ISLCCC

INTERNATIONAL SYMPOSIUM
ON LATE COMPLICATIONS
AFTER CHILDHOOD CANCER

2026

JUNE 4-6 2026

GENOVA, ITALY

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WELCOME LETTER

Welcome in Genova for ISLCCC 2026!

On behalf of the ISLCCC Scientific Committee we are pleased to welcome all the delegates to the 5th International Symposium on Late Complications after Childhood Cancer.

We are sure that the meeting will enable delegates from 5 continents to share the results of their research, discuss about new ideas, implement networking and establish future collaboration. The programmed lectures and the panel discussions will address several hot topics in survivorship research which will be complemented by the oral presentation of abstracts selected by the program committee. Indeed, this process was particularly challenging due to the very high quality of the 156 submitted abstract that made the final decision very difficult. However, abstracts that were not selected as oral presentation will be allocated significant space both as poster viewing and discussion in dedicated sessions of the congress

Trying to make your stay in Genova as much enjoyable as possible, we have also organized some social events during which we will give the opportunity to enjoy some culinary specialties (including but not limited to "pesto" and "focaccia"!) from our Region and experience some authentic aspects of Genoese culture and lifestyle deeply connected to our maritime heritage that has always shaped our Region.

We hope this meeting will fully meet your expectations and provide a fruitful and inspiring experience. We also hope you will have the opportunity to enjoy some pre or post conference sightseeing in our beautiful city and its surroundings, and that you will return safely to your institutions enriched by excellent science, new friendships, and, last but not least, wonderful memories of your time here.

Last, but not least, we want to express our gratitude to the Genova Municipality, the several charities which regularly support our Department, and the pharma companies who all have generously supported this initiative which couldn't have been so successfully organized without their contribution.
Wishing to all of you an enjoyable stay in Genova,

Sincerely,

Genova, June 4, 2026

The local Organizing Committee
Ric*cardo Haupt*
Monica Muraca
Carlo Dufour

LIST OF SPONSORS

SCHEDULE AT A GLANCE

Thursday, June 4

12:15 -2:15 AM	Pre-meeting: IGHG (International Guidelines Harmonization Group)	
2:15-3:00 PM	Welcome, Opening Remarks, Keynote 1 – Host: Riccardo Haupt, Monica Muraca, Carlo Dufour	
3:00-3:45 PM	Keynote 1: Global Child Cancer Survivorship Guidelines: An Emerging Unmet Need for Resource Appropriate Guidance: Michael Sullivan	
4:00- 4:55 PM	Oral abstracts 1: *Implementation/Guidelines*	Chairs: Matt Ehrhardt, Renée Mulder
4:55 – 5:40 PM	Panel discussion: Thrive Mode: Healthy Living After Childhood Cancer	Moderators: Kristen K. Ness, Saskia Pluijm Panelists: Aron Onerup, Elvira C van Dalen
5:40-6:35 PM	Oral abstracts 2: *Thrive*	Chairs: Kevin Krull, Gisela Michel
6:35-7.00 PM	*Evening Cocktail Reception / Poster viewing on your own*	

Friday, June 5

7:00 AM	The Dan Green Fun Run	Host: Monica Muraca; meet in Cala Mandraccio (Porto Antico)
7:15-8:00 AM	Mentee Breakfast: Career Opportunity for Late-Effects Clinical Specialists	Hosts: Paul Nathan, Riccardo Haupt
8:30- 9:15 AM	Keynote 2: Risk factors, Consequences and Management of Poor Bone Health in Childhood Cancer Survivors – Natascia Di Iorgi	
9:15-10:10 AM	Oral abstracts 3: *Endocrine outcomes*	Chairs: Greg Armstrong, Monica Muraca
10:10-10:40 AM	*Coffee Break*	
10:40-11:35 AM	Oral abstracts 4: *Cardiovascular*	Chairs: Saro Armenian, Helena van der Pal
11:35-12:30 AM	Panel discussion: Priorities for the Future of Survivorship	Moderator: Monica Muraca Panelists: Leontien Kremer, Melissa Hudson
12:30-2:00 PM	*Group Lunch / Poster viewing on your own*	
	Mentee Lunch: How to Develop a High Impact Research Proposal	Hosts: Greg Armstrong, Helena van der Pal
2:00-2:45 PM	Keynote 3: Psychosocial Factors and Employability in Childhood Cancer Survivors: Theoretical insights and practical implications for Work Reintegration - Alessandro Godono	
2:45-3:40 PM	Oral abstracts 5: *Digital Health*	Chairs: Monica Gramatges, Riccardo Haupt
3:40-4:10 PM	*Coffee Break*	
4:10-5:10 PM	Poster Rapid Review	Chairs: Melissa Hudson, Leontien Kremer
5:00-6:15 PM	Poster Viewing with Poster Presenters On-Site	
7:00 PM	***Social Dinner at Genova Aquarium***	

Saturday, June 6

8:30-9:15 AM	Panel discussion: Should Female CCS at Elevated Risk for Breast Cancer Be Offered Hormonal Replacement Therapy?	Moderators: Flora van Leeuwen Panelists: Kevin Oeffinger, Matteo Lambertini
9:15-10:10 AM	Oral abstracts 6: *Subsequent Malignant Neoplasms*	Chairs: Greg Armstrong, Cecile Ronckers
10:10-10:40 AM	*Coffee Break*	
10:40-11:35 AM	Oral abstracts 7: *Other*	Chairs: Scott Baker, Michael Sullivan
11:35-12:00 AM	Closing Remarks, Best Oral Presentation and Best Poster Award Ceremony, CME information, ISLCCC 2027 and 2028 details	Host: Riccardo Haupt, Monica Muraca

SCHEDULE IN DETAIL

Oral Research Abstract Presentation Schedule in Detail

(Full text of each abstract can be found on subsequent pages of the Program Book)

Thursday, June 4 – 4:00 to 4:55 PM – Implementation/Guidelines

Presenter	Title
Tara Henderson	The ASPIRES Study: Promoting Colorectal Cancer Surveillance in Childhood Cancer Survivors – A Randomized Intervention Trial from the Childhood Cancer Survivor Study (CCSS)
Priscilla Nambalirwa	Survivor/Caregiver and Health System Level Barriers to, Facilitators for, and Implementation Strategy Recommendations for Childhood Cancer Survivorship Care Delivery in Uganda
Ksenya Shliakhtsitsava	Continuity of Survivorship Care in Childhood Cancer Survivors: Risk-Based Follow-Up and Persistent Disparities
Selina Van Den Oever	Feasibility and Diagnostic Yield of the PanCareFollowUp Care Intervention

Thursday, June 4 – 5:40 to 6:35 PM – Thrive

Presenter	Title
Jiaoyang Cai	Improving Physical Activity Behaviors Among Childhood Cancer Survivors Through an Educational Intervention: A Mixed-Methods Pre–Post Study
Deborah Ogunsanmi	Impaired Fitness and Strength in Adolescent Survivors of Childhood Cancer and Their Associations with Treatment Exposures and Modifiable Risk Factors in the St. Jude Lifetime Cohort Study (SJLIFE)
Renee Van Laarhoven	Physical Activity Patterns, and Factors Associated with Low Physical Activity in the Dutch Childhood Cancer Survivors: A Dccss-Later 2 Study
Tara Brinkman	Digital Health Intervention for Comorbid Insomnia and Neurocognitive Impairment in Adult Survivors of Childhood Cancer: Results from a Randomized Clinical Trial in the Childhood Cancer Survivor Study

Friday, June 5 – 9:15 to 10:10 AM – Endocrine outcomes

Presenter	Title
Jennifer Dean	Reevaluating Bone Mineral Density Surveillance in Pediatric Acute Lymphoblastic Leukemia Survivors: A Single-Institution Retrospective Review
Maya Malini	Evaluation of Bone Mineral Density and Vitamin D Status in Long Term Survivors of Childhood Acute Lymphoblastic Leukemia in LMIC Setting
Angela Davey	Voxel-Based Analysis of Dose-Response Relationships within the Hypothalamuspituitary Axis as a Predictor of Growth Hormone Deficiency: A Muti-Centre Study
Monica Logan	An Exploratory Assessment of The GloBE-Reg Registry for Studying the Safety of Long-Acting Growth Hormone in Cancer Survivors (The SFE-Survivors Study)

Friday, June 5 – 10:40 to 11:35 AM – Cardiovascular

Presenter	Title
Rebecca Howell	Radiation Oncology Workflow-Integrated Individualized Risk Calculator to Comprehensively Predict Future Cardiac Disease Risk Among Pediatric and Adolescent Cancer Patients
Rivalin Aho Glele	Coronary Artery Calcium Score After Cardiac Irradiation and/or Anthracyclines Exposure in Childhood Cancer Survivors: The Corocan Study
Eric Chow	Impact of Treatment Intensity on Cardiometabolic Outcomes Among High Cardiovascular Risk Childhood Cancer Survivors: A Report from Ccss-Chiip
Elin Gustafsson	Predictive Value of Social Determinants of Health for Major Adverse Cardiovascular Events Among Childhood Cancer Survivors

SCHEDULE IN DETAIL

Friday, June 5 – 2:45 to 3:40 PM – Digital Health

Presenter	Title
Jop Teepen	Long-Term Disability and Financial Burden Among Survivors of Childhood Cancer Using the WHO ICF Framework: A Report from the St. Jude Lifetime Cohort Study (SJLIFE)
Anne Maas	Information and Support Needs of Childhood, Adolescent, and Young Adult Cancer Survivors (CAYACS) Across Europe: Results from the e-QuoL Project
David Noyd	An Electronic Health Records-based Informatics Approach to Enhance Care for Childhood, Adolescent, and Young Adult Cancer Survivors Through Population Health Management
Rachel Webster	Feasibility and Acceptability of a Digital Mindfulness Intervention to Improve Stress, Coping, and Cardiometabolic Risk in Survivors of Pediatric Leukemia and Lymphoma

Saturday, June 6 – 9:15 to 10:10 AM – Subsequent Malignant Neoplasms (SMN)

Presenter	Title
Allodji Rodrigue	Cancer Treatments-Related Factors for Subsequent Soft Tissue Sarcoma in Childhood Cancer survivors: A report from the PanCareSurFup consortium
Taumoha Ghosh	Association between Neighborhood-Level Social Vulnerability and the Incidence of Subsequent Malignant Neoplasms: A Report from the Childhood Cancer Survivor Study
Michael Betti	Transcriptome-Wide Association Studies Reveal Key Genetic Contributors to Subsequent Neoplasm Risk in Childhood Cancer Survivors: A Report from the St. Jude Lifetime Cohort and the Childhood Cancer Survivor Study
Elyse Zhang	Development and Validation of a Longitudinal Symptom-Based Mortality Prediction Model for Adult Survivors of Childhood Cancer

Saturday, June 6 – 10:40 to 11:35 AM – Other

Presenter	Title
Gauri Kapoor	Prevalence and Risk Factors for Ovarian Dysfunction Following Cancer Treatment in Childhood Cancer Survivors
Cindy Im	Development and Validation of Diabetes Mellitus Risk Prediction Models in Survivors of Childhood Cancer: a St. Jude Lifetime Cohort Study (SJLIFE) and Childhood Cancer Survivor Study (CCSS) Report
Cassie Argenbright	Pain Trajectories and Symptoms of Social Isolation and Loneliness in Adult Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study (CCSS)
Madeline Horan	Clinically Meaningful Symptoms in Adult Survivors of Childhood Cancer: a Comparison with the U.S. General Population Using the Modified PatientReported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE)

CONFERENCE CENTER FACILITY MAP

PORTO ANTICO CONFERENCE CENTER
VIA MAGAZZINI DEL COTONE, GENOVA, ITALY

The Porto Antico Conference Center, a post-industrial refurbishment, was originally, the Cotton Warehouses of Genova.
The facility is close to the largest historic centre in Europe, and to the palaces included in the UNESCO World Heritage List.
This facility is at a short distance from airport, train stations, highway and hotels.

ISLCCC is taking place on Level 1 of the center.
All scientific presentations will occur in the Sala Maestrale.
Mentee Events will be held in the Austro Room on Friday.
Posters will be displayed in the Modulo 8 from Thursday morning to Saturday morning.

PROGRAM COMMITTEE

Saro Armenian	City of Hope, USA
Greg Armstrong	St. Jude Children's Research Hospital, USA
K. Scott Baker	Fred Hutchinson Cancer Center, USA
Sharon Castellino	Children's Healthcare of Atlanta, USA
Eric Chow	Fred Hutchinson Cancer Center, USA
Louis Constine	Rochester University, USA
Charlotte Demoor-Goldschmidt	Centre Hospitalier Universitaire Angers, France
Stephanie Dixon	St. Jude Children's Research Hospital, USA
Monica Gramatges	Baylor College of Medicine, USA
Daniel Green	St. Jude Children's Research Hospital, USA
Riccardo Haupt	IRCCS Istituto G. Gaslini, Italy
Tara Henderson	University of Chicago, USA
Anna Holmqvist	Lund University, Sweden
Melissa Hudson	St. Jude Children's Research Hospital, USA
Leontien Kremer	Princess Maxima Center, The Netherlands
Kevin Krull	St. Jude Children's Research Hospital, USA
Wendy Landier	University of Alabama Birmingham, USA
Lillian Meacham	Children's Healthcare of Atlanta, USA
Gisela Michel	University of Lucerne, Switzerland
Monica Muraca	Istituto Giannina Gaslini, Italy
Paul Nathan	Sick Children's Toronto, Canada
Maria Otth	Children's Hospital of Eastern Switzerland, St. Gallen, Switzerland
Cecile Ronckers	DKFZ German Cancer Research Center, Heidelberg, Germany
Satomi Sato	St. Luke's International University, Japan
Helena van der Pal	Princess Maxima Center, The Netherlands
Hanneke van Santen	Princess Maxima Center, The Netherlands
Hamish Wallace	NHS Lothian, Edinburgh, United Kingdom

KEYNOTE LECTURES

KEYNOTE LECTURE 1

THURSDAY 4 JUNE, 3:15 PM

GLOBAL CHILD CANCER SURVIVORSHIP GUIDELINES: AN EMERGING UNMET NEED FOR RESOURCE APPROPRIATE GUIDANCE

Michael Sullivan

MB ChB DCH FRACP PhD MRSNZ
Professor of Paediatric Oncology, University Of Melbourne
Paediatric Oncologist/Neuro-Oncologist, Royal Children's Hospital, Melbourne
Co-Director, SIOP-St JUDE ARIA Global Childhood Cancer Guideline Collaboration

KEYNOTE LECTURE 2

FRIDAY 5 JUNE, 8:30 AM

RISK FACTORS, CONSEQUENCES AND MANAGEMENT OF POOR BONE HEALTH IN CHILDHOOD CANCER SURVIVORS

Natascia Di Iorgi

MD, PhD
Professor of Pediatric Endocrinology, Department of Pediatrics at the IRCCS Istituto Giannina Gaslini, Genova, Italy

KEYNOTE LECTURE 3

FRIDAY 5 JUNE, 2:00 PM

PSYCHOSOCIAL FACTORS AND EMPLOYABILITY IN CHILDHOOD CANCER SURVIVORS: THEORETICAL INSIGHTS AND PRACTICAL IMPLICATIONS FOR WORK REINTEGRATION

Alessandro Godono

MD, PhD
Associate Professor in Occupational Medicine, University of Torino, Italy

PANEL DISCUSSIONS

PANEL DISCUSSIONS 1

MODERATORS

Kirsten K. Ness

PT, PhD, FAPTA
Member and Vice Chair, Epidemiology and Cancer Control at St. Jude Children's Research Hospital, Memphis, TN, USA

Saskia Pluijm

PhD
Associate Group Leader and Senior Scientist on healthy living, healthy aging, and optimization of quality of life in survivors of childhood cancer.
Princess Máxima Center for pediatric oncology, Utrecht, The Netherlands

PANELISTS

Aron Onerup

MD, PhD
Pediatric oncologist at Queen Silvia Children's Hospital and Associate Professor at the University of Gothenburg, Sweden

Elvira C. Van Dalen

MD, PhD
Senior clinical scientist/epidemiologist at the Guideline Unit of the Princess Máxima Center for pediatric oncology, Utrecht, The Netherlands

PANEL DISCUSSIONS

PANEL DISCUSSIONS 2

MODERATORS

Monica Muraca

MD
Pediatric Endocrinologist and Late effects specialist.
Senior physician at the late effects DOPO Clinic at IRCCS Istituto Giannina Gaslini, Genova, Italy

SPEAKERS

Melissa Hudson

MD
Member and director of the Cancer Survivorship Division in the Department of Oncology at St. Jude Children's Research Hospital, Memphis, TN, USA

Leontien Kremer

MD, PhD
Professor of late effects after childhood cancer
Groups leader in late effect research of the Princess Máxima Center for pediatric oncology, Utrecht, The Netherlands

PANEL DISCUSSIONS

PANEL DISCUSSIONS 3

MODERATORS

Flora Van Leeuwen

MSc
Member Groupleader Epidemiology, Netherlands Cancer Institute, Amsterdam, The Netherlands

PANELIST

Matteo Lambertini

MD, PhD
Associate Professor in Medical Oncology at University of Genova, Italy

Kevin Oeffinger

MD
Director of the Duke Cancer Institute (DCI) Center for Onco-Primary Care and Professor of Medicine with Tenure at Duke University, Durham, NC, USA

THE DAN GREEN FUN RUN

FRIDAY JUNE 5 AT 7:00 AM
MEET AT CALATA MANDRACCIO (BESIDES THE BIG CRANE)

SUGGESTED ROUTE:

Run/walk of 3.5 km. No matter your level, the run is accesible to everyone!

Start at 7:00 AM at Calata Mandraccio, which will also be the finish point, by 8:00 AM to allow everyone to be at the Symposium by 8:30 AM for the first scientific session (contact: Monica Muraca, +39 328 0204 911)

FRIDAY MENTEE BREAKFAST DETAILS

FRIDAY JUNE 5 AT 7:30 AM

CAREER OPPORTUNITY FOR LATE-EFFECTS CLINICAL SPECIALISTS
Hosted by Paul Nathan, Riccardo Haupt

Paul Nathan

MD, MSc
Professor of Paediatrics
Head, Solid Tumor Section
Aftercare Program Director
SickKids, University of Toronto

Riccardo Haupt

MD
Pediatric Oncologist
Scientific coordinator of the late effects DOPO Clinic at the IRCCS Istituto Giannina Gaslini, Genova, Italy

FRIDAY MENTEE LUNCH DETAILS

FRIDAY 5 JUNE AT 12:30 PM

HOW TO DEVELOP A HIGH IMPACT RESEARCH PROPOSAL
Hosted by Greg Armstrong, Helena van der Pal

Greg Armstrong

MD, MSCE
Member, St. Jude Faculty - Chairman of Epidemiology and Cancer Control at St. Jude Children's Research Hospital, Memphis, TN, USA
Co-Leader, Cancer Control & Survivorship Program
Endowed Chair in Epidemiology & Cancer Control

Helena van der Pal

MD, PhD
Internist outpatient clinic late effects, clinical scientist late effects
Department: Late Effects Outpatient Clinic at the Princess Máxima Center for pediatric oncology, Utrecht, The Netherlands

ABSTRACTS SELECTED FOR ORAL PRESENTATION

Listed in alphabetical order by first author

OP01

Cardiovascular

CORONARY ARTERY CALCIUM SCORE AFTER CARDIAC IRRADIATION AND/OR ANTHRACYCLINES EXPOSURE IN CHILDHOOD CANCER SURVIVORS: THE COROCAN STUDY

R. Aho Glele [7], J. Motiejunaite [4], P. Balagny [4], F. Arnoult [4], C. Bancal [4], S. Bolle [2], C. Fayech [1], C. Khouri [1], J. Landman-Parker [5], L. Lenez [1], G. Leverger [5], V. Martin [2], V. Minard-Colin [1], N. Sellami [2], M. Tabone [6], T. Charrier [7], R.S. Allodji [7], N. Journy [7], F. De Vathaire [7], P. Ou [3], B. Fresneau [7]

[1]*Department of Children and Adolescents Oncology, Gustave Roussy, F-94805, Villejuif, France.*

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[3]*Radiology Department, Bichat University Hospital, Assistance Publique-Hôpitaux de Paris, Paris, France*

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[6]*Sorbonne Université, Department of Pediatric Hematology Oncology, Hôpital Armand-Trousseau, Assistance Publique-Hôpitaux de Paris, Paris, France.*

[7]*Université Paris Saclay, Gustave Roussy, Inserm, Unit 1018-CESP, Radiation Epidemiology Group, Villejuif, France*

BACKGROUND-AIM

Childhood cancer survivors (CCS) face high risk of coronary artery disease (CAD). The COROCAN study assessed coronary artery calcium score (CACS, a non-invasive radiological marker of CAD) in CCS and explored associations between CACS, therapeutic exposures, and cardiopulmonary function.

METHODS

CCS treated before age 25 with cardiac area radiotherapy and/or anthracyclines and in remission for ≥10 years were prospectively explored with CACS (Agatston method), transthoracic echocardiography, cardiopulmonary exercise testing (VO2max), and pulmonary function testing. CACS was classified using age- and sex-adjusted MESA percentiles. Multivariable logistic regression adjusted for sex, age at diagnosis, age at CACS, and cardio-vascular risk factors, estimated associations between therapeutic exposures and CACS >75th percentile. Secondary analyses evaluated cardiac and pulmonary function and explored integrated cardiopulmonary phenotypes using hierarchical clustering of major functional abnormalities.

RESULTS

Among 267 explored CCS (median age 36.7 years), 12.7% had increased CAC above the MESA-75thp: none before the age of 29, 13% between 30 and 39, 20% between 40 and 49 and 24% after 50y. Cardiac radiation dose was the strongest predictor of elevated CAC: compared to patients non-exposed to cardiac area irradiation, those exposed to a thoracic prescribed dose of 20-39 and≥40 Gy had a 4.5 and 7.1-fold higher risk of increased CACS, respectively (p=0.04). Total-body irradiation was also associated with increased CACS (Odds Ratio=5.9, 95%CI=1.0-33.7), contrary to anthracyclines and other chemotherapies. Elevated CACS frequently coexisted with cardiac and/or pulmonary dysfunction (88%), while normal VO2max was generally associated with normal cardiopulmonary function and no increased CACS (59%).

CONCLUSION

CACS increased in CCS after the age of 30 and was strongly associated with prior cardiac irradiation. These findings support the potential integration of CACS in cardiac follow-up of CCS exposed to cardiac radiation ≥20Gy and aged ≥30y to improve risk stratification and guide personalized follow-up.

OP02

Subsequent Malignant Neoplasms (SMN)

CANCER TREATMENTS-RELATED FACTORS FOR SUBSEQUENT SOFT TISSUE SARCOMA IN CHILDHOOD CANCER SURVIVORS: A REPORT FROM THE PANCARESURFUP CONSORTIUM

R. Allodji [31], R. Reulen [4], I. Diallo [30], D. Winter [4], G. Vu-Bezin [31], S. Bolle [5], M. Locquet [31], F. Bagnasco [27], E. Bárdi [28], E. Feijen [25], D. Alessi [6], M. Fidler-Benaoudia [3], S. Høgsholt [10], C. Bright [21], H. Linge [19], B. Fresneau [31], N. Haddy [31], C. Veres [30], D. Llanas [31], N. Journy [31], C. Demoor-Goldschmidt [31], J. Byrne [26], D. Bejarano-Quisoboni [31], D. Grabow [15], W. Zrafi [31], T. Gudmundsdottir [7], G. Michel [14], W. Gunnes [22], P. Kaatsch [15], C. Rubino [31], H. Jenkinson [2], M. Kaiser [15], R. Skinner [16], R. Aho-Glele [31], C. Ducos [1], N. Aba [31], T. Cole [32], N. Waespe [12], S. Nordenfelt [18], T. Charrier [31], M. Zidane [31], M. Jankovic [23], T. Lähteenmäki [29], M.M. Maule [6], C. Ronckers [11], H. Van Der Pal [25], F. Van Leeuwen [9], J. Teepen [25], M. Terenziani [24], T. Wiebe [19], C. Sacerdote [6], Z. Jakab [17], R. Haupt [13], P.M. Lähteenmäki [29], L. Zadravec Zaletel [20], C.E. Kuehni [12], J.F. Winther [8], L.C. Kremer [25], M.M. Hawkins [4], L. Hjorth [19], F. De Vathaire [31]

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[29]*Turku University and Turku University Hospital, Department of Pediatrics and Adolescent Medicine, Turku, Finland*

[30]*Université Paris-Saclay, Gustave Roussy, INSERM U1030, Molecular Radiation Therapy and Therapeutic Innovation, Villejuif, France.*

[31]*Université Paris-Saclay, Gustave Roussy, Inserm, UVSQ, Center for Research in Epidemiology and Population Health – Unit 1018, EpiRad (Radiation Epidemiology team), F-94805, Villejuif, France.*

[32]*West Midlands Regional Genetics Laboratory, Birmingham Women's Hospital, Birmingham, UK*

BACKGROUND-AIM

Previous studies analyzing risk factors for subsequent soft-tissue sarcoma (STS) among childhood cancer survivors (CCS) had small numbers of participants and were unable to comprehensively investigate the dose-response relationships with radiation dose and with cumulative exposure to specific cytotoxics. In this study, we investigate the

clinical and therapeutic factors associated with the long-term risk of subsequent STS, including anti-cancer treatment modalities and corresponding cumulative exposure doses.

METHODS

We conducted a nested case-control study, encompassing 275 subsequent STS cases and 275 matched controls w the Pan-European PanCareSurFup cohort of 69,460 five-year survivors from 12 countries. Controls were matched by country, sex, age at first primary neoplasm (FPN), calendar year of FPN, and retinoblastoma status. For each individual, detailed informations were collected on clinical characteristics, radiotherapy plans, and cumulative doses of anti-cancer treatments received during the interval between the diagnosis of the FPN and subsequent STS for the case and the corresponding interval in the matched control. Odds ratios (ORs) and 95% confidence intervals (CIs) for subsequent STS were calculated for different levels of radiation dose to the STS location (in Gray, Gy) and for cumulative doses of specific chemotherapeutic agents (in g/m^2). For each category, we calculated attributable risk (AR) among those exposed as AR = 100 × (OR − 1)/OR and population attributable risk (PAR) as PAR = AR × Pe, where Pe is the proportion of cases in the population who are exposed. Additionally, excess ORs per Gy (EOR/Gy) or per g/m2 (EOR/g/m^2) were calculated to assess dose-response relationships.

RESULTS

Of 275 patients who had subsequent STS, 155 were males, retinoblastoma was a prior diagnosis in 56 (20.4%). The median attained age at subsequent STS diagnosis was 28.6 years (range 6.0–62.1 years), which occurred a median of 20.4 years (range 5.2–61.6 years) after their FPN. The majority of cases (80.7%) and controls (64.4%) had received radiotherapy. Cases had much higher average cumulative radiation doses at the STS site than controls (13.2 Gy versus 4.8 Gy). Compared to The no radiation, the OR for subsequent STS was 22-fold [95% CI: 6.9-95.4] higher in soft tissue exposed to ≥30 Gy and was also in excess with lower dose (5-9 Gy) soft tissue exposure [OR=3.8, 95% CI: 1.3-12.0]. The corresponding attributable risks (AR) were 95.6% and 73.7% respectively, while the population attributable risks (PAR) were 14.7% and 3.3% respectively (Figure 1). The EOR/Gy was 0.86 [95% CI: 0.35-2.16], with a particularly high risk observed in survivors of neuroblastoma [EOR/Gy=5.52 95% CI: 0.71-52.31] or bone sarcoma [EOR/Gy=4.16 95% CI: 0.40-24.72], and in females [EOR/Gy=2.35 95% CI: 0.65-8.14]. For patients who had received a cumulative procarbazine dose ≥6.0 g/m^2, the OR was 4.7 [95% CI: 1.3–25.1] compared with non-exposure, adjusted for radiation dose. No association was found for other alkylating agents or other specific cytotoxic drugs.

CONCLUSION

Our study demonstrates an increased risk of subsequent STS following exposure to lower radiation doses (5–9 Gy) to soft tissue or after high-dose procarbazine in CCS. These new findings may have implications for planning treatment protocols and for developing or updating evidence-based clinical follow-up guidelines.

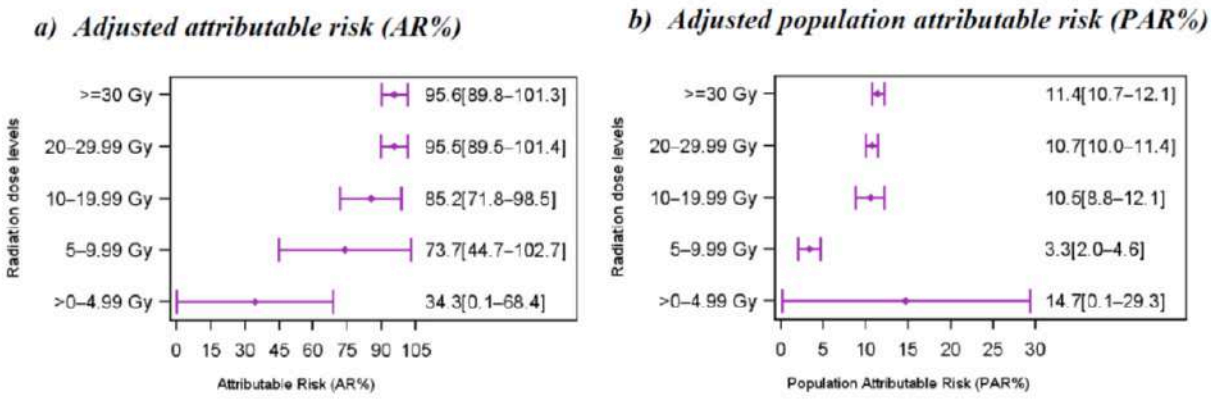

Figure 1: Attributable risk (AR%) and population attributable risk (PAR%) of subsequent soft-tissue sarcoma attributable to exposure to dose of radiation (in Gy) received to site of soft-tissue sarcoma, with adjustment for procarbazine exposure

OP03

QoL/Rehabilitation

PAIN TRAJECTORIES AND SYMPTOMS OF SOCIAL ISOLATION AND LONELINESS IN ADULT SURVIVORS OF CHILDHOOD CANCER: A REPORT FROM THE CHILDHOOD CANCER SURVIVOR STUDY (CCSS)

C. Argenbright [6], G. Zhou [2], K. Li [2], N. Alberts [7], C. Karlson [4], E. Van Der Plas [5], E. Chow [1], V. Nolan [3], R. Howell [8], K. Srivastava [2], I. Huang [3], G. Armstrong [3], K. Krull [6], T. Brinkman [6]

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BACKGROUND-AIM

Survivors of childhood cancer are at risk of developing chronic pain and social isolation/loneliness, which may persist decades following treatment. Despite shared biopsychosocial and neurobehavioral mechanisms, associations between pain and social health-related outcomes in survivors remain poorly understood. This study examined (1) cross-sectional associations between pain and social isolation and loneliness, (2) whether longitudinal pain trajectories are associated with social outcomes, and (3) the contribution of chronic disease burden to these associations.

METHODS

10,923 survivors (median age=41 years [min-max=21-70]; 52% female; 32% leukemia; 20% lymphoma; 16% CNS; 9% bone cancer; 6% soft tissue sarcoma; 10% Wilms; 7% Neuroblastoma) enrolled in the CCSS completed patient-reported assessments of pain (migraine, headache, cancer-related pain, bodily pain, pain interference) at T1 [CCSS follow-up 7 survey]. Pain status was categorized as no pain, pain without interference, or pain with interference. Social isolation was measured using the PROMIS Social Isolation scale (T-score $\geq$ 60), and loneliness was defined as endorsing "moderate" to "extreme" loneliness using an item from the Brief Symptom Inventory-18 (BSI-18). A subset of 7,875 survivors with T0 [CCSS follow-up 5 survey] pain data (median interval follow-up=5.04 years) was included in longitudinal analyses, in which pain trajectories (T0 to T1) were defined as none/decreasing, persistent, or increasing. Chronic health condition (CHC) burden scores were calculated using frequency and severity of CTCAE-graded conditions across cardiovascular, endocrine, musculoskeletal, neurological, gastrointestinal, and respiratory systems, and categorized as none, low, medium, high, and severe. Associations between pain and social outcomes were examined with multivariable logistic regression models adjusted for sex, age, race/ethnicity, treatment exposures, CHC burden, depression, and health behaviors (e.g., smoking, risky alcohol use).

RESULTS

At T1, 20.7% of survivors reported pain without interference; 14.3% pain with interference; 7.3% social isolation; and 12% loneliness. In cross-sectional analyses at T1, pain was significantly associated with social isolation (without interference: OR=1.74, 95% CI 1.36–2.24; with interference: OR=2.36, CI 1.80–3.08) and loneliness (without interference: OR=1.57, CI 1.25–1.97; with interference: OR=2.60, CI 2.08–3.25) in a dose-dependent manner. In longitudinal models, survivors with persistent pain from T0 to T1 had two-fold higher odds of social isolation (OR=2.07, CI 1.54–2.78) and loneliness (OR=2.03, CI 1.61–2.56) vs. survivors with none/decreasing pain. Increasing pain symptoms were also associated with significantly elevated odds of social isolation (OR=1.74, CI 1.28–2.36) and loneliness (OR=1.65, CI 1.27–2.16). Among survivors with persistent or increasing pain, risky health behaviors, but not CHC burden, increased the risk of social isolation and loneliness.

CONCLUSION

Pain and pain interference were associated with concurrent and future risk of social isolation and loneliness in adult survivors of childhood cancer, independent of CHC burden. These findings highlight social disconnection as an important yet underrecognized consequence of pain in survivors. Integrating assessment of and interventions for social isolation and loneliness into survivorship pain management may improve psychosocial well-being and long-term health outcomes.

OP04

Genetic/Genomics

TRANSCRIPTOME-WIDE ASSOCIATION STUDIES REVEAL KEY GENETIC CONTRIBUTORS TO SUBSEQUENT NEOPLASM RISK IN CHILDHOOD CANCER SURVIVORS: A REPORT FROM THE ST. JUDE LIFETIME COHORT AND THE CHILDHOOD CANCER SURVIVOR STUDY

M.J. Betti [1], C. Li [1], K. Li [1], J.N. French [1], K. Petrykey [1], K. Krull [6], S.B. Dixon [1], B. Ky [3], M.J. Ehrhardt [1], H.M. Conklin [6], L. Jacola [6], A. Delaney [1], M.M. Gramatges [4], E.J. Chow [7], K. Oeffinger [2], J. Neglia [5], L.M. Turcotte [5], K.K. Ness [1], M.M. Hudson [1], G.T. Armstrong [1], Y. Yasui [1], Y. Sapkota [1]

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BACKGROUND-AIM

Subsequent neoplasms (SNs) are among the most common treatment-related adverse effects among survivors of childhood cancer, with an estimated 30-year incidence of 20.5% for any SN and 7.9% for a subsequent malignant neoplasm (SMN). Prior research has identified specific treatment exposures that increase risk for SNs, and genome-wide association studies have identified genetic variants associated with risk for individual SNs in survivors. However, no study to date has utilized transcriptome-wide association studies (TWAS) to evaluate the role of genetically predicted enhancer RNA (eRNA) and gene expression in SN risk among survivors.

METHODS

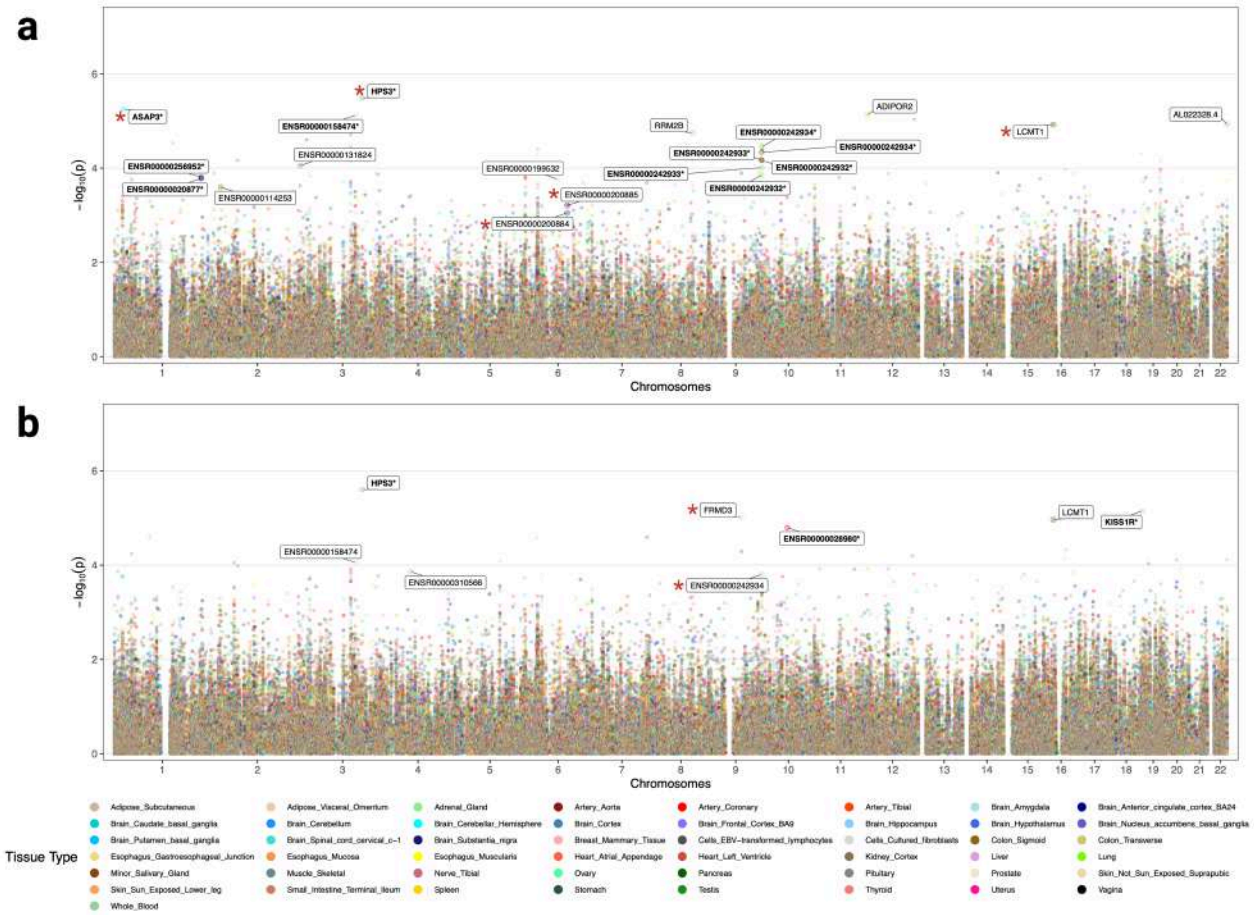
We applied expression quantitative trait locus (eQTL) models trained in the general population to whole genome sequencing data from the St. Jude Lifetime Cohort Study (SJLIFE) to impute genetically regulated eRNA and gene expression across 49 tissues. Using predicted expression, we performed logistic regression-based TWAS of SNs (656 cases and 2,569 controls of European ancestry), adjusted for age at primary cancer diagnosis, age at last follow-up, sex, treatment exposures within five years of primary diagnosis (maximum radiation dose to four brain segments, the abdomen, pelvis, chest, and neck, and cumulative doses of alkylating agents, anthracyclines, and epipodophyllotoxins), as well as genetic ancestry. We next performed a secondary TWAS for the subset of SN cases that were malignant (SMNs: 501 cases and 2,569 controls). Associations with a false discovery rate (FDR)<0.05 were considered significant, while FDR<0.1 was considered suggestive. Significant associations were tested for replication in the Childhood Cancer Survivor Study (CCSS) cohort (SNs: 1,264 cases and 4,725 controls, SMNs: 480 cases and 4,725 controls). Replication was defined as p<0.1 with concordant direction of effect in at least one tissue.

RESULTS

TWAS for SNs revealed 11 eRNA (two replicated) and six gene transcripts (three replicated) showing at least suggestive association. HPS3 (in whole blood), a gene involved in organelle biogenesis, was the strongest TWAS association for SNs (discovery: OR=1.23, $p=3.24x10^{-6}$; replication: OR=1.08, p=0.01). Other notable associations with SN risk were oncogene ASAP3 in the cerebellar hemisphere (discovery: OR=0.86, $p=5.6x10^{-6}$, replication: OR=0.95, p=0.07) and tumor suppressor gene LCMT1 in pancreas (discovery: OR=1.09, $p=1.19x10^{-5}$; replication: OR=1.07, p=0.06). In a secondary analysis restricted to individuals with an SMN, we identified four eRNA (one replicated) and four gene (one replicated) associations. In addition to HSP3 in whole blood (discovery: OR=1.22, $p=2.50x10^{-6}$, replication: OR=1.02, p=0.13) and LCMT1 in pancreas (discovery: OR=1.09, $p=1.08x10^{-5}$; replication: OR=1.01, p=0.38), genes that previously associated with risk for SNs, we also discovered an association with tumor suppressor gene FRMD3 in fibroblasts (discovery: OR=1.23, $p=9.6x10^{-6}$, replication: OR=1.04, p=0.02).

CONCLUSION

TWAS identified 17 unique transcripts associated with SNs and eight with SMNs, demonstrating the promise of TWAS for discovering biologically interpretable contributors to second cancer risk in childhood cancer survivors. Future work will utilize functional validation experiments to interrogate the causal mechanisms of these TWAS associations. Ultimately, these findings may help to improve risk prediction and identify therapeutic targets for future clinical intervention.



TWAS results for subsequent neoplasms (SNs) and subsequent malignant neoplasms (SMNs) in childhood cancer survivors. a, TWAS of SNs across 49 cell and tissue types (656 cases and 2,569 controls from the St. Jude Lifetime Cohort Study). Genome-wide significant associations (FDR<0.05) are labeled in bold, and suggestive associations (FDR<0.1) are labeled in non-bold font. eRNA names begin with the prefix "ENSR." Associations that replicated in the CCSS are marked with a red asterisk. b, TWAS of SMNs (501 cases and 2,569 controls from the St. Jude Lifetime Cohort Study).

OP05

Interventional research

DIGITAL HEALTH INTERVENTION FOR COMORBID INSOMNIA AND NEUROCOGNITIVE IMPAIRMENT IN ADULT SURVIVORS OF CHILDHOOD CANCER: RESULTS FROM A RANDOMIZED CLINICAL TRIAL IN THE CHILDHOOD CANCER SURVIVOR STUDY

T. Brinkman [5], K. Stratton [2], L. Ritterband [1], K. Ruble [6], C. Papini [5], R. Vejandla [3], S. Alston [3], V. Nolan [3], N.K. Shaikh [5], K. Ingersoll [1], D. Mulrooney [4], G. Armstrong [3], W. Leisenring [2], K. Krull [5]

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BACKGROUND-AIM

Survivors of childhood cancer are at risk of developing both insomnia and cognitive impairment, which may persist decades following treatment. Cognitive behavioral therapy for insomnia (CBT-I) focuses on changing maladaptive thoughts and behaviors that interfere with sleep and is the gold-standard treatment for insomnia; yet the impact of improved sleep on comorbid cognitive dysfunction has not been evaluated in survivors.

METHODS

Survivors enrolled in the Childhood Cancer Survivor Study (CCSS; median age 44 [range 23-66] years; 73% female; 37% leukemia, 23% lymphoma, 18% sarcoma, 14% Wilms, 8% neuroblastoma) with comorbid insomnia and neurocognitive impairment were randomized 1:1 to 9-week digital CBT-I vs. online sleep education (SE). Insomnia severity index (ISI, range 0-28, higher=worse), neurocognitive problems (CCSS-Neurocognitive Questionnaire [NCQ]), emotional health (Patient Health Questionnaire/Generalized Anxiety Disorder), and quality of life (PROMIS) were measured at baseline and 9-week and 6-month follow-ups. Intent-to-treat models estimated treatment effects for ISI (mean difference [MD] between CBT-I and SE of change from baseline to follow-ups) adjusted for age, sex, and cranial radiation. Cohen's d estimated effect size. Additional models estimated treatment effects on secondary outcomes and mediation by improved ISI.

RESULTS

439 of 541 randomized survivors completed baseline assessments and started the intervention (82% CBT-I; 81% SE); 353 of those completed 9-week (76% CBT-I; 85% SE) and 305 completed 6-month (61% CBT-I; 78% SE) post-intervention assessments. Mean ISI scores at baseline did not differ significantly between groups (CBT-I=14.3 vs. SE=15.0, p=0.07). Survivors randomized to CBT-I reported improved ISI scores at 9 weeks (MD=-2.4[95%CI -3.4, -1.4]; Cohen's d=0.50) and 6 months post-intervention (MD=- 3.5[-4.6, -2.4]; d=0.72) vs. SE (both p's<0.001). Survivors randomized to CBT-I reported greater improvement in memory (9wks: MD=-0.3SD [-0.5, -0.1], p=0.003; 6mos: MD=-0.5SD [-0.7, -0.3], p<0.001) and task efficiency (9wks: MD=-0.3SD [-0.5, -0.1], p=0.003; 6mos: MD=-0.5SD [-0.7, -0.3], p<0.001) vs. SE. Survivors randomized to CBT-I were also more likely to be responders (a decrease of >7 points on ISI) compared to SE (9wks: 40% vs. 18%; 6mos: 49% vs. 20%, both p's<0.001). Effects of CBT-I on cognitive function were mediated by improved ISI scores (42-65% mediated, all p's <0.001). Insomnia remitters (those who reported a change in ISI from >8 [mild to severe insomnia] to <8 [no insomnia]; 9wks: 49% CBT-I vs. 24% SE; 6mos: 60% vs. 25%, both p's<0.001) also reported improved quality of life (9wks: mental beta=1.7[95%CI 0.4, 3.0], physical=2.1[1.0, 3.1]; 6mos: mental=3.5[2.0, 5.0], physical=3.3[2.1, 4.5]), and emotional health (9wks: anxiety beta=-1.3[-2.1,-0.5], depression=-1.8[-2.6, -1.0]; 6mos: anxiety=-1.8[-2.7, -0.8], depression=-2.4[-3.4, -1.4]).

CONCLUSION

Use of a fully automated digital health treatment of insomnia confers short and long-term benefits to cognitive impairment and quality of life in survivors of childhood cancer. Given its efficacy and availability, digital CBT-I should be considered for the behavioral treatment of insomnia and comorbid symptoms in survivors.

