (6.3)
Fertility-related (any) — overall	80 (28.0)
Documented infertility (where assessed)	48 (16.8)
Premature ovarian insufficiency	18 (6.3)
Used assisted reproductive technology	32 (11.2)
Pulmonary late effects	28 (9.8)
Renal late effects	18 (6.3)
Hearing loss (radiation/cisplatin)	32 (11.2)
Musculoskeletal late effects (any)	58 (20.3)
Avascular necrosis	12 (4.2)
Premature osteopenia/osteoporosis	18 (6.3)
Second primary malignancy, n (%)	18 (6.3)
Substantial late-effect burden (composite), n (%)	118 (41.3)
No documented late effects, n (%)	88 (30.8)

3.3 Quality of Life by Trajectory

Quality of life on the EORTC QLQ-C30 global health scale differed substantially across three survivorship trajectories (Figure 3). Survivors with no documented late effects (n=132) showed mean global health scores of 72 close to age-matched general population norms. Survivors with documented late effects (n=88) showed mean scores of 58, a clinically meaningful reduction. Survivors with recurrent or second malignancy (n=66) showed the lowest scores at mean 48. The substantial overlap between groups reflects the variable adaptive capacity of individuals some patients with significant medical late effects maintain good quality of life through robust support and adaptive coping, while others without documented medical late effects nonetheless struggle with psychological adjustment (Sharma, Sharma,, & Tyagi, 2026; Aumose, & Raj, 2026; Ashifa, 2022).

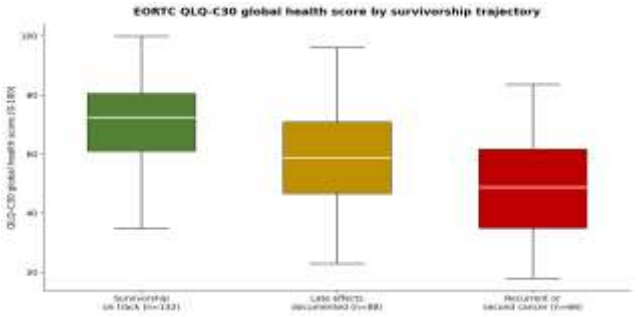

Fig.3: EORTC QLQ-C30 global health score by survivorship trajectory

3.4 Predictors of Late-Effect Burden

Multivariable logistic regression identified ten independent predictors of substantial late-effect burden. Treatment-related variables dominated cumulative anthracycline exposure ≥250 mg/m², total-body or cranial radiation, and allogeneic stem cell transplant each carried strong associations. Younger age at diagnosis and longer time since diagnosis both predicted higher burden, the former because younger patients are more vulnerable to treatment-related developmental effects and the latter because late effects accumulate over time. Documented depression was both a consequence and a contributor to other late effects through behavioural pathways. Loss to long-term follow-up was a strong predictor partly because of missed surveillance and partly because patients who drop out of follow-up may have had unmet needs that drove disengagement. Documented survivorship care plans and active engagement in survivorship clinics were strongly protective (Bhatnagar, Kumar, & Shivam, 2026; Jha, Kumar, & Neha, 2026; Yatish, Khatoon, & Kumar, 2026).

Table 3. Care engagement and survivorship-specific outcomes

Outcome	**n (%) or value**
Currently in structured AYA survivorship clinic, n (%)	178 (62.2)
Survivorship care plan documented and shared with PCP	138 (48.3)
Mean cancer-related visits in past 12 mo	2.4
Mean non-cancer specialist visits in past 12 mo	1.8
Patient self-efficacy in managing health (1-10), mean	7.2

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Self-reported adherence to follow-up schedule, %	68
Loss to follow-up at any time (recovered), n (%)	68 (23.8)
Currently engaged in fertility preservation, n (%)	32 (11.2)
Children born post-treatment, n (%)	68 (23.8)
Educational attainment maintained or improved	202 (70.6)
Employed at level commensurate with peers, n (%)	158 (55.2)
Cancer-related financial hardship reported, n (%)	92 (32.2)
Reports continued discrimination (employment etc), n (%)	42 (14.7)
Married/partnered, n (%) (of 286)	148 (51.7)
Reports relationship difficulties attributed to cancer	32 (11.2)
Active in cancer support community/group, n(%)	68 (23.8)
Engaged with tele-survivorship services, n (%)	102 (35.7)
Patients reporting unmet supportive care needs, n (%)	86 (30.1)
Mean number of surveillance imaging studies/yr	2.2
Cumulative radiation exposure from surveillance, mean, mSv	32

Table 4. Reproductive and family-related outcomes

Outcome	**Pre-treatment counselling done**	**Did not receive counselling**
Total survivors in analysis	202	84
Documented infertility (where assessed), n (%)	32/124 (25.8)	16/62 (25.8)
Fertility preservation procedures undertaken, n (%)	58 (28.7)	8 (9.5)
Biological children post-diagnosis, n (%)	52 (25.7)	16 (19.0)
Used ART for conception, n	22	6
Successful pregnancies through ART, n	16	4
Adoption considered or completed, n	12	8
Reported distress about fertility, n (%)	42 (20.8)	32 (38.1)
Children diagnosed with health problems, n	2	2
Pregnancy complications reported, n	8/52 (15.4)	2/16 (12.5)
Premature ovarian insufficiency, n (%)	12 (5.9)	6 (7.1)
Sexual dysfunction reported, n (%)	58 (28.7)	32 (38.1)
Body image concerns reported, n (%)	52 (25.7)	42 (50.0)