OP06

QoL/Rehabilitation

LONG-TERM DISABILITY AND FINANCIAL BURDEN AMONG SURVIVORS OF CHILDHOOD CANCER USING THE WHO ICF FRAMEWORK: A REPORT FROM THE ST. JUDE LIFETIME COHORT STUDY (SJLIFE)

J. Burns [1], G. Armstrong [1], J. Bass [10], N. Bhakta [2], H. Brandt [1], T. Brinkman [4], Y. Chen [1], A. Delaney [8], M. Ehrhardt [3], R. Ferguson [4], D. Green [3], I. Huang [1], M. Hudson [3], L. Jacola [4], K. Krull [4], J. Lavecchia [9], T. Merchant [5], S. Mirzaei [7], M. Neel [6], B. Potter [4], K. Shelton [1], J. Sparrow [10], K. Szymanek [10], A. Zaidi [1], K. Ness [1]

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BACKGROUND-AIM

Adult survivors of childhood cancer are at high risk for chronic health conditions that may result in long-term disability. However, the prevalence and financial burden of disability, defined using the World Health Organization International Classification of Functioning, Disability and Health (WHO ICF), have not been described in this population.

METHODS

Disability-related outcomes were ascertained using functional assessments, clinical evaluations and patient-reported data from participants in the St. Jude Lifetime Cohort Study. Items were classified according to WHO ICF components: impairments in body function or structure (strength, neurocognition, vision, hearing, speech, balance, neuropathy, ataxia, hemiparesis, tone, bowel and bladder, flexibility, gait, posture, pain, fatigue), activity limitations (motor function, communication, personal care), and participation restrictions (physical activity, education, independent living, employment, health-related quality of life). An Aggregate Disability Severity Score (ADSS) was calculated by summing dichotomized indicators (0 = none/mild; 1 = moderate, severe, or life-threatening disability) across 55 items spanning 3 components (38 body impairments, 5 activity limitations, and 12 participation restrictions). Disability thresholds were defined using age- and sex-specific z-scores from 815 community controls (0 = ≥ -1.5; 1 = < -1.5) or NCI Common Terminology Criteria for Adverse Events grades (0 = < 2; 1 = ≥ 2). The ADSS was refined using item-level redundancy analysis based on inter-item correlations and evaluation of internal consistency reliability using Cronbach's coefficient alpha. Multivariable logistic regression evaluated associations between disability and financial hardship (patient-reported cancer-related financial impact), adjusting for demographic characteristics (sex, race, age at evaluation) and cancer treatment exposures (chemotherapy, cranial radiation, amputation).

RESULTS

Among 3,549 survivors (mean age at evaluation 33.6 years; range 18.0–68.9; 52.1% male; 80.7% White non-Hispanic), the most common primary diagnoses were acute lymphoblastic leukemia (31.9%), central nervous system tumors (14.5%), and Hodgkin lymphoma (10.5%). The point (most recent visit) prevalence of $\geq$1 item rated as moderate or greater disability was 87.0% (95%CI 85.9–88.1). Prevalence by WHO ICF component was 73.0% (95%CI 71.5–74.4) for body impairments, 32.9% (95%CI 31.3–34.4) for activity limitations, and 63.3% (95%CI 61.7–64.9) for participation restrictions, all significantly higher than community controls ($p<0.001$). The ADSS was reduced from 55 to 47 items after removal of highly intercorrelated redundant items ($r>0.85$). The final 47-item ADSS, comprising 30 body impairments, 5 activity limitations, and 12 participation restrictions, demonstrated high internal consistency (Cronbach's $\alpha = 0.85$). Higher overall ADSS was associated with financial hardship (OR=3.01; 95%CI 2.09–4.34), with consistent associations observed across body impairments (OR=2.53; 95%CI 2.00–3.20), activity limitations (OR=2.28; 95%CI 1.91–2.72), and participation restrictions (OR=2.61; 95%CI 2.13–3.21).

CONCLUSION

WHO-defined disability is highly prevalent among adult survivors of childhood cancer and is strongly associated with financial burden. These findings underscore the need for comprehensive survivorship care models that address both long-term functional impairments and socioeconomic vulnerability.

OP07

Interventional research

IMPROVING PHYSICAL ACTIVITY BEHAVIORS AMONG CHILDHOOD CANCER SURVIVORS THROUGH AN EDUCATIONAL INTERVENTION: A MIXED-METHODS PRE–POST STUDY

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BACKGROUND-AIM

Childhood cancer survivors (CCS) are at increased risk of treatment-related long-term health complications, yet many engage in insufficient physical activity. Family concerns, limited risk awareness, and uncertainty regarding safe exercise may further restrict participation. Scalable and culturally-relevant education interventions targeting both survivors and caregivers remain underexplored in China.

METHODS

We conducted a mixed-methods, single-arm educational intervention study involving childhood cancer survivors and their caregivers. Physical activity behaviors, exercise-related cognition (Health Belief Model [HBM] constructs and the Exercise Benefits/Barriers Scale [EBBS]), and family support were assessed at baseline (T0) and 1–3 months after the intervention (T1) using validated questionnaires. Between-wave comparisons were performed treating T0 and T1 as independent samples. In addition, semi-structured interviews with a subset of caregivers and survivors were analyzed thematically to contextualize and enrich the quantitative findings.

RESULTS

A total of 106 CCSs and their caregivers completed the baseline questionnaire (T0), and 78 (73.6%) completed the follow-up assessment (T1). In addition, 18 caregivers and survivors participated in qualitative interviews. Compared with baseline, children reported significant increases in weekly moderate-to-vigorous physical activity (MVPA: 98.5 ± 135.0 to 172.3 ± 186.5 min/week; $p = 0.004$), total physical activity time (166.6 ± 168.5 to 318.0 ± 292.3 min/week; $p < 0.001$), and Godin Leisure-Time Exercise Questionnaire (GLTEQ) leisure scores (40.4 ± 35.1 to 56.0 ± 37.3; $p = 0.005$). Parental awareness of treatment-related cardiopulmonary risk increased from 50.0% (53/106) at T0 to 71.8% (n=56/78) at T1 ($p = 0.003$). Family support improved, with significant increases in parental encouragement ($p = 0.016$) and family co-exercise ($p = 0.006$). Among cognitive constructs, perceived severity of insufficient physical activity increased, as did perceived energy and vitality benefits of exercise. Qualitative interviews highlighted perceived benefits of exercise, reliance on medical advice, variable fatigue experiences, the importance of family involvement, and a preference for practical and personalized exercise guidance.

CONCLUSION

A brief, HBM-based educational intervention improved physical activity behaviors among childhood cancer survivors. Addressing perceived barriers and enhancing self-efficacy may be critical mechanisms for promoting sustainable behavior change in survivorship care.

OP08

Cardiovascular

IMPACT OF TREATMENT INTENSITY ON CARDIOMETABOLIC OUTCOMES AMONG HIGH CARDIOVASCULAR RISK CHILDHOOD CANCER SURVIVORS: A REPORT FROM CCSS-CHIIP

E. Chow [3], Y. Chen [6], S. Ngai [8], L. Baldwin [8], W. Bottinor [9], M. Hudson [6], P. Nathan [7], T. Ohlsen [5], C. Snyder [4], K. Syrjala [2], E. Tonorezos [10], Y. Yasui [6], G. Armstrong [6], K. Oeffinger [1]

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BACKGROUND-AIM

Childhood cancer survivors have an increased risk of cardiovascular disease (CVD) that is amplified by the presence of CVD risk factors like hypertension, dyslipidemia, and diabetes. However, among survivors with a history of cardiotoxic treatment exposures, the impact of CVD risk factor treatment intensity on these risk factors is unclear.

METHODS

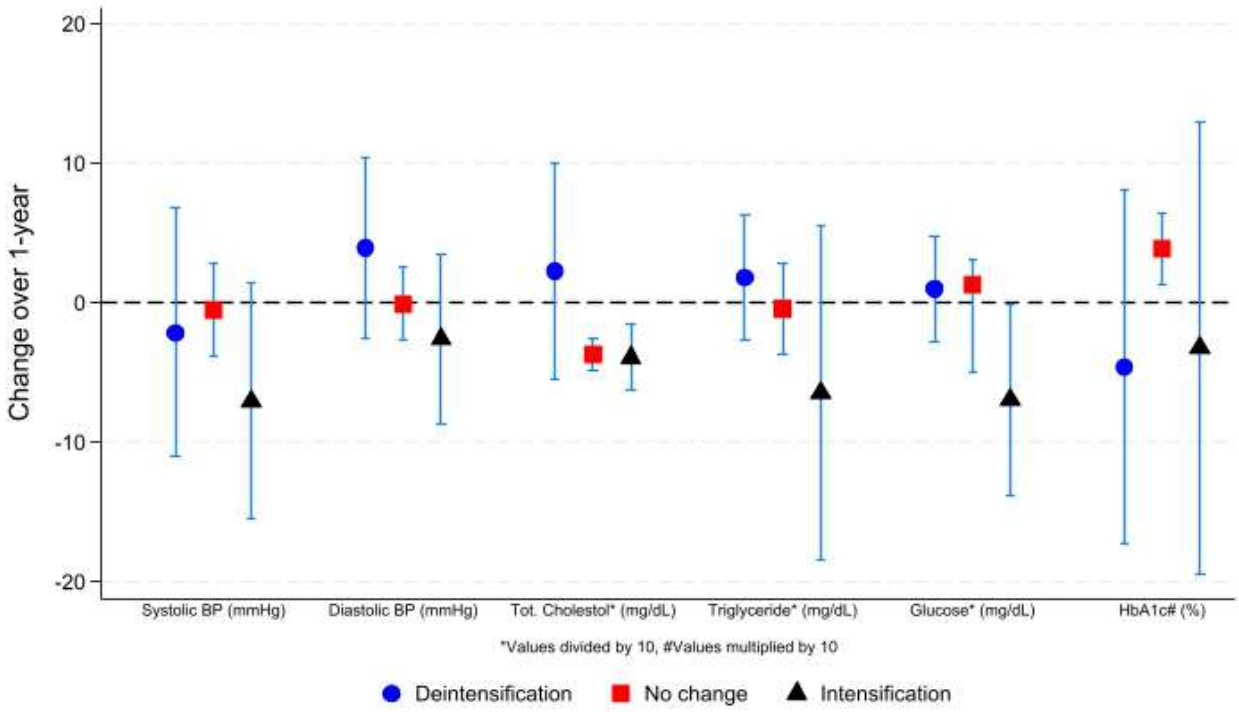
Participants from the Childhood Cancer Survivor Study (CCSS) at an increased risk of future CVD due to prior cancer therapies, and with undertreated hypertension, dyslipidemia, or diabetes (per standard clinical definitions) were enrolled into a 1y randomized trial (CHIIP, NCT3104543) that tested the impact of a survivorship care plan-based counseling intervention to reduce CVD risk factor undertreatment. Resting blood pressures (BP) and a randomly timed blood draw (lipid profile, glucose, and hemoglobin A1c [HbA1c]) were obtained by a trained home examiner at baseline and 1y, with results shared with participants and their primary care providers. Medical records over the study period, including names of medications (and doses) used to treat any of the 3 CVD risk factors, were then abstracted, with changes in treatment intensity classified (blinded to risk factor outcomes) as no change, deintensified, or intensified. Changes in BP, total cholesterol, triglyceride, glucose, and HbA1c over 1y were compared by treatment intensity status using paired t-tests. Generalized estimating equations (GEE) evaluated the change in each risk factor measurement by treatment intensity status (no change as referent), adjusting for body mass index.

RESULTS

Of 347 randomized participants, 293 (84%) had evaluable medical records and were included in this analysis (mean age 40y, mean 31y since cancer diagnosis, 51% male, 76% anthracycline-exposed, 69% chest radiation). At baseline, 31%, 20%, and 11% of participants were on medications for hypertension, dyslipidemia, and diabetes, respectively; 40% were on at least one medication with 14% on ≥3 medications. Data were evaluable for 274 participants at 1y, with 35%, 25%, and 12% now on medications for the 3 risk factors, and overall, 46% receiving treatment. For each risk factor, rates of treatment intensification ranged from 16-19% of affected participants, and 4-12% of participants experienced treatment deintensification. In univariate analyses, intensification was generally associated with improvements in risk factors, with a borderline reduction in systolic BP (-7 mmHg [95%CI -15, 1] p=0.10), and significantly lower total cholesterol (-39 mg/dL [-63, -15]) and glucose (-69 mg/dL [-138, -1]; Figure). Participants who had no changes in intensity and those who had deintensification generally had similar values at follow-up versus baseline across all 3 risk factors. In GEE analyses, compared with no change, treatment intensification continued to be associated with significant glucose reduction (-90 mg/dL [-145, -34]). Although intensification was not associated with lower total cholesterol levels versus no change, deintensification was associated with significantly higher cholesterol levels (+45 mg/dL [2, 88]).

CONCLUSION

Treatment intensity influences CVD risk factor outcomes among long-term survivors exposed to anthracyclines and chest radiotherapy. More aggressive management of undertreated CVD risk factors may reduce CVD risk in this population.


20
10
0
-10
-20
Change over 1-year
Systolic BP (mmHg)
Diastolic BP (mmHg)
Tot. Cholestol* (mg/dL)
Triglyceride* (mg/dL)
Glucose* (mg/dL)
HbA1c# (%)
*Values divided by 10, #Values multiplied by 10
Deintensification
No change
Intensification

Figure

OP09

Endocrine outcomes

VOXEL-BASED ANALYSIS OF DOSE-RESPONSE RELATIONSHIPS WITHIN THE HYPOTHALAMUS-PITUITARY AXIS AS A PREDICTOR OF GROWTH HORMONE DEFICIENCY: A MULTI-CENTRE STUDY.

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[6]*Patient Representative*

BACKGROUND-AIM

Growth hormone deficiency (GHD) is a common endocrine late effect after cranial radiotherapy in children and young people (CYP). Untreated GHD can result in short stature, metabolic dysfunction, and reduced quality of life. Dose to the hypothalamus-pituitary axis (HPA) is a recognised contributing factor, but dose-response of individual HPA substructures remains poorly understood. With improved tissue sparing in modern radiotherapy, dose to each substructure may vary and differentially influence outcomes.
This study applied a voxel-based analysis (VBA) approach to identify spatial dose-response patterns with no a-priori hypothesis in patients treated with photon radiotherapy. Extensions of this framework to proton-treated cohorts is underway.

METHODS

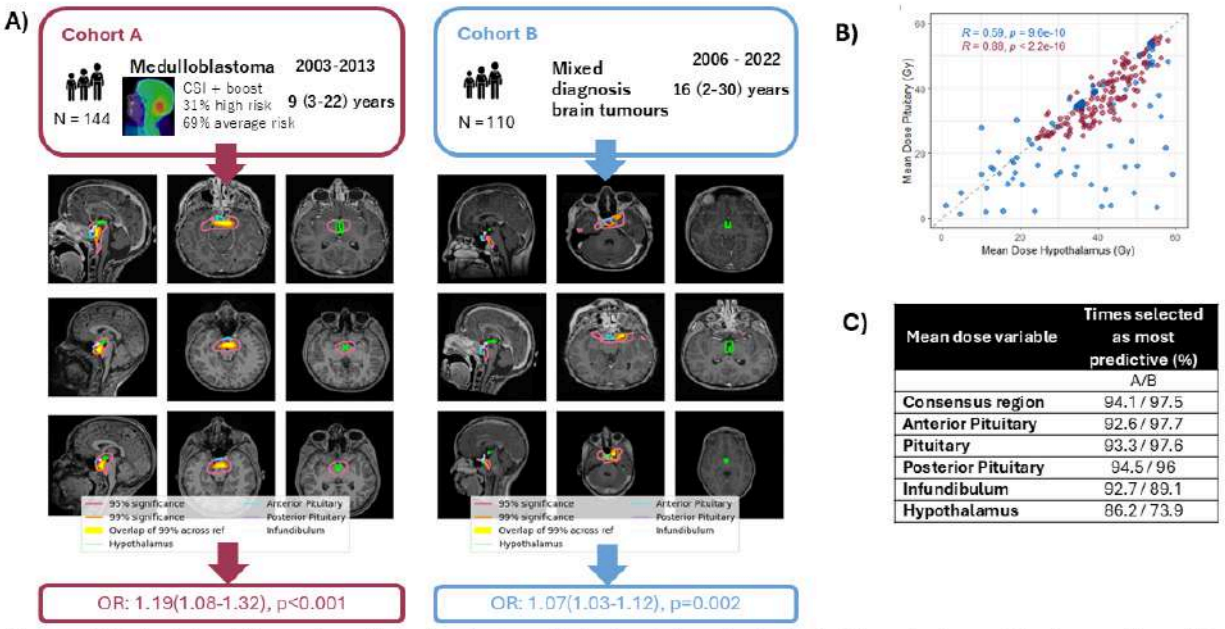
Data from 256 CYP treated with photon radiotherapy for brain tumours at two centres were analysed. Centre A (n=146) included medulloblastoma patients (median age 9 years); Centre B (n=110) included mixed diagnoses (median age 16 years). Planning MRI (Centre A) or CT (Centre B) scans were deformably registered to three reference anatomies. Dose distributions were mapped to reference space and blurred to account for registration uncertainty.
Voxel-wise t-tests compared dose for patients with and without GHD. Significance was assessed using permutation testing (n=1000). Mean dose to the consensus region (overlap of 99% significance region across reference anatomies) was entered into multivariable logistic regression.
For comparison, HPA substructures were segmented on reference anatomies. Volumetric overlap with the consensus region was quantified, and mean doses to key substructures were extracted including anterior/posterior pituitary, hypothalamus, and infundibulum and assessed with correlation analysis. Akaike Information Criterion (AIC) was used to determine whether each dose variable independently improved predictive power of a model containing clinical variables. Internal validation was performed with 1000 bootstrap iterations, recorded the frequency with which each dose variable significantly lowered AIC across each iteration.

RESULTS

GHD occurred in 79% of patients in Centre A and 42% in Centre B. Despite differences in age, diagnosis mix, and treatment, both cohorts independently demonstrated significant dose associations at the pituitary(Fig.1A).
In multivariable analysis, 1 Gy increase in mean dose to the consensus region increased odds of GHD by 19% (95% CI 8–32%) in Centre A and 7% (3–12%) in Centre B. In Centre A, older age at treatment reduced risk (20% per year); no additional predictors were significant in Centre B. Dose to the hypothalamus and pituitary was strongly correlated(Fig.1B). Across both cohorts, pituitary and consensus region were most predictive(Fig.1C).
Preliminary proton data show significantly less correlation between hypothalamic and pituitary dose, and approaches to model longitudinal blood test results rather than binary outcomes are being explored.

CONCLUSION

Using VBA, we independently identified similar spatial dose–response in two paediatric radiotherapy cohorts. Higher dose to the pituitary was consistently associated with increased GHD risk. These findings support efforts to minimise pituitary dose and suggest hypothalamus and pituitary doses should be considered independently in outcome modelling, particularly in proton cohorts. Results demonstrate association rather than causation, and future work will incorporate causal inference approaches.



Mean dose variable	Times selected as most predictive (%)
	A/B
Consensus region	94.1 / 97.5
Anterior Pituitary	92.6 / 97.7
Pituitary	93.3 / 97.6
Posterior Pituitary	94.5 / 96
Infundibulum	92.7 / 89.1
Hypothalamus	86.2 / 73.9

Figure 1. A) Cohort description and voxel-based analysis results for two independent cohorts. The region is consistent across three different reference anatomies as templates (independently in each cohort analysis) and across cohorts. In multivariable modelling, correcting for clinical variables, dose to this region remains a significant predictor of GHD in both cohorts. **B)** The consensus region identified covers the pituitary but not the hypothalamus, but the doses to the two regions are correlated. **C)** Dose to the consensus region or pituitary remains more predictive in bootstrap analysis then dose to the hypothalamus. Validation will be performed in a proton data-set with higher dose variability.

OP10

Endocrine outcomes

REEVALUATING BONE MINERAL DENSITY SURVEILLANCE IN PEDIATRIC ACUTE LYMPHOBLASTIC LEUKEMIA SURVIVORS: A SINGLE-INSTITUTION RETROSPECTIVE REVIEW

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BACKGROUND-AIM

Survivors of pediatric Acute Lymphoblastic Leukemia (ALL) are at risk for impaired Bone Mineral Density (BMD), largely due to corticosteroid exposure. Current Children's Oncology Group (COG) long-term follow-up guidelines, Version 6.0, recommend baseline dual-energy X-ray absorptiometry (DXA) screening for survivors entering long-term follow-up after corticosteroid therapy. More recent recommendations from the International Late Effects of Childhood Cancer Guideline Harmonization Group propose a more risk-adapted approach to BMD surveillance; however, these guidelines have not yet been adopted at our institution. The clinical utility and cost-effectiveness of our current DXA surveillance practice remain uncertain. We evaluated adherence to BMD screening recommendations, incidence of low BMD and fractures, and the impact of DXA findings on clinical management to assess whether surveillance strategies could be streamlined.

METHODS

We performed a single-institution retrospective chart review of pediatric patients diagnosed with ALL between 1989 and 2020. Demographic characteristics, ALL subtype, treatment specifics, DXA results, fracture history, and subsequent interventions were abstracted. Abnormal BMD was defined per radiology report as low Bone Mineral Density for age. Descriptive statistics were used to summarize demographic and clinical variables. Comparisons between groups were performed using chi-square testing for categorical variables. Statistical significance was defined as $p < 0.05$.

RESULTS

The cohort included 302 patients with ALL; 264 (87.4%) had pre-B cell ALL. Age at diagnosis ranged from 8 months to 20 years. DXA screening was performed in 220 patients (74%). Among those screened, 168 (76%) had normal BMD and 52 (24%) had low BMD. Fractures were documented in 27 patients (9% of the total cohort). Of patients with fractures, 16 (59%) had normal BMD, 6 (22%) had low BMD, and 5 (18%) had not undergone DXA screening. There was no statistically significant association between abnormal BMD and fracture occurrence ($p > 0.05$). Despite identification of low BMD, pharmacologic intervention was uncommon. Only 3 of 52 patients (6%) with abnormal DXA results received bisphosphonate therapy. The majority (49 of 52; 94%) were managed conservatively with calcium and vitamin D optimization and recommendations for increased weight-bearing physical activity. From a cost perspective, the approximate cost of a DXA scan is $300 compared to approximately $30 annually for calcium and vitamin D supplementation.

CONCLUSION

In this single-institution cohort of pediatric ALL survivors, most DXA screenings were normal and abnormal findings rarely altered clinical management beyond conservative supplementation strategies. The overall occurrence of fractures was low in the cohort. Fractures occurred more frequently in patients with normal BMD than in those with low BMD, and no significant association was observed between abnormal BMD and fracture risk. These findings suggest limited clinical impact of universal DXA screening and support consideration of a risk-adapted surveillance approach aligned with evolving international guidelines, emphasizing preventive strategies while reserving imaging for higher-risk subsets. Further analysis of the cohort is ongoing.

OP11

Subsequent Malignant Neoplasms (SMN)

ASSOCIATION BETWEEN NEIGHBORHOOD-LEVEL SOCIAL VULNERABILITY AND THE INCIDENCE OF SUBSEQUENT MALIGNANT NEOPLASMS: A REPORT FROM THE CHILDHOOD CANCER SURVIVOR STUDY

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BACKGROUND-AIM

It is unknown whether neighborhood-level social vulnerability impacts subsequent malignant neoplasm (SMN) risk among survivors of childhood cancer. We evaluated associations between neighborhood-level social vulnerability and SMN incidence among participants in the Childhood Cancer Survivor Study.

METHODS

This analysis included five-year survivors of childhood cancer diagnosed between 1970-1999 in the US with residential addresses from CCSS baseline that have been geocoded. Using the US Centers for Disease Control and Prevention's Social Vulnerability Index (SVI), we evaluated the quartiles (Q1 to Q4 = most to least vulnerable) of overall SVI and subdomains (socioeconomic status, household composition, minority status and language, and housing and transportation). All SMNs that developed > 5 years after the initial diagnosis, including breast, colorectal, and thyroid, were self-reported, confirmed by pathology review, and included. Relative rates (RRs) were adjusted for attained age, sex, age at primary cancer diagnosis, and treatment exposures specific to each outcome (breast, colorectal, and thyroid SMNs).

RESULTS

Among 20,739 survivors with baseline SVI data (median age at baseline: 25 years, IQR = 19-30 years), the 25-year cumulative incidence of SMNs was 13% (95% CI 13-14%). 1369 survivors developed an SMN, including 358 breast, 95 colorectal, and 272 thyroid SMNs. For all SMNs, there was a significant association observed between residence in a less socially vulnerable neighborhood and higher rates of SMNs (overall SVI, reference Q1 [most vulnerable]: Q4 RR 1.43, 95% CI 1.2-1.71; Q3 RR 1.23, 95% CI 1.02-1.48; Q2 RR 1.25, 95% CI 1.03-1.51; p-trend = < 0.001). Additionally, a significant association between lower vulnerability and a higher rate of SMNs was observed for the SVI socioeconomic subdomain (Q4 vs Q1 RR 1.25, 95% CI 1.05-1.49, p-trend = 0.0098) and household composition subdomain (Q4 vs Q1 RR 1.27, 95% CI 1.07-1.5, p-trend = 0.004). No statistically significant association was observed with neighborhood-level social vulnerability in either overall or subdomain SVI for subsequent breast or colorectal cancer (breast overall SVI Q4 vs Q1 RR 1.38; 95% CI 0.95-2.0 and colorectal overall SVI Q4 vs. Q1 RR 0.74; 95% CI 0.38-1.44). However, for thyroid SMNs, residing in lower neighborhood-level social vulnerability communities was significantly associated with an increased SMN rate (overall SVI Q4 vs. Q1 RR 1.61; 95% CI 1.08-2.41; p-trend = 0.04), but no individual SVI subdomains were significantly associated.

CONCLUSION

Among survivors of childhood cancer, residing in less socially vulnerable neighborhoods was associated with higher rates of SMNs overall, driven largely by thyroid SMNs. Given that rising incidence of some cancer types (e.g., primary thyroid cancers) may be attributed to increased detection related to advances in imaging, these findings raise the possibility that the relationship between neighborhood-level social determinants of health and SMN incidence may reflect improved diagnosis, detection bias, or some combination of the two. Future studies should evaluate the extent to which healthcare access and detection practices contribute to SMN burden, especially thyroid SMNs, among survivors.

OP12

Epidemiology/Research methods

PREDICTIVE VALUE OF SOCIAL DETERMINANTS OF HEALTH FOR MAJOR ADVERSE CARDIOVASCULAR EVENTS AMONG CHILDHOOD CANCER SURVIVORS.

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BACKGROUND-AIM

Childhood cancer survivors (CCS) are at increased risk of late cardiovascular disease (CVD), influenced by treatment-related risk factors and modifiable cardiovascular risk factors. Social determinants of health (SDOH) describe the social and economic conditions in which people are born, live, work, and age. While SDOH are established contributors to CVD risk in the general population, it remains unclear which individual-, family-, and neighborhood-level SDOH contribute to the risk of major adverse cardiovascular events (MACE) in CCS.
The aim of this study was to evaluate the predictive importance of multilevel SDOH for the 20-year risk of MACE from age 30 among CCS.

METHODS

This longitudinal study was conducted within the Swedish Cardiovascular Register Project (SCARP), a nationwide population-based study, using linkage of several national registries. For this study, all individuals diagnosed with childhood cancer at age 0–17 years in Sweden after 1970 were identified. Follow-up started at age 30 and continued until death, emigration, or end of follow-up (July 2024), with most data available from 1990 to 2022. Individuals with preexisting MACE were excluded, as were individuals who turned 30 before 1990 or who had not reached 30 years of age by the end of follow-up. The SDOH included were at the individual, family, and neighborhood level, from time of childhood cancer diagnosis and at age 30. MACE was defined as the first occurrence of myocardial infarction, stroke, heart failure, ventricular tachycardia/fibrillation, cardiac arrest, or cardiovascular death. Machine learning–based survival models quantified the relative predictive importance at age 30 of multilevel social determinants of health for 20-year risk of MACE.

RESULTS

13,049 CCS were identified. After excluding survivors who turned 30 before 1990 or had not yet reached 30 years of age at the end of follow-up, 7,466 CCS were included (50.9% female). The most common primary childhood cancer diagnoses were leukemia (19.0%) and central nervous system tumors (24.5%). 17.7% were diagnosed in 1970–1979, 30.6% in 1980–1989, 32.7% in 1990–1999, and 17.5% in 2000–2009. During a mean (SD) follow-up of 13.9 (9.2) years, 358 MACE were observed.
Permutation-based variable importance analyses showed that educational attainment at age 30 was among the strongest contributors to prediction of 20-year MACE, with a predictive importance comparable to that of primary childhood cancer diagnosis. Additionally, both mother's and father's employment status before childhood cancer diagnosis, area-level deprivation score at age 30, inpatient care for somatic disease at ages 20-30, household income prior to childhood cancer diagnosis, and household and individual income at age 30 contributed considerably to the prediction of MACE. In contrast, treatment era, sex, and age at cancer diagnosis contributed little or no information to model discrimination.

CONCLUSION

The results from this population-based study of childhood cancer survivors, performed in a setting with universal healthcare coverage and relatively high levels of social protection, suggest that several social determinants of health at both the individual, family, and neighborhood level, and at childhood cancer diagnosis and age 30 are important contributors to the prediction of future major cardiovascular events. These findings suggest incorporating SDOH into long-term cardiovascular risk stratification to facilitate more equitable identification of individuals at increased risk.

OP13

Interventional research

THE ASPIRES STUDY: PROMOTING COLORECTAL CANCER SURVEILLANCE IN CHILDHOOD CANCER SURVIVORS–A RANDOMIZED INTERVENTION TRIAL FROM THE CHILDHOOD CANCER SURVIVOR STUDY (CCSS)

T.O. Henderson [1], J.K. Bardwell [1], C.S. Moskowitz [5], L.F. Schwartz [1], G. Gallagher [5], A. Mcdonald [7], S. Alston [7], C. Vukadinovich [7], A. Jackson [7], H. Lam [1], M. Curry [5], K.C. Oeffinger [3], J.S. Ford [4], E.B. Elkin [2], P.C. Nathan [8], G.T. Armstrong [7], K. Kim [6]

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BACKGROUND-AIM

Survivors of childhood cancer exposed to abdominal, pelvic, spinal, or total-body radiotherapy (RT) have an elevated risk of developing subsequent treatment-related colorectal cancer (CRC). Adherence to guideline-recommended CRC surveillance screening is only 37%, leaving survivors vulnerable to potentially preventable cancer. Innovative interventions are needed to improve surveillance in this high-risk population.

METHODS

We conducted a three-arm randomized controlled trial comparing mHealth-based patient activation (PA) and patient plus primary care provider activation (PA+PCP) with a control arm that received a survivorship care plan with screening recommendations. Nested within the CCSS, eligible participants were 5-year survivors diagnosed before age 21 who had previously received abdominal, pelvic, spinal, or total-body radiotherapy and were not currently adherent to the Children's Oncology Group Long-Term Follow-Up CRC surveillance guidelines. Participants (n = 300) were randomized in a 1:1:1 ratio, stratified by age at enrollment (30–44 vs ≥45 years). The primary outcome was the proportion of participants who completed recommended surveillance within 12 months. Each intervention arm was compared with the control in an intent-to-treat analysis using the Cochran-Mantel-Haenszel test (# = 0.025/comparison). In secondary analyses, logistic regression, adjusted for age at enrollment, was used to estimate odds ratios (ORs) to identify moderators of the relationship between the intervention (grouping PA with PA+PCP) and the outcome.

RESULTS

Participants were 45% male and 8% non-white, with a median age of 41 years (range: 30 − 67 years). At 12 months, survivors in the PA group were significantly more likely than controls to have completed surveillance screening: 32/99 (32%) vs 14/102 (14%) [p = 0.003]. Surveillance screening completion was also higher in the PA+PCP group than in controls, but this difference did not meet the prespecified α (0.025): 26/99 (26%) vs 14/102 (14%) [p = 0.041]. Secondary analyses suggested the intervention was more effective among survivors without a chronic health condition (without: OR = 3.6; 95%CI 1.5, 10.1 vs. with: OR=1.9; 95%CI 0.8, 4.8) and with ≤ high school education (≤ high school OR=4.4; 95%CI 1.3, 20.2 vs. > high school OR=2.2; 95%CI 1.1, 4.7).

CONCLUSION

An mHealth-based patient activation intervention more than doubled adherence to guideline-recommended CRC surveillance compared with a survivorship care plan with surveillance recommendations alone. While patient plus PCP activation showed improvement, adding PCP activation did not confer a significant benefit compared with the control. Intervention effectiveness varied across subgroups, underscoring the importance of tailored approaches. As digital technologies continue to advance, mHealth strategies offer a promising and scalable pathway to improving surveillance screening among high-risk survivors of childhood cancer.

OP14

QoL/Rehabilitation

CLINICALLY MEANINGFUL SYMPTOMS IN ADULT SURVIVORS OF CHILDHOOD CANCER: A COMPARISON WITH THE U.S. GENERAL POPULATION USING THE MODIFIED PATIENT-REPORTED OUTCOMES VERSION OF THE COMMON TERMINOLOGY CRITERIA FOR ADVERSE EVENTS (PRO-CTCAE)

M.R. Horan [6], J. Choi [2], E. Zhang [2], N. Bhakta [3], D.K. Srivastava [1], K.K. Ness [2], M.M. Hudson [4], G.T. Armstrong [2], J.N. Baker [5], I. Huang [2]

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BACKGROUND-AIM

Symptom assessment for cancer survivors should prioritize prevalent and clinically meaningful symptoms. This study compared the prevalence of 140 symptoms between adult survivors of childhood cancer and the U.S. general population and identified those symptoms that healthcare providers (HCPs) considered clinically meaningful.

METHODS

This cross-sectional study included 1,208 5-year adult survivors of childhood cancer from the Childhood Cancer Survivor Study, sampled to reflect SEER distributions by age, sex, and cancer diagnosis, and 1,356 community controls from the Slice panel, sampled to reflect National Health Interview Survey distributions by age, sex, and race/ethnicity. A total of 140 symptoms across 12 domains (cardiovascular, digestive, head/neck, musculoskeletal, sexual, cognitive/psychological, respiratory, neurological, urinary, metabolic, skin, general) were assessed, including 62 original and 18 modified from the PRO-CTCAE and 60 newly created via qualitative interviews with survivors. Survivors and controls were propensity-score-matched on personal socio-demographics (age at survey, sex, race/ethnicity, education, marital status, income, insurance, employment, living arrangement, smoking) and neighborhood adversity per the Social Vulnerability Index. Symptom prevalence was compared using multivariable logistic regression on the matched sample. In addition, 232 international HCPs (oncologists, primary care physicians, nurses) from 21 countries caring for childhood cancer survivors rated each symptom across three dimensions of clinical significance (survivorship relevance, clinical manageability, assessment importance). Each symptom was clinically meaningful if >50% of HCPs endorsed it as highly (vs. slightly/moderately) relevant, manageable, and/or important.

RESULTS

The mean±SD attained age was 40.8±10.3 years in survivors and 54.7±15.7 years in controls; the mean±SD time since diagnosis was 33.6±8.0 years. Females comprised 57.0% of survivors and 54.1% of controls. Survivors reported a significantly higher prevalence of 26 symptoms vs. controls (odds ratios [ORs] range: 2.1-6.3; all $p<0.05$). Of these symptoms, 12 were newly identified via qualitative interviews. The most prevalent symptoms spanned multiple domains, with prominence in cognitive/psychological, skin, and general domains. In addition, 55 symptoms were rated as clinically meaningful by HCPs, including 26 newly identified. Sixteen symptoms were both more prevalent in survivors and HCP-rated as clinically meaningful (e.g., pain, memory problems, hearing loss). Psychological symptoms that were more prevalent in survivors vs. controls and clinically meaningful included slow thinking (OR=6.1, 95%CI=3.0-12.7) and memory problems (OR=3.5, 95%CI=1.7-7.4); physical symptoms more prevalent in survivors included blurry vision (OR=3.3, 95%CI=1.5-7.1), hearing loss (OR=3.8, 95%CI=1.3-10.7), and hematuria (OR=5.8, 95%CI=1.4-23.6).

CONCLUSION

Adult survivors of childhood cancer experience a high prevalence of multidomain symptoms, many of which clinicians consider clinically meaningful but are not captured by standard tools such as the PRO-CTCAE (e.g., hematuria, slow thinking). This concordance between survivor reports and clinician ratings reveals important gaps in current symptom surveillance and underscores the need for a survivor-specific symptom assessment framework to enhance symptom detection and support person-centered survivorship care.

OP15

Cardiovascular

RADIATION ONCOLOGY WORKFLOW-INTEGRATED INDIVIDUALIZED RISK CALCULATOR TO COMPREHENSIVELY PREDICT FUTURE CARDIAC DISEASE RISK AMONG PEDIATRIC AND ADOLESCENT CANCER PATIENTS

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BACKGROUND-AIM

Long-term survivors of pediatric and adolescent cancers face a high risk of treatment-related severe/life-threatening cardiac disease decades after diagnosis, driven primarily by radiation dose to the heart and cardiac substructures as well as exposure to anthracycline chemotherapy. To develop and validate radiation therapy (RT) workflow-integrated individualized cardiac substructure-level risk prediction models to estimate future risk of coronary artery disease (CAD), heart failure (HF), valvular heart disease (VHD), and any cardiac disease in pediatric and adolescent cancer patients treated with contemporary approaches.

METHODS

Piecewise exponential regression models were developed in the Childhood Cancer Survivor Study (CCSS) and externally validated in the St Jude Lifetime Cohort (SJLIFE) to predict severe or life-threatening CAD, HF, VHD, and any cardiac disease (events/participants: 1,076/19,838 CCSS; 295/4,361 SJLIFE). Mean cardiac substructure dose (MCSD) models used lasso regression with 10-fold cross validation to select predictors from mean heart dose (MHD), mean doses to 11 cardiac substructures (atria, coronary arteries, valves, ventricles), and heart V5 and V20. Models were adjusted for attained age, sex, race ethnicity, age at diagnosis, and anthracycline exposure, and compared with MHD only models. An in-silico study estimated cardiac risk for 22 patients aged 10 to 20 years treated with mediastinal intensity modulated radiotherapy (IMRT) versus simulated intensity modulated proton therapy (IMPT). A Python based risk calculator was implemented within the RayStation RT planning system.

RESULTS

Modeling: For HF, VHD, and any cardiac disease, MHD-models demonstrated strong discrimination (internal/external AUCs:0.730-0.802/0.736-0.845; all p<0.034 vs chest-RT dose models), with no improvement from adding MCSDs. For CAD, the MHD-model achieved internal/external AUCs of 0.736/0.686. Using left ventricle and left main coronary artery mean doses improved CAD prediction (internal/external AUC: 7.44/6.94; p=0.016 vs MHD).
In-silico Study: Using MCSD-models, the median predicted CAD rate (IQR:4.43-7.62) for IMRT was 5.22 per 1,000 person-years, decreasing by 40% to 3.19(IQR:2.75-4.57) with IMPT. For CAD, CHF, VHD, and any cardiac disease, median rates for IMRT predicted with MHD-models were 1.96(IQR:1.13-2.57), 4.99(IQR:2.52-10.70), 2.02(IQR:1.22-2.95), and 9.95(IQR:5.42-17.33) per 1,000 person-years, respectively, with IMPT reducing risk by ~15%. Figures 1 summarize in-silico results, including rates, rate ratios versus same-sex siblings without cancer, and the RayStation-integrated calculator (representative patient), which reports the higher of the MHD- and MCSD-based CAD risks for a conservative estimate.

CONCLUSION

We developed and validated a survivorship focused, RT workflow integrated cardiac risk calculator that enables real time estimation of long-term cardiac disease risk during treatment planning and supports risk informed modality selection to reduce late cardiac complications.

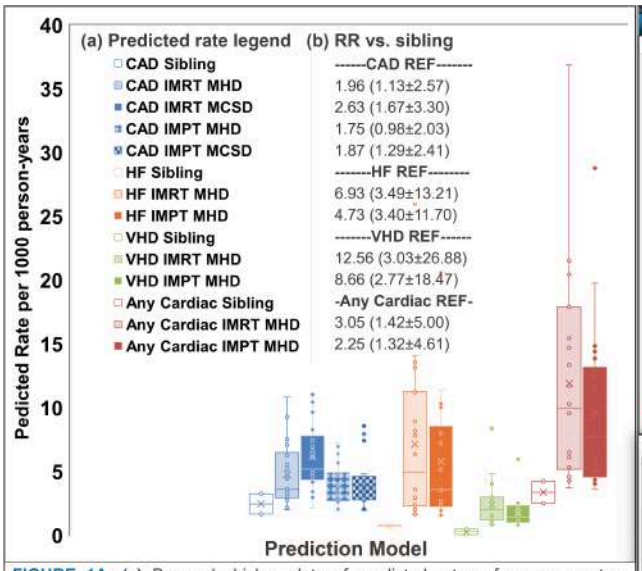

FIGURE 1A. **(a)** Box-and-whisker plots of predicted rates of coronary artery disease (CAD), heart failure (HF), valvular heart disease (VHD), and any cardiac disease for 22 patients treated with intensity modulated radiation therapy (IMRT) and anthracyclines, compared with rates for simulated intensity-modulated proton therapy (IMPT) plans prescribed to the same planning target volume and cumulative anthracycline doses. Also shown are median rates with interquartile ranges (IQRs) for each outcome in same-sex siblings from the CCSS sibling cohort without cancer; **(b)** Median rate ratios (RRs) with IQRs for CAD, HF, VHD, and any cardiac disease for each individual in the in-silico study, with rates normalized to the corresponding same-sex sibling.

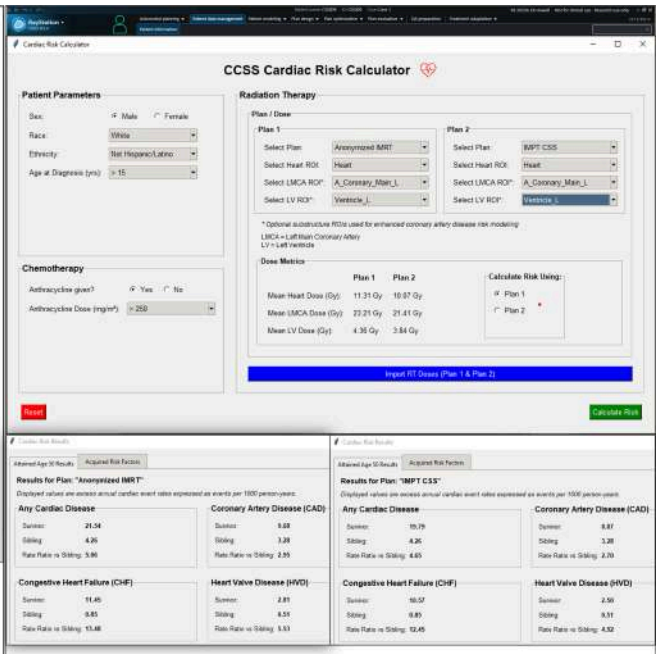

FIGURE 1B. Example input and output graphical user interfaces of the CCSS cardiac disease risk calculator implemented in the RayStation commercial treatment planning system (TPS), illustrated for IMRT and IMPT treatment plans for a representative patient in the in-silico study.

OP16

Endocrine outcomes

DEVELOPMENT AND VALIDATION OF DIABETES MELLITUS RISK PREDICTION MODELS IN SURVIVORS OF CHILDHOOD CANCER: A ST. JUDE LIFETIME COHORT STUDY (SJLIFE) AND CHILDHOOD CANCER SURVIVOR STUDY (CCSS) REPORT

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BACKGROUND-AIM

Diabetes mellitus (DM) is a prevalent late effect among survivors of childhood cancer. We developed and validated models to predict DM risks in survivors based on clinical characteristics available at the 5-year cancer survival milestone.

METHODS

Risk prediction models estimating DM risks by ages 30 and 40 years were trained using data from 5-year survivors in SJLIFE. DM was defined by Common Terminology Criteria for Adverse Events (CTCAE) grades ≥2 for abnormal glucose metabolism or hemoglobin A1c levels ≥6.5%. The XGBoost (eXtreme Gradient Boosting) machine learning algorithm was used to develop models using 3 levels of treatment information: (1) simple model, with treatment exposures without dose; (2) dose model, including delivered cranial, abdominal, and pelvic radiation therapy (RT) and cumulative chemotherapy doses; and (3) pancreatic tail dosimetry model. Other predictors included: sex; race/ethnicity; cancer diagnosis age; total body irradiation (TBI); hematopoietic cell transplantation (HCT). In those with available data, we developed models that also included categorical 5-year survival body mass index (BMI). In SJLIFE, cross-validated age-specific metrics (AUROC/AUPRC: area under the receiver operating characteristic curve/precision-recall curve) evaluated risk prediction performance. Model external validation was conducted in CCSS with self-reported DM (CTCAE grades ≥2). We compared models with Children's Oncology Group Long-Term Follow-Up Guidelines (COG LTFU, v6.0) recommending blood sugar screening following any abdominal RT or TBI.

RESULTS

Among 5086 SJLIFE participants, 147 and 424 developed DM by ages 30 and 40, with incidences of 4% and 12%, respectively. Simple, dose, and pancreatic models featuring treatment characteristics demonstrated modest discrimination (AUROC range: 0.62-0.69) and precision (AUPRC range: 0.09-0.29), with the simple model showing the weakest performance. However, when 5-year survival BMI was added (N=3561), each showed significantly improved discrimination (AUROC: 0.75-0.77, P<0.001) and precision (AUPRC: 0.20-0.24, P<0.01) in predicting DM risk by age 30. For DM risk prediction by age 40, the performance of models with BMI was sustained (AUROC: 0.74-0.80; AUPRC: 0.32-0.51). After adding 5-year survival BMI, abdominal/pancreatic tail RT and TBI were less influential; cancer diagnosis age, sex, and cranial RT were more influential. In external validation among CCSS survivors with BMI data (N=5518, incidence by age 30 and 40: 2% and 10%), all models predicting DM risk by age 30 showed good discrimination and precision (AUROC: 0.78-0.79; AUPRC: 0.13-0.14). Small decreases in performance for models predicting DM risk by age 40 were observed (AUROC: 0.73-0.73; AUPRC: 0.14-0.23). In CCSS, COG LTFU guideline-based classification was less predictive (AUROC: 0.56-0.66, P<0.05; AUPRC: 0.03-0.08, P<0.10). Among survivors recommended for screening, the DM incidence was 4% by age 30; the best model with BMI stratified risks by age 30 into low (<5%), medium (5-19%), and high (≥20%) risk groups with corresponding DM incidences of 1%, 6%, and 31%.

CONCLUSION

Leveraging treatment and 5-year survival BMI information, our newly developed models stratify childhood cancer survivors into distinct DM risk groups by ages 30 and 40 years. Communicating personalized risks can support interventions to prevent DM and reduce cardiovascular disease risk.

OP17

Endocrine outcomes

PREVALENCE AND RISK FACTORS FOR OVARIAN DYSFUNCTION FOLLOWING CANCER TREATMENT IN CHILDHOOD CANCER SURVIVORS

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BACKGROUND-AIM

With improving survival of childhood cancer fertility is assuming increasing significance among survivors and oncologists alike. Paucity of data from LMIC prompted the present study.
Aim: To study prevalence and risk factors for ovarian dysfunction among childhood cancer survivors (CCS).

METHODS

This single-centre, cross-sectional observational study conducted between January and December 2025, focused on female childhood cancer survivors off-therapy for at least two years and aged > 15 years at evaluation. Menstrual history and Tanner stage were evaluated during their survivorship clinic visits, while demographic details and gonadotoxic exposures were abstracted from the medical records. Treatment-related amenorrhea (TRA, > 4 months, IGHG guidelines), acute ovarian failure (Chemaitilly 2006), primary amenorrhea (ACOG) were studied. Endocrine evaluations (FSH/LH) were done for those with amenorrhea > 4 months. Descriptive statistics and logistic regression analysis were applied as appropriate.

RESULTS

Among 286 eligible survivors 126 consented for the study. Their median age evaluation was 20 yrs and median follow-up duration 9 years. The gonadotoxic exposures included cyclophosphamide equivalent dose (CED) >7.5g/m2 (21/126), pelvic radiotherapy (7/126) and hematopoietic stem cell transplantation (HSCT,11/126). The CCSS calculator was used to identify survivors at low (78.6%), moderate-low (11.9%), moderate (6.3%) and high (3.2%) risk of AOF. We observed TRA in 35%(44/126) survivors of which 20%(9/44) had AOF; majority of them belonged to moderate (TRA,87%; AOF,25%) and high (TRA,100%; AOF, 75%) risk groups ($p<0.01$). One out of 5 patients with TRA developed AOF. On multivariable analysis post-pubertal status, CED$\geq$7.5g/m^2, pelvic radiotherapy and HSCT ($p < 0.01$) were independent risk factors for ovarian dysfunction.

CONCLUSION

Ovarian dysfunction was observed in a substantial subset of CCS, risk factors included high dose alkylating agent exposure, pelvic radiotherapy and HSCT. Survivors with TRA represent a frequent, often reversible phenotype of ovarian injury requiring longitudinal ovarian surveillance. These findings support risk-adapted fertility preservation counselling, consistent with international survivorship guidelines.

Table 1a: Clinical and treatment-related characteristics of childhood cancer survivors stratified by menstrual status:

Variables	Total N=126	No amenorrhea N=82	Treatment related amenorrhea N= 44	P value
Age at diagnosis				
≤ 12 years	62 (49.2)	55 (67.1)	7 (15.9)	<0.00001
>12 years	64 (50.8)	27 (32.9)	37 (84.1)	
Pubertal status at diagnosis				
Prepubertal	63 (50)	60 (73.2)	3 (6.8)	<0.00001
Pubertal/ Postpubertal	63 (50)	22 (26.8)	41 (93.2)	
Disease				
Hematological	**79 (62.7)**	**61 (74.4)**	**18 (40.9)**	0.000201
Leukemia	48 (38.1)	38 (46.3)	10 (22.7)	
Lymphoma	31 (24.6)	23 (28.1)	8 (18.2)	
Solid tumors	**47 (37.3)**	**21 (25.6)**	**26 (59.1)**	
Bone sarcoma	23 (18.2)	9 (10.9)	14 (31.8)	
Embryonal*	8 (6.3)	5 (6.1)	3 (6.8)	
Others**	16 (12.7)	7 (8.5)	9 (20.4)	
Exposure				
CED < 7.5 (g/m2)	105 (83.3)	74 (90.2)	31 (70.5)	0.004499
CED ≥7.5 (g/m2)	21 (16.7)	8 (9.7)	13 (29.5)	
Pelvic RT / CS RT	7 (5.5)	2 (2.4)	5 (11.4)	0.037
No RT	119 (94.5)	80 (97.6)	39 (88.6)	
HSCT	11 (8.7)	1 (1.2)	10 (22.7)	0.000046
No HSCT	115 (91.3)	81 (98.8)	34 (77.3)	
Hormonal evaluation				
FSH (mIU/ml) mean (range)	52.44 (0.6-178)	5.7 (0.6-9.5)	74 (3.16-178)	
LH (mIU/ml) mean (range)	33.13 (0.07-151)	4.8 (0.07-10.6)	47.6 (1-151)	

Table 1b: Risk of Acute ovarian Failure Comparison of present study with Childhood Cancer Survivor Study (CCSS) and the St. Jude Lifetime Cohort (SJLIFE) study

Risk of AOF	Our study	CCSS study	SJLIFE study
Low (L) (<5%)	1/99 (1%)	119/5130 (2.3%)	8/796 (1.0%)
Medium-Low (M-L) (5- <20%)	3/15 (20%)	47/429 (11.0%)	8/34 (23.5%)
Medium (M) (20- <50%)	2/8 (25%)	55/145 (37.9%)	4/8 (50.0%)
High (H) (≥50%)	3/4 (75%)	132/182 (72.5%)	30/37 (81.1%)
Overall AOF	9/126 (7.1%)	353/5886 (6%)	50/875 (5.7%)

*Embryonal tumours include: Rhabdomyosarcoma, Wilms tumor, Neuroblastoma, Medulloblastoma **Other include: Germ cell tumor, nasopharyngeal carcinoma. ***CS RT: Craniospinal radiotherapy: Patients who received >20 Gy included.(CED: Cyclophosphamide Equivalent Dose, HSCT: Hematopoietic stem cell transplant)

Table

OP18

Endocrine outcomes

AN EXPLORATORY ASSESSMENT OF THE GLOBE-REG REGISTRY FOR STUDYING THE SAFETY OF LONG-ACTING GROWTH HORMONE IN CANCER SURVIVORS (THE SAFE-SURVIVORS STUDY)

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BACKGROUND-AIM

Growth hormone (GH) treatment is approved for paediatric and adult patients with GH deficiency (GHD), including cancer survivors, and has the potential to improve health outcomes in patients at risk for multiple chronic health conditions due to their cancer therapies. In addition to the well-established use of daily GH, several long-acting GH (LAGH) have also been recently approved for the treatment of GHD. The safety of daily GH has been previously studied in cancer survivors with GHD, and the results have been reassuring. However, given its different mechanistic action, there is a need to assess the safety of LAGH compared to daily GH formulation in cancer survivors, particularly regarding new cancer development and relapses.

METHODS

The Global Registry for Novel Therapies in Rare Bone and Endocrine Conditions (GloBE-Reg) (https://globe-reg.net/) was initiated in 2022 as a resource for collecting real world data on safety and effectiveness of GH therapy in people of all ages. In late 2025, a non-interventional, retrospective and prospective study, SAFE-Survivors was launched with the aim of using GloBE-Reg to study cases of all ages who received daily GH or LAGH following a cancer or tumour diagnosis with longitudinal data to be analysed at 12, 24, 60, and 120 months after GH initiation. The study intends to recruit new cases for a period of 10 years and the current report summarises the preliminary analysis of the first data tranche.

RESULTS

Since its launch in late 2022, 44 centres from 24 countries in 5 continents have enrolled 5,075 cases with a median current age of 12.2 (10th, 90th centile: 6.3, 18.1) in GloBE-Reg. Of these, 2,928 (58%) had GHD. Among the GHD cohort,

92 (3%) cases from 16 centres received GH following a cancer or tumour diagnosis. Of these, 10 (11%) were treated with LAGH, 2 had stopped GH and the remainder were on daily GH. In the first data tranche at the launch of the study, data was available for 74 (80%) survivors from 11 centres. The median age at start of therapy and the current age of these cases was 11 yrs (6.4, 14.8) and 14.5 yrs (9.8, 19.2), respectively. This cohort of 74 cases consisted of 64 reports of intracranial tumours including craniopharyngiomas (n,23) and pituitary tumours (n,8). Therapy data was available in 64 cases and the broad groups were surgery only (10), radiation only (3), chemotherapy only (3) and combined (48). The median duration of follow-up data available in this group of cases after GH initiation was 28 months (4.5, 96) and data were at 12, 24, 60 and 120 months in 23, 19, 9 and 3 cases respectively. In the data that was available, there were no documented reports of recurrences or secondary cancers for those treated with daily GH or LAGH.

CONCLUSION

This initial analysis of the SAFE-Survivors study using the GloBE-Reg platform serves as an important first step in assessing the long-term safety of LAGH in comparison to daily GH treatment in cancer survivors with GHD. No new cancers or recurrences were found in this cohort at the time of the first data tranche. However, this is based on a small sample and short follow up time. Increased patient recruitment and data collection of the GloBE-Reg over time will be crucial to fully understand the safety of LAGH in cancer survivors and inform clinical practice.

OP19

QoL/Rehabilitation

INFORMATION AND SUPPORT NEEDS OF CHILDHOOD, ADOLESCENT, AND YOUNG ADULT CANCER SURVIVORS (CAYACS) ACROSS EUROPE: RESULTS FROM THE E-QUOL PROJECT

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BACKGROUND-AIM

This study examined the prevalence of information and support needs among European childhood, adolescent, and young adult cancer survivors (CAYACS), their socio-demographic and clinical predictors, and associations with patient activation and health-related quality of life (HRQOL).

METHODS

The e-QuoL Needs Study is a cross-sectional survey conducted in 15 European countries. Adult CAYACS (≥18 years, diagnosed before age 25) completed the Childhood Cancer Survivor Study–Needs Assessment Questionnaire (CCSS-NAQ), Patient Activation Measure® (PAM®), and PROMIS Global Health scales (HRQOL). Logistic and linear regression models examined associations with socio-demographic and clinical characteristics, patient activation, and HRQOL.

RESULTS

A total of 571 CAYACS who completed ≥50% of items in ≥1 CCSS-NAQ domain were included (71% female; 75% aged 18–35 years; 47% diagnosed >10 years ago). In all domains except spirituality, most participants (62–90%) reported at least one need, with the highest prevalence for cancer-related health information (90%), psycho-emotional consequences (87%), and health system concerns (84%). Females, survivors residing in Eastern Europe, and those with neurocognitive late effects were most likely to report needs ($p<0.05$). Having needs was associated with lower patient activation and poorer mental and physical HRQOL.

CONCLUSION

Information and support needs remain highly prevalent among European CAYACS, even long after treatment, and vary across European regions. Routine assessment of needs and targeted strategies to provide information in survivorship care—such as stepwise information delivery, accessible written materials, survivorship passports, and digital tools—may help improve patient activation, reduce regional inequities, and optimize HRQOL.

OP20

Other 2

EVALUATION OF BONE MINERAL DENSITY AND VITAMIN D STATUS IN LONG TERM SURVIVORS OF CHILDHOOD ACUTE LYMPHOBLASTIC LEUKEMIA IN LMIC SETTING

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BACKGROUND-AIM

Acute lymphoblastic leukemia (ALL) is the most common pediatric malignancy. Improved survival has increased recognition of late effects, including reduced bone mineral density (BMD) and vitamin D insufficiency, predisposing survivors to early skeletal morbidity. This study evaluated bone health in long-term childhood ALL survivors (cALLs) by estimating Bone Mineral Density (BMD) and Vitamin D levels.

METHODS

A prospective study was conducted among cALLs who had completed a minimum of 5 years of treatment-free interval. It was conducted in long term follow up (LTFU) clinic in department of Pediatric Oncology. All consecutive cALLs consenting for study were included. BMD and serum Vitamin D levels were estimated during follow-up from 1st October 2023 to 31st May 2024. BMD was estimated by Dual Energy X-Ray Absorptiometry (DXA) and classified based on z-scores of L1-L4 lumbar spine (LS) (z-score ≥−1 normal, −1 to −2 low, ≤−2 very low). BMD of femoral neck (FN) was also recorded. Serum Vitamin D3 was classified based on revised Indian Academy of Pediatric (IAP) guidelines as sufficient (level ≥20 ng/mL), insufficient (12–20 ng/mL) and deficient (≤12 ng/mL). Burden of fractures was assessed and expressed as a percentage based on history. All children were treated with institutional modified BFM 95 ALL protocol. Details regarding bone toxic therapies received during ALL therapy- corticosteroids, methotrexate, cyclophosphamide, cranial radiation were collected from survivors.

RESULTS

Eighty-nine cALLs (75 B-ALL, 13 T-ALL and 1 MPAL) enrolled. 51 (57%) males and 38 (43%) females. Median duration of follow up of survivor cohort - 8.2 years (range 4.8 -17.2 years). Median age at time of primary diagnosis- 5 years (range - 10 months - 13.5 years) and at time of survivor enrolment was 15 years (range - 9 - 25 years). 75/89 (84%) of survivors post pubertal and 14/89 (16%) pre-pubertal. 48% high risk and 52% were standard risk as per NCI risk stratification.
BMD (n=89): Normal for 48% and reduced for 52% (33%- low BMD and 19% - very low).
Vitamin D (n=89): 79%- sufficient vitamin D levels, 18%- insufficiency and 3%- vitamin D deficiency.
Burden of Fractures: Five cALLs (5.6%) suffered fractures (4- long bone fractures and 1- compression fractures of lumbar vertebrae). All had decreased BMD [3(60%)- very low and 2(40%)– low].
Increased BMI of cALLs found to be statistically significantly associated with normal BMD with protective Odds ratio (OR)- 0.09. Those with reduced BMI were at risk for reduced BMD. There was statistically significant association found between those who suffered fractures and reduced BMD of L1-L4 LS. There was a moderate, positive correlation which is statistically significant (r (89) = .53) between BMD z-scores of L1-L4 LS and femoral neck. There was no association between vitamin D status and BMD status (p= 0.54). None of the bone toxic therapies had a significant association in affecting the BMD of L1-L4 LS.

CONCLUSION

Reduced BMD was observed in over half of long-term cALLs and was associated with fractures. BMI significantly influenced bone health. Routine BMD surveillance may enable early identification and intervention to improve long-term skeletal outcomes in survivors.

OP21

Epidemiology/Research methods

SURVIVOR/CAREGIVER AND HEALTH SYSTEM LEVEL BARRIERS TO, FACILITATORS FOR, AND IMPLEMENTATION STRATEGY RECOMMENDATIONS FOR CHILDHOOD CANCER SURVIVORSHIP CARE DELIVERY IN UGANDA

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BACKGROUND-AIM

Childhood cancer survival is improving in low- and middle-income countries, but survivorship care remains poorly defined, with limited attention to late effects, psychosocial needs, and life after treatment. This study sought to understand multi-level barriers and facilitators to survivorship care and to identify context-appropriate implementation strategies for strengthening services.

METHODS

We conducted a qualitative descriptive study to explore determinants of childhood cancer survivorship care and to link priority barriers to implementation strategies. Three half-day multi-stakeholder workshops were held at Uganda Cancer Institute, Kampala, with purposively sampled survivors, caregivers, clinicians, allied health professionals, institutional leaders, civil society, and other partners (n=104). Workshops combined brief presentations with small-group and plenary discussions informed by the constructs from the Consolidated Framework for Implementation Research (CFIR). The barriers and facilitators were mapped to potential implementation strategies guided by the Expert Recommendations for Implementing Change (ERIC). Audio-recordings and field notes were analyzed using NVivo using a framework approach with deductive CFIR-based and inductive coding, followed by ERIC-guided barrier–strategy mapping

RESULTS

Three multi-stakeholder workshops (n=104) identified multi-level determinants of childhood cancer survivorship care. At the health-system level, survivorship was not yet prioritized, with absent guidelines, constrained staffing and space, weak data systems, limited integration of psychosocial and oncofertility services, and minimal linkages to regional centers and community health workers. At the survivor and family level, catastrophic non-medical costs, stigma, school and workplace discrimination, poor understanding of survivorship, fear of relapse and infertility, and physical and emotional sequelae undermined long-term follow-up. Facilitators included a dedicated long-term follow-up clinic, emerging institutional commitment through a new Division of Palliative Care and Survivorship, expanding infrastructure, early survivorship/oncofertility projects and databases, an enabling policy mandate, and strong CSO and peer-support networks. CFIR–ERIC mapping yielded a package of strategies, including formal leadership commitments and implementation blueprints, context-adapted survivorship guidelines, task-shifting, electronic registries and quality monitoring, financial support for follow-up, and survivor- and caregiver-led education, peer navigation, and stigma reduction.

CONCLUSION

Childhood cancer survivorship care in Uganda is emerging but fragmented, limited by system, economic, and psychosocial barriers, yet supported by institutional, civil society, and community strengths. Mapped implementation strategies can inform contextualized interventions to improve the delivery of survivorship programs in Uganda and comparable low-resource settings over time.

OP22

Other 2

AN ELECTRONIC HEALTH RECORDS-BASED INFORMATICS APPROACH TO ENHANCE CARE FOR CHILDHOOD, ADOLESCENT, AND YOUNG ADULT CANCER SURVIVORS THROUGH POPULATION HEALTH MANAGEMENT

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BACKGROUND-AIM

Childhood, adolescent, and young adult cancer survivors are at significant risk for late treatment-related effects yet face challenges when transitioning to survivorship-focused care and longitudinal follow-up. Population-level tools offer a pragmatic approach to tracking these patients and ensuring the care they need.

METHODS

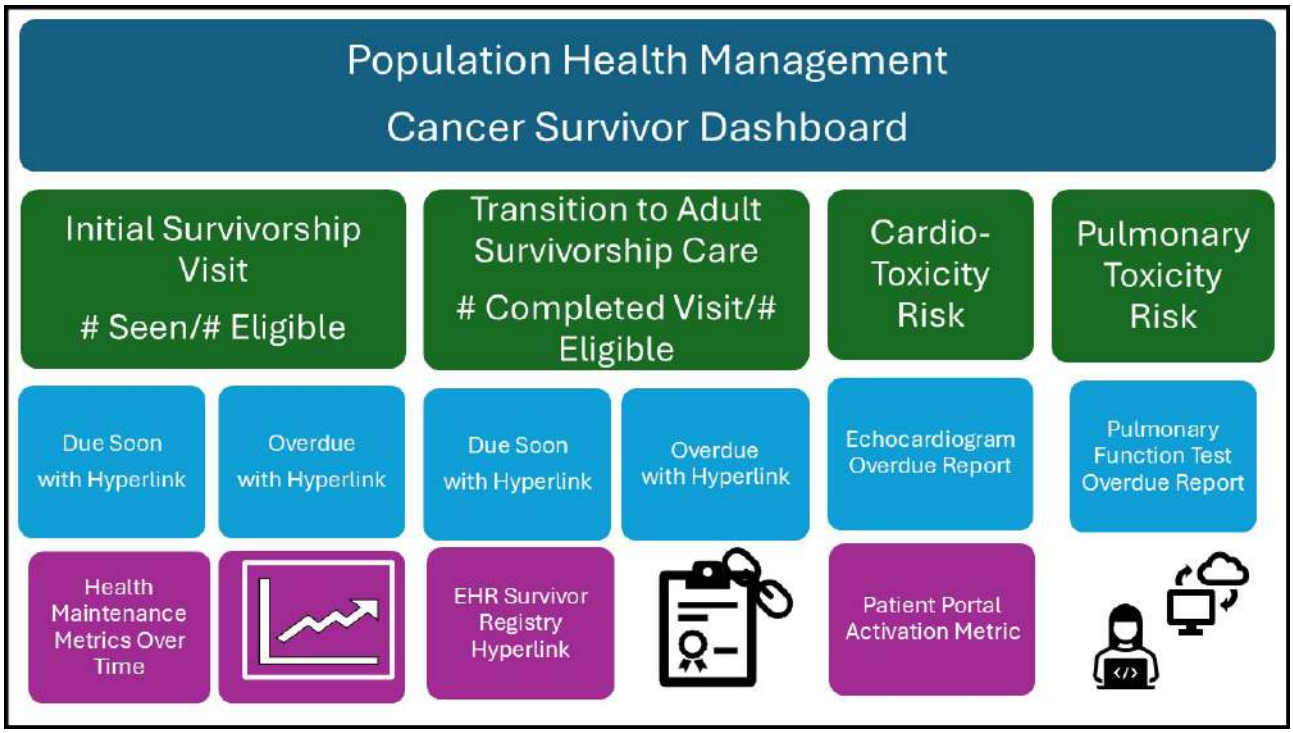
In January 2025, the Seattle Children's Hospital Cancer Survivor Program launched a population health management platform, embedded within the electronic health record (EHR), based on a validated registry of childhood, adolescent, and young adult survivors. Discrete data elements for cancer diagnoses, based on SNOMED concept groupers within the EHR, end-of-therapy dates, chemotherapy administration dates, vital status, and clinic encounters, were used to define the cohort and create the platform. Manual review and cross-validation with an external institutional Tableau dashboard were used to complete the validation. The building of the dynamic dashboard included making visible care gaps for the transition to survivorship care, providing exposure-based pulmonary and cardiac toxicity surveillance, and supporting transition to adult care. Reporting workbenches facilitated real-world data analysis of the transition to survivorship care and longitudinal follow-up among survivors.

RESULTS

The parent oncology registry demonstrated 99.7% alignment (4052/4066) with the external institutional report. On manual review of 10% of survivors, there was 100% concordance for clinic visit dates and 86.4% concordance for the end of therapy date. Among survivors who finished treatment between January 1, 2021, and April 30, 2022 (n=220), 47% had completed a long-term follow-up visit. There were no significant differences in the likelihood of follow-up based on age categories, defined as <15 years old, 15-17 years old, and 18-23 years old at the time of analysis (p=0.36). For survivors with established long-term follow-up (n=743), 76% of survivors had a survivorship visit in the preceding 30 months. Compared with children, adolescent survivors (OR 0.51, 95% CI 0.29-0.9), emerging young adults (OR 0.39, 95% CI 0.24-0.63), and young adults (OR 0.10, 95%CI 0.05-0.18) were less likely to have longitudinal care. This difference was attenuated when analysis was restricted to survivors < 22 years old and after adjustment for years off therapy, with OR of 0.67 (95%CI 0.37-1.21) and 0.82 (95%CI 0.45-1.50) among adolescents and emerging young adults, respectively, compared with children as the referent group.

CONCLUSION

An EHR embedded population health platform represents a feasible approach to measure longitudinal follow-up care and transitions among survivors. Clinical informatics tools have the potential to enhance evidence-based, guideline-concordant care to mitigate late effects in this population. The implementation of population health-level interventions, including bulk in-basket messaging to target transition to survivorship from the active oncology team and bulk ordering for self-scheduling of telehealth visits for survivors overdue for follow-up, is underway. Quality improvement methods will assess the impact of such strategies to enhance longitudinal care.



Overview of the Population Health Management Cancer Survivor Dashboard with Metrics and Reporting Tools

OP23

Other 2

IMPAIRED FITNESS AND STRENGTH IN ADOLESCENT SURVIVORS OF CHILDHOOD CANCER AND THEIR ASSOCIATIONS WITH TREATMENT EXPOSURES AND MODIFIABLE RISK FACTORS IN THE ST. JUDE LIFETIME COHORT STUDY (SJLIFE)

D. Ogunsanmi [2], M. Weiss [2], S. O'Neil [2], A. Santucci [2], D. Mulrooney [3], B. Ky [5], K. Srivastava [1], R. Partin [2], J. Burns [2], G. Armstrong [2], I. Huang [2], S. Taneja [2], J. Lucas [4], M. Hudson [3], M. Ehrhardt [3], K. Ness [2], S. Dixon [3]

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BACKGROUND-AIM

Adult survivors of childhood cancer experience an increased risk of exercise intolerance and muscle weakness compared to the general population. This study aims to examine the associations between treatment exposures, lifestyle factors, and impaired fitness and strength among childhood and adolescent survivors, which remain poorly established.

METHODS

Participants were recruited from the SJLIFE cohort, aged < 18 years, and survived ≥ 5 years since their original cancer diagnosis. Participants with medical contraindications to cardiopulmonary exercise testing (CPET) or strength testing were excluded. Outcomes included cardiopulmonary fitness (peak oxygen uptake [VO_2peak] during CPET) and muscular strength (peak torque values during isokinetic knee extension). Both outcomes were converted to Z-scores using normative values established from healthy children and adolescents, with Z-scores < -1 classified as impaired, and those without impairment were classified as good. Survivors were then categorized into four groups: good fitness and good strength (GFGS); good fitness and impaired strength (GFIS); impaired fitness and good strength (IFGS); and impaired fitness and impaired strength (IFIS). Covariates included prior cancer treatment exposures (chemotherapy and region-specific radiation; yes/no), prevalent cardiometabolic risk factors (overweight/obesity, hypertension, prediabetes/diabetes, dyslipidemia), diet quality (healthy eating index 2015), and physical inactivity (<420 minutes/week of moderate or vigorous activity). Age- and sex-adjusted logistic regression models estimated associations between impaired fitness or impaired strength and treatment exposures, diet, and physical inactivity. Covariates with P < 0.10 in these models were included in the final multivariable models with risk estimates reported as odds ratios (ORs) and 95% confidence intervals (CI).

RESULTS

Among 645 eligible participants, median age at assessment was 15.0 years (range 7.39-17.98), 51.2% were male, 56.6% (n=365) had impaired fitness, and 49.5% (n=319) impaired strength. Only 23.7% (n=153) were classified as GFGS, while 26.8% (n=173) were classified as IFGS, 19.7% (n=127) as GFIS, and 29.8% (n=192) as IFIS. Statistically significant between-group differences were observed in the prevalence of overweight, obesity, and hyperlipidemia (all p-values <0.01). Among survivors in the GFGS group, 9.2% had obesity compared to 42.8% of the IFGS and 25.5% of the IFIS groups. In multivariable models adjusted for age, sex and all selected treatment and lifestyle covariates, exposure to cisplatin chemotherapy and physical inactivity were each associated with a near 3-fold higher odds of impaired fitness (OR 2.8, 95% CI 1.6-4.9 and OR 2.9, 95% CI 2.0-4.2, respectively). Similarly, cisplatin chemotherapy and physical inactivity were each associated with increased odds of impaired strength (OR 2.8, 95% CI 1.4-5.5 and OR 1.5, 95% CI 1.0-2.1). High-dose methotrexate was associated with lower odds of impaired strength (OR 0.6, 95% CI 0.3-1.0).

CONCLUSION

Half of adolescent survivors had impaired cardiopulmonary fitness or impaired strength. Impairment was more common among survivors with obesity and other cardiometabolic disease, prior cisplatin exposure and physical inactivity. While future studies should confirm these findings, survivors who received cisplatin chemotherapy may benefit from closer monitoring and earlier interventions to remediate poor physical function.

	Impaired Strength (GFIS + IFIS) OR (95% CI)	**Impaired Fitness (IFGS + IFIS) OR (95% CI)**
Alkylating agent exposure (vs. no)	1.20 (0.73 -1.97)	-
Cisplatin exposure (vs. no)	**2.76 (1.40 -5.45)**	**2.81 (1.60 - 4.93)**
High dose methotrexate exposure (vs. no)	**0.57 (0.33 - 0.99)**	-
Cranial radiation exposure (vs. no)	1.11 (0.62 -2.01)	-
Chest radiation exposure (vs. no)	1.41 (0.25 -7.99)	-
Abdominal radiation exposure (vs. no)	1.55 (0.28 - 8.54)	-
Diet (Healthy Eating Index–2015)	-	0.99 (0.97 - 1.00)
Physically active (vs. yes)	**1.47 (1.01 - 2.14)**	**2.88 (1.98 -4.18)**

Each outcome was adjusted for age, sex, and all covariates shown in Table above.

Multivariable logistic regression models estimating odds of impaired muscular strength and impaired cardiopulmonary fitness among survivors <18 years.

OP24

Epidemiology/Research methods

CONTINUITY OF SURVIVORSHIP CARE IN CHILDHOOD CANCER SURVIVORS: RISK-BASED FOLLOW-UP AND PERSISTENT DISPARITIES

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BACKGROUND-AIM

Although 5-year survival for childhood cancers exceeds 85%, childhood cancer survivors (CCS) remain at risk for late effects including infertility, secondary malignancies, and cardiomyopathy. Risk-based survivorship visits are recommended, yet program attendance is not well characterized. We used a large institutional database to characterize continuity of survivorship care and identify correlates.

METHODS

We conducted a retrospective cohort study using a survivorship database integrated within Electronic Health Record (EHR) data at a large pediatric center in Texas, USA. CCS diagnosed <19 years who attended ≥1 survivorship clinic visit during 2013-2024 were included. Patients with non-oncologic or neuro-oncologic diagnoses, incomplete records, or not enough follow-up time to need an additional visit were excluded. Survivors were risk-stratified for late effects based on anthracycline, alkylating agent, and radiation exposure. We used previously published and externally validated methods to describe overall risk for late effects. CCS diagnosed with bone tumor, Leukemia, Lymphoblastic lymphoma, or sarcoma should attend one visit every 6 months; all others should attend one visit every year. Continuity of survivorship care was measured using the ratio of observed to expected visits and was measured until whichever occurred first: CCS turned 19, or end of study. Care was categorized as continuous (ratio≥1) or discontinuous (ratio<1) characterized the associations between ACS and demographic characteristics, cancer type, and treatment exposures using logistic regression.

RESULTS

The cohort included 1,052 survivors (median age: 10.5 years at first survivorship visit, median follow-up: 4.31 years). The most common diagnosis was leukemia (51.7%), and 43.3% of survivors self-identified as Hispanic. Most patients received chemotherapy (97.6%), 21.6% received radiation, and 6.4% underwent HSCT. Overall risk of late effects was high for 28.1%, moderate for 38.5%, and low for 33.4% of patients.
Median ratio was 0.89 (IQR 0.50–1.00). Care discontinuity was less likely for survivors with high overall risk (vs low; odds ratio [OR]=0.66, p=0.02); known cardiomyopathy risk (vs none; high OR=0.52, p<0.001; moderate: 0.49, p<0.001; low 0.64, p=0.02); high or low infertility risk (vs none; high OR=0.54, p=0.01; low 0.65, p=0.01); high risk for a second primary cancer (vs none; colon, breast, or skin; OR=0.55, p=0.03); and lymphoma and renal tumors (vs leukemia; lymphoma OR=0.39, p<0.001; renal=0.36, p=0.003). Non-Hispanic Black survivors were more likely to have care discontinuity (vs non-Hispanic White; OR=2.69; p<0.05). Spanish language was marginally associated with discontinuity (vs English; OR=0.72, p=0.09). In a multivariable model adjusted for race and ethnicity, diagnosis age, sex, and cancer type, associations with cardiomyopathy and infertility, but not second primary cancer, risk were stable. In a separate, similarly adjusted model with only overall risk score describing risk for late effects, the association was attenuated.

CONCLUSION

Although risk-adapted follow-up protocols may effectively prioritize patients at risk, some variation in care continuity across treatment-based exposures and social characteristics persists. These findings highlight the value of EHR-enabled survivorship registries to monitor care delivery, identify disparities in real time, and inform targeted interventions to improve equitable survivorship care.

OP25

Interventional research

FEASIBILITY AND DIAGNOSTIC YIELD OF THE PANCAREFOLLOWUP CARE INTERVENTION

S. Van Den Oever [11], H. Van Der Pal [11], L. Feijen [11], C. Follin [8], K. Roser [14], G. Michel [14], E. Bouwman [12], I. De Beijer [11], J. Te Dorsthorst [9], S. Essiaf [4], L. Elmerdahl Frederiksen [2], H. Gsell [1], R. Haupt [3], M. Van Helvoirt [7], R. Hermens [12], L. Hjorth [8], T. Kepak [6], K. Kepakova [6], A. Kienesberger [1], M. Kokla [2], J. Loonen [12], M. Muraca [3], K. O'Brien [10], M. Renard [7], C. Schneider [1], F. Schulte [13], R. Skinner [5], A. Uyttebroeck [7], L. Kremer [11], S. Pluijm [11]

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BACKGROUND-AIM

The PanCareFollowUp Care intervention was developed to facilitate the implementation of evidence-based, high quality long-term follow-up (LTFU) care for childhood cancer survivors across Europe. To evaluate the PanCareFollowUp Care intervention's feasibility and effectiveness across multiple outcomes, a prospective cohort study was conducted at four LTFU care clinics in Belgium, Czechia, Italy, and Sweden. With this substudy we assessed the intervention's feasibility and diagnostic yield.

METHODS

The PanCareFollowUp Care intervention consisted of a clinic visit with a LTFU care provider, followed by diagnostic testing performed either during the visit or through referral, in line with international surveillance guidelines. In addition, survivors received a personalised survivorship care plan (SCP) which was finalised during a follow-up phone call two weeks after the clinic visit. Feasibility was assessed by three adherence measures, including the percentage of survivors who attended the follow-up call, the percentage of survivors who received a SCP, and the percentage of survivors who received care according to their SCP, as reported by their LTFU care provider. Diagnostic yield was defined as the percentage of test results determined abnormal by the LTFU care provider. Diagnostic tests were categorised as 1) clinical diagnostic tests (mammography, MRI of the breasts, MRI of the brain, thyroid ultrasonography, spirometry, DXA scan, ECG, cardiac echo, audiometry, and X-ray), 2) blood tests, and 3) urine, semen, and faecal tests.

RESULTS

In total, 798 survivors completed the clinic visit and were included in this analysis. The follow-up call was completed by 791 (99%) survivors and a finalised SCP was provided to 751 (94%). Furthermore, 635 (80%) participants received care in accordance with their SCP. Deviations from the SCP were all caused by the fact that one or multiple tests that still had to be performed. Across the total cohort, 1,003 clinical diagnostic test results were collected of which 214 (21%) were abnormal. In addition, 11,261 blood test results were obtained, with 1,380 (12%) classified as abnormal. For urine, semen, and faecal testing, we collected 823 results, of which 133 (16%) were abnormal. Semen analysis demonstrated the highest yield, with 77% abnormal results, whereas magnesium blood testing had the lowest yield (1%).

CONCLUSION

Findings indicate that implementation of the PanCareFollowUp Care intervention is feasible. In addition, the intervention demonstrated a high diagnostic yield, emphasising the critical importance of LTFU care for the childhood cancer survivor population.

OP26

Other 2

PHYSICAL ACTIVITY PATTERNS, AND FACTORS ASSOCIATED WITH LOW PHYSICAL ACTIVITY IN THE DUTCH CHILDHOOD CANCER SURVIVORS: A DCCSS-LATER 2 STUDY

R. Van Laarhoven [2], H. Maurice-Stam [2], E. Bouwman-Geneugten [3], E. Van Dalen [2], L. Feijen [2], M. Van Den Heuvel-Eibrink [2], R. Hermens [3], B. Hoeve [6], A. Keijzer-Schellekens [2], R. Van Litsenburg [2], M. Louwerens [1], S. Neggers [2], A. Penson [3], C. Ronckers [5], H.M. Van Santen [7], J. Teepen [2], P. Van Der Torre [2], A. De Vries [4], L. Kremer [2], S. Pluijm [2]

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BACKGROUND-AIM

Childhood cancer survivors (CCS) are known to be at risk for adverse health outcomes later in life. An active lifestyle may prevent or reduce the severity of some of these late effects, such as obesity or early frailty, yet many survivors do not meet physical activity guidelines. Moreover, knowledge on specific physical activity patterns, such as intensity and type, in survivors compared to the general population, is limited. More insight into physical activity behavior of survivors, and in those at risk of low activity, is needed to support them with targeted health promotion. The aim of this study was to assess adherence to Dutch physical activity guidelines among adult CCS and to compare this with the general population. We also identified factors associated with non-adherence.

METHODS

Survivors from the Dutch Childhood Cancer Survivor Study (DCCSS)-LATER 2 diagnosed with cancer between 1963-2002 with an age of ≥18 and ≤ 45 at the time of this study, <18 years at diagnosis and ≥5 years since diagnosis completed the Short Questionnaire to Assess Health-enhancing Physical Activity (SQUASH). Potential associated factors, such as sociodemographic characteristics, cancer and treatment history, lifestyle behaviors (smoking, alcohol and drug use), sleep, fatigue, psychological risk factors, (anxiety, depression), and health-related quality of life were collected with questionnaires and from medical records. Adherence to the Dutch physical activity guideline was defined as (I) engage in at least 150 minutes of moderate to vigorous activity per week spread over multiple days and (II) perform bone and muscle strengthening activities at least twice a week. The prevalence of adherence to the guideline, and to the two recommendations separately, in survivors was compared with the Dutch general population matched on age. In addition, multivariable logistic regression analysis was used to determine associated factors for not adhering to the Dutch physical guideline and to the two recommendations separately.

RESULTS

A total of 967 participants with complete and reliable data were included in the analyses (mean age 34.1± 6.4 years; 47.2% female). Overall, 59.8% of the survivors adhered to the Dutch physical activity guideline, 86.8% met the muscle and bone enhancing recommendation, and 65.8% met the moderate to vigorous exercise recommendation. In the Dutch general population, adherence rates were slightly lower, approximately 52%, 80% and 56% respectively. Age >35 years (vs. age 18-35 years (odds ratio (OR): 1.46 [1.08-1.99])) and severe fatigue (score ≥ 35 vs <35 (OR: 1.61 [1.12-2.32])) were associated with not adhering to the guideline. Male sex and being obese were associated with non-adherence to bone- and muscle-strengthening exercises (OR: 1.97 [1.28-3.04] and OR: 1.91 [1.06-3.48] respectively, while living independently (versus independently) was associated with non-adherence to the moderate-to-vigorous activity recommendation (OR: 1.53 [1.04-2.24]).

CONCLUSION

Overall, Dutch CCS were slightly more physically active than their age-matched peers in the general population. Higher age and severe fatigue were identified as factors associated with low physical activity levels. It is likely that the observed association may be bidirectional where low physical activity can also contribute to fatigue and vice versa. This finding underscores the clinical relevance of considering both factors in the design of future intervention studies.

OP27

Interventional research

FEASIBILITY AND ACCEPTABILITY OF A DIGITAL MINDFULNESS INTERVENTION TO IMPROVE STRESS, COPING, AND CARDIOMETABOLIC RISK IN SURVIVORS OF PEDIATRIC LEUKEMIA AND LYMPHOMA

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BACKGROUND-AIM

Adult survivors of pediatric leukemia and lymphoma face an elevated risk for cardiometabolic disease due to treatment exposures and psychological stress. Stress stimulates inflammation and autonomic pathways, and when compounded by socioeconomic disadvantage, can exacerbate cardiometabolic outcomes. Mindfulness interventions reduce stress and associated morbidities; but, most require trained personnel or in person delivery, limiting accessibility. This research aimed to evaluate the feasibility and acceptability of a 30 day, low-touch, remotely delivered, mindfulness intervention for highly stressed young adult survivors of childhood leukemia and lymphoma residing in areas with high/extreme resource deprivation.

METHODS

Adult survivors of pediatric leukemia/lymphoma (≥5 years from diagnosis) recruited from the St. Jude Lifetime Cohort Study with elevated Perceived Stress Scale scores (PSS ≥14) engaged in an app-based, 30-day, 10-minute daily mindfulness practice targeting attentional control and stress-regulation processes, completed pre/post assessments (at intervention completion) of stress (PSS) and coping behaviors (Brief COPE); wore wrist based biosensors to monitor autonomic activity; provided dried blood spots; and reported daily stress levels during weeks 1 and 4 of the intervention. Feasibility metrics included recruitment, adherence, retention, and data completeness. Acceptability was measured post intervention (Acceptability and Adherence Scale). Sociodemographics were self-reported, and neighborhood deprivation was derived from the Area Deprivation Index (≥60 indicating high/extreme deprivation). Paired-sample t tests assessed pre-to-post changes across domains, with effect sizes converted to Hedges' g to correct for small-sample bias. Logarithmic transformations were used for skewed data.

RESULTS

Of 68 eligible survivors approached, 50 enrolled (74% recruitment; 18-41 years of age; 40% non-Hispanic Black or Hispanic; 60% resided in high/extreme deprivation neighborhoods). Forty-three (82%) participants completed the mindfulness intervention with participants averaging 4.03 sessions per week. All participants wore biosensors for 79% of the intervention time window (10 hours daily), 82% completed follow-up assessments, and 64% completed dried blood spot collection. Acceptability was high, 93% of participants found sessions easy to complete, 98% preferred mindfulness over other coping strategies, and 88% would recommend the intervention. Preliminary findings (Table 1) indicate pre-post reductions in average daily stress (g=.24, p=.05), average daily autonomic activity (g=.29, p=.04), average peak autonomic activity (g=.35, p=.02), cardiovascular and inflammatory biomarkers [vascular cell adhesion molecule–1 (g = 0.29, p = .05); homocysteine (g = 0.27, p = .05), high-sensitivity C-reactive protein (g = 0.37, p = .04)], and improvements in several coping behaviors [planning (g = 0.30, p = .02), positive reframing (g = 0.54, p < .001), meditation/religious coping (g = 0.72, p < .001), emotional support (g = 0.28, p = .04)]. No adverse events occurred.

CONCLUSION

A brief, low-touch, digital mindfulness program was feasible, acceptable, and engaged a diverse group of highly stressed survivors. Although findings should be interpreted cautiously due to the small sample, observed changes across stress, autonomic activity, biomarkers, and behavioral coping support the potential of this accessible, low-burden intervention to reduce psychological stress and cardiometabolic risk.

Table 1. Changes in Perceived Stress, Autonomic Nervous System Activity, Cardiovascular and Inflammatory Biomarkers, and Coping Behaviors among Adult Survivors of Pediatric Leukemia and Lymphoma After a 30-Day Mindfulness Intervention.

	Baseline Assessment	Follow-up Assessmen	
	Mean (Standard Deviation)	**Mean (Standard Deviation)**	**Hedge's g[t]**
Changes in Perceived Stress, N=41			
Average Daily Stress Summed Across Week 1 and Week 4	1.64 (0.44)	1.55 (0.41)	**0.24***
Perceived Stress Scores	23.17 (3.83)	23.32 (2.94)	0.05
Changes in Autonomic Nervous System Activity, N=43			
Average Daily Electrodermal Activity Summed Across Week 1 and 4	1.07 (1.48)	0.74 (.68)	**0.29***
Peak Electrodermal Activity Averaged Across Week 1 and 4	21.44 (17.15)	16.82 (11.49)	**0.35***
Changes in Cardiovascular and Inflammatory Biomarkers, N=32			
Oxidized low-density lipoprotein (units/liter)	8.33 (5.95)	8.26 (4.85)	0.01
Pro–B-type natriuretic peptide (Logarithmic transformation)	4.12 (0.99)	4.17 (1.10)	0.05
P-selectin (Logarithmic transformation)	6.49 (0.49)	6.62 (0.45)	0.02
Vascular Cell Adhesion Molecule-1 (nanograms/milliliter)	203.646 (58.32)	183.79 (49.49)	**0.29***
Homocysteine (micromoles/liter)	9.04 (2.34)	8.37 (2.21)	**0.27***
High-sensitivity C-Reactive Protein (milligrams/liter)	0.23 (0.33)	0.13 (0.20)	**0.37***
Changes in Coping Behaviors, N=41			
Behavioral Disengagement	3.15 (1.31)	3.02 (1.39)	0.09
Planning	5.80 (1.60)	6.24 (1.45)	**0.30***
Positive Reframing	4.78 (1.90)	5.68 (1.57)	**0.54***
Meditation/Religious Coping	4.33 (2.13)	5.30 (1.91)	**0.72***
Self-Blame	5.29 (1.85)	4.93 (1.81)	0.21
Emotional Support	4.51 (1.70)	4.93 (1.93)	**0.28***

[t]Hedge's g presented in absolute values. *p≤.05. Hedge's g effect of .20-.49 indicates small effect; .50-.79 indicates moderate effect; .80-1.19 indicates large effect; >1.20 indicates very large effect

OP28

QoL/Rehabilitation

DEVELOPMENT AND VALIDATION OF A LONGITUDINAL SYMPTOM-BASED MORTALITY PREDICTION MODEL FOR ADULT SURVIVORS OF CHILDHOOD CANCER

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BACKGROUND-AIM

Survivors of childhood cancer face a higher risk of late mortality than the general population. However, no prior study has integrated patient-reported symptoms with treatment exposures to predict late mortality risks.

METHODS

A total of 9,569 survivors from the Childhood Cancer Survivor Study who completed two surveys (baseline [T1], follow-up [T2]) reported 37 symptoms spanning 10 domains (cardiac, pulmonary, sensory, musculoskeletal, nausea, pain, fatigue, memory, anxiety, depression) at T1 and T2. Additional predictors included sociodemographic and lifestyle factors, address-linked Area Deprivation Index, and treatment exposures. Standardized mortality ratios (SMRs) were calculated by individual symptoms and corresponding symptom domains at T2 and T1-T2 change to compare mortality rates between survivors and the general population 5 years after T2. Multivariable Cox proportional hazards models with LASSO regularization were used to predict 5-year health-related, cause-specific (cardiac, pulmonary, subsequent neoplasms), and all-cause mortality after T1 and T2. The dataset was randomly split into training and test datasets at a 7:3 ratio, and prediction performance was assessed using the area under the receiver operating characteristic curve (AUC).

RESULTS

Among 9,569 survivors (52.4% female), the median age at T1 and T2 was 27.1 and 36.9 years; median years from diagnosis to T1 and T2 were 16.6 and 26.3. Acute lymphoblastic leukemia (31.3%) and Hodgkin lymphoma (15.3%) were the most frequently observed primary diagnoses. After T2, deaths were most commonly due to subsequent neoplasm (419; 44.6%) and cardiac (170; 17.9%) causes. Compared with the sex/age/race/calendar year-matched general population, survivors had significantly higher 5-year health-related mortality after T2, with an SMR of 4.21 (95%CI 3.76-4.70). Presence of cardiac and pulmonary symptom domains at T2, and their persistence and worsening from T1 to T2, were associated with >10-fold higher SMRs. Presence, persistence, and worsening of individual symptoms, including angina pectoris, chest pain with exercise, chronic cough, trouble breathing, and pain in general, were associated with SMRs >10. Subsequent neoplasms showed the highest 5-year mortality after T2 (SMR 7.66; 95%CI 6.56-8.90), followed by pulmonary (SMR 4.08; 95%CI 2.42-6.46), and cardiac (SMR 3.61; 95%CI 2.77-4.62) causes. For 5-year health-related mortality after T2, the symptom-based model yielded an AUC of 0.79 (95%CI 0.75-0.84), surpassing the symptom-agnostic model (AUC 0.76; 95%CI 0.71-0.81) and the T1 model (AUC 0.73; 95%CI 0.67-0.79). Symptom-based models also showed strong discrimination for 5-year cause-specific mortality after T2, with AUCs of 0.87 (95%CI 0.76-0.98) for cardiac, 0.89 (95%CI 0.85-0.92) for pulmonary, and 0.78 (95%CI 0.72-0.84) for subsequent neoplasm mortality. For 5-year all-cause mortality after T2, the symptom-based model yielded an AUC of 0.78 (95%CI 0.73-0.82), outperforming symptom-agnostic (AUC 0.74; 95%CI 0.69-0.79) and T1 (AUC 0.72; 95%CI 0.67-0.76) models.