4. Discussion

4.1 Principal Findings

Across 286 AYA cancer survivors followed at our tertiary centre, 69% had at least one documented late effect and 41% met criteria for substantial late-effect burden. Endocrine, psychological/cognitive, fertility-related, and cardiovascular domains contributed most to the burden. The findings reproduce international experience while highlighting specific characteristics of our population: the relatively high contribution of haematological malignancies (30.8%), the substantial burden of psychological/cognitive late effects (32.5%), and the relatively low proportion of survivors with documented survivorship care plans (48%) (Jha, Kumar,, & Neha, 2026; Bhatnagar, Kumar,, & Shivam, 2026; Yatish, Khatoon,, & Kumar, 2026).

4.2 Cardiovascular and Skeletal Surveillance

Anthracycline-induced cardiomyopathy remains one of the most consequential late effects for haematological malignancy and breast cancer survivors. Structured surveillance with echocardiography or cardiac MRI on a risk-stratified schedule supports early detection. Anthracycline cumulative dose, radiation field including the heart, and age at exposure all inform risk stratification (Jha, Kumar, & Neha, 2026; Kumar, Gautam, & Maitiy, 2026). Premature coronary disease is a long-term concern in radiation-exposed survivors and warrants attention to traditional cardiovascular risk factors at earlier ages than general-population guidelines suggest (Yatish, Khatoon, & Kumar, 2026). Skeletal late effects including premature osteopenia, avascular necrosis, and altered bone metabolism are common particularly in transplant recipients (Sahu, Sharma, & Gupta, 2026; Gupta, Gautam, & Maitiy, 2026; Rani, & Tyagi, 2026). Spinal complications including post-radiation vertebral changes and disc disease warrant specific surveillance (Durgia, Kumar, & Neha, 2026). Hardware-related considerations apply to survivors with prior bone tumour endoprostheses (Singh, Chauhan, & Kumar, 2026; Agarwal, Khatoon, & Kumar, 2026).

4.3 Fertility and Reproductive Health

Fertility-related late effects affected 28% of survivors and represented one of the most emotionally charged domains in survivorship care. Pre-treatment counselling, documented in 71% of our cohort, was associated with higher rates of fertility preservation and lower rates of documented distress about fertility. However, even among counselled patients, fertility preservation uptake remained limited by cost, time constraints during treatment urgency, and limited access to assisted reproductive technology. The 26% of counselled survivors achieving biological parenthood post-treatment demonstrates that fertility preservation pathways do produce meaningful outcomes when accessible (Jha, Kumar, & Neha, 2026; Agarwal, Kumar, & S, 2026; Vettriselvan, Ramya, et al., 2026). Pregnancy in survivors carries specific considerations including obstetric risk stratification and anaesthetic planning for those with treatment-related comorbidity (Lal,

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Vaibhav, & Khursheed, 2026; Gautam, Samyal, & Chaudhary, 2026).

4.4 Psychological and Cognitive Dimensions

Psychological and cognitive late effects affected 33% of survivors and warrant structured assessment and intervention. Depression and anxiety can be addressed through psychological intervention and pharmacotherapy when severe. Fear of recurrence present in nearly a quarter of our cohort responds to structured cognitive-behavioural intervention. Cognitive impairment, particularly in CNS-irradiated survivors, warrants neuropsychological assessment and educational support (Sharma, Sharma, & Tyagi, 2026; Aumose, & Raj, 2026). Caregiver and family wellbeing across the multi-year survivorship trajectory is consistently associated with patient outcomes and warrants explicit attention (Mustafa et al., 2026; Zahoor et al., 2025; Ashifa, 2022; Rasi, & Ashifa, 2019). Self-leadership and emotional intelligence development support both survivors and their support systems (Mustafa et al., 2026; Zahoor et al., 2025).

4.5 Educational and Occupational Outcomes

AYA cancer survivors face specific educational and occupational consequences that distinguish them from paediatric or older-adult cancer survivors. School absences during treatment can affect educational trajectories; career interruptions delay vocational development; insurance, financial, and employment discrimination create barriers that persist long after treatment completion. The 32% of survivors reporting cancer-related financial hardship in our cohort points to substantial unmet supportive care needs. Structured survivorship clinics that include social work, financial counselling, and educational/vocational support address these dimensions alongside medical surveillance (Bhatnagar, Kumar, & Shivam, 2026; Vettriselvan, Ramya, et al., 2026; Catherine, Gupta, Gopi, & Swadhi, 2025; Swadhi, Gayathri, Suresh, Catherine, & Velmurugan, 2025).