CONCLUSION

Adult survivors of childhood cancer experience elevated SMRs, with the greatest excess late mortality found in those reporting cardiopulmonary symptoms. Longitudinal symptom-based models yielded the highest predictive performance, outperforming single-time-point and symptom-agnostic models. Incorporating symptom data can strengthen mortality prediction and inform targeted survivorship care.

ABSTRACTS SELECTED FOR POSTER PRESENTATION

001

Cardiovascular

CARDIORESPIRATORY FITNESS AND ITS DETERMINANTS IN ADULT CHILDHOOD CANCER SURVIVORS – RESULTS OF THE CARDIOONCO STUDY

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BACKGROUND-AIM

Childhood cancer survivors show reduced cardiorespiratory fitness measured by cardiopulmonary exercise testing compared with age-matched peers. This is relevant, since a lower cardiorespiratory fitness is associated with increased all-cause mortality in the general population. However, the factors contributing to reduced fitness in survivors remain poorly understood. Cardiorespiratory fitness reflects the integrated function of cardiovascular, pulmonary and skeletal muscle systems, and impairment in any of these systems may contribute to lower fitness. We assessed the prevalence of reduced cardiorespiratory fitness in Swiss childhood cancer survivors and examined associations with resting cardiac and pulmonary function and sports activity.

METHODS

As part of the CardioOnco study, a prospective multicenter cohort, we invited childhood cancer survivors ≥18 years of age, diagnosed at 0–20 years, treated in one of five pediatric oncology centers across Switzerland between 1976–2019, and who survived ≥5 years. Survivors underwent echocardiography, an interview assessing sports activity, cardiopulmonary exercise testing and spirometry. We assessed cardiac function by measuring systolic and diastolic function using left ventricular ejection fraction (LVEF) and average early diastolic mitral annular velocity (e'). We assessed pulmonary function using forced vital capacity (FVC) and calculated z-scores according to Global Lung Initiative reference equations. We categorized sports activity into three levels: no sports, light activity, and moderate activity. We calculated % predicted VO_2peak using SHIP equations adjusting for age, sex, height, and weight. We defined reduced cardiorespiratory fitness as VO_2peak <85% of predicted. Associations with cardiac and pulmonary function and sports activity were assessed using multivariable linear regression with % predicted VO2peak as continuous outcome.

RESULTS

We performed CPET in 128 survivors, with a median age at study of 31 years (interquartile range [IQR] 26 – 41) and a median time since cancer diagnosis of 24 years (IQR 16 – 33). Three survivors with submaximal tests (respiratory exchange ratio [RER] < 1.1 and peak heart rate < 80% predicted) were excluded. The overall prevalence of reduced cardiorespiratory fitness was 26% (32/125). Survivors reporting no regular sports activity (reference = moderate activity; β = -18.5; 95%CI -27.4 - -9.5) and male survivors (β = -9.1, 95%CI -16.9 - -1.4) were at increased risk of reduced cardiorespiratory fitness (table 1). Also lower FVC z-scores were associated with reduced fitness, though the effect size was modest (β = -6.1, 95%CI -9.2 - -2.9; per 1 z-score decrease). Resting cardiac systolic and diastolic function were not associated with cardiorespiratory fitness (average e' velocity: β = -0.5, 95% CI -2.3 – 1.2, per 1 cm/s decrease; LVEF: β = -3.9, 95% CI -11.2 – 3.4, per 10% decrease).

CONCLUSION

In our cohort, one in four survivors had reduced cardiorespiratory fitness. Survivors who do not engage in regular sports and male survivors were at higher risk for reduced fitness as were those with lower lung volumes, whereas resting cardiac function assessed by conventional echocardiography contributed little. Follow-up care should pay attention to fitness and sports activity and promote regular exercise.

Table 1: Factors associated with cardiorespiratory fitness (% predicted VO_2peak) derived from multivariable linear regression

	Unit / Reference	β	95%CI	p-value
Age at study	per year	0.4	(-0.06, 0.9)	0.09
Sex	Male	**-9.1**	(-16.9, -1.4)	**0.02**
LVEF	per 10% decrease	-3.9	(-11.2, 3.4)	0.29
Average e' velocity	per 1 cm/s decrease	-0.5	(-2.3, 1.2)	0.56
FVC z-score	per 1 z-score decrease	**-6.1**	**(-9.2, -2.9)**	**<0.001**
Sports activity				
No sports		**-18.5**	**(-27.4, -9.5)**	**<0.001**
Light activity		-10.6	(-21.9, 0.8)	0.07
Moderate activity	Ref.			

adjusted R^2 = 0.32

Abbreviations: LVEF, left ventricular ejection fraction; FVC, forced vital capacity; FEV_1, forced expiratory volume in 1 second;

002

Cardiovascular

CARDIOVASCULAR RISK FACTORS AND CAROTID ARTERY MEASURES IN SURVIVORS OF CHILDHOOD ACUTE LYMPHOBLASTIC LEUKAEMIA TREATED WITH THE NOPHO ALL2008 PROTOCOL IN FINLAND

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BACKGROUND-AIM

While current cure rates for childhood acute lymphoblastic leukaemia (ALL) exceed 90%, the survivors are at increased risk for various late effects, which may have a significant impact on their later life. Metabolic syndrome is a known risk factor for cardiovascular disease, and insulin resistance is one of the key factors influencing the development of endothelial dysfunction, vascular wall thickening and eventually cardiovascular disease. Increased carotid intima media thickness (IMT) has been shown to be an early clinical marker for the development of atherosclerosis and future vascular events.
Our aim was to study, whether survivors of childhood ALL treated with the NOPHO ALL2008 high risk chemotherapy (HR) arm without haematopoietic stem cell transplant, present worse cardiovascular risk profile compared to survivors treated with standard (SR) and intermediate risk (IR) chemotherapy.

METHODS

All Finnish patients treated with the NOPHO ALL2008 high-risk chemotherapy arm and participating in the HALLON study, were invited to this carotid ultrasound study. Patients in the standard risk and intermediate risk arms treated at the Oulu and Turku University Hospitals were invited as controls.
Antropometric and laboratory measures were performed at the study visit. The age- and sex-adjusted International Obesity Task Force body mass index (ISO-BMI) was calculated according to the Finnish reference values. The homeostasis model assessment insulin resistance (HOMA-IR) index was calculated using Matthew's formula (insulin (mU/l) x glucose (mmol/l) /22.5). Ultrasound assessments were performed to measure the left common carotid artery IMT. From the digitally stored images, measurements of the common carotid artery diastolic and systolic diameters were taken and from these, arterial stiffness was evaluated by calculating three elasticity indices.

RESULTS

Ninety-seven survivors participated, including 27 (28%) HR survivors, 28 (29%) IR survivors and 42 (43%) SR survivors. The mean age of the survivors was 14.2 years (SD 4.8, range 6.1–25.6). The mean ISO-BMI or HOMA-IR did not differ significantly between the treatment risk groups.
The prevalence of overweight (ISO-BMI ≥25 kg/m²) was 43% in the HR, 36% in the IR, and 44% in the SR group. The HOMA-IR value of 2.5, indicating insulin resistance, was exceeded in 59% in the HR group, 50% in the IR group, and 33% in the SR group.
No significant differences were observed in mean IMT and elasticity measures between the groups. In multivariable model adjusted for sex, current age, systolic blood pressure, LDL cholesterol, ISO-BMI and HOMA-IR, male sex and higher age emerged as consistent determinants of both increased IMT values and worse arterial elasticity.

CONCLUSION

While it may seem reassuring that these cardiovascular risk factors and early markers of atherosclerosis were comparable between the treatment risk groups, it is alarming that over 40% of the ALL survivors were overweight or obese. Importantly, over 40% had a high HOMA-IR indicating insulin resistance. The prevalence of overweight/obesity in our study was close to twice as high compared to the Finnish general population of the same age (23.5% in 2023). Our results emphasize the fact that survivors of childhood ALL treated with chemotherapy only, are at increased risk of overweight, obesity and insulin resistance, despite their treatment risk group. This may have a detrimental effect on their later health, and effective interventions are needed.

003

Cardiovascular

DIASTOLIC DYSFUNCTION AMONG CHILDHOOD CANCER SURVIVORS – RESULTS OF THE CARDIOONCO STUDY

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BACKGROUND-AIM

Childhood cancer survivors (CCS) are at increased risk of heart failure due to their treatments. Diastolic dysfunction may represent an early manifestation of cardiotoxicity, possibly occurring before a decline of systolic function and contributing to the later development of heart failure. Assessment of diastolic function may therefore help identify survivors at risk of cardiotoxicity. Diastolic dysfunction develops along a spectrum from early to more advanced stages and can be assessed by echocardiography using different parameters. We assessed the prevalence of early and advanced diastolic dysfunction in Swiss survivors, compared it to systolic function and determined risk factors.

METHODS

We invited CCS aged ≥18 years at study, diagnosed < 20 years, treated in one of five Swiss pediatric oncology centers (1976–2019) for an echocardiographic assessment of diastolic function. We assessed early diastolic dysfunction by septal and lateral mitral annular e' velocities (abnormal defined by age-specific cut-offs), advanced dysfunction by average E/e' (mitral inflow E velocity divided by mean annular e' velocity) and late-stage dysfunction by left atrial volume index (LAVI). We assessed systolic function by left ventricular ejection fraction (LVEF) and defined reduced LVEF based on sex-specific cut-offs (male LVEF < 52%; female LVEF < 54%). We stratified survivors based on their treatment exposure in anthracyclines only, heart-relevant radiotherapy only, both, and standard risk group. We investigate demographic, treatment-, and lifestyle-related factors using linear regression models. We used multiple imputation by chained equations to impute missing data.

RESULTS

We included 441 CCS with a median age at study of 31 years (interquartile range [IQR] 23-38). Early diastolic dysfunction was present in 10% of survivors (44/441, septal or lateral e' abnormal) and most common in those exposed to both anthracyclines and heart-relevant radiotherapy (19%, 11/57, p=0.02). Advanced and late-stage diastolic dysfunction were less common (E/e' >14, 1%, 5/441; LAVI >34 mL/m², 3%, 15/441). Most diastolic abnormalities occurred in survivors with reduced LVEF; however, 8% (29/360) of those with preserved LVEF still showed early diastolic dysfunction. Survivors of older age, those exposed to heart-relevant radiotherapy or HSCT and those with hypertension, diabetes or higher waist-to-hip ratio were at risk for impaired diastolic function (table 1). Findings remained consistent after multiple imputation.

CONCLUSION

Early diastolic dysfunction, reflected by e' velocity, is common in CCS, even among those with preserved LVEF. Survivors exposed to HSCT, heart-relevant radiotherapy, or with modifiable cardiovascular risk factors were at highest risk for diastolic function impairment. These survivors may benefit from diastolic function assessment, as relying on LVEF alone may miss early cardiac dysfunction.

Table 1: Factors associated with diastolic function parameters in childhood cancer survivors derived from multivariable linear regression

	Diastolic dysfunction											
	early stage → *late stage*											
	e' lateral			e' septal			E/e'			LAVI		
Variable	**Beta**	**95% CI**	**p-value**	**Beta**	**95% CI**	**p-value**	**Beta**	**95% CI**	**p-value**	**Beta**	**95% CI**	**p-value**
Age at examination	**-0.2**	**-0.21, -0.13**	**<0.001**	**-0.1**	**-0.14, -0.07**	**<0.001**	**0.1**	**0.03, 0.09**	**<0.001**	0.1	-0.03, 0.17	0.2
Sex												
Female	-0.5	-1.3, 0.30	0.2	0.1	-0.66, 0.77	0.9	0.3	-0.19, 0.79	0.2	0.3	-1.5, 2.1	0.8
Anthracyclines, 100mg/m^2	-0.1	-0.34, 0.18	0.5	-0.1	-0.34, 0.12	0.4	0.1	-0.02, 0.30	0.086	-0.1	-0.68, 0.54	0.8
Heart-relevant radiotherapy, Gy	**-0.3**	**-0.64, -0.06**	**0.019**	-0.2	-0.48, 0.04	0.1	**0.3**	**0.16, 0.51**	**<0.001**	-0.3	-1.0, 0.38	0.4
Alkylating agents g/m^2	0.0	0.00, 0.01	0.6	0.0	-0.01, 0.00	0.4	0.0	0.00, 0.02	0.2	0.0	-0.05, 0.04	0.8
Cisplatin mg/m^2	0.0	-0.04, 0.01	0.2	0.0	-0.03, 0.01	0.5	0.0	-0.01, 0.00	0.4	0.0	-0.01, 0.02	0.4
HSCT, yes	**-1.6**	**-2.9, -0.19**	**0.026**	**-1.5**	**-2.7, -0.26**	**0.017**	**1.3**	**0.43, 2.1**	**0.003**	-2.3	-5.7, 1.1	0.2
Hypertension, yes	**-1.4**	**-2.3, -0.51**	**0.002**	-0.5	-1.3, 0.32	0.2	**0.7**	**0.12, 1.2**	**0.017**	-1.0	-3.0, 1.1	0.3
Diabetes mellitus, yes	-2.0	-4.1, 0.10	0.061	-1.5	-3.3, 0.42	0.13	**1.9**	**0.64, 3.2**	**0.003**	-0.5	-5.1, 4.1	0.8
Dyslipidemia, yes	0.4	-0.96, 1.8	0.5	-0.6	-1.9, 0.62	0.3	0.3	-0.56, 1.2	0.5	0.0	-3.1, 3.1	>0.9
Waist-hip ratio	-1.7	-6.4, 2.9	0.5	-4.0	-8.2, 0.20	0.062	-1.5	-4.3, 1.4	0.3	**11.1**	**0.60, 22**	**0.038**
Pack years	-0.1	-0.13, 0.00	0.059	0.0	-0.05, 0.07	0.9	0.0	-0.03, 0.05	0.7	0.0	-0.20, 0.11	0.6

Abbreviations: CI, confidence interval; HSCT, hematopoietic stem cell transplantation; Gy, gray;

004

Cardiovascular

DIGITAL HEALTH SURVEILLANCE AND COUNSELING FOR CARDIOVASCULAR HEALTH OPTIMIZATION AND PATIENT ENGAGEMENT IN SURVIVORS OF HODGKIN LYMPHOMA IN CHILDHOOD OR ADOLESCENCE – DESIGN OF THE CARDIO-HOPE RANDOMIZED CONTROLLED TRIAL

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BACKGROUND-AIM

Cancer survivors face a lifelong increased risk of late cardiovascular complications, especially following treatment with anthracyclines or chest irradiation. As both treatment modalities are commonly combined in the treatment of Hodgkin's lymphoma (HL), long-term survivors represent a high-risk group for late cardiotoxicity. There is strong evidence that physical activity can mitigate this effect. Digital tools may provide valuable data on physical performance and cardiac function, thereby supporting prevention and treatment strategies within precision cardio-oncology follow-up care.
The Cardio-HOPE study aims at integrating digital health data into long-term follow-up strategies for HL survivors.

METHODS

Cardio-HOPE is a randomized controlled, open, three-armed trial. The study consortium includes long-term follow-up care specialists, cardiologists, exercise specialists, psychologists, patient-reported outcome measure expertise, biostatisticians, experts for human-device interaction, and patient representatives, allowing for a multi-stakeholder perspective for development of optimal care pathways. Included will be survivors of a HL diagnosed at age <21 years, who were exposed to both anthracyclines and chest irradiation, and whose cancer treatment has been completed for at least 5 years. Survivors with active heart disease will be excluded.
The primary study outcome is a) the evaluation of a six months intervention aiming at increasing moderate to intensive physical activity measured via wearables. Further, secondary outcomes include b) assessment of the quality of digitally collected data and association with objectified health measures, c) AI based identification of patterns to support early risk prediction for cardiac health issues as well as d) examination of patient-centered outcomes and experiences, including acceptance and usability of the digital tool. This joint project will be conducted at 5 partner sites in Germany from 02/2026 to 02/2029. The study is funded by the German Federal Ministry for Research, Technology and Space (BMFTR funding number 16SV9594).

RESULTS

Patients will be invited starting 10/2026 via a HL diagnose-specific late-effect registry (LEaHL) as well as the German Childhood Cancer Registry to present at one of the two recruiting sites (Leipzig and Gießen).
A digital application is further developed for use in n=200 HL survivors treated with anthracyclines and chest RT. The application combines established digital outcome methods with innovative approaches for continuous assessment of cardiac performance and physical activity in daily life relying on medical, sport-scientific and technology-based expertise. Based on these data, participants will be stratified according to their activity level and randomized (1:1:1) into one of three treatment groups: 1) a tailored personalized supportive intervention, 2) regular feedback or 3) observation only (=control group) aimed at identifying optimal strategies to increase physical activity and thereby reduce cardiovascular risk. To ensure clinical validity and long-term applicability in follow-up care, the digital data will be objectified by a cardio-oncological and sports scientific assessment conducted at one of two study sites.

CONCLUSION

Results derived from the Cardio-HOPE study are expected to support the development of more efficient, personalized, and needs-oriented cardio-oncology follow-up care pathways.

005

Cardiovascular

EARLY-ONSET CANCER THERAPY-RELATED CARDIAC DYSFUNCTION IN CHILDREN: ELECTROCARDIOGRAPHIC AND ECHOCARDIOGRAPHIC RESULTS OF THE EARLY STUDY

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BACKGROUND-AIM

Cancer therapy-related cardiac dysfunction (CTRCD) is mainly caused by anthracyclines, anthraquinones and radiotherapy involving the heart. Although CTRCD during long-term follow-up after childhood cancer treatment has been well-described, little is known about CTRCD during and shortly after treatment. The primary objective of the EARLY pilot study (Early detection of acute and early-onset cARdiovascuLar toxicitY in children with cancer using a multiparametric approach) was to describe the prevalence of CTRCD in childhood cancer patients during and shortly after treatment. Associations with known risk factors for late-onset CTRCD were investigated.

METHODS

Newly diagnosed patients receiving anthracyclines as part of childhood cancer treatment were eligible for inclusion. Electrocardiography (assessed according to the Minnesota Code Manual of Electrocardiographic Findings) and advanced echocardiography (including four-dimensional (4D) measurements and global longitudinal strain (GLS)) were performed before (T0), between three and four months after (T1), and one year after (T2) start of anthracycline treatment.

RESULTS

One hundred childhood cancer patients (N=56 male, median age at diagnosis 6 years) were included. Reduced ejection fraction according to 4D measurement (1% at T0, 16% at T1 and 18% at T2; p=0.005) and abnormal GLS (3% at T0, 9% at T1 and 13% at T2; p=0.007) were observed during and shortly after treatment. Prevalence of major (56% at T0, 52% at T1 and 49% at T2; p=0.331) and minor (85% at T0, 85% at T1 and 85% at T2; p=0.905) electrocardiographic abnormalities did not change over time. We did not find significant associations between the occurrence of early-onset CTRCD and the known risk factors for late-onset CTRCD such as sex, age at childhood cancer diagnosis, cumulative doxorubicin equivalent anthracycline/anthraquinone dose and radiotherapy involving the heart.

CONCLUSION

Prevalence of CTRCD was shown to be up to 18%, and persisted during and shortly after cardiotoxic childhood cancer treatment. In patients without clinically significant electrocardiographic findings (such as QT prolongation) before start of childhood cancer treatment, our findings do not support routine electrocardiographic surveillance during treatment. Comprehensive follow-up of cardiac function in childhood cancer patients may contribute to early detection, prevention and treatment of heart failure.

006

Cardiovascular

EXAMINING PEDIATRIC ONCOLOGY SURVIVORSHIP UPTAKE, REACH, & ENGAGEMENT (EXPOSURE)

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BACKGROUND-AIM

Pediatric cancer survivors face significant health risks, yet many do not seek recommended follow-up care. The project examines the program reach, initiation, and engagement in pediatric survivor services and assesses the patient- and family-level factors related to care engagement at a large National Cancer Institute (NCI)-designated Cancer Center in the United States.

METHODS

We conducted a cohort study of pediatric oncology patients (<18 years) who became eligible for survivorship care in 2016–2019 (N=259). Electronic health record data were used to characterize demographics, treatment factors, and 5-year clinic attendance. Addresses were geocoded and linked to Area Deprivation Index (ADI) and Rural Urban Commuting Area (RUCA) classifications. Reach was defined as attending ≥1 survivor care visit at the treatment center within five years of eligibility. Initiation of survivor services was classified as: timely (i.e., first visit between 24-30 months off therapy), delayed (i.e., first visit more than 30 months off therapy), and never seen. Five-year engagement patterns were classified as: annual engagement, intermittent engagement, or single visit. Caregivers (N=129) provided outcome measures of family psychosocial risk, survivor quality of life, caregiver health, and health beliefs during the off-therapy window prior to eligibility for survivor care. Predictors of reach, initiation, and engagement were assessed using chi-squared, Fisher's exact, Wilcoxon rank-sum, and Kruskal–Wallis tests. Multivariable analyses are ongoing.

RESULTS

Program reach was high: 88% (229/259) of survivors attended at least one survivor clinic visit, but only 36% engaged within 6 months of the Children's Oncology Group (COG) Long-Term Follow-Up Guideline recommended 2 years off therapy. Regarding long-term follow-up patterns, 53% (137/259) of survivors were seen annually, 26% (67/259) were seen intermittently, and 10% (25/259) were seen only once. Socioeconomic disadvantage demonstrated strong association with lack of reach and delayed initiation of survivor care. Survivors were less likely to be reached if they had public insurance (p=0.049). Higher ADI national rank scores, indicating more disadvantaged neighborhoods, were associated with lower reach (p=0.005) and delayed initiation (p=0.019). Cancer type was associated with engagement, with survivors of solid tumors being more likely to have never been reached (p=0.005) and to delay initiation (p<0.001) versus leukemia survivors. Higher caregiver-reported psychosocial risk scores increased the likelihood of reach (p=0.007) but also delayed initiation (p=0.023). Caregiver-perceived vulnerability to late effects in survivors was associated with higher reach (p<0.001). No differences in reach or timing of initiation were observed by sex, race/ethnicity, distance to clinic, RUCA classification, survivor quality of life, or caregiver health. Reduced distance to survivor clinic was the only significant predictor of annual long-term engagement (p=0.027). Multivariable analyses are ongoing.

CONCLUSION

Socioeconomic disadvantage and cancer type are major determinants of reach and timely engagement in pediatric survivorship care, while psychosocial risk and caregiver health beliefs further influence engagement. Findings highlight the need for equity-focused interventions addressing structural barriers and modifiable family-level factors to support long-term survivorship care engagement.

007

Cardiovascular

EXPLORING CARDIOMETABOLIC RISK AND DIETARY PATTERNS OF ADULT CHILDHOOD CANCER SURVIVORS IN AN ONCO-PRIMARY CARE SURVIVORSHIP CLINIC

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BACKGROUND-AIM

Adult Childhood Cancer survivors (CCS) face long term treatment and exposure-related complications with multifactorial disease effects, including cardiometabolic risk factors. Understanding the dietary behaviors of adult CCS can lead to identifying modifiable lifestyle factors, particularly nutrition, that may help reduce long term cardiometabolic risk. This study provides a descriptive analysis of adult childhood cancer survivors and their dietary habits, using the validated Mini-EAT screening tool, in relation to their cardiometabolic risk factors as well as their medical and cancer treatment histories.

METHODS

A retrospective chart review was conducted for adult CCS <40 years seen between October 1, 2024, and December 31, 2025, at two university onco-primary care survivorship clinics that provide guideline concordant long-term follow up survivorship care alongside primary care. Dietary habits were assessed using the validated Mini-EAT tool: a 9-item rapid dietary screener assessing diet quality and supporting patient-provider communication. Results were scored as unhealthy (0-59), intermediate (60-69), or healthy (70-100). An additional question assessed interest in a culinary medicine class for cancer survivors, including hands-on cooking and nutrition education led by a registered dietitian. Chart review included oncological and past medical history, GLP-1 prescriptions and discussions, lifestyle counseling, and referrals for nutrition/exercise. Overweight and obesity were defined by documented BMI using standard measures. Primary outcome focused on patients at risk of cardiomyopathy due to anthracycline and exposure. Descriptive statistics were performed.

RESULTS

Sixty-four adult CCS included in the analysis, (survivorship-only visit: 28, combined survivorship/primary care visit: 36). Hematological malignancies were the most common diagnosis (32% leukemia, 17% lymphoma). Among the total study cohort, 57% were overweight or obese, and 79.7% had a history of anthracycline exposure. Of those with anthracycline exposure, 51% were obese or overweight, 7.7% patients had a history of hypertension, 7.7% had a history of type 2 diabetes mellitus, 30.8% had a history of hyperlipidemia, 23% were either prescribed or discussed the option for GLP-1 therapy, and lifestyle counseling was documented for 100%. Dietary screening demonstrated that 34.6% had dietary habits categorized as “unhealthy” or “intermediate”. Additionally, 50% of patients expressed interest in culinary medicine classes.

CONCLUSION

Our study population demonstrated a high burden of anthracycline exposure, a high prevalence of being overweight or obese, and a portion were found to have dietary habits categorized as “unhealthy” or “intermediate”. These findings underscore a critical opportunity to address modifiable cardiometabolic risk factors among adult CCS, including both weight management and dietary habits. They support the integration of routine dietary screening, assessment of nutrition-related risk, and targeted, nutrition-focused interventions across all healthcare settings. In addition, further evaluation of comprehensive cardiometabolic risk management strategies, such as lifestyle interventions and the appropriate use of GLP-1–based therapies, is warranted to optimize long-term health outcomes in CCS.

Table 1. Patient characteristics, treatment exposures, cardiometabolic risks factors and dietary behaviors among adult survivors of childhood cancer

Overall patient population characteristics	Total N (SD or %) (n=64)
Age at the Time of Visit, Mean (SD)	24.6 (5.6)
Age of Cancer Onset, Mean (SD)	8.7 (5.5)
Race [a]	
Asian / Asian American	6 (9.4)
Black / African American	10 (15.6)
White	35 (54.7)
Unknown	13 (20.3)
Ethnicity [a]	
Hispanic / Latina/o / Latinx	17 (26.6)
Not Hispanic / Latina/o / Latinx	41 (64.0)
Unknown / Other / Prefer Not to Answer	6 (9.4)
Gender [a]	
Male	30 (46.9)
Female	34 (53.1)
Health Insurance [a]	
Private	56 (87.5)
Medicaid	6 (9.4)
None	2 (3.1)
Tobacco Smoking [a]	
Current	0 (0.0)
Former	2 (3.1)
Never	62 (96.9)
Smokeless Tobacco Use [a]	
Current	0 (0.0)
Former	2 (3.1)
Never	62 (96.9)
Alcohol Use [a]	
Everyday	1 (1.6)
Someday	22 (34.4)
Former	6 (9.3)
Never	35 (54.7)
Primary Cancer Diagnosis [b]	
Brain/CNS	9 (14.1)
Leukemia	21 (32.8)
Lymphoma	11 (17.2)
Other [c]	12 (18.7)
Sarcoma	11 (17.2)
Received Chemotherapy [b]	
Yes	62 (96.9)
No	2 (3.1)
Received Radiation Therapy [b]	
Yes	23 (35.9)
No	41 (64.1)
Exposure to Anthracycline [b]	
Yes	51 (79.7)
No	13 (20.3)
Radiation to the chest [b]	
Yes	3 (4.7)
No	61 (95.3)
BMI Category/Measure [d]	
Underweight (<18.5)	7 (10.9)
Normal (18.5-24.9)	25 (39.1)
Overweight (25.0-29.9)	19 (29.7)
Obesity (>30.0)	13 (20.3)

Characteristics of anthracycline exposure population	Total N (%) (n=51)
BMI Category/Measure [d]	
Underweight (<18.5)	7 (13.7)
Normal (18.5-24.9)	18 (35.3)
Overweight (25.0-29.9)	15 (29.4)
Obesity (>30.0)	11 (21.6)
History of obesity [b]	
Yes	11 (21.6)
No	40 (78.4)
History of CHF [b]	
Yes	16 (31.4)
No	35 (68.6)
History of prediabetes [b]	
Yes	2 (3.9)
No	49 (96.1)
History of Type 2 Diabetes Miletus [b]	
Yes	3 (5.9)
No	48 (94.1)
History of Hypertension [b]	
Yes	2 (3.9)
No	49 (96.1)
History of Hyperlipidemia [b]	
Yes	10 (19.6)
No	41 (80.4)
Mini-EAT Assessment Scores [e]	
Unhealthy (0-59)	15 (29.4)
Intermediate (60-69)	6 (11.8)
Healthy (70-100)	30 (58.8)

Abbreviations: BMI: body mass index; GLP-1: Glucagon-like peptide-1; Mini-EAT: Mini-Eating Assessment Tool

[a] Race, gender, ethnicity, tobacco and alcohol use categories are all based on patient self-report which are available on the electronic medical record.

[b] Chart review, specifically from ICD-10 codes, past medical history, and the problem list available on the electronic medical record, no additional data interpretation was performed.

[c] These patients had the following cancers: Ovarian, Kidney, Testicular, hemophagocytic lymphohistiocytosis, Langerhans's Cell Histiocytosis, and TAR Syndrome.

[d] Data was obtained from the standard adult BMI cut off metrics as documented on the current electronic medical record.

[e] Data was obtained through patient self reported dietary assessment using the validated 9 item questionnaire, additional interest in culinary medicine was polled.

008

Cardiovascular

HEALTH STATUS AND TREATMENT KNOWLEDGE AMONG ANTHRACYCLINE EXPOSED CHILDHOOD CANCER SURVIVORS: THE JCCG SURVIVOR STUDY, CARDIOVASCULAR WORKING GROUP EPRO SURVEY

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BACKGROUND-AIM

For the JCCG (Japan Child Cancer Group) Survivor Study, medical records of childhood cancer survivors diagnosed between January 1990 and December 2017 were collected from 121 JCCG-affiliated institutions. Concurrently, as part of the JCCSG Survivor Study, recruitment for an ePRO study targeting survivors was conducted. The Cardiovascular Working Group administered a cardiac health questionnaire to survivors exposed to anthracyclines (ATC). This study aimed to evaluate the health status and treatment related knowledge of ATC exposed survivors.

METHODS

Among 16,835 survivors in the JCCG Survivor Study who had visited a hospital within the past three years, 10,246 had a history of ATC exposure. Of these, 808 survivors (389 males, 419 females) completed the cardiac ePRO survey and were analyzed. Survey responses were linked with clinical data using study IDs. Median age at diagnosis was 7.5 years, and median age at survey was 21 years.

RESULTS

Primary diagnoses included hematologic malignancies (n=640; ALL 394, AML 118, lymphoma 108), solid tumors (n=162; including 74 bone/soft tissue sarcomas), and CNS tumors (n=6). Treatment exposures included ATC in all participants, alkylating agents in 86.8%, platinum agents in 17.7%, chest irradiation in 18.7%, and stem cell transplantation in 29.3%. Recurrence occurred in 128 survivors, and subsequent neoplasms in 39. ECOG performance status was 0–1 in 97.4%.
Any level of cardiovascular complications was recognized in 52 survivors (6.4%), endocrine/metabolic complications in 237 (29.3%), and renal complications in 64 (7.9%). Among endocrine/metabolic disorders, gonadal dysfunction (48.1%), obesity/dyslipidemia (35.0%), impaired glucose tolerance/diabetes (17.7%), and thyroid dysfunction (21.5%) were most common.
Regarding treatment knowledge, 30.8% of participants responded that they should be careful about their heart, but only 11.4% of ATC exposed survivors and 70.2% of chest irradiated survivors correctly reported their exposure history. No participant could report cumulative ATC dose. A total of 21.7% reported being advised to undergo regular echocardiography, while 41.3% had undergone echocardiography within the past 10 years (62.6% of them within 3 years). Twenty-four survivors reported being instructed to continue follow up due to reduced cardiac function, and two reported a diagnosis of heart failure. Ninety-seven survivors reported severe late complications requiring treatment, including heart failure (n=1), arrhythmia (n=4), hypertension (n=12), diabetes (n=11), and hyperlipidemia (n=8).

CONCLUSION

ATC-exposed Childhood cancer survivors have a considerable burden of late complications, particularly cardiovascular and endocrine/metabolic disorders. However, their knowledge of treatment information—especially cumulative ATC dose—was limited. It is necessary not only to provide survivors with treatment summaries, but also to guide them so that they can understand their late effect risks and actively make appropriate follow up choices with easier way.

009

Cardiovascular

HIGH FREQUENCY OF CARDIAC LATE SEQUELAE IN CHILDHOOD HODGKIN LYMPHOMA SURVIVORS – SLOVENIAN POPULATION-BASED STUDY

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BACKGROUND-AIM

Childhood cancer survivors, especially those treated for lymphoma, are at high risk of cardiac late sequelae in adulthood, which is also one of the most important causes of late mortality in these survivors. Our aim was to analyse cardiac late sequelae in at least 10-years survivors of Hodgkin lymphoma (HL) treated in Slovenia.

METHODS

One hundred fifty pts were treated for HL between 1971 and 2006 at the age of 16 years or less. Eighteen of them died less than 10 years after diagnosis (0 to 8, med. 2 years). Of 132 pts 15 are not visiting long-term follow-up (LTFU) clinic mostly because they live abroad. One hundred seventeen pts are regularly followed at the LTFU clinic and 101 of them received cardiotoxic therapy. We analysed cardiac function in these pts. They were treated for HL at the age of 3 to 16 (med. 13) years of age, follow-up time at the end of 2025 was 14 to 53 (med. 34) years. Therapy in 101 pts was as follows: 37 received chemotherapy with anthracycline (ChT-A) and mediastinal irradiation (med-RT), 47 got med-RT without ChT-A, 17 got ChT-A without med-RT. Doses of med-RT in 84 pts were 15 – 65 Gy (med. 30 Gy), doses of anthracycline in 54 pts were 80 – 370 (med. 160 mg/m2). Patients were examined by cardiologist, heart ultrasound was performed as well.

RESULTS

Sixty-three (62%) pts had normal cardiac function. Cardiac late sequelae were found in 38 (38%) pts. Eighteen had degenerative changes of valves, mostly aortic; 3 pts needed replacement of aortic and one of mitral valve. Eight had dilatative cardiomyopathy (CMP), all after med-RT with 24-50 (med. 30) Gy (3 got ChT-A as well), 3 of them died. Eight pts had ischemic cardiac disease; 6 acute myocardial infarction (3 death), 2 acute coronary syndrome, all after med-RT with 24-42 (med. 30) Gy. Two pts had constrictive pericarditis after med-RT with 30 and 36 Gy. Six pts had hypertensive CMP. Sixteen of 117 at least 10-years survivors died 14 to 43 (med. 31,5) years; 6 because of heart disease (3 ischemic heart disease, 3 dilatative CMP) 23 to 41 (med. 39) years after diagnosis, 6 because of subsequent neoplasm. All 12 pts had med-RT with 24-50 (med. 30) Gy.

CONCLUSION

Frequency of cardiac late sequelae in our cohort of Slovenian at least 10-years survivors of HL, who received cardiotoxic treatment, was 38% at a median follow-up time of 34 years. Mediastinal RT was important causative factor as all but two of these pts received med-RT and less than third got ChT-A. Life-long LTFU of this cohort of patients, regular control of cardiovascular risk factors and promoting healthy life-style are mandatory.

010

Cardiovascular

LONGITUDINAL ASSESSMENT OF CARDIAC FUNCTION AFTER CRANIOSPINAL IRRADIATION IN PEDIATRIC CENTRAL NERVOUS SYSTEM TUMOR SURVIVORS

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BACKGROUND-AIM

Survival among children with central nervous system (CNS) tumors has improved markedly; however, the long-term cardiac effects of craniospinal irradiation (CSI) remain poorly defined. Emerging data suggest subclinical systolic dysfunction, despite the absence of CSI-specific cardiac surveillance recommendations. We evaluated longitudinal echocardiographic measures of systolic and diastolic function in CSI-treated patients and explored clinical and treatment-related predictors of cardiac dysfunction.

METHODS

Retrospective multi-institutional study (January 2000-September 2024). We included pediatric patients (diagnosed <18 years) with a primary CNS tumor treated with CSI, without prior anthracycline exposure and at least one post-CSI echocardiogram. Echocardiographic assessment included M-mode evaluation of left ventricular ejection fraction (EF) and shortening fraction (SF), speckle-tracking analysis of global longitudinal strain (GLS), and conventional Doppler measurements of diastolic function parameters.

RESULTS

Among 129 CSI-treated CNS tumor survivors (median age at diagnosis: 8 [IQR 5-11] years; median age at study: 23 [IQR 18-27] years), medulloblastoma was the most common diagnosis (80%) and most patients received photon-based CSI (mean heart dose: 1.217 [IQR 2.340-3.600] cGy). The majority were exposed to cisplatin and cyclophosphamide (91% n=118 and 79% n=102, respectively), two-thirds developed endocrine comorbidities, and 28% had cardiovascular risk factors. Left ventricular EF and SF declined over time post-CSI ($p=0.006$ and $p<0.001$), remaining stable through early adolescence, but progressively decreasing at older ages ($p<0.001$). EF remained ≥45% in all patients, whereas SF was <28% in 14 patients (11%). Diastolic parameters were largely stable. GLS showed early post-CSI improvement followed by gradual decline with extended follow-up ($p<0.001$); five patients had GLS <16%. Older age at cancer diagnosis was associated with greater decline in EF and SF ($p=0.041$ and $p<0.001$), endocrine comorbidities correlated with lower EF as attained age increased ($p=0.037$). SF trajectories were influenced by cyclophosphamide dose, with mid-to-low doses linked to steeper declines after age 15 ($p=0.002$). GLS trajectories differed by sex, with females showing lower values at younger ages ($p=0.015$); these differences attenuated during adolescence. Cardiovascular comorbidities did not significantly affected GLS patterns.

CONCLUSION

Progressive long-term decline in systolic function was identified in CSI-treated CNS patients, despite modest cardiac radiation doses and absence of anthracycline exposure. Age at diagnosis, sex, and endocrine comorbidities modulate these trajectories, while diastolic indices remained largely preserved. These findings suggest that even low-dose CSI may contribute to subclinical myocardial remodeling, underscoring the rationale for dedicated cardiac surveillance in this vulnerable population.

011

Cardiovascular

METABOLIC SYNDROME AND ITS DETERMINANTS IN SURVIVORS OF A HEMATOPOIETIC STEM CELL TRANSPLANTATION FOR HEMATOLOGICAL MALIGNANCY IN CHILDHOOD

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BACKGROUND-AIM

Hematopoietic stem cell transplantation (HSCT) in childhood has been associated with an increased risk of metabolic syndrome (MetS) as a late effect. Previous studies reported widely varying MetS prevalence estimates and were limited by small and/or heterogenous populations. We aimed to determine the prevalence of MetS by age and sex, and its determinants, including sociodemographic, treatment-related and inflammatory factors, and lifestyle behaviors in a well-defined cohort of survivors of an HSCT.

METHODS

The Metabolic Syndrome, Vascular Damage and accelerated Aging (MetVasA-study) is a nationwide cross-sectional pooled cohort study in survivors of an HSCT for a hematological malignancy in childhood. Cohort 1 comprised 102 adult survivors (DCCSS-LATER 2 study) transplanted between1963-2001. Cohort 2 included 89 survivors, both children (age ≥ 4 years (y)) and adults, transplanted between 2002-2021. A comparison cohort included 1,059 adult survivors of the DCCSS-LATER2 study, diagnosed between 1963-2001 with a hematological malignancy who were treated with chemotherapy and/or radiotherapy only. MetS was defined as having ≥3 of 5 components (hypertension, adiposity (waist circumference), insulin resistance (fasting glucose and/or HOMA-IR), high triglycerides, and/or low HDL-cholesterol), using sex- and age-specific cut-offs.

RESULTS

For the analyses, we included in total 152 survivors who had an HSCT with a mean age of 26.2y (SD 9.2, range 4-47) and a median follow-up (FU) of 17.5y [IQR 12.5], 55.9% was male. In children (n=29), the mean age was 14.2y (SD 3.4) and median FU was 6.5y [IQR 5.8]. In adults (n=123), the mean age was 29.1y (SD7.5) and median FU was 19.8y [IQR 8.2]. Survivors in the comparison cohort (n=1,059) had a mean age of 34.7y (SD 9.0) and median FU of 26.5y [IQR 13.2], 55.5% was male.

The prevalence of MetS in the pooled cohort was 15.8% (95%CI 10.0-21.7); in children (4-18 years of age) 1 of 29 (3.4%) was diagnosed with MetS. In adults, 23/123 (18.7%, 95%CI 11.7-25.7%) were diagnosed with MetS. In the comparison cohort, the prevalence of MetS was 14.5% (95%CI 12.5-16.8).

The prevalence of MetS in the pooled cohort increased with age; <30y: 10.4% (95%CI 4.2-16.6), 30-39y: 17.8% (95%CI 6.2-29.4), and ≥40y: 54.5% (95%CI 19.5-89.6). In contrast, the prevalence of MetS in the Dutch general population aged 30-39y and 40-49y is 14.4% and 22.4%, respectively. Multivariable analyses showed that a higher attained age (≥40y vs. <30y: OR 5.4, 1.2-24.3), longer follow-up time (<20y vs. ≥20y; OR 2.5, 1.0-6.2) and TBI as conditioning for HSCT (yes vs. no: OR 3.0, 95%CI 0.84-10.4), but not gender, were significantly associated with the presence of MetS.

CONCLUSION

MetS prevalence was 15.8% in survivors of an HSCT for hematological malignancy, increasing to 54.5% in those aged ≥40 years. Higher attained age, longer follow-up time, and TBI are potential determinants of MetS in this group of survivors. Our study will increase knowledge on HSCT survivors most at risk and early diagnosis of MetS may allow for timely interventions, especially at a younger age.

012

Cardiovascular

PERSONALISED CARDIOTOXICITY SURVEILLANCE IN PAEDIATRIC CARDIO-ONCOLOGY: STRATEGIES FOR EARLY DETECTION OF SUBCLINICAL CARDIAC DYSFUNCTION

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BACKGROUND-AIM

Improved survival in pediatric oncology has increased the number of childhood cancer survivors, in whom cardiovascular complications represent one of the major causes of long-term morbidity and mortality. Exposure to anticancer therapies, particularly anthracyclines and chest radiotherapy (CT), is associated with cardiac dysfunction that may emerge years after treatment. Advanced echocardiographic parameters such as Global Longitudinal Strain (GLS) and cardiac biomarkers, including NT-proBNP, are emerging as sensitive tools for early detection of cardiotoxicity, but their integration into survivorship care is not yet standardized.
Our purpose is to evaluate current cardio-oncology surveillance practice in relation to national recommendations by the Italian Society of Paediatric Cardiology (SICP) based on international guidelines (IGHG, ESC), focusing on cardiac monitoring methods and their ability to detect subclinical dysfunction during treatment and long-term follow-up, supporting personalised risk-adapted strategies.

METHODS

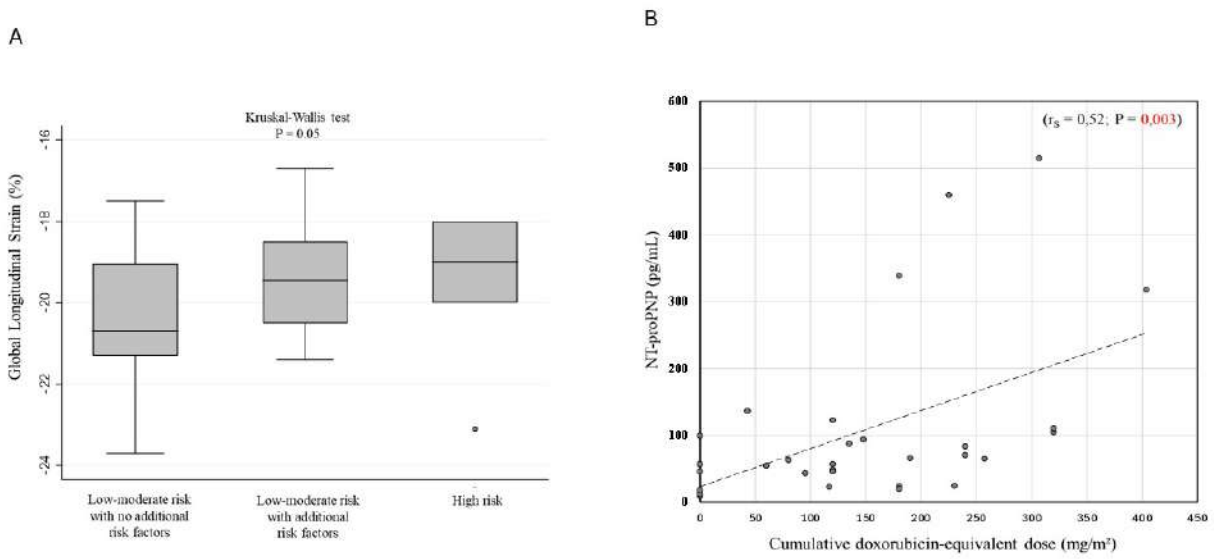
This descriptive observational study included pediatric patients during (ONTx) and after (OFFTx) anticancer treatment undergoing cardiological evaluation between February and September 2024 at the Gaslini Institute (Genoa) and Ospedale Maggiore della Carità (Novara). Patients were stratified into three cardiotoxicity risk classes based on doxorubicin-equivalent dose (DED) and CT according to recommendations, further refined by individual cardiovascular risk factors (e.g. metabolic comorbidities, heart disease, previous cardiotoxicity, genetic conditions). Clinical data, ECG, echocardiography focused on ejection fraction (EF) and GLS, and cardiac biomarkers were analyzed as early indicators of cardiotoxicity, compared between ONTx and OFFTx groups.

RESULTS

Among 73 patients (51% female; median age at cancer diagnosis 4.8 years; median age at cardiological evaluation 12.5 years), 47 (64%) were OFFTx at the time of evaluation (median follow up 4.8 years, range 2.9-6.6). Haematological malignancies were predominant, mainly acute lymphoblastic leukaemia (36%). Overall, 42 children (58%) had received anthracyclines (mean cumulative DED 180.6±90.1mg/m²). Patients were classified as low-moderate risk (n=54), low-moderate risk with additional risk factors (n=9), and high risk (n=10). No significant differences in clinical or risk characteristics were observed between ONTx and OFFTx groups.
Echocardiographic assessment showed progressive functional impairment across risk classes, with significant deterioration in both EF and GLS, without differences between ONTx and OFFTx groups. Pathological GLS was observed in 29% of high and 12.5% of low-moderate risk patients with additional risk factors, versus 2.8% in the low-moderate risk group ($p<0.05$). Diastolic dysfunction was associated with higher BMI. NT-proBNP levels correlated with DED ($p<0.05$), although biomarker availability was limited.

CONCLUSION

Despite the small sample size, our findings support the importance of structured specific cardiovascular surveillance in pediatric patients treated for cancer. Monitoring strategies should include individual cardiovascular risk factors, particularly when potentially modifiable, reassessed at each evaluation. Integration of advanced echocardiographic techniques such as GLS, together with standardized biomarker monitoring, may improve early identification of subclinical cardiotoxicity to reduce long-term cardiovascular burden in this population.



Distribution of Global Longitudinal Strain (GLS) values across cardiotoxicity risk classes in all patients evaluated (A) and distribution of NT-proPNP values compared to cumulative doxorubicin-equivalent dose (B)

013

Cardiovascular

VASCULAR CHANGES IN PEDIATRIC AND YOUNG ADULT ALLOGENEIC HCT SURVIVORS WITH CHRONIC GVHD

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BACKGROUND-AIM

Allogeneic hematopoietic stem cell transplant (allo-HCT) survivors with chronic graft versus host disease (cGVHD) are at risk of cardiovascular disease (CVD) due to a persistent pro-inflammatory environment and chronic immune suppression.
Aim: Evaluate large vessel elasticity in pediatric and young adult allo-HCT survivors with cGVHD using pulse wave analysis (PWA) and carotid-femoral pulse wave velocity (cfPWV), measured by the noninvasive validated SphygmoCor device (AtCor Medical).

METHODS

HCT survivors with a history of/active cGVHD were enrolled at Cincinnati Children's Hospital. Central aortic stiffness was measured via cfPWV, gold standard for predicting adverse CVD events. PWA included central blood pressure (cBP), augmentation pressure (AP) and augmentation index (AIx), which are measures of left ventricular workload and vascular stiffness. Three PWA-cfPWV measurements were obtained at assessment and averaged to control for variability. Vascular data were compared with published age and sex-matched normative percentiles when available or via SphygmoCor system interpretation. Descriptive analyses were performed to characterize transplant-related variables and CVD risk factors.

RESULTS

Eighteen patients with median age 19 years (range 7-31 years) were enrolled (Table 1). Ten patients underwent HCT for hematological malignancy. Seventeen patients had moderate or severe cGVHD (NIH consensus criteria) and 1 patient had mild cGVHD. Twelve patients were on >/1 systemic immunomodulator or had exposure to a systemic agent within 2 weeks of assessment. Six patients were off treatment or receiving targeted ocular/oral agents.
The median BMI was 22.2 kg/m2 (range, 12.9-34.52) and 3 patients had evidence of dyslipidemia on screening. Six patients had chronic kidney disease, 2 patients were on an anti-hypertensive (HTN) agent, 1 patient was on a beta-blocker for heart rate control, and 1 patient was treated for biventricular dysfunction at the time of assessment. Three patients had type 1 diabetes and four had reported a history of smoking/vaping. Six patients had a history of transplant-associated thrombotic microangiopathy.
On vascular assessment, 8 patients had elevated systolic cBP >/90th percentile, of whom 6 patients were #97th percentile. Five of the patients had severe GVHD with higher lung score or multiorgan involvement and 3 had moderate cGVHD. Six of the patients had failed a median of 4 (range, 2-8) systemic agents, including prolonged steroid exposure prior to their current treatment. All 4 patients receiving anti-HTN or cardiac remodeling agents were #97th percentile systolic cBP and were discrepant with reassuringly normal peripheral BP measurements. Five patients were >/ 21 years old with internal SphygmoCor system AP and AIx interpretations available, of whom 3 had increased AP and AIx values above the reference range for their respective age reflecting increased arterial stiffness. cfPWV was borderline elevated (50th-75th percentile) in 5 patients, between the 75th-90th percentile in 3 patients and >/90th in 2 patients.

CONCLUSION

Subclinical vascular abnormalities are detectable in HCT survivors with cGVHD and may be missed by routine BP monitoring or echocardiogram. Patients with moderate/severe cGVHD or prior exposure to multiple systemic therapies, may warrant additional risk-stratified vascular surveillance. Prospective studies are needed to define CVD prognostic significance and guide early intervention.

Table 1. Patient characteristics and cGVHD treatment exposure

	Number of patients (range/%)
Age in years at the time of transplant (y), median	15.2 (4.8-29.0)
Age in years at assessment (y), median	18.9 (6.8-31.3)
Sex (male/female)	11:7
Primary Disease Malignancy Non-malignant condition	 10 (56) 8 (44)
cGVHD Grading NIH-CC	
Mild	1 (5)
Moderate	5 (28)
Severe	12 (67)
Organ Involvement	
Gastrointestinal	9 (50)
Joints/ Fascia	2 (11)
Liver	4 (22)
Pulmonary	9 (50)
Ocular	7 (39)
Oral	5 (28)
Skin	10 (56)
Genitourinary	1 (5)
Systemic agent exposure at time of assessment or within 2 weeks prior to assessment	
Alpha 1 Anti-trypsin (A1AT)	3 (17)
Abatacept	2 (11)
Axitilimab	5 (28)
Basiliximab	1 (5)
Belumosudil	7 (39)
Budesonide (*Entocort*)	2 (11)
Budesonide (*Uceris*)	1 (5)
Calcineurin Inhibitor	1 (5)
Dupilumab (*Dupixent)*	1 (5)
Efgartigimod alfa (*Vygart*)	1 (5)
Infliximab	2 (11)
Pirfenidone	3 (17)
Prednisone/ steroid equivalent*	4 (22)
Ruxolitinib	4 (22)
Vedolizumab	1 (5)

***Prednisone equivalent: >0.25mg/kg/day exposure**

Table 1- Patient characteristics and cGVHD treatment exposure

014

Cardiovascular

VISUALIZING RENAL VASCULAR LATE EFFECTS AFTER CHILDHOOD ALL THERAPY: RESULTS FROM THE HEALED PILOT STUDY

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BACKGROUND-AIM

As survival rates in pediatric oncology continue to increase, long-term organ toxicity in general and nephrotoxicity in particular have come into focus. Relevant therapy-associated late effects of the kidney often remain clinically silent for years. Conventional markers such as serum creatinine, estimated glomerular filtration rate (eGFR) or albuminuria lack sensitivity for early renal damage. Growing evidence suggests that endothelial and microvascular injury contributes substantially to long-term organ toxicity after cancer therapy.
Contrast-enhanced ultrasound (CEUS) allows functional assessment of renal perfusion, while Ultrasound Localization Microscopy (ULM) enables high-resolution visualization of microvascular architecture and perfusion dynamics beyond the limit of conventional ultrasound. Our pilot study (HEALED) aims to detect subclinical renal vascular alterations in survivors of childhood acute lymphoblastic leukemia (ALL) using CEUS and ULM.

METHODS

HEALED is an ongoing monocentric pilot study including childhood and adolescent ALL survivors. Participants undergo renal CEUS and ULM imaging using intravenously administered microbubbles (SonoVue). CEUS time–intensity curves are analyzed to derive quantitative perfusion parameters, including wash-in rate (WIR), rise time (RT), and fall time (FT). ULM enables microvascular reconstruction and quantification of perfusion parameters in unprecedented resolution. Imaging findings are correlated with time since therapy and conventional kidney function markers (serum creatinine, eGFR, albuminuria). Feasibility and safety are systematically evaluated.

RESULTS

To date, renal CEUS and ULM imaging has been successfully performed in 15 ALL patients. In all participants, the measurements yielded evaluable results, demonstrating excellent feasibility. Both CEUS- and ULM-based analyses revealed reduced cortical microvascular perfusion.
As shown in Figure 1a, CEUS imaging illustrates marked, cortically emphasized differences between renal perfusion before therapy and 13 years after ALL diagnosis during follow-up. In long-term survivors, quantitative CEUS analysis demonstrated a lower wash-in rate and prolonged rise and fall times (Figure 1b), indicating delayed contrast inflow and washout compared to pre-therapy imaging, consistent with impaired renal microcirculation. Cortical hypoperfusion appeared more pronounced with increasing time since therapy; however, statistical analysis is limited by sample size. No association was observed between vascular impairment and conventional kidney function markers at this stage, as also reflected by initial ULM-based microvascular analyses.

CONCLUSION

Renal CEUS and ULM are feasible and sensitive imaging modalities for detecting vascular renal alterations in childhood ALL survivors. The observed cortical hypoperfusion with reduced wash-in and delayed inflow and outflow may represent an early imaging marker of chronic renal injury, preceding laboratory abnormalities. These findings support the hypothesis that vascular damage contributes to long-term nephrotoxicity after ALL therapy. Ongoing recruitment and longitudinal analyses will clarify the clinical relevance of cortical microvascular impairment and its potential association with broader vascular late effects, with the aim of improving risk stratification and long-term follow-up care in childhood cancer survivors.

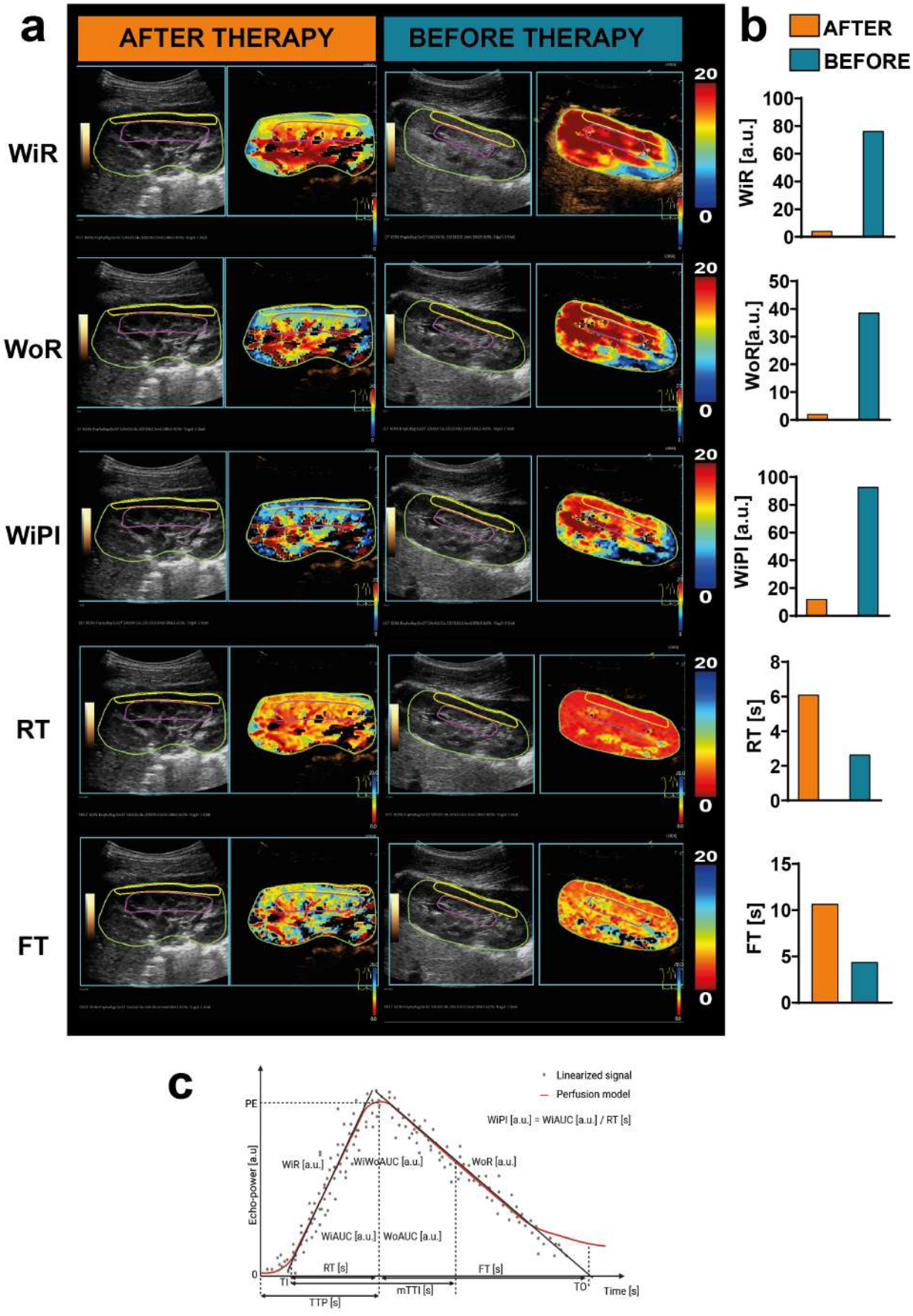

Figure 1 Contrast-enhanced ultrasound (CEUS) reveals differences in cortical renal perfusion before and after chemotherapy in pediatric patients a Color-coded maps of dynamic flow parameters in a patient 13 years after chemotherapy (left) and a patient before chemotherapy (right); WiR = Wash-in Rate, WoR = Wash-out Rate, Wip| = Wash-in Perfusion Index, RT = Rise Time, FT = Fall Time b Quantification of dynamic flow parameters Time [s] c Schematic illustration of dynamic flow parameters

015

Education

CANCER SURVIVORSHIP CARE – INSIGHTS INTO THE DEVELOPMENT AND IMPLEMENTATION OF A NATIONWIDE PILOT CURRICULUM

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BACKGROUND-AIM

With increasing awareness of the need for lifelong, risk-adapted long-term follow-up care, the number of physicians involved in the care of cancer survivors is expected to rise. However, education on cancer survivorship is not yet routinely included in medical training in many countries.
We developed a dedicated continuing medical education program to strengthen high-quality, evidence-based care, which was piloted in Germany in November 2025 in cooperation with the Medical Chamber of Westphalia-Lippe.

METHODS

The interdisciplinary and multiprofessional Cancer Survivorship Care curriculum was delivered in a blended-learning format. The total of 7 modules and 37 teaching units covered I) cancer survivorship care, evidence-based recommendations and care structures, II) secondary malignancies, III) and IV) specific late effects including cardiovascular, dermatological, endocrinological, gastrointestinal, gynecological and urological, musculoskeletal, nephrological, neurological, oral and dental, psychological and pulmonological late effects, V) entity- and therapy-specific survivorship strategies and survivorship across the lifespan, VI) social-legal aspects, the role of social support persons and prevention, as well as a concluding module VII) with a strong focus on group-reflection and practical-oriented work. The course was accredited with 51 continuing medical education (CME) points.
The accompanying evaluation included quantitative and qualitative feedback on content, didactics, and organization, as well as self-assessments of knowledge, confidence in clinical practice, and practical experience.

RESULTS

Twenty-seven practicing healthcare professionals (81.3% female, aged 30–65 years) from eight federal states participated in the pilot course, the majority working at university hospitals (60.0%) and with an internal medicine background (46.7.6%). Participants rated the curriculum very positively overall (median 1.3, on a scale 1-5), particularly with regard to scientific quality, practical relevance, and overall importance. All respondents recommended the course without reservation. Areas for improvement mainly related to workload, time structure, and user-friendliness of the asynchronous learning components.

CONCLUSION

The results demonstrate the high relevance of a practice-oriented, interdisciplinary training program. Identified optimization needs, particularly regarding course structure and technical implementation, will be specifically addressed in a second iteration in 2026. In the longer term, increased patient involvement and a stronger multiprofessional orientation are expected to support sustainable implementation.

016

Education

CROSS SECTIONAL ANALYSIS OF EDUCATION SUPPORT SYSTEMS UTILIZED BY LONG TERM PEDIATRIC CANCER SURVIVORS AT A MID-SIZE ONCOLOGY PROGRAM.

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BACKGROUND-AIM

Long term childhood cancer survivors experience issues in their quality of life (QOL) commiserating with the treatment intensity. These issues extend to educational difficulties often requiring identification and establishment of appropriate school/educational support. In the USA, the two common support systems directed through federal constitution in public schools for children are an individualized education program (IEP) for children with disabilities and Section 504 plan. IEP is truly individualized for each child to improve educational results for children with disabilities. While section 504 requires that school districts provide a free appropriate public education to qualified students who have a physical or mental impairment that substantially limits one or more major life activities. Pediatric cancer survivors often meet criteria for 1 or both support programs depending on the type of physical and/or mental long term side effect.

METHODS

We conducted a cross-sectional analysis of long term pediatric cancer survivors (> 4 years since end of therapy) seen at a mid-size oncology program between June 2024- January 2026 to determine the utilization of these support programs and the interventions put in place by the education coordinator. Number of patients who required additional school support system such as Individual Education Plan (IEP) or 504 plan vs. no support was collected. Patient variables such as age at the time of the long-term survivorship visit, diagnoses and school grade were collected.

RESULTS

A total of 148 pediatric long term survivors were assessed by the education coordinator over approximately 19 months. Mean age was 15.3 years (range: 5-34 years). The top 6 of the most common diagnoses seen were ALL 35 (23.6%), Wilms tumor 22 (14.8%), neuroblastoma (any stage) 20 (13.5%), classical Hodgkin lymphoma (cHL) 14 (9.5%), brain tumor and hepatoblastoma 8 each (5.4%). About 40.5% (60) have formal accommodations (IEP- 34; 504 plan- 26) [Figure 1]. The top 3 diagnoses that were frequently noted to need formal school support needs in our cohort were ALL: 54.3%, followed by Wilms tumor: 18.2% and neuroblastoma (any stage): 7.4%. Brain tumor cases skew to 504 plans 7/8 (62.5%), suggesting accommodations that are often classroom/testing-based modifications. Neuroblastoma & hepatoblastoma survivors have relatively higher IEP utilization 50% (5/10) for each diagnoses hinting at more frequent intensive school planning needs in our cohort. Children (N=8) who were homeschooled do not have access to school support system.

CONCLUSION

Our cohort showed similar utilization rates for education support systems in long term childhood cancer survivors. Due to fewer allogeneic stem cell transplant diagnoses in our cohort, this was underrepresented. Education coordinator plays a critical role in assessing children during survivorship visits regarding their performance, struggles and need for any accommodation to ensure that the child can utilize the federal programs to improve the experience and optimize education environment.

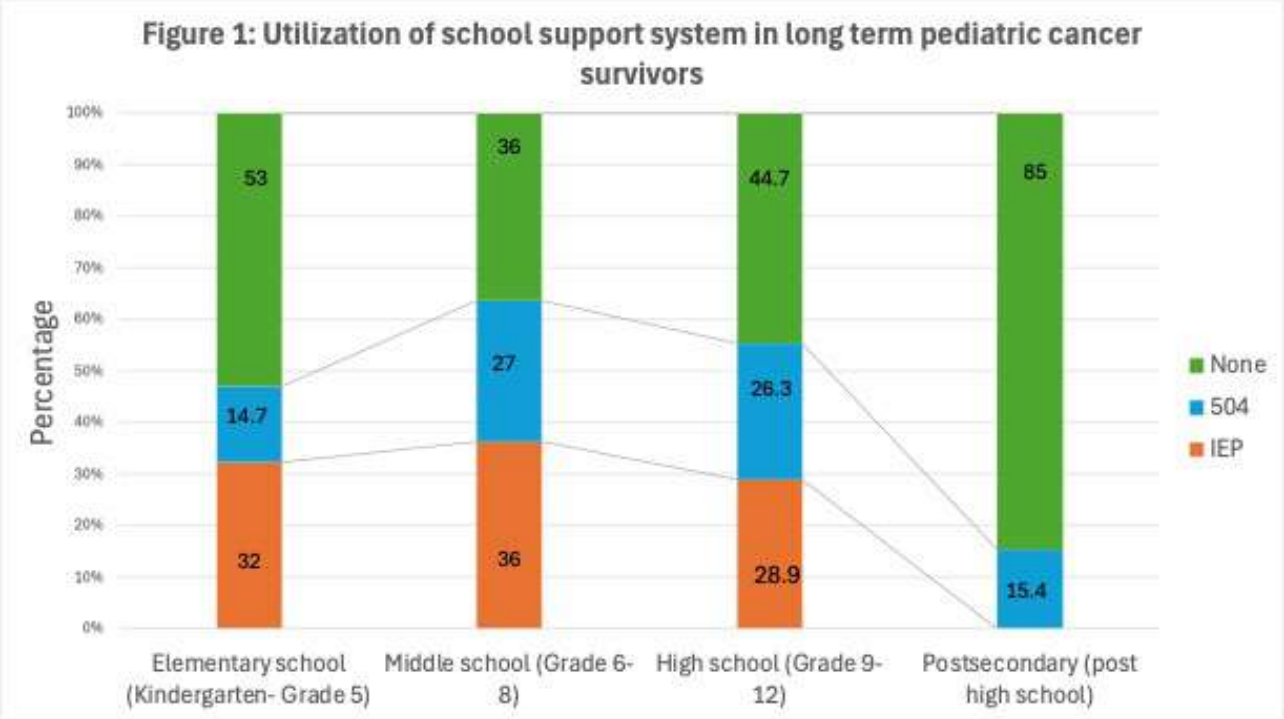

Figure 1. Utilization of school support systems in pediatric long term survivors.

017

Education

EMPOWERING CHILDHOOD CANCER SURVIVORS THROUGH STRUCTURED SURVIVORSHIP EDUCATION: ADDRESSING LONG-TERM CARE KNOWLEDGE GAPS

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BACKGROUND-AIM

Advances in paediatric oncology have resulted in an increasing number of childhood cancer survivors; however, many survivors and their families report limited understanding of survivorship-related health risks, late effects, and long-term follow-up care. Inadequate education may negatively impact self-management, adherence to follow-up, and overall quality of life. This study aimed to explore survivorship education needs and to develop a structured, family-centred educational approach to support childhood and adolescent cancer survivors during the transition from active treatment to survivorship.

METHODS

A structured survivorship education framework was developed based on clinical experience, current survivorship guidelines, and identified gaps in routine follow-up care. The educational content focused on late effects, health surveillance, psychosocial well-being, healthy lifestyle behaviours, and transition to adult services. Survivors and caregivers participated in tailored education sessions integrated into follow-up care. Feedback was collected using structured questionnaires and reflective discussions to evaluate relevance, clarity, and perceived usefulness of the educational intervention.

RESULTS

Participants reported improved understanding of survivorship-related health risks, follow-up requirements, and self-management strategies following the education sessions. Survivors and caregivers highlighted increased confidence in recognising potential late effects and engaging proactively with healthcare providers. Education delivered in an age-appropriate and family-centred manner was perceived as highly relevant, with particular value placed on clear explanations and practical guidance for long-term health monitoring.

CONCLUSION

Structured survivorship education is a critical component of comprehensive paediatric oncology care. Integrating targeted educational interventions into routine follow-up can empower survivors and families, promote engagement with long-term care, and support improved survivorship outcomes. This educational framework may be adaptable to diverse paediatric oncology settings and supports the growing emphasis on holistic, survivor-focused care models.

018

Education

EVALUATING THE UTILITY OF THE CHILDREN'S ONCOLOGY GROUP (COG) HEALTH LINK IN SURVIVORSHIP CLINICS: INSIGHTS FROM THE COG LONG-TERM FOLLOW-UP TRANSLATIONAL TASK FORCE

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BACKGROUND-AIM

Risk-based survivorship education is critical for childhood cancer survivors, yet guideline-concordant care is often inconsistently delivered in community settings. The Children's Oncology Group (COG) Health Links provide risk-based survivorship education for use in the care of childhood cancer survivors, but little is known about real-world use, workflow integration, and perceived utility. Understanding these factors is critical to optimizing survivorship care.

METHODS

An online survey was distributed to clinicians and staff at COG-affiliated programs in the United States, Canada, Australia, and New Zealand. Respondents provided information about their clinical site, role, and use of the Health Links in practice. Health Link awareness, accessibility, perceived utility, and satisfaction were assessed on a 5-point Likert scale. Information on workflow integration, use of specific Health Links and language translation were also collected. A free response option for additional feedback on Health Links was also provided.
Associations between provider role, frequency of use, and perceived helpfulness were evaluated using chi-square or Fisher's exact tests.

RESULTS

One hundred and four respondents from seventy-four institutions included physicians (53%), advanced practice providers (27%), and nurses (18%) across clinics ranging from solo practices (2%) to large multidisciplinary programs (21%). Health Link awareness was high (87.5% "very aware"), and 91% reported easy access. Overall, 90% reported use, most often several times per month (45%) or monthly (25%), primarily at the initial survivorship visit (81%). Integration relied on paper handouts (89%) and in-clinic counseling (63%), with minimal electronic medical record incorporation (8%) or routine sharing with primary care providers (11%).
Health Links were rated helpful in supporting survivor health care needs (83%) and survivor education (82%), though perceived usefulness for primary care providers was lower (42% neutral). Higher frequency of use was associated with greater perceived helpfulness (p $p<0.05$). Use varied by provider role ($\chi^2(2, N=91)=11.96$, $p=0.003$), with high-frequency use reported by 88% of nurses, 65% of advanced practice providers, and 41% of physicians. Health links covering cardiovascular health (72.9%), reproductive health (55.1%), nutrition and physical activity (51.7%), mental health (44.9%), and introduction to long-term follow-up (69.7%) were most frequently used. Reported barriers included excessive length (56%), limited adolescent and young adult tailoring (32%), navigation challenges (18%), and lack of formal implementation training (17%), yet overall satisfaction remained high (82%).

CONCLUSION

Providers are aware of COG Health Links and are considered helpful tools in survivorship care, but use is episodic, front-loaded at initial visits, and largely paper based. Opportunities exist for longitudinal integration, streamlined content, digital delivery, adolescent/young adult tailoring, and enhanced primary care engagement. These findings provide actionable guidance for scalable, guideline-concordant educational tools to support equitable, risk-based survivorship care globally.
We wish to acknowledge NCTN Operations Center Grant U10CA180886.

019

Education

MORE THAN WORDS: INTERPRETER-INFORMED CLINICIAN TRAINING TO PROMOTE LANGUAGE EQUITY IN PEDIATRIC CANCER SURVIVORSHIP

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BACKGROUND-AIM

Medical interpreters play a critical role in pediatric oncology beyond translation by guiding conversations, interpreting cultural and emotional cues, and ensuring families with limited English proficiency (LEP) can access medical information. As pediatric cancer survival rates continue to improve, families engage in care over longer time horizons, increasing the need for effective and consistent communication throughout survivorship—yet few clinician training resources focus on interpreter-mediated communication. This study aimed to (1) identify communication best practices and challenges from the perspective of professional medical interpreters and (2) develop an interpreter-informed educational toolkit for clinicians to promote equitable, patient-centered communication for families with LEP.

METHODS

We conducted semi-structured individual interviews and one focus group with Spanish medical interpreters from six freestanding children's hospitals across the United States between December 2024 and October 2025. Participants primarily provided in-person interpretation for pediatric oncology and survivorship encounters. Verbatim transcripts were thematically analyzed in Dedoose. Identified themes were iteratively reviewed and directly informed creation of an educational toolkit for clinicians.

RESULTS

Sixteen interpreters (15 female, 1 male) participated. Interpreters emphasized that in-person professional interpretation uniquely supports survivorship care by enabling recognition of non-verbal communication cues, serving as patient/family advocates, providing cultural and linguistic tailoring, explaining idiomatic or metaphorical clinical language, and fostering continuity of interpreters across visits. Challenges included fragmented communication across medical teams, limited clinician understanding of cultural nuance, exclusion of parents from conversations, and overreliance on remote interpreting. Based on these themes, we developed recommendations for clinicians focused on building collaborative relationships with interpreters, allowing adequate time for interpretation, and actively checking patient and family understanding. We then designed a multi-component educational toolkit consisting of: 1) a badge reference card with a pre-, during-, and post-visit checklist; 2) a case-based decision-making learning module featuring first-person scenarios navigating interpreter-mediated oncology and survivorship encounters; and 3) a self-paced modular course with structured lessons to support deeper learning.

CONCLUSION

Interpreters identified concrete practices that enhance equitable, patient-centered care across the pediatric oncology survivorship continuum, with particular strengths evident during in-person interpretation, and challenges that undermine equitable communication. These insights informed a clinician-facing educational toolkit to improve interpreter-clinician encounters. Future studies will pilot and iteratively refine the toolkit, with ongoing interpreter engagement, to support more inclusive survivorship care delivery.

020

Education

MYCARE E-QUOL: DEVELOPMENT OF A PATIENT-CENTERED DIGITAL TOOL FOR NEEDS-BASED SURVIVORSHIP CARE

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[1]*CHU Angers, CHU Caen, U 1018 Villejuif, France*
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[3]*Epiconcept, France*
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[5]*university of Oslo, Norway*

BACKGROUND-AIM

Long-term follow-up (LTFU) of childhood, adolescent, and young adult cancer survivors (CAYACS) requires structured, sustainable, and patient-centered tools capable of capturing evolving needs while integrating clinical workflows. Digital solutions offer an opportunity to provide survivorship care models beyond traditional visit-based follow-up.
Objective : To describe the design and development of MyCare e-QuoL, a digital platform dedicated to LTFU and needs-driven support for CAYACS.

METHODS

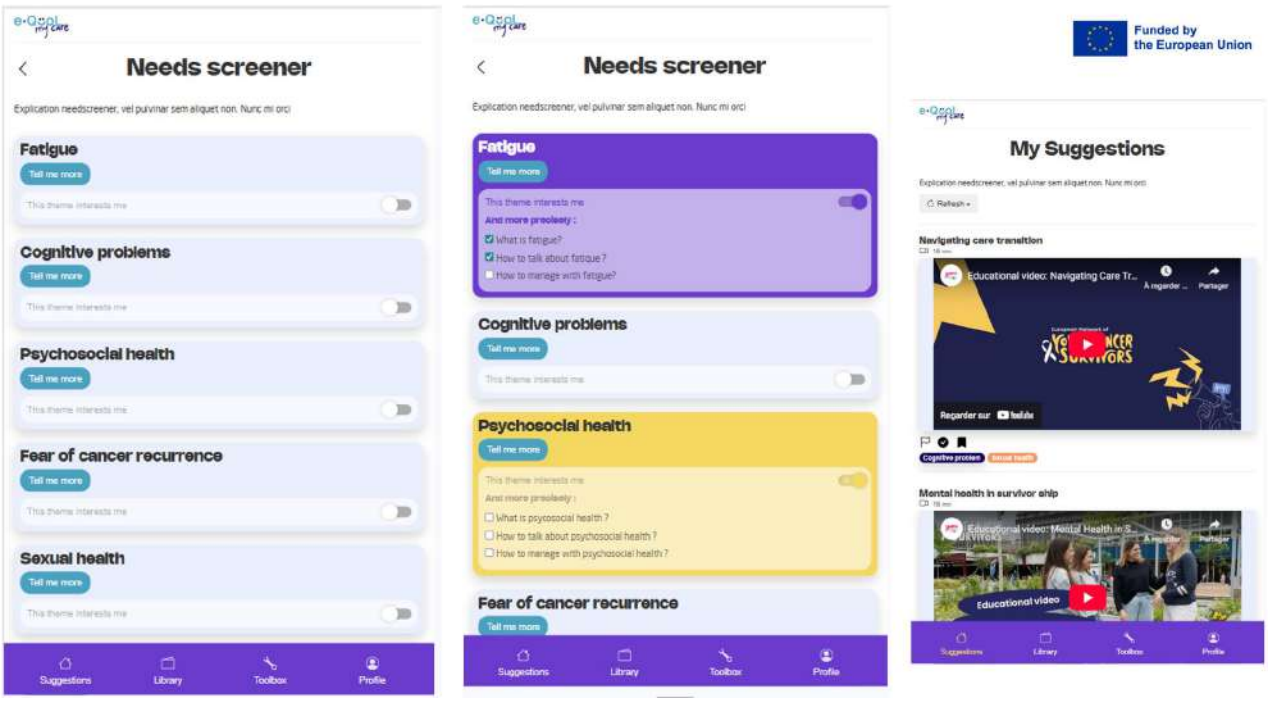
MyCare e-QuoL was co-developed by clinicians, researchers, CAYACS, and digital health experts. The platform integrates healthcare professional interfaces for patient enrollement, monitoring, and clinical data collection, alongside survivor-facing interfaces enabling secure access to validated questionnaires (e.g. PAM-13, EORTC QoL) that will be used to analyse the impact of the tool during a clinical study, longitudinal needs assessment, and educational resources such as video, testimony, articles.
Longitudinal self-measurement tools are also made available to CAYACS on topics such as fatigue for higher empowerment.
A dual scoring algorithm ranks educational resources according to their relevance for each survivor, combining expressed needs (themes, questions, and tags selected during needs assessment) with predefined population and clinical criteria. The algorithm prioritizes content fully aligned with patient identified needs, while allowing weighted adjustments based on survivor clinical characteristics and preferred content formats

RESULTS

The tool supports standardized enrollement, longitudinal patient-reported outcome collection, automated reminders, and dynamic needs assessment. The modular architecture allows multilingual deployment and adaptation across healthcare systems, while ensuring role-based access and data protection.

CONCLUSION

MyCare e-QuoL development demonstrates how a digital, needs-driven platform can operationalize patient-centered survivorship care. By combining structured clinical workflows with personalized content and survivor empowerment, the tool addresses key QoL challenges in long-term follow-up of CAYACS. The impact of the tool will be analysed during a clinical study that will be launched in 2026.



Prototype of the tool, MyCare with examples of materials from EU CAYAS NET project

021

Education

QUESTIONNAIRE SURVEY OF HEALTH MANAGEMENT AMONG CHILDHOOD CANCER SURVIVORS LOST TO FOLLOW-UP VISITS: A COMPARATIVE STUDY

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BACKGROUND-AIM

According to the large-scale national studies report that approximately 60% of childhood cancer survivors in Japan experience at least one late complication. Meanwhile, it has been noted for about 20 years that the rate of regular follow-up visits among survivors declines over time. Under the circumstances, a certain number of survivors have been lost to follow-up (LOF). Therefore, we conducted a single-site questionnaire survey and compared those who were LOF with those who continued follow-up.

METHODS

The subjects were pediatric cancer survivors who had their first visit to our department between 1990 and 2018 and who had “not attended a follow-up appointment for over two years despite having a scheduled appointment.” They were aged 18 or older at the time of the survey.
Information was extracted from chart reviews. Medical background, current health status, and health management practices were evaluated. A QR code for the questionnaire was sent to the parents, and the patient themselves responded to the questionnaire. The questionnaire asked about their current health status, cancer screening attendance, and awareness of transition-of-care services. Additionally, pediatric cancer survivors who continued regular follow-up visits were designated as the comparison group (CONT).

RESULTS

During the target period, the total number of childhood cancer patients was 569. Among these, the LOF group comprised 26% (148 individuals), while those alive and CONT group accounted for 39%. Within the LOF group, questionnaires were mailed to 145 individuals.
Respondents included 22 in the LOF group (9 males, 13 females; age at survey 33.0±6.6 years; median follow-up 12.7±5.3 years) and 15 in the CONT group (8 males, 7 females; age at survey 26.7±6.9 years; median follow-up 18.2 ± 7.7 years). The LOF group tended to have relatively older ages at the time of the survey and shorter follow-up periods. Hematological vs. solid original cancers included 20:2 in the LOF and 10:5 in the CONT group. Comparison of the LOF and CONT groups revealed no differences in current symptoms, pain, sleep duration, and exercise habits; however, the LOF had significantly higher rates of smoking ($p=0.07$), alcohol consumption ($p<0.01$), employment ($p<0.01$), and menstrual severity ($p<0.01$). In contrast, women in the CONT group had a higher rate of check-up for uterine cancer screening ($p=0.02$). Among women, the most common outpatient visiting department was the gynecology department (57% in the CONT group and 31% in the LOF group). The LOF group displayed a tendency toward higher smoking and drinking habits, whereas women in the CONT group showed higher rates of cancer screening. Awareness of the term “transitional care” was low, at 33% in LOF group and 40% in CONT group, with no significant difference between groups. Furthermore, approximately one-quarter of the LOF group responded that they “would like to continue visiting our hospital's pediatric department in the future,” suggesting a potential latent need for consultation even among those not currently attending.

CONCLUSION

These findings highlight the importance of raising awareness of secondary cancer screening, especially for CCS who are lost to follow-up.

022

Education

SUCCESSFUL IMPLEMENTATION OF A DEDICATED INTERPROVINCIAL LONG-TERM FOLLOW-UP PROGRAM FOR SURVIVORS OF CHILDHOOD AND ADOLESCENT CANCERS IN MARITIME CANADA

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BACKGROUND-AIM

Treatment-related late effects are becoming increasingly recognized amongst survivors of childhood cancer and dedicated survivorship care is essential for early detection and intervention. Patients from remote areas are at increased risk of treatment-related morbidity and mortality. The IWK Health Centre in Nova Scotia, Canada, uniquely serves pediatric patients of three provinces with a combined annual new malignancy diagnosis rate of 50-60 cases. Prior to 2023 there was no formal survivorship program. The only dedicated staffing resource for survivors was one full-time registered nurse. Patients were seen in the general oncology clinic by providers with no formal survivorship training. Additionally, there were no alternative means for out-of-province and remote patients to access care, other than traveling long-distance.

METHODS

Several interventions were implemented between the 2018/2019 and 2024/2025 fiscal years including addition of a physician and a nurse practitioner (NP) with formal survivorship training and experience, scheduling of full-day Long-Term Follow-Up (LTFU) clinics, monthly patient review meetings, quarterly LTFU journal clubs, extension of age cutoffs to include adolescents/young adults (AYAs), implementation of pre-visit mental health screeners, inclusion of trainees in LTFU clinics, offering of virtual clinics for patients based in rural and remote settings, and routine invitation to participate in Passport for Care (PFC) at all survivorship visits. Program data was reviewed from pre- and post-intervention to assess clinic capacity in terms of patient visits/contact hours and number of adult patients (≥ 18 years).

RESULTS

Within the study period the LTFU cohort has grown from 284 to 340 patients. Based on a random sample, 30% of patients previously followed evidence-based recommendations for visit frequencies. This improved to 100% post-intervention. A total of 192 clinic visits took place in the 2018/2019 fiscal year, 96% of which lasted only 30 minutes. In 2024/2025, 296 LTFU visits occurred, each 60 minutes in duration equating to a 196% increase in patient contact hours. Of these visits, 31 (10%) were conducted virtually. 100% of eligible patients are now referred from active care and short-term follow-up programs to LTFU. 141 LFTU patients have enrolled in PFC to date. The interprovincial scope of the patient cohort is: 143 patients (42%) reside outside of Nova Scotia, including 105 (31%) in New Brunswick, 36 (11%) in PEI, and 2 non-Maritime residents. Adult patients ≥ 18 years of age make up 40% of the current LTFU patient cohort. Medical Students and Postgraduate trainees in Pediatrics, Pathology, Adult Hematology and Radiation Oncology programs have attended 80% of physician-led LTFU clinics since June 2025, and 9 NP students were precepted by the clinic NP in the past year. LTFU journal clubs have been deemed “very helpful” by 95% of attendees including trainees, nurses, NPs and non-LTFU physicians.

CONCLUSION

Dedicated survivorship care in medium-sized pediatric oncology centers can be successfully coordinated across provinces to ensure adherence to evidence-based surveillance guidelines. LTFU-focused educational opportunities have been well-attended and reviewed positively by trainees and providers. As this clinic grows, organized transitions to adult-focused practitioners will be essential. Future quality improvement studies within our center will include patient and provider satisfaction surveys and objective reviews of mental health screeners.

023

Endocrine outcomes

ASSOCIATION BETWEEN BONE MINERAL DENSITY AND BODY MASS INDEX IN CHILDHOOD ACUTE LYMPHOBLASTIC LEUKAEMIA SURVIVORS IN SINGAPORE

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BACKGROUND-AIM

Low bone mineral density (BMD) remains a significant late effect among childhood cancer survivors. Despite international recommendations for BMD surveillance using dual-energy X-ray absorptiometry (DXA) at the start of long-term follow-up (2–5 years post-treatment), persistent BMD deficits continue to be reported. Data on bone health outcomes in childhood cancer survivors from Southeast Asia remain limited. Our prior work demonstrated that Singaporean childhood cancer survivors were predominantly affected by metabolic and musculoskeletal late effects including low BMD. This study aimed to further evaluate patient-, disease-, and treatment-related factors associated with low BMD, with a particular focus on the relationship between BMD and body mass index (BMI), in survivors of childhood acute lymphoblastic leukaemia (ALL) in Singapore.

METHODS

A retrospective audit was conducted among ALL survivors enrolled in the long-term follow-up programme at KK Women's and Children's Hospital between September 2017 and December 2023. Data was analysed till March 2024. Eligible survivors had completed at least two years of therapy and achieved a minimum of five years in remission. Anthropometric data, leukaemia risk group (standard-SR, intermediate-IR, high-risk-HR), and cumulative steroid and methotrexate treatment doses were analysed. DXA assessments were performed at ≥17 years of age, or earlier in survivors with a history of fractures. Low BMD was defined as a Z-score ≤ −2.0 or T-score ≤ −2.5, with or without fragility fractures.

RESULTS

A total of 190 survivors were analysed. Low BMD was identified in 26% of the cohort. The mean age at assessment was 21.7 years (SD 5.1). Majority of the cohort are B cell ALL (83.2%, 158/190) and T cell ALL survivors (11.6%, 22/190). SR, IR and HR represent 42.1% (80/190), 43.7% (83/190) and 14.2% (27/190) respectively. Nearly half of survivors with low BMD (47%, 23/49) were diagnosed 15–19 years after ALL diagnosis. Males had a significantly higher occurrence of low BMD compared to females (36% [39/107] vs 12% [10/83]). All five documented fractures occurred in the low BMD group. Of those whose vitamin D status were screened (22%, 42/190), the proportion of vitamin D insufficiency and deficiency in the low BMD group was 39% (13/33) and 6% (2/33), respectively. Cumulative steroid and methotrexate exposure did not differ significantly between low and normal BMD groups when based on risk stratification (P>0.05). Mean BMI was significantly lower in the low BMD group compared to those with normal BMD (19.96 [SD 3.50] vs 23.97 [SD 4.98]). Underweight status (BMI <18.5 kg/m²) was present in 62% of survivors with low BMD compared to 38% with normal BMD. The odds ratio for low BMD was 6.86 (95% CI 2.94–15.99, P<0.01) for BMI <18.5 kg/m² and 2.89 (95% CI 1.33–6.24, P<0.01) for BMI <23 kg/m². Scatterplot analysis demonstrated a significant positive correlation between BMI and BMD Z-scores (P<0.01).

CONCLUSION

Low BMD remains a substantial late effect among childhood ALL survivors in Singapore and is strongly associated with lower BMI. These findings highlight the need for prospective studies evaluating body composition, including lean muscle mass, and for earlier bone health surveillance in Asian survivors. Given the observed fracture risk, targeted rehabilitation and exercise interventions may play an important role in mitigating long-term skeletal morbidity in this population.

024

Endocrine outcomes

BONE HEALTH OUTCOMES IN PEDIATRIC ACUTE LYMPHOBLASTIC LEUKEMIA SURVIVORS: A FIVE-YEAR RETROSPECTIVE ANALYSIS

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BACKGROUND-AIM

Children, adolescent and young adult (CAYA) survivors with acute lymphoblastic leukemia (ALL) and acute lymphoblastic lymphoma (LBL) face significant long-term bone health complications due to treatment-related factors including prolonged corticosteroid exposure, methotrexate therapy, and cranial radiation. CAYA survivors demonstrate lower bone mineral density (BMD) than their peers (Velentza et al., 2024). Despite recognition of these risks, optimal screening protocols and management strategies for bone health in ALL/LBL survivors remain incompletely defined. This study aimed to evaluate the prevalence of low BMD in CAYA ALL/LBL survivors at least two years after therapy completion and assess outcomes of different management approaches.

METHODS

We conducted a retrospective chart review of 130 ALL/LBL CAYA patients who underwent X-ray bone densitometry (DXA) scanning at least two years after completion of therapy at UC Davis Pediatric Oncology Cancer Center between 2020-2025. Patients were stratified by DXA Z-scores into low BMD ($Z \leq -1.5$) and normal BMD ($Z > -1.5$). For patients with low BMD, we documented management strategies including exercise, pharmacologic treatment, or active monitoring with serial DXAs. We collected data on fracture history and documented osteonecrosis (AVN) across all patients.

RESULTS

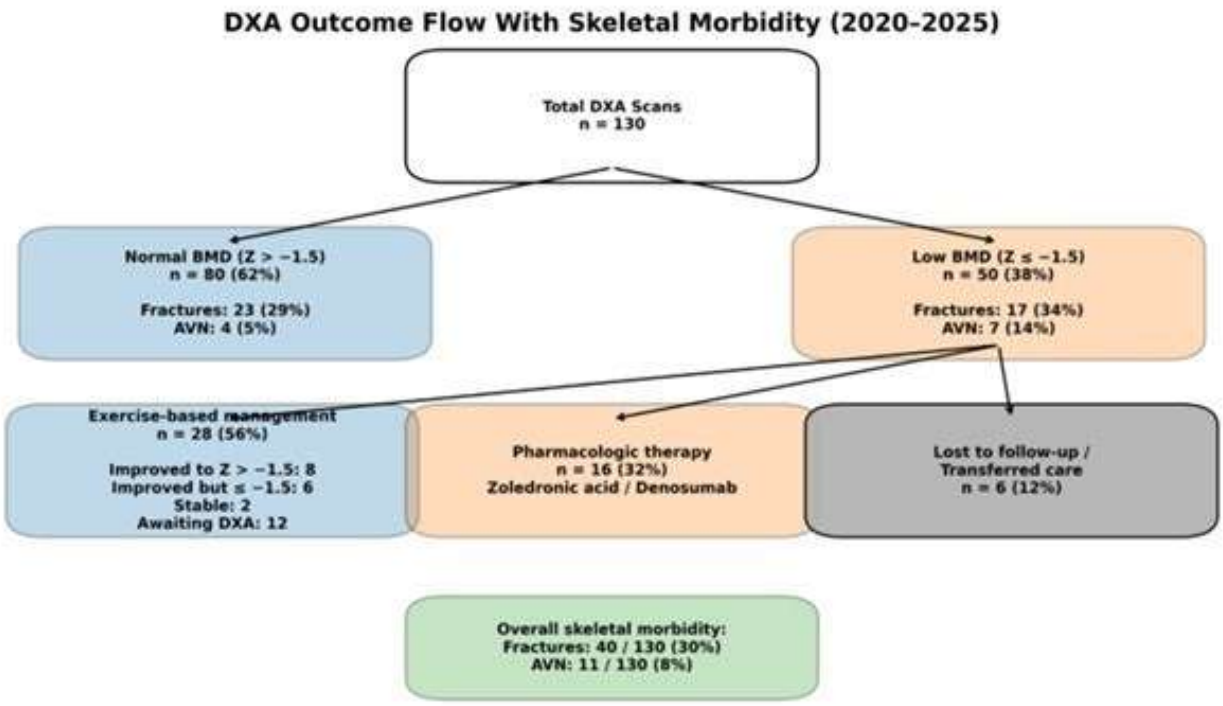
Of 130 DXA scans analyzed, 50 patients (38%) demonstrated low BMD with Z-scores ≤ -1.5. 28 of these patients were offered exercise only; 8 patients improved Z score > -1.5, 6 improved, Z Score < -1.5, 2 remained stable, and 12 are awaiting repeat DXA scan. 16 patients were treated with zoledronic acid or denosumab. 6 patients with low BMD were lost to follow up or transferred care. In patients with low BMD, fractures were present in 17/50 and AVN occurred in 7/50. The remaining 80 patients (62%) had Z-scores >-1.5 on DXA scans. Among these 80 patients, 23 had a fracture history and 4 had AVN. Across both BMD groups, fractures occurred in 40/130 patients (30%) and AVN in 11/130 patients (8%).