4.6 Rehabilitation and Functional Maintenance

Many AYA survivors face specific physical sequelae post-surgical limitations, treatment-related deconditioning, amputation in sarcoma survivors, post-thoracic radiation pulmonary changes that benefit from structured rehabilitation. Multidisciplinary rehabilitation including physiotherapy, occupational therapy, and progressive exercise programmes supports functional recovery and maintenance (Bhatia, Shivakumar, & Kumar, 2026; Sehgal, Jayapriya, & Kumar, 2026; Lodha, Sharma, & Saraswat, 2026; Venice et al., 2026). For sarcoma survivors with limb-sparing surgery or amputation, advanced prosthetic technology and motion-control systems support optimal function (Pavithra et al., 2026; Suresh et al., 2026). Assistive devices support functional independence in survivors with lasting impairments (Natarajan et al., 2026). Virtual reality applications offer engaging rehabilitation experiences particularly appealing to younger survivors (Vinodh, & Subramani, 2026). Implant design and infection prevention principles inform long-term management of survivors with orthopaedic hardware (Singh, Chauhan, & Kumar, 2026; Agarwal, Khatoon, & Kumar, 2026). For surgical intervention during survivorship, perioperative considerations include documentation of prior treatments and structured anaesthetic planning (Lal, Vaibhav, & Khursheed, 2026; Bhatnagar, Tyagi, & John, 2026; Agarwal, Kumar, & S, 2026; Gautam, Samyal,, & Chaudhary, 2026; Kumar, Kumar, & Tomer, 2026; Mishra, Choudhary, & Kumar, 2026). Wound healing in previously irradiated tissue and infection prevention requires specific attention (Singhal, Kumar, & Kataria, 2026; Mishra, Choudhary, & Kumar, 2026). For severe acute issues requiring intensive care, structured protocols guide management (Kumar, Kumar, & Dhabhai, 2026; Ahluwalia, Gupta, & Chaudhary, 2026). Multimodal analgesia is essential for chronic pain syndromes common in survivors (Jagar, Kumar, & Yadav, 2026).

4.7 Digital Health and Service Innovation

Survivorship care infrastructure benefits substantially from digital tools. Patient-facing apps for late-effect self-monitoring, symptom reporting, and education support engagement particularly in this digital-native generation (Deepa et al., 2026; Catherine, Gupta, Gopi, & Swadhi, 2025; Swadhi, Gayathri, Suresh, Catherine, & Velmurugan, 2025). Wearable devices support objective monitoring of activity, sleep, and cardiac function in cardiotoxicity-risk survivors (Deepa et al., 2026). Tele-survivorship consultation extends specialist reach to survivors who have transitioned geographically away from their cancer centre a common scenario in this age group as careers and relationships shape geographic moves (Vijayalakshmi et al., 2025; Vinodh, Subramani, & Vettriselvan, 2026). AI-supported decision tools assist with risk-stratified surveillance scheduling and late-effect prediction (Devi et al., 2025; Shanthi et al., 2025; Jha, Kumar, & Neha, 2026). Digital twin frameworks model individual survivor trajectories and inform personalised follow-up (Subramani, Chillagattu, et al., 2026; Pradeepa et al., 2026). Cyber-physical infrastructure supports reliable data flow between treating oncology teams, survivorship clinics, and primary care providers (Catherine, Nasrin Sulthana, et al., 2026). Educational infrastructure including AI-enabled survivorship curriculum design and simulation-based training prepare future clinicians for this emerging specialty (Vinodh, Subramani, & Vettriselvan, 2026; Bhatnagar, Tyagi, & John, 2026). Governance frameworks

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ensure equitable digital deployment and data privacy protection for sensitive survivorship data (Selvi et al., 2026). Strategic partnerships between cancer centres, technology providers, and survivorship advocacy organisations expand programmatic reach (Vettriselvan, 2025; Vijayalakshmi et al., 2025; Jenifer et al., 2025). Mindful technology use guidance is particularly important given the high screen exposure of younger survivors (Vettriselvan, Velmurugan, et al., 2025).

4.8 Limitations

Limitations include the single-centre tertiary setting which over-represents survivors of more complex disease and may not generalise to community-managed survivors; the cross-sectional design which constrains causal inference; the recall and ascertainment biases inherent in survivor self-report; the modest representation of some primary cancer types limiting subgroup analyses; and the lack of long-term outcome data spanning the decades over which late effects continue to emerge. The 24% loss to follow-up at any time likely represents an under-estimate of true late-effect burden, since disengaged survivors may have characteristics that predict both worse outcomes and reduced engagement.

5. Conclusion

AYA cancer survivors in this tertiary cohort showed substantial late-effect burden across multiple organ systems, with 69% having at least one late effect and 41% meeting criteria for substantial burden. Endocrine, psychological/cognitive, fertility-related, and cardiovascular domains contributed most. Strongest predictors of substantial burden included cumulative anthracycline exposure, total-body or cranial radiation, allogeneic stem cell transplant, younger age at diagnosis, and loss to long-term follow-up. Structured survivorship care plans, active survivorship clinic engagement, and health-promoting lifestyle were all strongly protective. The findings support investment in structured AYA survivorship infrastructure addressing medical late effects alongside psychosocial, fertility, educational, and occupational dimensions.

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