CONCLUSION

Our findings demonstrate that more than one-third of CAYA ALL/LBL survivors exhibit significant low BMD at least two years after therapy completion. Our data reveals skeletal morbidity across the entire cohort, with 30% experiencing fractures and 8% developing AVN, suggesting that DXA screening alone may not capture all clinically relevant bone pathology. These results support implementation of routine comprehensive bone health screening for all survivors in long-term follow-up, regardless of initial DXA results, and underscore the need for individualized, multidisciplinary management strategies. Some skeletal deficits may be reversible with appropriate interventions, emphasizing the importance of early identification and comprehensive long-term follow-up care. Further prospective studies are needed to identify optimal timing for interventions and to better predict which patients will benefit most from specific treatment approaches.

REFERENCES

Velentza, L., Filis, P., Wilhelmsson, M., Kogner, P., Herold, N., & Sävendahl, L. (2024). Bone mineral density in survivors of childhood cancer: A meta-analysis. Pediatrics, 154(2), e2024066081. https://doi.org/10.1542/peds.2024-066081


DXA Outcome Flow With Skeletal Morbidity (2020–2025)
Total DXA Scans
n = 130
Normal BMD (Z > −1.5)
n = 80 (62%)
Fractures: 23 (29%)
AVN: 4 (5%)
Low BMD (Z ≤ −1.5)
n = 50 (38%)
Fractures: 17 (34%)
AVN: 7 (14%)
Exercise-based management
n = 28 (56%)
Improved to Z > −1.5: 8
Improved but ≤ −1.5: 6
Stable: 2
Awaiting DXA: 12
Pharmacologic therapy
n = 16 (32%)
Zoledronic acid / Denosumab
Lost to follow-up /
Transferred care
n = 6 (12%)
Overall skeletal morbidity:
Fractures: 40 / 130 (30%)
AVN: 11 / 130 (8%)

025

Endocrine outcomes

CHARACTERIZING THE NUTRITIONAL HABITS, PHYSICAL ACTIVITY, AND SEDENTARY PROFILE OF CHILDHOOD CANCER SURVIVORS: A NATIONWIDE COMPARATIVE ANALYSIS

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BACKGROUND-AIM

The risk of metabolic and cardiovascular late effects in childhood cancer survivors (CCS) is a critical concern for long-term survivorship care, as this population often exhibits unique physiological and behavioral profiles following treatment. We aimed to characterize the nutritional habits as well as physical activity (PA) and sedentary behavior patterns of CCS and to compare them to a representative sample of the Israeli pediatric population.

METHODS

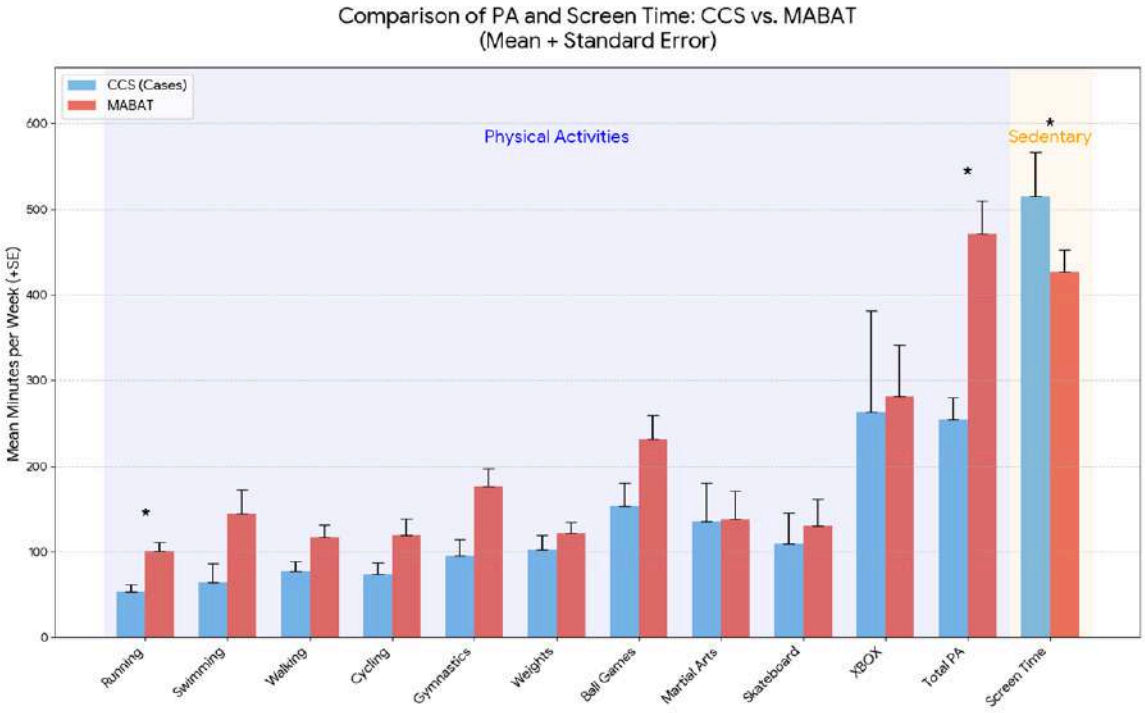
A cross-sectional analysis included 119 survivors (mean age 14.9±3.8 years, 53.8% female) who were at least one-year post-treatment (average 7.2±4.1 years). Nutritional habits were assessed using a validated questionnaire including a Food Frequency Questionnaire (FFQ). PA levels and sedentary behaviors were compared to data from 542 healthy peers from the national MABAT survey.

RESULTS

Weight distribution among CCS was similar to the general population, with 60.1% having a normal weight and 36.5% classified as overweight or obese. While total caloric intake was comparable to the general population, CCS consumed significantly higher proportions of energy from protein and fat and lower proportions from carbohydrates ($p < 0.001$). Male CCS consumed significantly less fiber than their healthy peers ($p = 0.003$), and among survivors, a higher carbohydrate intake was positively correlated with BMI increase over a one-year period ($r = 0.294$, $p = 0.020$). Regarding energy expenditure, CCS reported significantly lower total physical activity levels compared to the MABAT group, with a median of 165 (IQR77.5-314.0) minutes per week versus 260 (IQR 105.0-560.0) minutes in the general population ($p=0.0011$). Survivors had significantly lower participation rates in school PA lessons (46.9% vs. 71.2%, $p<0.0001$), running (38.6% vs. 54.9%, $p=0.0017$), and ball games (34.5% vs. 49.3%, $p=0.0039$), however they were more likely to report walking as a primary activity (66.4% vs. 51.6%, $p=0.0044$). Regarding sedentary behavior, survivors reported spending a median of 420 (IQR 205.0-720.0) minutes/week of screen time compared to 240 (IQR 120.0-540.0) minutes/week in the MABAT group ($p=0.004$). Additionally, CCS reported higher levels of social media use ($p=0.019$) and a lower frequency of completing homework (57.4% vs. 73.4%, $p=0.0007$).

CONCLUSION

Childhood cancer survivors exhibit a distinct lifestyle habits profile characterized by specific dietary shifts, significantly lower levels of physical activity, and excessive sedentary time compared to their healthy peers. This combination suggests a high potential for energy imbalance that persists despite a similar weight distribution at this stage of follow-up. Survivorship clinics should implement early, targeted interventions that address both nutritional quality and active living to mitigate the cumulative long-term risk of metabolic and cardiovascular late complications.



Comparison of physical activity and screen time

026

Endocrine outcomes

ENCOURAGING IMPACTS OF RIC COMPARED TO MAC-SCT ON PRESERVING FEMALE FERTILITY

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BACKGROUND-AIM

Childhood cancer becomes curable in more than 80% of children. Many of long-term survivors have late complications. Ovarian insufficiency is one of the serious long-term complications of childhood cancer treatment in women. Causes of fertility impairment in this patient population may include chemotherapy, radiation therapy and hematopoietic stem cell transplantation (SCT). We compared the effects of chemotherapy and SCT on female fertility.

METHODS

Patients eligible for the analysis were females aged over 15 years, diagnosed under 15 years old, treated for hematological/neoplastic diseases at our institute between 1990 and 2020, and available for follow-up at least five years after treatment. Data including disease, treatment, serum levels of FSH/LH/estradiol and pregnancy rate were collected using electronic medical records. Laboratory data are presented as median values for age 15-20 years old. We investigated the details of these data and retrospectively analyzed the relationship between treatment intensity and gonadal function.

RESULTS

A total of 166 patients was evaluated. Patients receiving myeloablative conditioning (MAC) -SCT (n=27) had significantly higher FSH levels (median 33.6 mIU/mL, range 4.2-122.8) and lower estradiol levels (39.3 pg/mL, 8-112) compared to reduced intensity conditioning (RIC) -SCT (n=32) /high dose chemotherapy (n=14) /chemotherapy (n=93) ($p<0.05$). Twenty patients (74%) treated with MAC-SCT received hormone replacement therapy. Those who gave birth were 7.4% of MAC-SCT versus 12.5% of RIC-SCT patients.

CONCLUSION

Our results suggest that RIC-SCT causes significantly less fertility impairment compared to MAC-SCT. Patients undergoing chemotherapy/SCT should be counseled about the potential high risk of infertility and be offered fertility preservation options as appropriate, as well as undergo screening for gonadal failure during long-term follow-up.

027

Endocrine outcomes

OVARIAN TISSUE CRYOPRESERVATION IN PEDIATRIC ONCOLOGY: SAFE AND TIMELY

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BACKGROUND-AIM

Cryopreservation of ovarian tissue is currently the only established fertility preservation option for prepubertal patients and for postpubertal patients who cannot delay oncological treatment to allow oocyte cryopreservation. The aim of this retrospective analysis was to evaluate the safety and feasibility of ovarian tissue cryopreservation (OTC), in terms of time required to initiate cancer-directed therapy (chemotherapy [CT] or radiotherapy [RT]), and the incidence of short-term postoperative complications.

METHODS

All patients were treated at the Pediatric Oncology Unit of the Fondazione IRCCS Istituto Nazionale Tumori in Milan, while laparoscopic procedures were performed at four IRCCS or pediatric hospitals located in Milan. For patients requiring oophoropexy in addition to OTC, radiotherapy evaluation was obtained beforehand. Clinical and demographic data were collected. The day of OTC was defined as day "0", and the number of days required to start CT or RT was calculated.

RESULTS

Between 2012 and 2025, 62 children and adolescents with solid tumors (17 Central Nervous System tumors, 17 bone sarcomas, 10 rhabdoyosarcomas, 3 Wilms tumors, 3 lymphomas, 11 other histologies) underwent OTC (9 with concomitant oophoropexy). The median [IQR] age at diagnosis was 12 [2-20] years, which was unchanged at the time of OCT. Nine patients underwent OTC during surgical tumor excision and were excluded from the present analysis. Of the remaining 53 patients, 17 underwent OTC at diagnosis before any treatment, while 36 underwent OTC between chemotherapy cycles. The median time to treatment initiation (RT in 2 patients and CT in 51 patients) after OTC was 4 [2-18] days. 3/53 (5.6%) patients experienced a delay in treatment initiation (on days 5, 6, 9 after OTC) due to fever requiring antibiotics following surgery. 4/53 (7.5%) patients required modifications to their chemotherapy schedule in relation to laparoscopy: two had a drug omission (vincristine) and two had chemotherapy dose reductions (vincristine, adriamycin). In 46/53 (86%) patients no modification of the treatment plan was required as a result of the laparoscopic procedure. Five patients started chemotherapy with a delay of 11, 11, 12, 15, and 18 days after OTC in accordance with baseline diagnostic evaluations or protocol schedules, and not due to procedure-related complications. No major surgical complications were observed.

CONCLUSION

OTC is a safe and feasible procedure, even when performed during chemotherapy, and allows for a rapid initiation of the planned oncological treatment. This outcome was achieved even when procedures were performed at centers other than the primary treatment center, through close collaboration between pediatric oncologists and fertility preservation specialists.

028

Endocrine outcomes

PREGNANCY RATES AND PREGNANCY OUTCOMES OF FEMALE CHILDHOOD CANCER SURVIVORS – FINDINGS FROM SWISS CHILDHOOD CANCER SURVIVOR STUDY (SCCSS)

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BACKGROUND-AIM

Advances in paediatric oncology have significantly improved the survival rates of childhood cancer, consequently creating a growing population of adults facing long term treatment effects. Fertility impairment is a key concern with profound implications for quality of life. Yet, Switzerland has lacked national data on reproductive outcomes in female childhood cancer survivors (CCS). This study fills that gap by providing the first population based assessment of pregnancy rates and pregnancy outcomes (live birth, maternal age, pregnancy number) in Swiss CCS compared with sibling controls.

METHODS

We analyzed data from the Swiss Childhood Cancer Survivor Study (SCCSS) and the Swiss Childhood Cancer Registry (ChCR), which included female CCS aged ≥20 years and ≥5 years post diagnosis, alongside female siblings as controls. Questionnaire data collected between 2007–2022 were used to evaluate pregnancy, pregnancy outcomes (livebirths, abortion, still-birth), maternal age, and self-reported fertility issues. We used sociodemographic and prior diagnosis/ therapeutic information as predictors. Linear and logistic regression was fitted to identify predictors of pregnancy.

RESULTS

We used 924 female CCS and 443 female siblings, of which 772 CCS (83.5%) and 410 siblings (92.6%) were available for analysis. Age-stratified pregnancy rate of female CCS was lower (35.6%) compared to sibling control (47.3%) (age-adjusted OR 0.68, 95% CI 0.50, 0.92, p 0.013). Live birth following first pregnancy was lower among CCS (76% vs 89%, p=0.007). Total number of pregnancies per family was lower in CCS than in sibling control (2.0 pregnancies/female vs 2.7, p-value <0.001). Age at first pregnancy and pregnancy duration were comparable between groups.

CONCLUSION

Swiss female CCS experience reduced fertility and lower live birth rates compared with siblings, despite similar timing and duration of pregnancies. Continued analysis will help clarify the impact of treatment modalities and demographic factors. Ongoing research aims to inform survivorship care strategies to enhance reproductive health and overall QoL among CCS.

029

Endocrine outcomes

PRESERVING FERTILITY AND QUALITY OF LIFE IN BELGIAN FEMALE PAEDIATRIC CANCER SURVIVORS: THE PRINCESS PROJECT

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BACKGROUND-AIM

Among female survivors of childhood and adolescent cancers, fertility preservation and reproductive health are emerging as critical concerns, yet they remain under-researched. There is limited information about ovarian damage in patients who have received low (LR) to intermediate doses (IR) of chemotherapy—defined as LR: 0–4 g/m² Cyclophosphamide Equivalent Dose, IR: 4–8 g/m². There is also no consensus on the benefit-risk balance of ovarian cryopreservation in conjunction with these chemotherapy doses.
The objectives of the PRINCESS project are (1) to evaluate the impact of LR-IR dose of chemotherapy associated or not with ovarian cryopreservation on ovarian function and fertility in female survivors of paediatric cancer, and (2) to identify multi-omics biomarkers to predict the risk of premature ovarian insufficiency (POI).

METHODS

The PRINCESS Project, launched on October 9, 2024, is a multicentric, multidisciplinary, cross-sectional, case-control study using databases from the Paediatric Late Effects (https://kankerregister.org/en/node/2584) and PRINCESS survey (participation reasons, clinical & personal & family history, fertility counseling & evaluation, biological evaluation, ovaries & uterus ultrasound). It aims to include 170 female pediatric cancer survivors and 170 age-matched controls. Eligible patients were diagnosed with cancer including benign central nervous system tumors before age 17, treated with chemotherapy in Belgium, and aged 18 or older at inclusion. Controls were females aged 18+ with no cancer history. We considered the following endpoints: fertility index — occurrence of premature or delayed puberty — use of medical help to become pregnant — negative pregnancy outcome — incidence of diminish ovarian reserve (DOR) and POI. The DOR was defined as: AMH ≤ 0.5 ng/mL.

RESULTS

Of the 320 eligible patients from the 3 participating institutions, 91 patients and 68 controls have been enrolled to date. We present here preliminary results from CHU de Liège.
In response to the question “Why did you agree to participate in this study?”, 95% of patients and controls cited a desire to contribute to research.
In response to the question ‘‘When did you received information about fertility for the first time’’, 75% of patients did not received information before the beginning of the treatment.
In response to the question “Have you ever had a fertility evaluation?’’, 66% of controls and 77% of patients answered negatively.
Mean age ± SE at the evaluation point was not different between patients and controls 25.17 ± 1.vs 27.5 ± 1.14 years old (p>0.1). No significant difference in the age at puberty onset was observed between patients and controls, 12,2 ± 0.27 vs. 13 ± 0.42 years old (p=0.17). In the group of women who tried to have children, 14/24 patients and 11/23 controls gave birth. Results of AMH, FSH, Estradiol, AFC will be presented orally.

CONCLUSION

We have shown that the PRINCESS Project addresses patients’ needs. It seeks to improve understanding of reproductive health in female childhood cancer survivors and to assess the impact of ovarian cryopreservation across LR–IR groups. Its findings will help tailor fertility preservation strategies. The study also revealed significant gaps in fertility counseling and assessment, showing the need for systematic counseling before and after treatment to improve long-term survivorship care.

The PRINCESS project is founded by Foundation Against Cancer Grant (OST-2022/2173), Fondation Léon Fredericq and CHU de Liège.

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Endocrine outcomes

TREOSULFAN-BASED CONDITIONING AS A LESS TOXIC CONDITIONING REGIMEN BEFORE ALLOGENEIC HCT FOR NON-MALIGNANT DISEASES. A PEDIATRIC SINGLE-CENTER EXPERIENCE

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BACKGROUND-AIM

Conditioning regimens (CR) including Treosulfan (Treo) are considered reduced-toxicity CR. In pediatric setting, Treo is increasingly included in CR for allogeneic Hematopoietic Stem Cell Transplantation (allo-HCT) for both non-malignant and malignant diseases. The aim of this retrospective, single-center study is to describe acute toxicities, late gonadal failure and survival in pediatric patients who received Treo based CR before allo-HCT for non-malignant diseases.

METHODS

Data were extracted from the local registry and, when necessary, supplemented with information from individual medical record. Acute mucositis was graded according to WHO criteria. Gonadal failure was evaluated only in post-pubertal patients.

RESULTS

During the period between 2006 and 2025, 87 pediatric patients with a median age of 14 years (range 3 months-18 years) (females=27; males=60) received Treo prior to a first HCT (n= 82), second HCT (n=4), or third HCT (n=1). Forty-two patients underwent HCT for primary immunodeficiencies, 20 for hemoglobinopathies, 17 for inherited bone marrow failure syndromes and 8 for metabolic diseases. Twenty-five patients received a haploidentical HCT with $\alpha\beta$/CD19 depletion, 30 were transplanted from a matched related donors, 24 from a matched unrelated donors, 8 from haploidentical donors with post transplant cyclophosphamide. Treo was associated with thiotepa and fludarabine in 76 patients, and with fludarabine alone in the remaining 11.
Acute mucositis was grade 0-1 in 60 patients (69%), grade 2 in 24 (27.6%), and grade 3-4 in only 3 3.4%). No cases of veno-occlusive disease, or acute pulmonary, cardiac, or CNS toxicity were observed.
Fourteen females with a median age at last follow-up of 21 years (range 11-31 years) were available for the analysis of gonadal failure. 12 out of 14 females (85.7%) had a normal pubertal development and had normal menstrual cycles, 1 required hormonal replacement therapy and one was lost to follow-up. Two females had physiological pregnancy without complication and with healthy newborns. Of 26 evaluable males, 22 (84.6%) did not require testosterone replacement therapy, 4 patients were lost to last follow-up. Spermiogram performed in 3 patients was normal in 2; the third patient had azoospermia, but he has undergone a prior HCT with a CR busulfan-based.
At the last follow-up (median 7.8 years, range 1 month-18 years), 14 (16.1%) patients died: 11 for transplant-related mortality, 2 developed for cancer (sarcoma) and one for metabolic primary disease progression. The cumulative survival at 2 years post-transplant was 86.4% (95% CI, 76.8–92.2), Figure 1, declining to 52.8% at 17 years due to two deaths related to malignant neoplasms but one patient received busulfan in the first HCT.

CONCLUSION

In our single-center experience, we confirmed that the acute toxicity related to Treo is lower than other myeloablative CR. Notably, gonadotoxicity is almost absent in females. More data regarding sperm function are necessary to confirm the good results demonstrated in females.

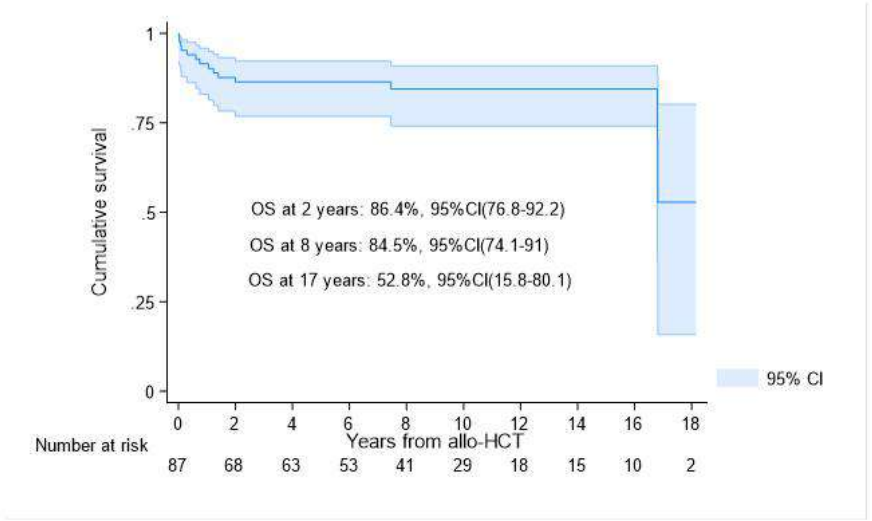

Figure 1. Cumulative survival

031

Endocrine outcomes

TWO SPECIALTIES, ONE SURVIVOR: MULTIDISCIPLINARY ENDOCRINE/ONCOLOGY CARE.

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BACKGROUND-AIM

Childhood cancer survivors (CCS) are at increased risk for endocrine late effects of treatment, with risk and severity varying by therapeutic modality. This class of late effects has been reported in up to 50% of CCS, and can significantly impact quality of life, morbidity, and mortality. As such, many CCS benefit from endocrine follow-up. A multidisciplinary approach to care can improve compliance, early detection, and ultimately outcomes. While many endocrinologists are able to screen patients for the aforementioned complications, establishing an endo-oncology program can promote collaboration, compliance, and provide customized screening as well as treatment plans specifically designed for childhood cancer survivors.
Our initiative aims to forge a seamless endo-oncology program, streamlining referrals while enhancing surveillance and outcomes.

METHODS

Patients were identified for this multidisciplinary pilot if they met ≥1 criterion: corticosteroids as part of antineoplastic therapy (excluding anti-emetic use), cyclophosphamide equivalent dose ≥4 g/m2, radiation to endocrine organs, or other endocrine concerns (e.g. growth or bone density). Patients established with endocrinology in the prior 3 years were excluded. Eligible patients were invited by the Survivorship RN Coordinator to schedule in the multidisciplinary clinic. Prior to the clinic day, the team meets to review patients and discuss goals for the visit.
Oncology clinic space is dedicated quarterly to this program. Pediatric-specific participants include: endocrinology, oncology, oncology nurse practitioner, psychology, neuropsychology, dietician, and nurse coordinator; medical students, residents, and psychology interns regularly participate in the clinic. On the day of the appointment, families are given a list of providers that they will be seeing, and are invited to opt in/out. Team members see the patient individually, then discuss a unified plan including lab/imaging orders, referrals, and follow-up.

RESULTS

From December 2024-2025, 473 patients were screened and 251 deemed eligible; 34 patients have been seen to date. Demographic and clinical characteristics are detailed in Table 1. New endocrine diagnoses made include: pre-diabetes (3), hyperlipidemia (1), obesity (5), osteopenia (1), vitamin D deficiency (7), growth/pubertal delay (8), premature adrenarche (1), and secondary amenorrhea (1).
Potentially modifiable risk factors (hypertension, obesity, dyslipidemia) were present in 7 patients (21%). Of this cohort, 16 (47%) will continue endocrine care, either independently or within the endo-onc program.

CONCLUSION

This project highlights the value of multidisciplinary care and screening for endocrine complications in CCS. Notably, none of the patients in this pilot year were previously seen by endocrinology, thus these co-morbid diagnoses may have gone undetected. Program implementation required institutional support to accommodate schedule changes and initial RVU impact, but benefits have emerged for both patients and providers. As part of a quality improvement project, many families have reported via survey their appreciation for the thorough experience. This collaboration has improved survivor-specific expertise, education, and fostered plans for combined research projects. Collaboration between medical and psychosocial specialties can ultimately enhance the overall well-being and quality of life for our patients.

Characteristic	N (%)
Current Age (mean)	6-22 (13.8)
Male Gender	21 (62)
Race White Black Other	 27 (79) 4 (12) 3 (9)
Hispanic ethnicity	9 (26)
Years since end of treatment 2-5 5-10 >10	 15 (44) 11 (32) 8 (24)
Cancer diagnoses Acute lymphoblastic leukemia Hodgkin lymphoma Rhabdomyosarcoma CNS tumor Retinoblastoma Wilm's tumor Neuroblastoma Burkitt lymphoma Osteosarcoma Allogeneic marrow transplant	 18 (53) 4 (12) 3 (8.5) 3 (8.5) 1 (3) 1 (3) 1 (3) 1 (3) 1 (3) 1 (3)
Mean cumulative alkylator dose (n=30)	13,768 mg/m2
Qualifying risk factors Steroid exposure Alkylator ≥4 g/m2 Radiation exposure to endocrine organ Gonadal function concern Growth concern Other	 24 (71) 12 (35) 11 (32) 11 (32) 13 (38) 12 (35)

Table 1: Demographic and clinical characteristics of patients seen in the multidisciplinary endo/survivor clinic at Dell Children's Medical Center of Central Texas (n=34).

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Epidemiology/Research methods

A NATIONWIDE PROSPECTIVE AND SYSTEMIC FOLLOWUP OF CHRONIC HEALTH CONDITIONS AND PATIENTS-REPORTED OUTCOMES IN LONG TERM CHILDHOOD CANCER SURVIVORS IN TAIWAN

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BACKGROUND-AIM

Advances in pediatric oncology allow nearly 80% of children with cancer to survive long term and return to daily life. Yet long-term childhood cancer survivors (LTCCSs) remain at risk for chronic health conditions (CHCs). Incidence varies by cancer type and treatment, reaching 73% in Western studies, but remains underreported in Taiwan.

METHODS

Since 2020, a national LTFU group has been organized through collaboration of institutions, supported by the Childhood Cancer Foundation of R.O.C. and funding from the Ministry of Health and Welfare. The group's mission is to establish a prospective follow-up platform for evaluating LTCCSs in Taiwan, applying harmonized definitions of CHCs and emphasizing late effects and patient-reported outcomes. Disease-specific follow-up protocols were developed from COG guidelines, then adapted to align with national insurance coverage. Eligibility requires diagnosis at age 18 or younger, treatment with chemotherapy, radiotherapy, surgery, or transplant, and survival at least two years post-treatment.

RESULTS

Platform setup: A standardized follow-up program was established, engaging 19 hospitals across Taiwan caring for childhood cancer patients. Five protocols were developed: four disease-specific (ALL, MB, Lymphoma, OS) and one universal. The TPOG-Cancer Survivorship-CTCAE handbook was also produced in Traditional Chinese. LTCCSs underwent multidisciplinary evaluations CHCs, while patient-reported outcomes were assessed using the "Symptom phenotype," "PROMIS Pediatric Profile-25 v2.0," and "Cognitive SF 7a v1.0" questionnaires. Between 2022 and 2025, 554 visits were recorded, including 334 at Taipei VGH, 70 at KFSYSCCT, 45 at TMUH, 35 at NCKUH, 31 at Taichung VGH, 19 at LK-CGMH, 11 at MMH, and 9 at CCH.

Followup results: Among 554 visits, 482 with complete data were analyzed, including 135 for leukemia/lymphoma, 95 for brain tumors, 206 for other solid tumors, and 45 for transplants. The median age at diagnosis was 8.0 years (range 0.1–19.4), while the median age at follow-up was 17.9 years (range 2.7–40.2), with a male-to-female ratio of 1.45. Across these visits, 2,109 CHCs were documented, of which 288 (13.7%) were graded significant (≥ Grade 3). Multiple CHCs were observed in 379 visits (78.6%), and more than one ≥ Grade 3 CHC was noted in 189 visits (39.2%). Brain tumor survivors had the highest burden, averaging 7.9 CHCs of any grade and 0.9 of ≥ Grade 3, exceeding other cancer groups (Figure 1). PROMIS T-scores revealed significantly reduced cognitive function in brain tumor survivors, with impaired mobility also noted in brain and solid tumor groups compared to leukemia/lymphoma and transplant survivors.

CONCLUSION

LTCCSs in Taiwan experience a considerable burden of CHCs, particularly among brain tumor survivors. This nationwide cohort study, conducted through a standardized platform, sought to characterize CHC patterns across cancer types. Incomplete data arose because 13% of visits were not conducted in the Comprehensive Clinic. This gap reflected the lack of dedicated assistants and insufficient institutional support across hospitals for establishing integrated clinics, underscoring the need for stronger administrative commitment to ensure effective and complete long-term follow-up in Taiwan.

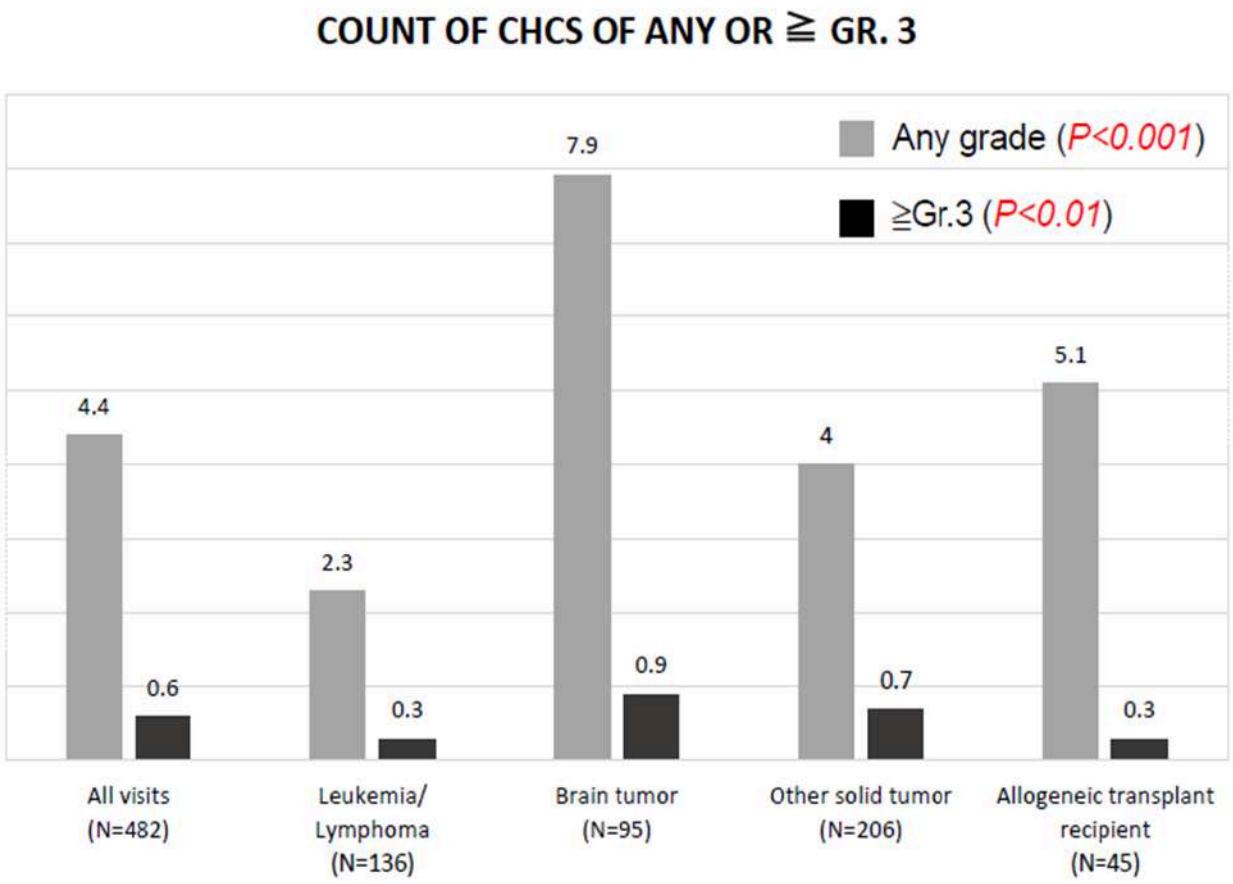

Figure 1. Count of CHCs among different disease groups in Taiwan

033

Epidemiology/Research methods

AGE–PERIOD–COHORT PATTERNS OF LATE MORTALITY AMONG >5-YEAR CHILDHOOD CANCER SURVIVORS IN THE SEER-8 REGISTRY

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BACKGROUND-AIM

Survival after childhood cancer has improved substantially, leading to a growing population of long-term survivors. Despite these advances, late mortality remains markedly higher than in the general population. How late mortality has evolved over time and varies by cause of death is not fully understood, underscoring the need to disentangle age, period, and cohort effects in childhood cancer survivorship.

METHODS

Using data from the SEER-8 registries accessed through SEER*Stat version 9.0.42.4, we identified individuals diagnosed with cancer at ages 0–19 years between 1975 and 2009 who survived at least five years after diagnosis. Mortality follow-up extended through 2022. Excess mortality was quantified using standardized mortality ratios (SMRs) and excess absolute risks (EARs), comparing observed deaths with expected deaths derived from general population mortality rates.

Age–period–cohort (APC) analyses were conducted using grouped data on observed deaths (all causes, neoplasm-related, and non-neoplastic medical causes) and person-years at risk, stratified by four age-at-diagnosis groups (0–4, 5–9, 10–14, and 15–19 years) and seven diagnosis periods (1975–1979 to 2005–2009), using the US National Cancer Institute APC Web Tool. APC models estimated age, period, and cohort deviations, rate ratios (RRs), net drift (annual percent change), and local drifts. Model outputs were exported and visualized using R version 4.5.0 to facilitate combined graphical presentation across causes of death.

RESULTS

A total of 24,742 five-year childhood cancer survivors contributed 509,284 person-years of follow-up, during which 3,093 deaths occurred. Overall mortality was more than fourfold higher than expected (SMR = 4.53, 95% CI: 4.37–4.69; EAR = 47.3 per 10,000 person-years). Excess mortality was most pronounced for neoplasms (1,927 deaths; SMR ≈ 19.9, 95% CI: 19.05–20.85), cardiovascular diseases (298 deaths; SMR = 3.25, 95% CI: 2.89–3.64), and respiratory diseases including pneumonia (70 deaths; SMR = 4.43, 95% CI: 3.45–5.59).

APC analyses demonstrated distinct temporal patterns across causes of death. For all-cause mortality, fitted period-specific rates declined from approximately 120 to 60 per 100,000 person-years, corresponding to a significant net drift of −2.7% per year (95% CI: −3.0% to −2.4%). Period RRs decreased after the early 1990s, reaching RR ≈ 0.49 (95% CI: 0.26–0.94) in 2005–2009. Cohort RRs declined progressively from RR = 5.05 (95% CI: 2.87–8.90) in the 1960 birth cohort to RR = 0.24 (95% CI: 0.08–0.71) in the 2000 cohort and RR = 0.06 (95% CI: 0.01–0.48) in the 2005 cohort.

For non-neoplastic medical causes, declines were more pronounced, with fitted rates decreasing from approximately 203 to 26 per 100,000 person-years and a net drift of −7.4% per year (95% CI: −9.1% to −5.7%). In contrast, neoplasm-related mortality showed more limited improvement, with a smaller net drift of −1.8% per year (95% CI: −2.4% to −1.1%) and persistently elevated cohort-related risks.

CONCLUSION

Childhood cancer survivors face substantial excess late mortality, particularly from neoplasm-related causes. APC analyses reveal pronounced temporal improvements for non-neoplastic medical causes but slower progress for neoplasm-related mortality. Combining SMR-based estimates with APC modeling provides a robust framework to characterize both the magnitude and temporal structure of late mortality in childhood cancer survivorship.

Integrated age–period–cohort analysis of cause-specific late mortality in >5-year childhood cancer survivors

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Epidemiology/Research methods

DISPARITIES IN HEALTHCARE UTILIZATION AND SURVIVORSHIP CARE ACCESS BY ETHNICITY AMONG SURVIVORS OF CHILDHOOD SOLID TUMORS

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BACKGROUND-AIM

Latino children experience disparities in cancer incidence and survival; however, data on healthcare utilization and access among Latino survivors is limited, which hinders opportunities for intervention. Therefore, we compared healthcare utilization and perceived facilitators and barriers to survivorship services between Latino and non-Latino survivors of childhood solid tumors.

METHODS

We administered a 37-item survey in the Texas-based, multi-institutional Survivorship and Access to Care for Latinos to Understand health outcome Differences (SALUD) cohort to survivors of solid tumor ≥ 1 year off therapy who were in remission (2021-2025). Survey responses were collected on Likert scales and dichotomized for analysis. Multivariable logistic regression estimated adjusted odds ratios (aOR) and 95% confidence intervals (CI) for outcomes by ethnicity (Latino vs. non-Latino), adjusting for age and sex.

RESULTS

A total of 401 respondents completed the survey (159 survivors, 235 parents/guardians on behalf of survivors <18 years, and 7 with unknown respondent type). The mean age at the survey completion was 14.7 ± 6.7 years. Overall, 47% identified as Latino, 53% were male, and 32% were brain tumor survivors; 61% completed the survey >5 years after end of treatment; and 20% lived >100 miles from the hospital where the survivor received cancer treatment. Race was reported as 78% White, 6% Black, 4% Asian, 3% American Indian or Alaska Native, with the remainder preferring not to answer.

Over 90% reported having an established primary care provider (PCP), and among those with a PCP, Latino survivors had higher odds of a past-year PCP visit (aOR 2.9, CI 1.2-7.4) compared with non-Latino survivors. Overall, 13% rated their health as fair or poor, with no difference by ethnicity. Latino survivors had lower odds of reporting health problems since cancer diagnosis (aOR 0.5, CI 0.3-0.8), yet higher odds of health-related worry, including concern about potential late effects (aOR 1.8, CI 1.2-2.8), the chance of getting sick (aOR 3.5, CI 2.2-5.5), frequent worry about their health (aOR 3.6, CI 2.3-5.8), and worry that a health problem would be discovered during a routine check-up (aOR 1.9, CI 1.2-3.0). In addition, Latino survivors were less likely to report high confidence in describing their treatment (aOR 0.5, CI 0.3-1.0) compared with non-Latino survivors. Regarding access to survivorship services, Latino survivors were more likely to report health insurance as a barrier to obtaining care (aOR 3.0, CI 1.6-6.1). Finally, Latino survivors were more likely to report difficulty seeing a specialist (aOR 2.2, CI 1.3-3.8) and difficulty obtaining screening tests (blood test or X-ray) (aOR 4.0, CI 2.1-8.3) compared with non-Latino survivors; these associations did not change after additionally adjusting for distance to clinic.

CONCLUSION

Compared with non-Latino survivors, Latino survivors of childhood solid tumors reported higher primary care utilization and fewer health problem, yet greater worry about late effects, lower confidence in describing their treatment, and greater difficulty accessing specialty care and recommended screening. Latino survivors also more frequently endorse barriers to survivorship services, including health insurance. These findings highlight the need for targeted strategies to improve access to survivorship services in this population.

035

Epidemiology/Research methods

GROWTH TRAJECTORIES IN CHILDREN WITH CENTRAL NERVOUS SYSTEM TUMOURS

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BACKGROUND-AIM

Central nervous system (CNS) tumours commonly impair hypothalamic-pituitary hormone secretion either by mass effects, or treatment with chemotherapeutic agents or cranial radiation. Growth impairment is among the most common endocrine side effects of childhood cancer.
In this study we evaluated growth trajectories in patients diagnosed with childhood CNS tumours in Switzerland, stratified by malignant and non-malignant (i.e., benign and uncertain behaviour) diseases.

METHODS

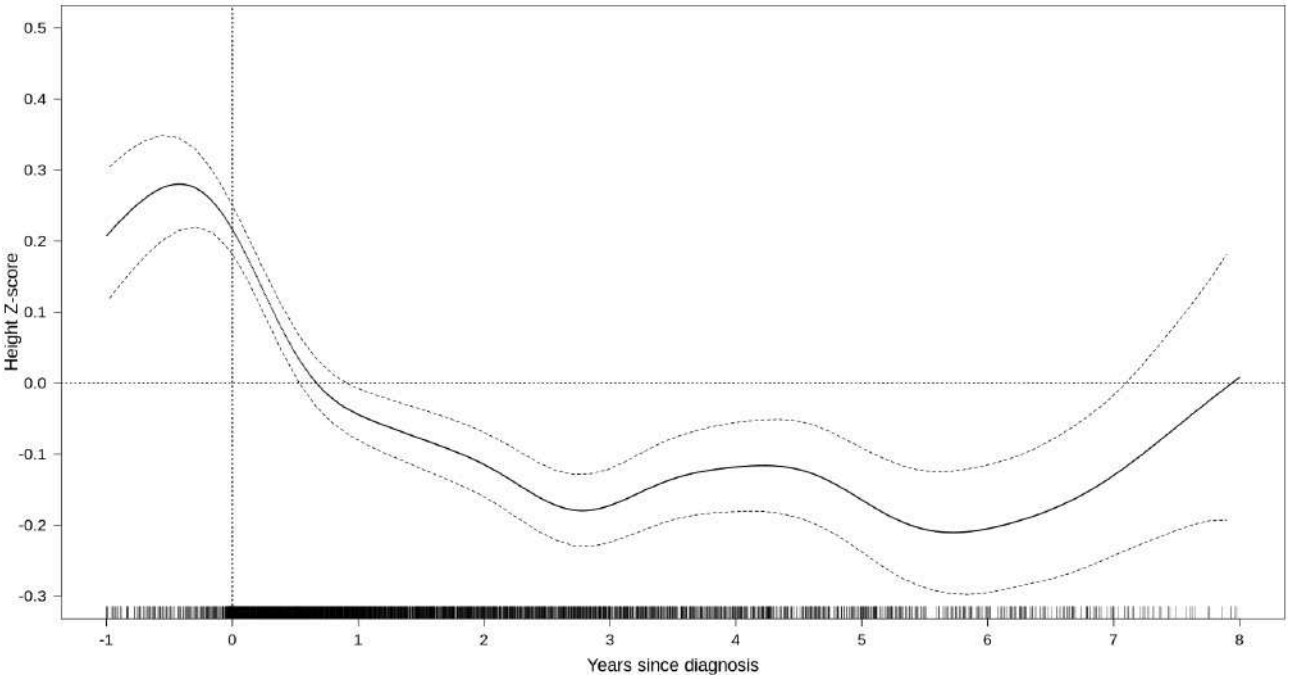
In this multicentre study, we retrospectively analysed medical record data from all Swiss university hospitals (Basel, Bern, Geneva, Lausanne, Zurich) between 2017-2023, using a new paediatric infrastructure (SwissPedHealth), that provides routine anthropometric data in a standardized way (SwissPedGrowth). We included patients diagnosed with a CNS tumour below the age of 20 years. We further classified diseases as either malignant or non-malignant based on ICD-10 codes. We calculated sex- and age-specific height Z-scores based on WHO growth references from diagnosis till eight years after diagnosis. We applied hierarchical generalised additive models to assess the non-linear relationship between height and time, to estimate growth trajectories.

RESULTS

Out of 373 patients diagnosed with malignant or benign CNS tumours recorded in SwissPedGrowth, we excluded 116 patients who did not have a height measurement within 45 days of diagnosis (33/373, 9%) or had less than three height measurements in total (83/373, 22%). We included 257 patients in the analysis, of whom 132 (51%) were boys. Median age at diagnosis was 7 years (IQR: 3, 12). Malignant neoplasms accounted for 58% (150/257) of all tumours, the cerebellum being the most frequently affected (50/257, 20%). A median of 13 height measurements per patient (IQR: 7, 23) were available. Median height Z-score at diagnosis was 0.3 (-0.5, 1.1). We observed a slight yet significant decrease in height Z-scores after diagnosis of childhood cancer. Three years after diagnosis the average height Z-score was -0.2, on average 1.1 cm below the 50th percentile of the WHO growth reference. Six years after diagnosis, height Z-scores increased again, normalizing eight years after diagnosis to the 50th percentile of the WHO reference. The decrease after diagnosis was particularly pronounced in patients with malignant tumours and in patients who received radiotherapy. We did not find any decrease in height Z-scores in patients with non-malignant tumours.

CONCLUSION

Linear growth is negatively affected in patients after diagnosis of a malignant CNS tumour and this impairment may persist for several years. However, the drop in height Z-score is limited and may partially or completely recover over time.



Height z-scores over time with 95% CI bands for children diagnosed with CNS tumours (n=257) based on the WHO growth reference.

036

Epidemiology/Research methods

IMPROVING NEUROPSYCHOLOGICAL AND ENDOCRINOLOGICAL LATE-EFFECTS CARE IN PEDIATRIC CNS TUMORS SURVIVORS: THE HORIZON EUROPE SCARLET TWINNING PROJECT IN LITHUANIA

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BACKGROUND-AIM

Childhood cancer survival rates at Vilnius University Hospital Santaros Klinikos (VULSK) have markedly improved over recent decades, reaching 80–90%. VULSK diagnoses 10-15 new cases of central nervous system (CNS) tumors in children every year. As survival rate increases, a growing population of childhood cancer survivors (CCS) treated for CNS tumors faces a high risk of long-term late effects, particularly neuropsychological and endocrinological, which significantly impact quality of life and long-term functioning. Addressing these challenges requires structured survivorship care and strengthened research capacity. Toward this aim, the Horizon Europe twinning project SCARLET (SCAling up early and late effects Research in Lithuanian childhood cancer survivors through Education and Twinning) was launched to enhance late-effects care for CNS tumor survivors and to advance childhood cancer survivorship research in Lithuania.

METHODS

The SCARLET project applies a multidisciplinary approach combining professional training, service development, and patient-centered evaluation. Psychologists are being trained in neuropsychological assessment of pediatric CNS tumor survivors, while pediatric and adult endocrinologists have received training focused on long-term follow-up and transition care. Stakeholder-oriented recommendations will be developed, and an interdisciplinary advisory system for early and late toxicities will be established.

RESULTS

Since October 2024, the consortium has identified an estimated 1,360 Lithuanian CCS who were diagnosed with a childhood cancer between 1993 and 2019 and survived more than 5 years. CNS tumor survivors accounted for 173 individuals (12.7%). The primary CNS tumor diagnosis was defined as ICD-10-AM C70-C72. To date, the multidisciplinary expert board has discussed 14 patients who were treated for CNS tumors in childhood. The board evaluated potential early and late treatment-related effects and provided individualized care plan recommendations to parents of pediatric patients and to adult CCS. To strengthen neuropsychological follow-up, two psychologists completed specialized training in neuropsychological assessment at University Medical Center Hamburg-Eppendorf and the Princess Máxima Center (PMC). Additionally, to implement a structured endocrinological long-term follow-up and transition system at VULSK, pediatric and adult endocrinologists have been trained at the PMC.

CONCLUSION

The EU-funded twinning project SCARLET (2024–2027) will strengthen neuropsychological and endocrinological late-effects care for pediatric CNS tumors survivors, while enhancing quality of life and research capacity at VULSK.

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Epidemiology/Research methods

INTEGRATION OF THE OFF-THERAPY REGISTRY AND THE SURVIVORSHIP PASSPORT (ROT–SURPASS) IN THE AIEOP PLATFORM: MIGRATION OF HISTORICAL DATA AND PROSPECTIVE IMPLEMENTATION

F. Bagnasco [10], A. Cattoni [3], D. Saraceno [4], A. Mastronuzzi [2], M. Pillon [11], E. Biasin [5], F. Felicetti [5], G. Giorgiani [7], M. Muraca [1], R. Tallone [1], A. Beccaria [1], C. Gorio [6], G. Aloj [8], D. Fraschini [3], M. Terenziani [9]

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BACKGROUND-AIM

The Off-Therapy Registry (ROT), active since 1980, has collected data in an Access database from centres of the Associazione Italiana di Ematologia ed Oncologia Pediatrica (AIEOP) on haematological and oncological patients (diagnosed since 1960) who have reached the elective end of treatment (OT). The Survivorship Passport (SurPass) has been available on the AIEOP platform since 2018. In November 2024, the integrated ROT–SurPass system was launched, combining demographic and diagnostic data from the AIEOP registration module (Mod.1.01) with therapeutic information from the ROT. This integration enables automatic generation of the SurPass, screening recommendations (based on expert consensus from the AIEOP Late Effects Working Group), and longitudinal clinical follow-up to collect post-OT pathological conditions coded according to the modified CTCAE. To enable this integration, migration of historical ROT data to the ROT–SurPass platform was required.

METHODS

In March 2025, after harmonisation of unique patient numbers (UPN) and personal data between the ROT and Mod.1.01, cancer diagnoses were recoded according to ICD-O-3 and ICCC-3 classifications. Treatments were reclassified using SurPass coding systems, including chemotherapeutic agents (ATC), congenital conditions (ICD-10 and/or Orphanet), and anatomical areas exposed to radiotherapy (SurPass-specific codes). Following these procedures, the ROT database was migrated to the ROT–SurPass platform.

RESULTS

The ROT included data on 14,368 OT patients (Figure 1, panel A). Of these, 1,263 (8.8%) were already registered in both Mod.1.01 and SurPass and were therefore excluded from migration. The remaining 13,105 (91.2%) records were successfully migrated to the ROT–SurPass platform. Among them, 10,406 patients were already present in Mod.1.01, requiring data correction in some cases (2.6% UPN reassignment and 9.7% personal data inconsistencies), while 2,699 patients were newly registered.

As January 23rd 2026, a total of 410 OT patients were prospectively enrolled in the ROT-SurPass study. The distribution of diagnoses across major cancer categories was relatively homogeneous (Figure 1, panel B). Specifically, leukemias accounted for 78 (19%) patients, with acute lymphoblastic leukemia being the most prevalent subtype. Solid tumors (excluding tumours of the bone, soft tissues, central and peripheral nervous system) were observed in 76 (18.5%) patients, predominantly gonadal or uro-renal tumors. Lymphomas included 75 (18.3%) patients, with Hodgkin lymphoma as the most frequent diagnosis. Bone and soft tissue tumors were reported in 71(17.3%) patients, with bone tumors being more prevalent. Neuroblastoma was diagnosed in 56 (13.7%) patients, while central nervous system tumors were observed in 54 (13.2%) patients.

CONCLUSION

The ROT represents one of the largest European cohorts of OT paediatric haematology-oncology patients. Integration into the ROT–SurPass platform enables prospective data updating and establishes a robust epidemiological observatory, supporting long-term, personalised follow-up and survivorship care.

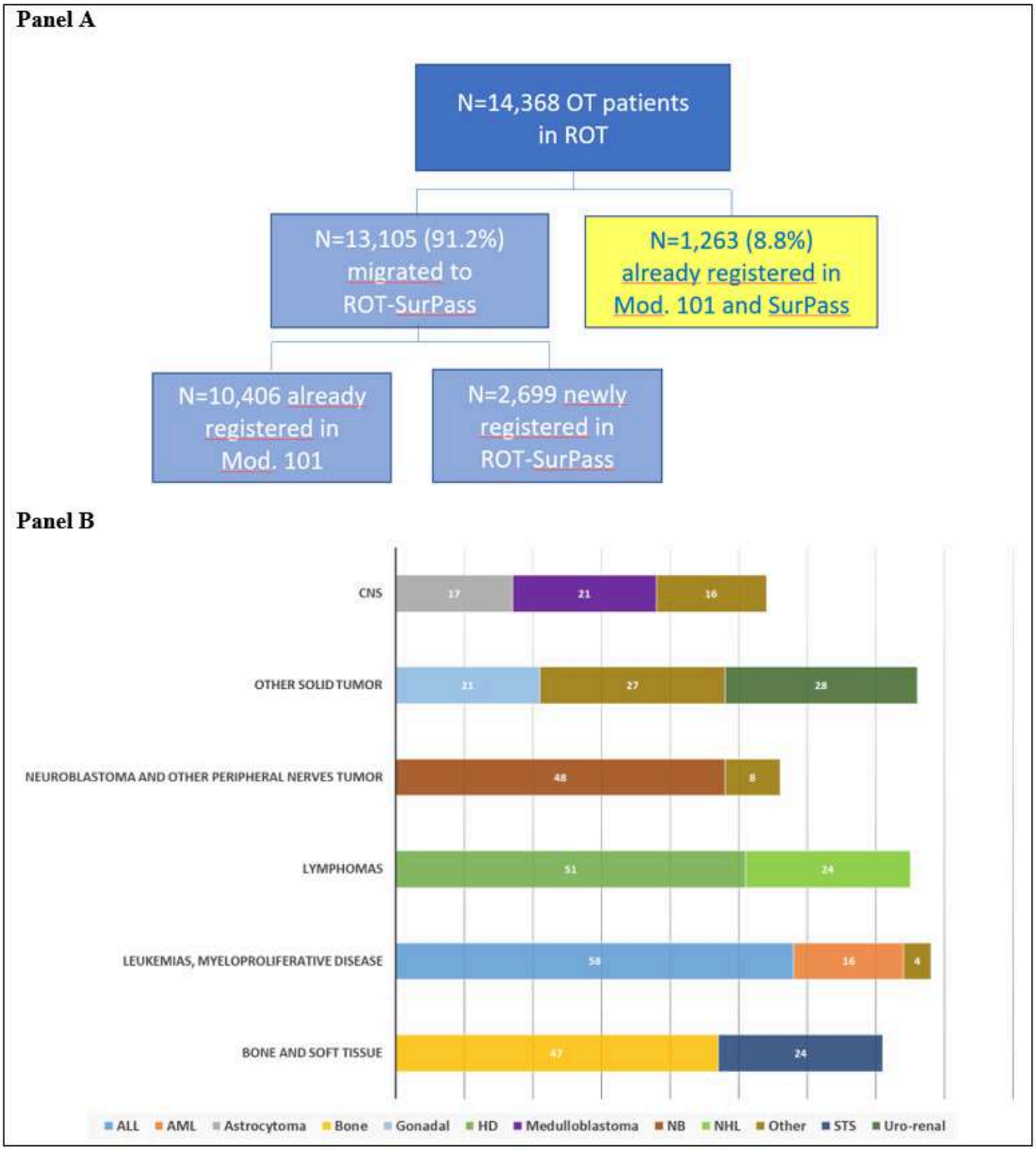

Figure 1. Migration process of historical OT patients (Panel A) and distribution of the 410 OT patients prospectively enrolled in the ROT-SurPass study according to cancer diagnosis (Panel B).

038

Epidemiology/Research methods

LIFESTYLE BEHAVIORS AND PHYSICAL HEALTH IN CANADIAN CHILDHOOD, ADOLESCENT, AND YOUNG ADULT CANCER SURVIVORS

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BACKGROUND-AIM

Healthy lifestyle behaviors are found to be associated with good physical health in survivors of childhood, adolescent, or young adult (CAYA) cancer, yet longitudinal studies investigating the directionality of this relationship are lacking. Understanding the directionality of the relationship between lifestyle and physical health is important to inform the development of effective interventions. With this study, we aimed to investigate the longitudinal relationships between lifestyle behaviors and physical health in survivors attending the Long-Term Survivor's Clinic (LTSC) in Calgary, Alberta, Canada.

METHODS

Survivors attended the LTSC once or twice a year and completed a questionnaire at each visit. In total, 766 responses from 312 CAYA cancer survivors were included, with an average of 2 responses per participant. Participants were diagnosed <25 years old, at least 2 years off cancer treatment, ≥11 years old at follow-up, and provided informed consent for sharing at least one questionnaire response for research purposes. Physical health was captured using two outcomes: the number of self-reported physical health problems and the number of physical health-related medications used. Self-reported lifestyle behaviors, including physical activity, alcohol, tobacco, and cannabis use, and sleep quality were scored as healthy (1) or unhealthy (0), and combined into a sum score ranging from 0-5. Multivariable, generalized linear mixed models (GLMM) were estimated to assess the association between lifestyle behaviors (sum score and individual behaviors) and physical health outcomes, irrespective of time. Cross-lagged GLMMs, incorporating a time component, were estimated to assess directionality between lifestyle sum score and the number of physical health problems.

RESULTS

A healthier lifestyle sum score (estimate -0.15, SE 0.06, p-value 0.02) and sufficient physical activity (estimate -0.23, SE 0.11, p-value 0.04) were associated with fewer physical health problems. No significant associations were found between lifestyle and the number of medications used. Lifestyle behaviors at an earlier time did in life not predict better physical health at a later time and vice versa.

CONCLUSION

Findings confirmed an association between a healthy lifestyle and fewer physical health problems. Additional studies are warranted to further elucidate directional pathways between a healthy lifestyle and better physical health.

039

Epidemiology/Research methods

LOSS TO FOLLOW-UP AMONG CHILDHOOD CANCER SURVIVORS ATTENDING THE LONG-TERM FOLLOW-UP CLINIC AT THE UGANDA CANCER INSTITUTE: A RETROSPECTIVE COHORT STUDY

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BACKGROUND-AIM

As survival after childhood cancer improves, long-term follow-up (LTFU) clinics are essential to detect and manage late effects and support lifelong health. However, many survivors disengage from survivorship care, limiting opportunities for risk-based surveillance and timely interventions, an evidence gap in sub-Saharan Africa. We described the time to loss to follow-up after completion of curative therapy among childhood cancer survivors enrolled in the Uganda Cancer Institute (UCI) LTFU clinic and identified factors associated with disengagement.

METHODS

We conducted a retrospective cohort study using routine clinical records from the UCI pediatric survivorship (LTFU) clinic in Kampala. We included all available records (census sampling) for survivors diagnosed before 18 years, who completed curative-intent treatment between 1 January 2013 and 31 December 2023 and were ≥12 months post-treatment, with follow-up documentation abstracted from 1 January 2015 to 31 December 2023. The primary outcome was time to loss to follow-up, operationalized as discontinuation of clinic attendance, with event time defined as the last documented visit plus one year. We used Kaplan–Meier methods to estimate cumulative LTFU and Cox proportional hazards regression to evaluate associated factors, including age at diagnosis, age at treatment completion, caregiver sex, region of residence, and whether any health concern was documented at any survivorship visit.

RESULTS

Ninety-nine survivors were included. Median age at diagnosis was 6 years (IQR 3–10); 57.6% were male, and 54.1% resided in Central Uganda. Lymphomas (38.4%) and renal tumors (28.3%) were most common; 54.6% received chemotherapy alone. Median follow-up duration after the first LTFU clinic visit was 4.9 years (IQR 2.7–6.5). Survivors attended a median of 10 appointments (IQR 7–13) overall, including 6 (IQR 4–7) within the first two years post-treatment and 3 (IQR 2–6) between years 2 and 7. Cumulative LTFU was 6.1% at 2 years and 75.8% at 5 years. In adjusted analyses, higher risks of LTFU were observed among survivors with no documented health concern at any visit (aHR 2.9, 95% CI 1.2–7.0), those diagnosed at ages 0–9 years (aHR 5.1, 95% CI 1.5–17.9), those completing treatment at ages 10–19 years (aHR 12.7, 95% CI 3.4–47.2), and those with male caregivers (aHR 2.3, 95% CI 1.02–5.14).

CONCLUSION

Three-quarters of childhood cancer survivors were lost to survivorship follow-up by five years after treatment completion. Disengagement was more likely among survivors self-perceived as “well,” those completing treatment during adolescence, and those with male caregivers. Strengthening transition processes at treatment completion, improving risk communication and survivor/caregiver education, and implementing clinic tracking and reminder systems, potentially with shared-care approaches closer to home, may improve retention in survivorship care in resource-constrained settings.

040

Epidemiology/Research methods

MITOCHONDRIAL OXIDATIVE CAPACITY IN SKELETAL MUSCLE OF ADULT SURVIVORS OF CHILDHOOD ALL AND ITS RELATIONSHIP TO SARCOPENIA

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BACKGROUND-AIM

Adult survivors of childhood acute lymphoblastic leukemia (ALL) experience high rates of late-onset morbidity consistent with accelerated physiological aging, including sarcopenia and frailty. Approximately 25-35% of ALL survivors meet criteria for sarcopenia, which is strongly associated with weakness, impaired physical function, and increased cardiometabolic risk. Skeletal muscle mitochondrial oxidative phosphorylation (OXPHOS) plays a central role in energy metabolism and its decline is implicated in age-related impairments in muscle function; however, the extent to which ALL and its treatment result in persistent impairments in skeletal muscle bioenergetics remains incompletely defined (Fig. 1A). Creatine-weighted chemical exchange saturation transfer (CrCEST) magnetic resonance imaging (MRI) enables non-invasive muscle-specific assessment of OXPHOS capacity by quantifying post-exercise creatine (Cr) recovery kinetics (Fig. 1B).

METHODS

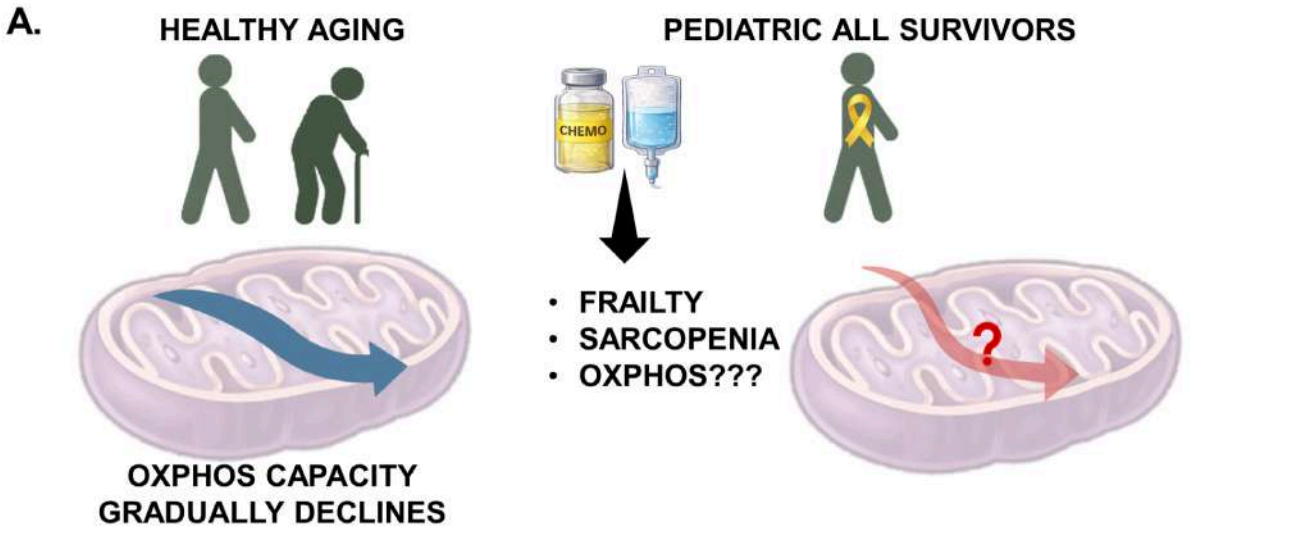
As part of a pilot study, we performed dynamic CrCEST MRI of the calf muscles in nine participants (7 males; 33.2±7.4 years) without cranial radiation exposure, implanted devices, or current peripheral motor neuropathy. In a separate cohort of healthy individuals, eighteen healthy adults (10 males; 33.2±7.8 years) served as age-matched controls. The CrCEST protocol included pre-exercise scans (one image with no saturation, B_1 map using WASSR, B_0 map, and CEST images acquired at six saturation offsets (±1.5, ±1.8, ±2.1 ppm)); 2 minutes mild plantarflexion exercise; followed by post-exercise scans (CEST images, B_0 map, B_1 map, one reference image). Lateral (LG) and medial gastrocnemius (MG) muscles were delineated from the pre-exercise reference image and post-exercise CEST images. Magnetization transfer ratio asymmetry (MTR_{asym}) was calculated after correcting for B_0 and B_1 inhomogeneities. Cr recovery was spline-fitted to derive the Cr recovery half-recovery time (T_{Cr}), defined as the time it takes for the MTR_{asym} to reach the half value from first post-exercise timepoint.

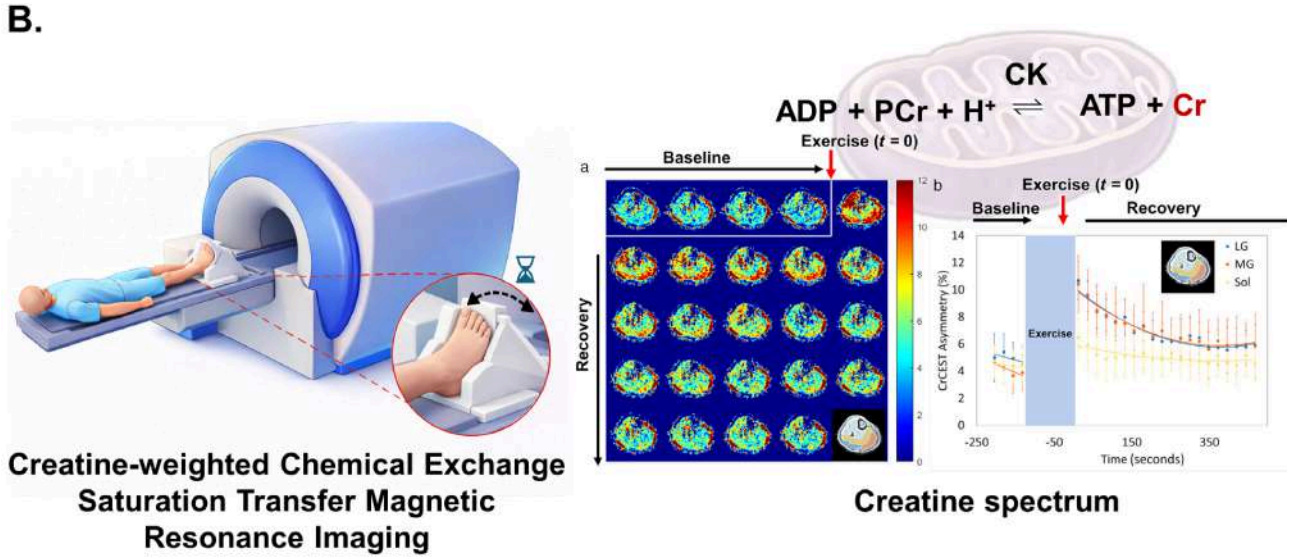
RESULTS

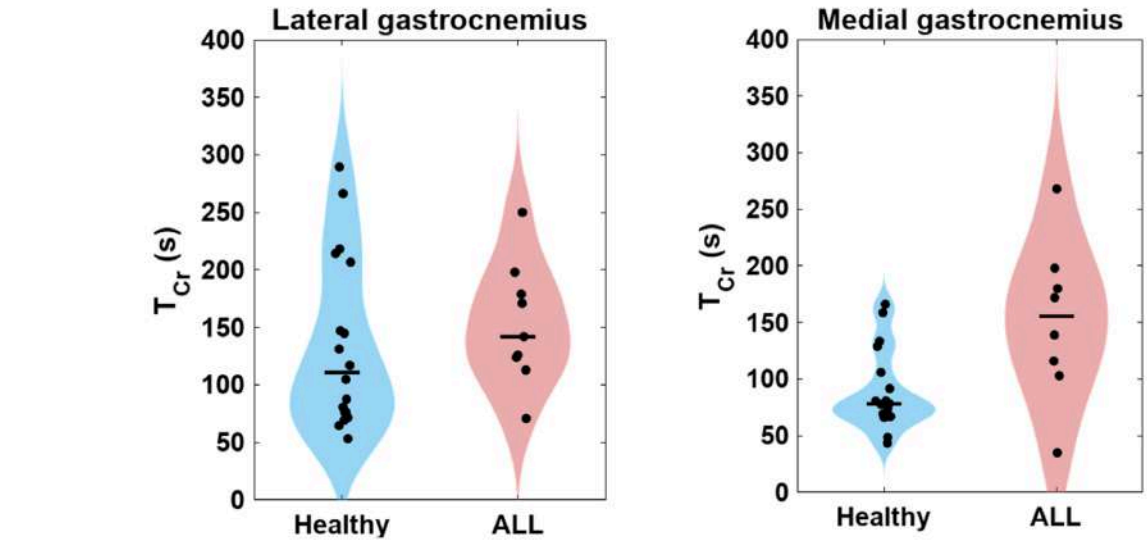
In healthy controls, CrCEST-derived T_{Cr} was 134.5±71.9s in LG and 89.3±34.3s in MG. Among ALL survivors, T_{Cr} was found to be 152.7±50 s in LG and 151.4±65.5s in MG. In a linear model adjusting for age and sex, group was not significantly associated with LG T_{Cr} (P=0.51). Age was independently associated with lower LG T_{Cr} across the entire cohort (β=−4.4s/year, P=0.008). In contrast, for MG, group was significantly associated with T_{Cr} after adjusting for age and sex, with ALL survivors demonstrating longer recovery times compared to healthy controls (β=−65.9s for Healthy vs. ALL, P=0.003) suggestive of impaired mitochondrial OXPHOS activity. Violin plots showed significantly higher MG T_{Cr} values in the ALL cohort (Fig. 1C).

CONCLUSION

Adult survivors of childhood ALL demonstrated prolonged post-exercise creatine recovery in MG, independent of age and sex, suggesting localized impairment in mitochondrial OXPHOS capacity. Dynamic CrCEST MRI provides a feasible, non-invasive method for assessing in vivo muscle OXPHOS capacity using clinically available hardware. Ongoing analyses integrating sarcopenia indices, muscle strength, and physical performance will determine the clinical relevance of these bioenergetic measures and help identify survivor subgroups at highest risk for functional decline.







Skeletal muscle mitochondrial oxidative capacity in adult survivors of childhood ALL. (A) Schematic showing decline in OXPHOS in healthy aging versus in pediatric ALL survivors predisposed to chemotherapy/treatments. (B) Dynamic calf-muscle creatine-weighted chemical exchange saturation transfer magnetic resonance imaging during rest, plantar flexion exercise, and recovery; post-exercise creatine recovery time constant TCr, a quantitative index of in vivo mitochondrial OXPHOS, is derived. (C) Violin plots of TCr in LG and MG in healthy controls (blue) and ALL survivors (red). MG TCr was significantly prolonged in ALL survivors compared with healthy controls, whereas no significant group difference was observed in LG.

041

Epidemiology/Research methods

MULTIPHASE CO-DESIGN AND ADAPTATION OF A SEXUAL DYSFUNCTION SCREENING INTERVENTION AND IMPLEMENTATION PROTOTYPE

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BACKGROUND-AIM

Sexual dysfunction (SD) occurs in 20-50% of adolescent and young adult childhood cancer survivors (AYA-CCS). Despite research demonstrating patient interest in SD conversations and national guidelines recommending discussions of sexuality throughout cancer care, this need often goes unrecognized. This multiphase project aims to develop and refine an acceptable, feasible, appropriate and effective SD screening intervention for AYA-CCS, with the objective of improving quality of sexual healthcare provided to AYA-CCS.

METHODS

The "Discover-Design-Build-Test" framework was used to engage users in intervention development. In the Discover phase of this project, we conducted semi-structured qualitative interviews with AYA oncology patients (n=24) aged 15-24 years and pediatric oncology providers (n=25, physicians, advanced practice providers, nurses) to identify how to facilitate conversations regarding SD. Interviews were guided by the Consolidated Framework for Implementation Research. In the Design phase, a series of five co-design sessions were conducted with 6 pediatric oncology providers at a single academic children's hospital with the purpose of developing a prototype screening intervention and implementation approach. In the initial Build-Test phase, we iteratively tested and adapted the screening prototype across 3 cycles using convergent mixed methods with assessment of patient (5 surveys/cycle) and provider (5 surveys and 3 interviews/cycle) facing outcomes (feasibility, acceptability, appropriateness). Adaptations were performed using a co-design approach. The refined intervention is currently undergoing further testing in a pilot type 1 hybrid effectiveness-implementation trial across 4 clinics at 2 academic children's hospitals. The primary outcome of this trial is patient-reported provider-initiated communication about sexual health.

RESULTS

During the Discover phase, patients and providers agreed with previously identified barriers and were in favor of utilizing a screening instrument assessing patient-reported sexual function to facilitate SD conversations, thereby reducing barriers such as patient and provider discomfort, and lack of knowledge. The NIH PROMIS Sexual Function and Satisfaction Brief v2.0 tool (variable length of 4-13 questions), was found by AYA-CCS to be acceptable and useful, with response process validity and content validity. During the Design phase, provider participants reached consensus on key intervention components, including use of a standardized electronic medical record-based screening, workflows for ensuring privacy and questionnaire follow-up, development of patient and provider resources, and provider education. In the preliminary Build-Test phases, the intervention underwent 15, 5, and 0 adaptations over 3 cycles respectively, before reaching acceptability, appropriateness and feasibility targets. The intervention is currently undergoing testing at 3 sites and is being implemented at the final site.

CONCLUSION

This multiphase study engaged patients and providers to develop and adapt a SD screening intervention and implementation strategy, yielding a prototype both groups found to be acceptable, appropriate, and feasible for delivery in a clinic setting. Iterative cycles identified challenges from both provider and patient stakeholders, allowing targeted adaptation. An ongoing trial is evaluating the effectiveness of the intervention at improving patient-provider communication, as well broader implementation outcomes.

042

Epidemiology/Research methods

MULTI-SITE QUALITY IMPROVEMENT: IMPLEMENTATION OF ROUTINE FATIGUE SCREENING AMONG SURVIVORS OF PEDIATRIC CANCER IN THREE U.S. LONG-TERM FOLLOW-UP PROGRAMS

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BACKGROUND-AIM

Quality improvement (QI) strengthens the relevance and real-world impact of healthcare research through patient-centered clinical translation. Fatigue is one of the most common and distressing late effects experienced by pediatric cancer survivors, significantly affecting physical functioning, school/work participation, and quality of life. Although the Children's Oncology Group (COG) long-term follow-up guidelines recommend routine fatigue screening, implementation in clinical practice remains inconsistent. Supported by the COG Nursing Discipline, three medium-sized survivorship programs participated in a collaborative QI initiative to implement routine fatigue screening using patient-reported outcomes (PROs). The primary aim was to implement fatigue screening across three U.S. pediatric oncology survivorship clinics over up to six months. A secondary aim was to collect experiential data to inform scalability and best practices.

METHODS

Independent QI projects were conducted at three sites using the Model for Improvement framework. Nurses implemented fatigue screening through iterative Plan–Do–Study–Act (PDSA) cycles using validated, age-appropriate PRO tools, including the Pediatric Patient-Reported Outcomes Common Terminology Criteria for Adverse Events (PRO-CTCAE) and the PROMIS Fatigue Short Form. Each site determined screening eligibility criteria, PRO selection, and data monitoring processes. Implementation strategies included staff education, clarification of team roles, and integration into clinic workflows and documentation. Monthly screening rates were tracked using run charts and a secure REDCap™ database.

RESULTS

Baseline assessment revealed variable screening practices and inconsistent documentation. Over six months, documented fatigue screening improved to 75% overall, with 161 total screenings across sites (Site A: n=122, 75.4%, 6 months; Site B: n=62, 96.7%, 6 months; Site C: n=11, 54.5%, 3 months). Key drivers of improvement included workflow integration, provider engagement, and standardized documentation. Barriers included institutional review board processes, documentation burden, competing clinic priorities, feasibility challenges in younger or developmentally delayed patients, and variability in clinic workflows.

CONCLUSION

Routine fatigue screening in pediatric cancer survivorship care was feasible and improved across all sites through application of QI methodology. Embedding PRO screening into clinic workflows enabled standardized assessment and created a mechanism to support referral to targeted interventions. This multi-site collaborative QI initiative provides a pragmatic, evidence-based framework that balances rigor with real-world implementation and supports scalable practice change across the COG network. Future work includes linking screening results to interventions, evaluating PRO utility, incorporating longitudinal screening, and further integration within the electronic medical record.

043

Epidemiology/Research methods

OUTCOME DISPARITIES AMONG CHILDHOOD HEMATOLOGIC CANCER SURVIVORS BY ETHNICITY

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BACKGROUND-AIM

Childhood cancer survivors are at risk for treatment-related health conditions, but engagement in survivorship care remains low, especially among older survivors. Moreover, due to a relatively low representation of Hispanic survivors in existing survivor cohort studies, late effects risk in this population is not well understood. The Texas-based-multi-institutional Survivorship and Access to Care for Latinos to Understand and address Disparities (SALUD) cohort study (NCI UG3/UH3CA260607) was established to address these gaps. We conducted a survey to evaluate health behaviors and facilitators/barriers to access survivorship care in SALUD participants, and report here results for survivors of hematologic malignancies.

METHODS

A 37-item survey was administered to survivors in one of six pediatric oncology facilities/programs: El Paso Children's, Children's Health (Dallas, TX), Cook Children's (Ft. Worth, TX), Christus Children's (San Antonio, TX), Texas Children's (Houston, TX), and the Vannie Cook Children's Clinic (McAllen, TX). Responses were scored on a Likert scale. Differences between Hispanic vs. Non-Hispanic respondents were evaluated using a Fisher's Exact test. Multivariate logistic regression was then used to assess if associations persisted after adjusting for age, sex, and race.

RESULTS

Between 1/1/2021 and 6/3/2025 there were 666 respondents (293 survivor respondents, 361 parent/guardians of survivors <18 years, and 12 with unknown respondent type). Ninety-one respondents completed the survey in Spanish (14%), 60% self-identified as Hispanic, 47% were female, 510 (77%) were survivors of leukemia, and 156 (23%) were survivors of lymphoma. The median patient age at survey completion was 15 years (range 3.4 to 47.4 years). Self-reported race distribution was 80% White, 5.5% Black, 4% Asian, 1.9% American Indian/Alaska Native, and 0.3% Native Hawaiian, with the remainder reporting more than one race or unknown. Twenty-five percent of respondents reported living more than 50 miles from where they received their cancer treatment.

Nearly 85% of participants reported having a primary care provider, with no difference between Hispanics and Non-Hispanics. Compared to non-Hispanics, Hispanics were more likely to deny health problems after their cancer diagnosis (OR 1.6 [1.2, 2.1]) but also less likely to describe their overall health as "very good" or "excellent" during the three months prior to survey completion (OR 0.5 [0.4, 0.7]). Hispanics were more likely to worry "very often" or "almost always" about their or their child's health (OR 2.6 [1.8, 3.8]).

Regarding access barriers, Hispanic respondents were more likely than non-Hispanics to report insurance coverage as a significant barrier to accessing cancer treatment (OR 2.1 [CI 1.1, 4.0]). They were also less likely to report high confidence in describing the type of cancer they or their child had (OR 0.5 [0.3, 1.0]) and the type of cancer treatment received (OR 0.6 [0.3, 0.9]). Hispanics were more likely to report difficulty finding a specialist (OR 2.5 [1.6, 4.0]) and getting a prescribed x-ray, blood test, or screening test in the past year (OR 2.5 [1.4, 4.4]).

CONCLUSION

Results from this survey provide insights regarding disparities in health concerns and barriers to care among survivors of hematologic malignancies. Qualitative assessments of specific groups are under way to better appreciate factors underlying these differences.

044

Epidemiology/Research methods

PATTERNS AND DETERMINANTS OF PHYSICAL ACTIVITY IN ADOLESCENT SURVIVORS OF CHILDHOOD CANCER – FINDINGS FROM THE SWISS CHILDHOOD CANCER SURVIVOR STUDY

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BACKGROUND-AIM

Healthy behaviors, including regular physical activity (PA), are fundamental to long-term well-being, particularly for childhood cancer survivors (CCS), who face elevated health risks. Most research on PA in CCS focuses on adults in midlife, while little is known about PA among adolescent CCS, despite adolescence being a critical period for establishing lifelong activity patterns. This study investigates patterns and determinants of PA in adolescent CCS.

METHODS

As part of the Swiss Childhood Cancer Survivor Study, we surveyed CCS diagnosed prior the age of 14 who survived at least 5 years after diagnosis. The questionnaire covers type and duration of weekly sport participation, type and duration of daily commute to/from school/work (e.g., bike or car), and weekly physical education (PE) for those who attend school. We obtained cancer-related information from the Swiss Childhood Cancer Registry. We used descriptive statistics for patterns, and multivariable regression for determinants of sport participation and active commuting.

RESULTS

Out of 876 adolescent survivors (aged 15 to 20 years) contacted, 608 participated (response rate = 69%). Mean age at diagnosis was 6.5 years and mean time since diagnosis was 11.5 years. The most common cancer types were leukemia (32%), CNS tumors (19%), and lymphomas (15%). 217 adolescent survivors (36%) attended regular school (PE = 2.25 hrs/week), whereas 235 (39%) attended vocational education training (PE = 1.50 hrs/week) at the time of participation. 156 survivors (26%) were not exposed to regular PE.

360 survivors (59%) reported engaging in sport with a median duration of 4 hours per week. 34 survivors (6%) reported not participating in sport due to physical or psychological impairments. The most common sport types were fitness-related (47%), sports games (39%), and outdoor activities (26%) among active survivors. Older survivors (Odds Ratio = 0.77; 95% CI = 0.65-0.90), survivors from the non-German-speaking region of Switzerland (vs. German-speakers; 0.66; 0.45-0.97), those with a migration background (vs. no migration background; 0.64; 0.41-0.98), current smokers (vs. non-smokers; 0.52; 0.32-0.82), those diagnosed at a younger age (0.92; 0.87-0.97), and those treated with radiotherapy (0.51; 0.34-0.78) were less likely to participate in sport. Regarding daily commuting, 8% reported active commuting (i.e., by foot and/or bike), while 25% reported passive commuting (i.e., by public transport and/or car). Most survivors (60%) reported using mixed (active and passive) transportation. Median duration of active commuting was 60 minutes per day. Current age was the only significant predictor of active or mixed (vs. passive) commuting (0.73; 0.61-0.87). Sport participation was not associated with active or mixed commuting, $\chi^2(1) = 2.48$, $p = .116$.

CONCLUSION

Most adolescent CCS engage in regular sport, supporting favorable PA patterns during a critical life stage. While PE lessons represent an important context for PA, activities outside educational settings also contribute substantially. In contrast, levels of active commuting are low, indicating a potential target for increasing overall PA. Smoking was strongly associated with non-participation in sport and represents a potentially modifiable factor. Overall, adolescent CCS demonstrate encouraging PA patterns that may support a successful transition into adulthood, while leaving room for targeted improvements.

045

Epidemiology/Research methods

PREVALENCE OF ALCOHOL USE AND ASSOCIATED FACTORS AMONG SWISS ADOLESCENT CHILDHOOD CANCER SURVIVORS

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BACKGROUND-AIM

Most childhood cancer survivors (CCS) survive their initial cancer diagnosis but remain at increased risk of treatment-related late effects, which contribute to higher morbidity and mortality. Adopting a healthy lifestyle may help reduce these risks and is therefore particularly important. Adolescence is a critical period when many health behaviors are initiated, including risky habits such as alcohol use. While alcohol use among adult CCS has been studied, little is known about its prevalence in adolescents. This study investigates alcohol use among Swiss adolescent CCS and associated factors.

METHODS

We used data from the Swiss Childhood Cancer Survivor Study, including CCS diagnosed before age 14 who survived at least five years and completed the questionnaire at age 15-20 years. Outcomes included current use and lifetime drunkenness. Clinical data were obtained from the Swiss Childhood Cancer Registry. We examined sociodemographic and clinical correlates of alcohol use and intoxication using multivariable logistic regression.

RESULTS

The study included 609 adolescent CCS (53% male; mean age 17.73 years, SD 1.24), with a response rate of 69%. The most common cancer types were leukemia (33%), CNS tumors (19%), and lymphoma (15%). Mean age at diagnosis was 6.5 years (SD 4.0), with a mean time since diagnosis of 11.5 years (SD 3.8). Overall, 478 (78%) participants reported current alcohol use, most commonly beer, alcopops, and cocktails. Among current drinkers, 289 (61%) drank occasionally, 115 (24%) once a week, 72 (15%) several times a week, and only 2 (<1%) daily. Of the 567 survivors who answered the question, 289 (51%) reported being drunk at least once in their lifetime, including 83 who had been drunk more than three times in the past year. Older CCS (OR 1.41 per year, 95% CI 1.09–1.84), and those with a history of smoking (OR 3.57, 95% CI 1.22–13.28) or cannabis use (OR 3.54, 95% CI 1.27–12.69) had higher odds of current alcohol consumption, whereas those with CNS tumor diagnosis (OR 0.36, 95% CI 0.14–0.87) or a migration background (OR 0.20, 95% CI 0.11–0.38) were linked to lower odds. Episodes of drunkenness were more likely among older adolescents (OR 1.75 per year, 95% CI 1.42–2.17), males (OR 1.63, 95% CI 1.03–2.59), and those with a history of smoking (OR 4.01, 95% CI 1.97–8.56) or cannabis use (OR 15.22, 95% CI 7.46–34.30).

CONCLUSION

These results indicate that alcohol use is common among Swiss adolescent CCS, with over three-quarters reporting any consumption and half having been drunk at least once. Although frequent or daily drinking was rare, this highlights the importance of targeted prevention and monitoring of alcohol, along with smoking and cannabis, in this vulnerable population.

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Epidemiology/Research methods

SIMPLIFYING INPUTS OF MACHINE LEARNING-BASED RISK CALCULATORS TO IMPROVE CLINICAL USABILITY: A REPORT FROM THE CHILDHOOD CANCER SURVIVOR STUDY AND THE ST JUDE LIFETIME COHORT

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BACKGROUND-AIM

Automatic variable selection is inherent in machine learning algorithms and supports the development of medical risk calculators with better risk prediction performance. However, from the user perspective, automatic variable selection results in models with high administrative burden because data for all considered inputs is needed. For example, the published risk calculator for basal cell carcinoma (BCC) for childhood cancer survivors currently available on the Childhood Cancer Survivor Study (CCSS) website needs 19 different clinical inputs. To improve the usability of these calculators, we aim to leverage the benefits of machine learning algorithms and simplify the number of model inputs with little if any sacrifice in prediction accuracy.

METHODS

We developed a manual variable selection approach for the machine learning algorithm Extreme Gradient Boosting (XGBoost), which was the best performing algorithm underlying our published risk calculators. Our approach, XGBoost-Elbow (XGBoost-E), sequentially removes the least important variable (i.e., smallest SHAP value) until the reduced set shows worse performance than the previous larger set in all three evaluation metrics: discrimination (AUROC), precision (AUPRC), and overall performance (sBrS), i.e., an inflection point or "elbow" in performance. A simulation study was conducted where the simulated outcome Y depended on a function of 5 key inputs. Five noise inputs were added to the dataset to assess whether XGBoost-E could remove noise inputs and keep key inputs. We then applied XGBoost-E for a BCC risk prediction model using real-world data in CCSS followed by external validation in the St. Jude Lifetime Cohort (SJLIFE), using the full set of 19 inputs as a benchmark.

RESULTS

In 500 simulation datasets (n=5365, mean event rate=0.27), XGBoost-E kept on average 4.4 variables, of which <1 (mean=0.76) was a noise input. Three of five key inputs were always kept; the remaining two key inputs were rarer exposures (9% and 3% exposed) and were kept inconsistently (55% and 9%, respectively). Compared to the XGBoost models with the full input set, the XGBoost-E models with reduced inputs had similar or better prediction performance with respect to the three metrics: 71% (AUROC), 50% (AUPRC), and 48% (sBrS), respectively, using a nested cross-validation framework. In the BCC real-world example, XGBoost-E selected 12 inputs from the original 19 predictors resulting in a reduced model with similar or better prediction performance than the full XGBoost model evaluated at age 40, internally in CCSS (reduced vs. full: AUROC 0.747 vs. 0.745; AUPRC 0.153 vs. 0.155; sBrS 0.049 vs. 0.050) and externally in SJLIFE (AUROC 0.762 vs. 0.760; AUPRC 0.321 vs. 0.308; sBrS 0.079 vs. 0.074). Dropped inputs included radiation therapy doses to the limbs and pelvis, and specific chemotherapies (anthracyclines, vinca alkaloids, platinum, corticosteroids).

CONCLUSION

Our new approach XGBoost-E consistently drops noise inputs. The models with reduced input sets perform comparably to full-set XGBoost models in our simulation study. In our use case, BCC risk prediction with XGBoost-E selected reduced inputs that performed better than the full-set XGBoost model in external validation data. Updating our survivor-specific medical risk calculators with this approach will improve their clinical usability.

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Epidemiology/Research methods

THE IMPACT OF A FORMAL REFERRAL PROCESS TO ACHIEVING A SUCCESSFUL TRANSITION TO LONG-TERM FOLLOW-UP CARE

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BACKGROUND-AIM

Despite improved survival rates, little is known about the factors associated with a successful transition from pediatric cancer treatment to long-term survivorship care. Aims of this study are to examine factors associated with a successful transition after treatment to an institutional long-term pediatric survivorship care clinic, and identifying contributors to effective follow-up and barriers to care for childhood cancer survivors (CCS).

METHODS

This is a retrospective chart review using data from an electronic medical record embedded database of pediatric cancer survivors diagnosed at Children's Health between January 1, 2010, and December 31, 2014, excluding neurological cancer survivors. The primary outcome variable focused on a "successful transition" defined as documented attendance at ≥1 survivorship clinic visit. At our institution, transition to survivorship care occurs through a formal internal referral process. Survivors were typically referred to the survivorship clinic 2–3 years after completion of treatment, with a warm hand off to the program scheduling team which was encouraged by the treating oncology clinician at the end of this period. The process involved filling out an electronic medical record note by the attending oncologist, completing a post–follow-up appointment paper slip indicating that the next expected visit will take place in the survivorship clinic, and provision of education and survivorship resources. Treatment level, demographic and clinical variables assessed included age at diagnosis, sex, race/ethnicity, primary cancer type, language, and referral to the survivorship program. Descriptive statistics were performed, as well as univariate and multivariate modeling.

RESULTS

Two thousand, two hundred and twenty-four patients were initially identified as diagnosed during 2010-2014. After exclusions, 452 pediatric cancer survivors were included in the final cohort, including 370 (81.9%) who received a formal referral after treatment to the pediatric survivorship program. Another (356) 78.8% successfully transitioned to survivorship care. In adjusted analyses, increasing age at diagnosis was associated with decreased odds of successful transition (OR 0.91 per year, 95% CI 0.87–0.95), while Hispanic ethnicity (compared with White patients) was associated with increased odds of successful transition (OR 2.31, 95% CI 1.22–4.59). Referral was a prerequisite for transition, as no unreferred patients attended survivorship visits. Among referred patients, no sociodemographic or clinical variables were independently associated with successful transition.

CONCLUSION

The majority of CCS after treatment transitioned to the pediatric survivorship program for at least 1 encounter. In adjusted analyses, differences in successful transition were observed by Hispanic ethnicity (compared with White patients) and age at diagnosis. Because referral was a prerequisite for transition, observed differences in successful transition were attenuated when referral status was considered. These findings highlight areas for further evaluation of referral practices. Lastly, further research incorporating variables such as distance from the hospital, type of residence, socioeconomic status, and insurance coverage is needed to better characterize factors associated with successful transition.

	Unsuccessful Transition (%)	Successful Transition (%)	p-value	Odds Ratio (95% CI)	p-value
Age at Diagnosis (years)	9.42 ± 5.96	6.90 ± 5.22	<0.001**	0.913 (0.87–0.95)	< 0.001**
Sex			0.48		
Male	56 (22.67%)	191 (77.33%)		Ref: Male	
Female	40 (19.51%)	165 (80.49%)		1.226 (0.76–1.99)	0.405
Race/Ethnicity			<0.001**		
White	48 (25%)	144 (75%)		Ref: White	
Black	22 (35.48%)	40 (64.52%)		0.602 (0.32–1.14)	0.116
Hispanic	20 (11.70%)	151 (88.30%)		2.307 (1.22-4.59)	0.013*
Other	6 (22.22%)	21 (77.78%)		1.087 (0.42–3.17)	0.868
Primary Language			0.01235*		
English	90 (31.58%)	295 (76.62%)		Ref: English	
Spanish	6 (8.96%)	61 (91.04%)		1.508 (0.57–4.48)	0.428
Cancer Type			0.4629		
Leukemia and Lymphoma	65 (20.19%)	257 (79.81%)		Ref: Leukemia and Lymphoma	
Solid Tumors	31 (23.85%)	99 (76.15%)		0.752 (0.45–1.27)	0.280
Treatment Modality			0.4629		
Chemo	65 (20.19%)	257 (79.81%)			
Chemo + Radiation	31 (23.85%)	99 (76.15%)			
Referred to Survivorship Care			< 0.001**		
Referred	14 (3.78%)	356 (96.22%)			
Not Referred	82 (100.00%)	0 (0.00%)			

Table 1 - Unadjusted and Adjusted Associations with Successful Transition to Pediatric Survivorship Care. Univariable results are presented as counts (%) or mean ± SD. Adjusted odds ratios (ORs) and 95% confidence intervals (CIs) are derived from a multivariable logistic regression model adjusting for age at diagnosis, sex, race/ethnicity, primary language, and cancer type. Referral status and treatment modality were not included in the multivariable model due to complete separation and collinearity with cancer type, respectively.

Variables Associated with Successful Transition to Follow-Up Care

048

Epidemiology/Research methods

UNDERNUTRITION IN CHILDHOOD CANCER PATIENTS - RESULTS FROM A SWISS MULTICENTRE STUDY

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BACKGROUND-AIM

Undernutrition may be present at the time of childhood cancer diagnosis or develop during intensive oncological treatment. As undernutrition increases the risk of treatment-related complications and impacts overall survival, diagnosis and treatment of undernutrition is essential. We aimed to assess the prevalence of undernutrition in newly diagnosed childhood cancer patients, describe the occurrence and course of undernutrition during treatment, and determine whether nutritional support was received.

METHODS

In this multicentre study, we used retrospectively collected medical record data from five university hospitals across Switzerland (Basel, Bern, Geneva, Lausanne, Zurich) from 2017 to 2023, using a new paediatric infrastructure (SwissPedHealth), that provides routine anthropometric data in a standardized way (SwissPedGrowth). We included patients diagnosed with childhood cancer below the age of 20 years. We calculated body mass index (BMI, kg/m^2) and derived sex- and age-specific BMI Z-scores based on the WHO growth references. We defined undernutrition as a BMI Z-score <−2 at diagnosis or weight loss > 10% within six months after diagnosis. We applied an algorithm (growthcleanr) to identify and correct unit errors and swapped height-weight recordings, remove duplicate and carried-forward values, and to identify and flag implausible height and weight values based on expected growth velocity thresholds. For all patients classified as undernourished at diagnosis or during treatment, we assessed the duration of nutritional interventions (supplemental enteral nutrition, parenteral nutrition).

RESULTS

Out of 1,590 patients diagnosed with childhood cancer between 2017-2023 in the five participating centres, we excluded 693 patients without a weight (n = 305, 44%) or height (n = 388, 56%) measurement within 45 days of cancer diagnosis and within 6 months after diagnosis. We included 897 patients: 52% (467/897) were male, 31% (279/897) were adolescents (12 to 20 years), and 30% (268/897) in preschool age (1 to 6 years) at the time of cancer diagnosis. At diagnosis, 4% (36/897, range: 3-6%) of the patients were undernourished. Undernutrition at diagnosis was most frequently observed in boys (24/36, 66%) and among patients diagnosed with a CNS neoplasm (9/36, 25%), leukemia (6/36, 16%) or soft tissue and other extraosseous sarcoma (4/36, 11%). When stratified by age, the frequency of undernutrition was comparable across age groups.
At diagnosis, 64% (23/36) of undernourished patients received nutritional support. We observed substantial between-hospital variation, with 11%–80% of patients receiving nutritional support.
Within 6 months of diagnosis, we observed that undernutrition doubled during treatment, reaching 9% (73/897), with varying prevalence between hospitals (range: 5-12%). Prevalence of undernutrition during treatment was similar across sex and age groups.

CONCLUSION

The rate of undernutrition at diagnosis was low but increased during cancer treatment. The substantial variability of nutritional management observed across Swiss hospitals and variability in prevalence during treatment indicates that a timely diagnosis and treatment of undernutrition is important.

049

Genetic/Genomics

LONGITUDINAL PATTERNS OF EPIGENETIC AGING AMONG LONG-TERM SURVIVORS OF HODGKIN LYMPHOMA (HL): A REPORT FROM THE ST. JUDE LIFETIME COHORT (SJLIFE)

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BACKGROUND-AIM

While five-year overall survival rates for HL exceed 95%, the intensive nature of treatments carries significant risks for long-term morbidity. Notably, survivors of HL experience accelerated biologic aging decades after therapy, manifesting as a higher epigenetic age (EA) compared to chronologically age-matched, non-cancer peers and even survivors of other pediatric cancers. However, no studies have evaluated longitudinal changes in EA over time among survivors of HL.

METHODS

143 long-term survivors of pediatric HL in SJLIFE (mean[SD] age 38[7] years, 23[8] years post-diagnosis) underwent a laboratory assessment, a comprehensive clinical exam, and self-reported health behaviors at two time points (T1, T2). Treatment history was abstracted from medical records. Chronic health conditions (CHCs) were graded with a modified version of the NCI CTCAE and combined into a severity-burden score representing the frequency and grade of CHCs (high/severe vs. moderate/low). Genome-wide DNA methylation data were generated with peripheral blood mononuclear cell-derived DNA using Infinium Methylation EPIC V1 arrays. EA was generated for several epigenetic clocks (Horvath, Hannum, PhenoAge, CauseAge, DamAge, and GrimAge). ∆EA was calculated as the absolute difference between EA and chronological age at each time point. Epigenetic age acceleration (EAA) for each clock was defined as the residual from GEE regressing the EA on chronological age. DunedinPACE, an epigenetic measure of the pace of aging, was also generated. GEE estimated mean ∆EA and compared the two time points adjusted for age and sex. Linear regression examined associations between treatment exposures (yes/no) or health behaviors and change in EAA over time adjusting for EAA at T1, age, sex, and time between visits. Lastly, multinomial logistic regression estimated the odds of high/severe CHC severity-burden score at T2 associated with EAA at T1 or change in EAA adjusting for CHC severity-burden score at T1, age, and sex.

RESULTS

Mean(SD) time between assessments was 3.7(1.7) years. Survivors experienced a significant increase in ∆EA over time for Hannum, Horvath, PhenoAge clocks as well as DunedinPACE (p's<0.05 Fig. 1). EAA on the Hannum clock increased, on average, 0.67 years each calendar year (ß[95%CI] 0.67[0.17, 1.17] p=0.009. EAA on the Horvath clock increased, on average, 0.26 each year (0.26[-0.01, 0.54] p=0.064). DunedinPACE indicated a 1% faster aging rate per year (0.01[0.00, 0.01] p=0.040).

Bleomycin was associated with increasing EAA between T1 and T2 for PhenoAge (1.73[0.16, 3.29] p=0.031), CauseAge (1.93[0.57,3.29] p=0.005), and DamAge (1.56[0.29, 2.84] p=0.017). Vincristine was associated with increasing EAA on DamAge (1.28[0.11, 2.45] p=0.032), and smoking was associated with increasing EAA on Grim Age (1.23[0.42, 2.04] p=0.003). Although not statistically significant, chest radiation was associated with increasing GrimAge (1.32[-0.22, 2.87] p=0.094) and DunedinPACE (0.05[-0.01, 0.12] p=0.098). DunedinPACE at T1 was associated with an increased odds of being in the high/severe severity burden CHC group at T2 (OR[95%CI] 1.47[1.07, 2.02] p=0.018).

CONCLUSION

In these preliminary analyses, long-term survivors of HL experience epigenetic aging that is increasing over time. Tracking these changes may be useful in identifying survivors at risk for poor outcomes or who are early responders to interventions.

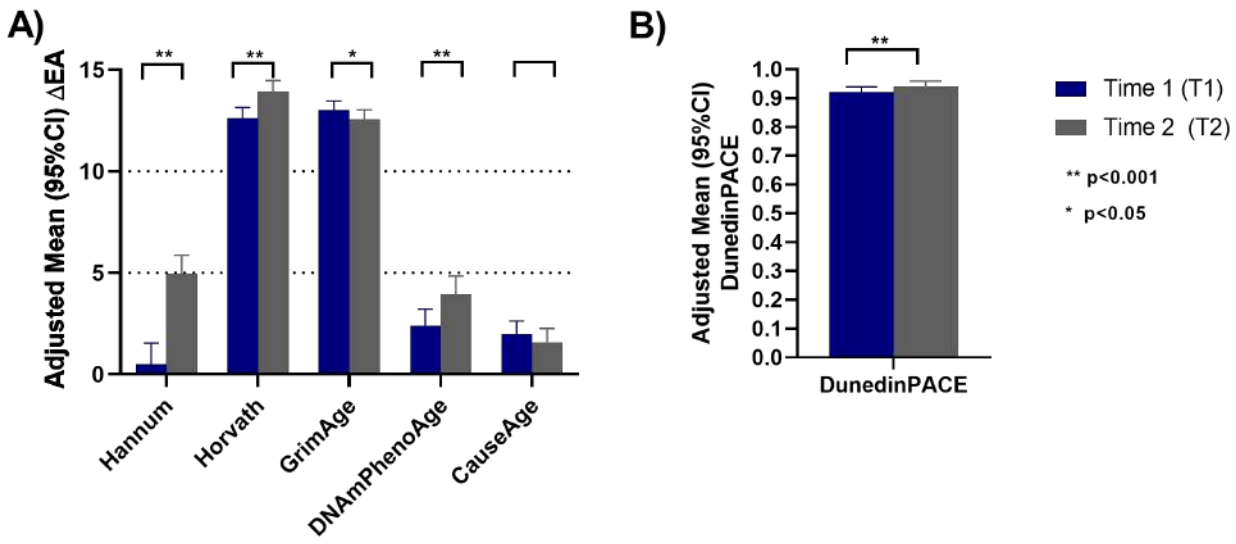

Figure 1: Adjusted mean and 95% confidence intervals at Time 1 and Time 2 for A) the AEA or the difference between epigenetic and chronological age where a positive number signifies the number of years biologically older they are than their chronological age and B) the mean DunedinPACE which reflects the pace of aging, a higher value reflects a higher pace of aging, a clinically meaningful difference is 0.10. Models are adjusted for age and sex.

050

Genetic/Genomics

TREATMENT-SPECIFIC EQTLS IN CHILDHOOD CANCER SURVIVORS OF EUROPEAN AND AFRICAN ANCESTRY

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BACKGROUND-AIM

Genome-wide association studies (GWASs) in childhood cancer survivors have identified genetic variants associated with risk of chronic health conditions (CHCs). However, pinpointing functionally causal variants has been difficult. Expression quantitative trait loci (eQTLs), genetic variants that affect expression of nearby genes, may help clarify the GWAS discoveries and identify mechanisms of CHC risk. Yet, to date, eQTLs have not been evaluated in childhood cancer survivors.

METHODS

We performed ancestry-stratified cis-eQTL analyses of common genetic variants (MAF>5%), using whole-genome and RNA-sequencing of peripheral blood mononuclear cells from 208 5-year survivors of European ancestry (EUR) and 102 survivors of African ancestry (AFR) from the St. Jude Lifetime Cohort Study. Analyses were performed using linear regression models adjusted for sex, ages at primary cancer diagnosis and sample collection, exposures to radiation and chemotherapy, the first five genotype-based principal components and the first five expression-based probabilistic estimation of expression residuals. To identify treatment-specific eQTLs, interaction terms were added between each genetic variant and five common treatment exposures (alkylating agents, platinum agents, and radiotherapy to the abdomen, chest and neck). eQTLs were considered statistically significant at a false discovery rate <0.05. To demonstrate the relevance of these eQTLs, we conducted colocalization analyses between eQTLs interacting with chest radiotherapy and summary statistics from two GWASs for left ventricular ejection fraction (LVEF) in survivors (one in EUR and one in AFR). Colocalizations were considered significant at P<1x10-4 with posterior probability (PP)>0.50.

RESULTS

Among EUR survivors, we identified 7,694 and 1,538 eQTLs that significantly interacted with platinum agent and alkylating agent exposure, respectively (731 and 32 eQTLs in AFR survivors). For radiotherapy-specific effects, we identified 891, 894, and 5,284 eQTLs in EUR survivors that significantly interacted with neck, chest and abdominal radiation, respectively. Even though fewer AFR survivors were included in the study, we identified more radiotherapy-specific eQTLs in AFR (2,588, 2,376, and 9,845, respectively). Among EUR, one chest radiotherapy-specific eQTL colocalized with the GWAS for LVEF (PP=0.90). This variant, rs10876671, is an eQTL for DGKA, an isoform of diacylglycerol kinase, which plays a role in the development of cardiac hypertrophy and heart failure. Among AFR, nine chest radiotherapy-specific eQTLs colocalized with findings from the LVEF GWAS. These nine eQTLs regulate the expression of nine genes, including CLK4 and TNFRSF1A. CLK4 is downregulated in the myocardia of individuals with heart failure and mouse-model knockouts resulted in cardiac hypertrophy and heart failure. TNFRSF1A, a transmembrane receptor expressed in cardiomyocytes, was associated with heart failure severity in mouse-model knockouts.

CONCLUSION

To our knowledge, this is the first eQTL analysis conducted among childhood cancer survivors, highlighting the impact of cancer treatment exposures on the genetic regulation of gene expression. Colocalization with GWAS summary statistics demonstrates the utility of treatment-specific eQTLs in elucidating the genetic underpinnings of CHCs among childhood cancer survivors. With a deeper understanding of the genetic contribution to CHCs, improved risk prediction and personalized treatment may be possible.

051

Interventional research

BRIDGING HEALTH DISPARITIES IN PEDIATRIC CANCER SURVIVORS: STRATEGIES FOR ENGAGING SPANISH-PREFERRING FAMILIES IN A LIFESTYLE INTERVENTION

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BACKGROUND-AIM

Obesity rates in pediatric cancer survivors (PCS) are alarmingly high (>40% in the US) and associated with long-term health risks. Promoting healthy behaviors in PCS is challenging, and few healthy lifestyle interventions have included Spanish speaking families. We have an ongoing multi-site randomized control trial (NOURISH-T+) targeting parents as agents of change to promote healthy eating and physical activity in PCS with overweight or obesity. This presentation focuses on strategies we identified in a multi-site trial to engage and retain Spanish-preferring dyads in our lifestyle intervention.

METHODS

Of the 209 parent-child dyads, 37.8% identified as Hispanic/Latino (n=79) with n=42 of these parents preferring delivery of NOURISH-T+ in Spanish. Dyads were randomized to NOURISH-T+, a 6-session, manualized intervention, with an additional dietician session and 2 PCS sessions, or to Enhanced Usual Condition (EUC), a one-time informational session, and nationally available brochures. Participants completed demographic and behavioral surveys (Child Feeding Questionnaire; Child Food and Activity questionnaire) via REDCap link. An adherence score was developed using the percentage of completed study components (eg, surveys & sessions). Descriptive statistics, Chi-square/Fisher's exact and Mann–Whitney U tests were used.

RESULTS

PCS were ≥6 months off treatment (M=4.3±2.9 years), with a mean age of 10.6±2.6 years and BMI percentile of 94.4±6.4. Spanish-preferring families had lower levels of education and income ($p<0.001$) and a lower likelihood of initiating the intervention at the scheduled time (OR=0.69, 95% CI [0.43, 1.10]). They reported greater daily soda/pop intake ($p=0.020$), higher daily vegetable intake at lunch ($p=0.035$) and snacks ($p=0.016$), lower physical activity practice ($p<0.045$) and duration ($p=0.011$), but lower screen time ($p=0.016$) at baseline. Spanish-preferring caregivers expressed greater concern about child weight ($p=0.042$), had more frequent use of pressure-to-eat practices ($p<0.001$) and lower levels of dietary monitoring ($p=0.004$). This aligns with the impression of our bilingual interventionists who reported that Spanish-preferring parents were often less engaged, more permissive, required more extensive discussion of parenting styles, and generally took longer to complete intervention sessions. Tailored strategies implemented for Spanish-preferring families included validating parenting experiences, acknowledging multiple stressors, spending more time explaining concepts, being more directive in sessions, being flexible with scheduling, and considering financial difficulties in developing meal planning goals. Despite differences, Spanish-preferring dyads demonstrated adherence scores comparable to those of non-Spanish-preferring families for completion of intervention sessions and post-intervention questionnaires in both the EUC (54.9±31.3 vs. 57.8±31.1; $p=0.372$) and NOURISH-T+ (59.5±44.6 vs. 77.7±30.5; $p=0.219$) intervention groups.

CONCLUSION

The strategies implemented to accommodate Spanish-preferring parents of PCS appear to have been effective in maintaining family engagement in the intervention. Tailoring strategies to address the cultural and linguistic needs of diverse families proved to be important for supporting participation. Future work should focus on identifying underlying factors associated with optimal achievement of intervention behavior-change goals and sustained protocol adherence.

052

Interventional research

CHANGE IN LIFESTYLE BEHAVIOURS IN SURVIVORS OF CHILDHOOD CANCER AFTER ATTENDING A PERSON-CENTERED, LONG-TERM FOLLOW-UP OUTPATIENT CLINIC: A PANCAREFOLLOWUP STUDY

S. Van Den Oever [12], M. Rijken [9], L. Kremer [12], H. Van Der Pal [12], P. Spreeuwenberg [9], G. Michel [14], E. Bouwman [13], J. Te Dorsthorst [10], S. Essiaf [4], L. Feijen [12], C. Follin [8], L. Elmerdahl Frederiksen [2], H. Gsell [1], R. Haupt [3], M. Van Helvoirt [7], R. Hermens [13], L. Hjorth [8], T. Kepak [6], K. Kepakova [6], A. Kienesberger [1], M. Kokla [2], M. Muraca [3], S. Oberti [3], K. O'Brien [11], M. Renard [7], K. Roser [14], C. Schneider [1], R. Skinner [5], A. Uyttebroeck [7], D. Vanrusselt [7], S. Verschueren [7], J. Falck Winther [2], J. Loonen [13], S. Pluijm [12]

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BACKGROUND-AIM

To optimise long-term follow-up care after childhood cancer and enhance survivors' empowerment, the European PanCareFollowUp Care intervention was developed. This intervention comprised one clinic visit, during which survivors received late effects surveillance. After the clinic visit, survivors received a survivorship care plan which, among personalised screening recommendations, included a general recommendation on healthy lifestyle behaviours for all survivors. The aim of this study was to assess the effects of the delivery of this recommendation on survivors' physical activity, smoking, alcohol use, and drug use.

METHODS

Survivors were recruited in four European countries (Belgium, the Czech Republic, Italy, and Sweden). Outcomes included physical activity (minutes of moderate to vigorous physical activity per week), alcohol consumption (number of drinks per week), current smoking (yes/no), and drug use in the past year (yes/no) at baseline and six months post-intervention. Separate multilevel regression models were estimated to assess changes in these four outcomes over time.

RESULTS

In total, 777 survivors were included in this analysis. At baseline, the median duration of physical activity was 150 minutes per week (IQR 14-330), the median alcohol consumption was 1 drink per week (IQR 0-2), 15% of survivors smoked, and 9% reported drug use in the past year. We did not find significant changes in the duration of physical activity, the number of alcoholic drinks, or smoking status, whereas drug use was significantly reduced to 5% (estimate -0.50, SE 0.11, p=0.02).

CONCLUSION

The results from this study suggest no evidence for an effect of providing a general lifestyle recommendation during a survivorship care visit on survivors' lifestyle behaviour. More comprehensive lifestyle support programs are needed to optimise lifestyle behaviours in this population.

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Interventional research

DEVELOPING AN EVIDENCE-BASED AND THEORY-INFORMED INTERVENTION TO SUPPORT SURVIVORS OF CHILDHOOD, ADOLESCENT AND YOUNG ADULT CANCER TO BE PHYSICALLY ACTIVE: FINDINGS OF THE BEACON STUDY

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BACKGROUND-AIM

Despite the importance of physical activity (PA) to overall health, including cardiovascular health, survivors of childhood, adolescent and young adult (CAYA) are less active than non-cancer peers. Moreover, PA support for CAYA survivors is lacking.
We recently completed empirical, evidence-synthesis and co-design work to develop an early prototype of a theoretically-informed, multi-component intervention to improve PA levels of survivors of CAYA cancer in follow-up care in the UK (the BEACON study) with the purpose of reducing survivors' risk of cardiovascular morbidity and mortality. This research aimed to identify and understand what helps and hinders CAYA cancer survivors to be physically active, and how best to support them.

METHODS

This work included: 1) a systematic review of studies exploring the influences that CAYA cancer survivors perceive on their PA; 2) theory-informed interviews with CAYA cancer survivors; 3) theory-informed interviews with parents of CAYA cancer survivors; and 4) a series of co-design activities with CAYA cancer survivors to understand their preferences and needs for a PA intervention. Survivors and parents were recruited via four hospitals in England. Recognised frameworks for intervention development were used to guide the activities and processes of the research.

RESULTS

Our early prototype comprises a blended multi-component intervention delivering multiple behaviour change techniques both face-to-face and online: 1) provision of brief PA advice by a trusted healthcare professional at clinic and referral to a trained PA coach; 2) online 'real-time' regular exercise and support sessions with PA coach; and 3) access to an interactive web-app.
Based on the results of our ongoing co-design activities with young people, parents and a range of healthcare professionals, we will refine the design of the BEACON intervention to ensure it is tailored to the needs and preferences of key stakeholders, including importantly CAYA survivors.

CONCLUSION

The project is aiming to maximise intervention effectiveness of an evidence-based and theory-informed PA intervention by enabling tailoring to accommodate survivor- and tumour-specific impairments and barriers to PA. Next steps will be to gain funding so that we can work with stakeholders to operationalise the intervention and test it for feasibility and acceptability.

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Interventional research

FINDINGS FROM THE 'SUPPORTING YOUNG CANCER SURVIVORS WHO SMOKE OR VAPE' STUDY: THE PRISM STUDY

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BACKGROUND-AIM

Childhood, adolescent and young adult (CAYA) cancer survivors are vulnerable to adverse late-effects. Whilst it is known that tobacco smoking is an important preventable cause of ill-health and early death, the long-term effects of vaping are not yet established. Formative research exploring smoking and vaping in CAYA cancer survivors is lacking.
To address this, we recently completed a programme of empirical work (the PRISM study) which explored 1) published smoking cessations interventions for CAYA cancer survivors; 2) the views and experiences of CAYA cancer survivors who smoke and/or vape; and 3) the views and current practices of healthcare professionals regarding smoking and vaping discussions with CAYA cancer survivors in their care.

METHODS

Our programme of formative research included: 1) a scoping review of published smoking cessation interventions in CAYA cancer survivors; 2) theoretically-informed interviews with CAYA cancer survivors who smoke and/or vape; and finally 3) theoretically-informed interviews with healthcare professionals who care for CAYA cancer survivors.

RESULTS

We found that few smoking cessation interventions have been developed, tested and published for CAYA cancer survivors. In the CAYA cancer clinical context, multiple barriers exist which impede the potential for disclosure, discussion and support provisions for smoking and vaping behaviours. These include factors which hinder patient's willingness to disclose their smoking status (e.g., presence of parents, feelings of embarrassment, worries of confidentiality). Healthcare professionals also reported barriers to initiating conversations around smoking such as factors which prevented ascertaining patients true smoking status, a lack of engagement from known smokers and vapers regarding offers of cessation support, and ultimately a view that they as healthcare professionals had limited influence over their patients choice of behaviours. Both healthcare professionals and survivors acknowledged the limited information on the long-term effects of vaping, and even more limited knowledge
around vaping cessation.

CONCLUSION

Several challenges to addressing smoking and vaping behaviours within cancer care exist from both the healthcare provider and the survivor perspective. Further considerations are needed to enable open and honest discussions between survivors and their clinicians, and how to best support young cancer survivors who smoke or vape.

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Interventional research

LOCAL APPLICATION OF OTOPROTECTIVE COMPOUNDS OTHER THAN SODIUM THIOSULFATE TO CISPLATIN-INDUCED OTOTOXICITY AND ITS LATE SEQUELAE IN CHILDREN WITH CANCER, A NARRATIVE REVIEW.

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BACKGROUND-AIM

Cisplatin-induced hearing loss (CIHL) in pediatric cancer patients is a direct and irreversible adverse effect with a devastating impact on speech and language development, neurocognitive development, and acquiring social-emotional skills, with consequent serious late consequences on academic performance and overall quality of life. Sodium thiosulfate (STS) has recently been approved for systemic administration as an otoprotective agent in children. However, implementation of systemic STS has its challenges, and there is currently limited evidence to support local STS for children. This review investigates the potential value of locally administered otoprotective agents other than STS with a focus on future pediatric implementation.

METHODS

We conducted a narrative review on the efficacy and safety of locally applied non-STS otoprotective agents in in-vivo settings. This included a summary of investigated drug delivery methods and administration routes. We identified 70 preclinical and eight clinical studies. Agents were categorized based on biological mechanisms: anti-inflammatory, chemical deactivators, calcium blockers, biologicals, and miscellaneous mechanisms.

RESULTS

Preclinical studies investigated 45 different agents. Dexamethasone and N-acetylcysteine were identified as efficacious agents recurrently and progressed to clinical trials. Dexamethasone was investigated in three randomized clinical trials (RCT) and three non-randomized clinical studies and showed statistically significant but not clinically relevant benefit in two trials. N-acetylcysteine was investigated in two clinical trials and one RCT and was minimally effective in the RCT and in one clinical study.

CONCLUSION

Our review did not identify available studies of local alternative otoprotective agents that could reliably replace systemic STS in terms of safety and efficacy for pediatric patients. Therefore, further clinical research on efficacy, the optimal dosage, delivery methods, and timing of otoprotective agents is required.

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Neurocognitive outcomes

ASSESSING A NOVEL NEUROPSYCHOLOGICAL SCREENING TOOL IN PEDIATRIC CANCER PATIENTS AND SURVIVORS

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BACKGROUND-AIM

Childhood cancer patients and survivors are vulnerable to neurocognitive deficits based on malignancy, treatment received, and associated co-morbidities. This study assessed a novel parent-report screening tool for recommendations for referral for formal neuropsychological evaluation developed by the Clinical Neuropsychology Collaborative for Childhood Cancers (CNC3). It evaluated the screening tool in comparison with formal neuropsychological evaluation findings among pediatric cancer patients and survivors.

METHODS

The CNC3 Cognitive Screener (CNC3-CS) was created by a multidisciplinary group of neuropsychologists from U.S. and Canadian institutions with expertise in pediatric oncology. The measure integrates components of established, validated instruments and includes additional symptom items grouped by cognitive domains such as executive functioning, memory, and processing speed. The CNC3-CS was administered to parents of children completing comprehensive neuropsychological assessments, and screener results were examined in relation to formal test outcomes to evaluate its effectiveness in identifying children at risk for neurocognitive impairment.

RESULTS

Of 64 participants, 58 (90.6%) had completed therapy and 26 (40.6%) had a history of central nervous system tumor. Among a cumulative result incorporating testing of intelligence, visual-spatial skills, processing speed, academics, and executive functioning, we found relatively high rates of deficits, with moderate deficits (>2SD below the mean) in 30 patients (46.9%) and mild or moderate deficits (>1SD below the mean) in 49 patients (76.6%). Youden's J analyses were conducted to determine optimal symptom-percentage cutoffs for each cognitive domain assessed by the CNC3-CS (including attention, processing speed, etc.), relative to performance on formal neuropsychological examinations. A cumulative recommendation on the CNC3-CS for referral for formal neuropsychological examination was calculated based on domain positivity with 48 (75%) of patients positive for recommending referral. The CNC3-CS demonstrated 83.3% sensitivity when compared with moderate deficits on formal neuropsychological assessment results. Multiple complementary analytic approaches revealed the individual domains of the CNC3-CS of processing speed, memory, visual spatial skills and academics were significantly associated with moderate deficits on formal neuropsychological examinations.

CONCLUSION

There is not a standard screening tool for neurocognitive deficits among this population that is consistently clinically being used across institutions. The CNC3-CS demonstrates appropriate sensitivity for screening for neurocognitive concerns and was significantly associated with formal neuropsychological evaluation. It is a helpful, efficient tool to identify pediatric cancer patients and survivors who would benefit from referral to neuropsychology services. Further studies will evaluate additional psychometric properties of this new screening tool across participating institutions.
*Preliminary analyses from this study have been presented at the Children's Oncology Group 2025 and 2024 Fall Meeting.

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Neurocognitive outcomes

COGNITIVE AND PSYCHOLOGICAL SEQUELAE IN PEDIATRIC AND ADOLESCENT PATIENTS WITH PINEAL REGION TUMORS: INSIGHTS FROM 35 YEARS AT A TERTIARY REFERRAL CENTER

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BACKGROUND-AIM

Pineal region tumors (PRTs) represent 2.8% of central nervous system tumors diagnosed in individuals up to 19 years of age. Advances in treatment enable over two-thirds of patients to achieve disease remission; however, subsequent late effects may negatively impact survivors' quality of life. The present study seeks to determine the prevalence of cognitive and psychological late effects among PRT survivors.

METHODS

Demographic and medical information, along with age-appropriate cognitive and psychological assessments, were retrospectively collected from childhood and adolescent PRT survivors followed at Gaslini Children's Hospital between 1988 and 2023. Neurocognitive evaluations utilized the Wechsler scale, and psychological assessments employed the Child Behavior Checklist, Beck Depression Inventory, State-Trait Anxiety Inventory, Trauma Symptom Checklist for Children, and Impact of Event Scale–Revised.

RESULTS

A total of sixty patients (53 males, 88%) were included; the median age at diagnosis was 12.8 years (Interquartile Range [IQR]: 9.0–15.7 years). The main tumor types identified were germinoma (17, 28%), non-germinomatous germ cell tumor (16, 27%), bifocal germinoma (13, 22%), pineoblastoma (6, 10%), and teratoma (3, 5%). Neuroaxis spread was observed in 20/60 patients (33%), hydrocephalus in 48/60 (80%), surgical intervention in 41/60 (68%), ventricular-peritoneal shunt placement in 16/60 (27%), chemotherapy in 51/60 (86%), and radiotherapy in 56/60 (93%). The median follow-up period was 8.9 years (IQR: 4.1–15.2). Six patients died, five of whom succumbed to progressive disease. IQ scores were available for 43/60 individuals, yielding a median value of 91 (IQR: 85–107). Comprehensive cognitive and neuropsychological assessments were conducted for 25/60 patients, revealing symptoms of anxiety (16/25, 64%), depression (20/25, 80%), and post-traumatic stress (7/25, 28%).

CONCLUSION

This cohort demonstrated average IQ scores among PRT survivors alongside a high prevalence of anxiety and depressive symptoms. Further research is warranted to elucidate the mechanisms underpinning cognitive and psychological late effects, with particular consideration for demographic factors, treatment modalities, disease-specific variables, and tumor location.

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Neurocognitive outcomes

EXERCISE CAPACITY AND NEUROCOGNITIVE FUNCTION IN ADULT SURVIVORS OF CHILDHOOD ACUTE LYMPHOBLASTIC LEUKEMIA

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BACKGROUND-AIM

Adult survivors of childhood acute lymphoblastic leukemia (ALL) are at risk for reduced exercise capacity, lower levels of physical activity, fatigue and neurocognitive deficits. Evidence from other populations indicates that higher exercise capacity can be associated with improved neurocognitive functioning. The aim of this study was to determine the exercise capacity (watt max) of adult survivors of childhood ALL and to examine how their exercise capacity was associated with neurocognitive outcomes including processing speed and frontal cortical network connectivity (modularity and global efficiency).

METHODS

This cross-sectional study is comprised of 47 adult survivors of childhood ALL, 29 of whom were male (61.7%) with a median age 29 years (min-max 21-47). Participants completed questionnaires, underwent a maximal exercise test on a cycle ergometer, performed neurocognitive tests and underwent frontal cortical brain imaging with functional near-infrared spectroscopy (fNIRS). Associations between watt max and fatigue (fatigue severity scale), processing speed (processing speed index) and brain network functional connectivity in the frontal cortex (global efficiency and modularity), were analyzed using linear regression.

RESULTS

Of the 47 participants, 20 (42.6%) did not meet the WHO-recommended levels of physical activity. The mean age- and sex-adjusted watt percentage (M = 83.3%, SD = 13.1) was significantly lower than the Swedish reference value of 100%, with a mean difference of −16.2 percentage points ($p < 0.001$). Statistically significant associations were identified between higher watt max values and increased fatigue, β = -0.33 (95% CI [-0.66, −0.05], $p = 0.02$). No significant associations were found between exercise capacity (watt max) and processing speed ($p = 0.212$) or modularity ($p = 0.986$) and global efficiency ($p=0.500$).

CONCLUSION

In the present study, the exercise capacity of adult survivors of childhood ALL was reduced in comparison with the normative values. Moreover, it demonstrated an association between exercise capacity and fatigue level in a sample of 47 adult survivors of childhood ALL. No statistically significant associations were observed between exercise capacity and brain functional connectivity or cognitive measures.

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Neurocognitive outcomes

NEUROPSYCHOLOGICAL BURDEN BEFORE AND AFTER CANCER DIAGNOSIS IN A SINGLE CENTER COHORT

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BACKGROUND-AIM

Pediatric cancer is increasingly curable, but survivors experience life-long late effects related to their cancer and treatment. Among these late effects are neuropsychological late effects. Understanding the neuropsychological burden in pediatric oncology populations before, during, and after therapy is important to identify potential genetic predispositions, optimize supportive care, and improve survivors' long-term outcomes. For example, autism spectrum disorder (ASD) has previously been shown to complicate cancer treatment and is associated with worse outcomes. However, prior studies examining the co-occurrence of ASD and malignancy have found varying results. In this study, we aimed to quantify the prevalence of children with neuropsychological disorders, particularly ASD, at a single institution and compare these rates to estimates in the general population.

METHODS

We performed a retrospective cohort study including 500 pediatric oncology patients treated at a single center in Missouri (MO). We collected patient demographics, cancer diagnoses, neuropsychological disorders, and timing of neuropsychological diagnoses relative to cancer diagnosis. We analyzed the entire cohort and did a pre-determined subgroup analysis on patients ages 4 years and older (4+) given more than 70% of children with ASD have their first evaluation by age 3 years. We used comparison data from the Autism and Developmental Disabilities Monitoring Network for the United States (US) and MO. Multivariate logistic regression models and Kaplan-Meier (KM) curves were generated.

RESULTS

The neuropsychological burden in this pediatric cancer sample before and after cancer diagnosis was substantial. Overall, 38% of patients (40% of those aged 4+) were diagnosed with a neuropsychological disorder. Of these, 26% (30% of those 4+) had a diagnosis preceding their cancer diagnosis, with attention deficit hyperactivity disorder being most common (14% overall, 19% aged 4+), followed by ASD (5% overall, 7% aged 4+). After diagnosis, 12% of patients received new neuropsychological diagnoses. Children with cancer demonstrated an elevated risk of ASD compared to the general population data: 2.72 times higher than MO children and 2.41 times higher than US children. The risk was even more pronounced in the 4+ age group (3.35 times higher than MO, 2.96 times higher US). Females with cancer showed particularly elevated relative risk (4.90 times MO, 3.99 times US). Among children with ASD, 81%
were male, 46% had CNS tumors, and 31% had co-occurring intellectual or global developmental delay compared to 6% of children without ASD. Multivariate analysis confirmed significant associations between ASD and increasing age, sex, and intellectual/developmental delay. While not statistically significant, children with ASD or intellectual developmental delay demonstrated increased hazard ratios for death.

CONCLUSION

Children with cancer experience substantial neuropsychological burden, with elevated rates of ASD relative to general population estimates. We show ASD diagnosis predominantly preceded cancer diagnosis suggesting shared underlying mechanisms rather than treatment-related effects. These findings highlight the need for prospective screening for neuropsychological disorders in pediatric oncology populations, comprehensive genetic testing to identify potential cancer predisposition syndromes, and optimization of supportive care strategies with co-occurring conditions.

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Neurocognitive outcomes

OPTIMIZING NEUROCOGNITIVE MONITORING IN PEDIATRIC ONCOLOGY: INTRODUCING THE PEDIATRIC COGNITIVE MONITORING QUESTIONNAIRE (PCMQ)

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BACKGROUND-AIM

Cognitive late effects (CLE) are a significant concern for pediatric patients with brain tumors, leukemia, and those treated with neurosurgery, neurotoxic chemotherapy, and/or cranial radiation. CLE commonly emerge two to three years post-treatment as a result of disrupted neurodevelopment. Early identification of CLE is critical for improving health and functional outcomes. To address this need, a tiered model of care was implemented that offers a menu of neuropsychological services, with Tier 1 consisting of a universal monitoring questionnaire. There is a lack of such a tool, especially considering clinical needs and feasibility. This led to the development of a brief universal monitoring questionnaire for use in multidisciplinary oncology clinics.

METHODS

The goal was to create a brief, symptom-specific measure with parallel patient and proxy versions, written at a low literacy level in plain language to support accessibility and translation. The measure was designed to assess the primary cognitive domains at risk for CLE. Measure development followed standard scale-construction procedures: needs assessment, literature review, construct definition based on a theoretical framework, item generation, expert review, pre-testing, pilot testing, psychometric analysis, and revision and refinement. The resulting instrument, the Pediatric Cognitive Monitoring Questionnaire (PCMQ), a 7-item symptom-specific measure, is currently in pilot testing with early psychometric analyses underway.

RESULTS

The preliminary sample of patients (N=31) had a mean age of 5.3 years (SD=3.8) at diagnosis and 13.8 years (SD=3.1) at Tier 1 testing. Sixty-five percent of the sample were female. The sample was racially and ethnically diverse with 45.2% Hispanic, 41.9% White, 9.7% Black, and 3.2% Asian. Sixty-one percent of them were monolingual English speakers. Patient and parent PCMQ total scores were strongly correlated ($r = .80$, $p < .001$). The correlation was also significant for PCMQ Item 7, which assessed struggling in school ($r = .64$, $p < .001$). Among 31 patients, 28 received chemotherapy with methotrexate and 3 received chemotherapy without methotrexate. Mean patient PCMQ total scores (items 1-6) were 6.9 (SD 4.2) and 6.3 (SD 3.8) for the with and without methotrexate groups respectively, while mean parent PCMQ total scores were 7.7 (SD 4.8) and 5.7 (SD 3.5) respectively. For item 7 regarding struggling in school, 29% (N=8) of patients in the with methotrexate group and 0% in the without methotrexate group reported struggling, while 36% (N=10) and 33% (N=1) of parents reported their child was struggling in the with and without methotrexate groups respectively. Notably, the small sample size in the without methotrexate group limits meaningful comparison between groups.

CONCLUSION

The PCMQ is a quick (7-item) and clinically feasible, universal monitoring tool for CLE, designed for both patient and proxy reports. It is written at a low reading level, free of clinical jargon, and structured to support translation into multiple languages. Early psychometric analyses suggest strong agreement between patient and parent reports as well as emerging evidence of measuring functional impact of treatment. Next steps include expanded pilot testing, full psychometric validation on a larger clinical sample, and preparation for implementation in the electronic medical record to support routine clinical use, and pilot testing of the recent Spanish translation.

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Neurocognitive outcomes

THE CREATION OF A SINGLE SESSION INTERVENTION TO EMPOWER AND EDUCATE PARENTS ON NEUROCOGNITIVE DEFICITS IN PEDIATRIC CANCER PATIENTS AND SURVIVORS

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BACKGROUND-AIM

Few studies have explored how parents/caregivers can influence cognitive outcomes among pediatric cancer survivors. Parents play a prominent role in promoting a child's cognitive development and parents of pediatric cancer survivors are particularly interested in targeting their child's specific needs, ensuring their best learning. Often, these parents are doing this while navigating other resources (e.g., outpatient therapies, special education services), with steep learning curves and limited free time. Single Session Interventions (SSIs) have shown success with improving mental health outcomes among the general pediatric population by engaging parents/caregivers. Given the demands placed on caregivers, providing a one-time interactive module with elements of experiential learning may be a feasible way to provide parents/caregivers tools to promote cognitive skills training among their children. We aim to create an educational self-administered computerized module on teaching about neurocognitive deficits using the SSI framework for parents/caregivers of pediatric cancer patients and survivors. This initial phase of our study will elicit feedback of the SSI from parents/caregivers through individual semi structured qualitative interviews.

METHODS

Parents/caregivers of pediatric cancer patients and survivors (ages 5-17.99 years old) were recruited at Oncology and Survivorship clinics at a large children's hospital in the midwestern United States. Emphasis was placed on diversifying the sample in terms of diagnosis, treatment stage, and survivorship. Sociodemographic, educational, and medical histories were collected from parent-report surveys and electronic medical record data. Semi- structured qualitative interviews were conducted virtually with the parent/caregiver. These sessions gathered information from caregivers surrounding their knowledge of cognitive effects, their knowledge of their child's risk for cognitive effects, information provided by their care team surrounding this, and feedback on the SSI's proposed framework and content provided.

RESULTS

Recruitment is ongoing and results will be presented at time of conference. Total number of participants will be determined after thematic saturation. The proceedings of the interviews will be audio-recorded and transcribed for further analysis. Rapid qualitative analysis will be used to identify, describe, and synthesize salient categories of previous knowledge of neurocognitive deficits, concerns parents have in how this relates to their children, and feedback of the proposed SSI. Preliminary qualitative data gathered from interviews demonstrates minimal knowledge of neurocognitive deficits, minimal information provided by the care team concerning the risk for these deficits, and an extremely positive feedback on the SSI's proposed framework and content.

CONCLUSION

We anticipate that an SSI designed for parents/caregivers of pediatric cancer patients and survivors focused on educating them about cognitive late effects and neuroprotective behaviors will serve as a valuable educational resource. This intervention aims to enhance parent knowledge and promote autonomy in identifying and addressing concerns related to their children's cognitive functioning. Findings from this phase of the study will inform a subsequent phase evaluating the acceptability and feasibility of the SSI in a larger cohort of parents/caregivers of pediatric cancer patients and survivors

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Neurocognitive outcomes

TRANSLATING THEORY INTO CLINICAL PRACTICE: OPTIMIZING NEUROCOGNITIVE MONITORING IN PEDIATRIC ONCOLOGY USING A TIERED MODEL

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BACKGROUND-AIM

Cognitive Late Effects (CLE) are a significant concern for pediatric patients with brain tumors, leukemia, and those treated with neurosurgery, neurotoxic chemotherapies, and/or craniospinal irradiation. Traditional models of care emphasize comprehensive neuropsychological evaluations, which average about 13.5 hours for pediatric cases. However, rising survival rates have resulted in increased demand, long waitlists, and variable accessibility and equity. Neuropsychological evaluation within one to three years post-treatment was achieved in only 26% of eligible patients, compared to a target of at least 75% at the study's institution. To address this gap, a tiered model of neuropsychological care was implemented and customized to the needs of patients, multidisciplinary programs, and the institution.

METHODS

An evidence-based neurocognitive monitoring model was developed and designed to deliver right-sized care accounting for patient needs and institutional resources. Tier 1 consists of the Pediatric Cognitive Monitoring Questionnaire (PCMQ), a brief, 7-item parent- and patient-report measure developed to align with clinical workflows, accommodate variable literacy levels, and target cognitive domains most vulnerable to CLE. Tier 2 consists of the Attention, Memory, & Frontal Abilities Screening Test (AMFAST), a brief targeted cognitive screener, with an administration and scoring time of about 15 minutes, administered by a neuropsychologist during multidisciplinary survivorship visits and/or specialized neuropsychology intakes. Tier 3 involves traditional comprehensive neuropsychological evaluation.

RESULTS

Implementation of the tiered model within the survivorship clinic has demonstrated strong feasibility and accessibility among patients, caregivers, and medical colleagues. Our preliminary sample (N=31) of patients had a mean age of 5.3 years (SD=3.8) at diagnosis and 13.8 years (SD = 3.1) at Tier 1 assessment. The majority were female (64.5%) and English monolingual (61.3%), with 38.7% bilingual in English and Spanish. Regarding race/ethnicity, 45.2% identified as Hispanic, 41.9% as White, 9.7% as Black, and 3.2% as Asian. Based on Tier 1 screening, 80.7% of patients (N=25) were triaged to Tier 2 per patient PCMQ score and 87.1% of patients (N=27) were triaged to Tier 2 per parent PCMQ score. Mean AMFAST score in our sample was 71.9 (SD=13.6). AMFAST scores triaged 77.4% (N=24) of patients to Tier 3, including 16 patients with significant neurocognitive dysfunction and 8 patients with mild neurocognitive dysfunction.

CONCLUSION

Overall, the tiered model of neurocognitive monitoring has demonstrated feasibility, facilitated earlier access to care, and provided targeted education about CLE as they relate to individual patients. This approach has supported improvements in children's healthcare outcomes and optimized neurocognitive monitoring in pediatric oncology. Future directions include continued data collection on the English version of the PCMQ, implementation of electronic dissemination, broader circulation and validation of the Spanish version of the PCMQ, ongoing evaluation of Tier 2 data to support triaging decisions, and expansion of this tiered model to on-treatment oncology clinics.

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Neurocognitive outcomes

VALIDATION OF THE JAPANESE VERSION OF THE CHILDHOOD CANCER SURVIVOR STUDY: NEUROCOGNITIVE QUESTIONNAIRE (CCSS-NCQ)

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BACKGROUND-AIM

Neurocognitive impairment is a significant and common late effect in childhood cancer survivors (CCS). It adversely affects long-term outcomes such as academic achievement, social adaptation, employment, and personal independence and health-care utilization, all of which reduce overall health-related quality of life. However, in Japan, standardized tools for simple and systematic assessment or screening of neurocognitive function in clinical settings are still insufficient. The current study describes the validation of the Japanese version of the Childhood Cancer Survivor Study–Neurocognitive Questionnaire (CCSS-NCQ), a widely used tool to assess cancer outcomes in North America. This study aimed to validate the Japanese version of the CCSS-NCQ by examining whether its factor structure is consistent with that of the original North American version.

METHODS

The English version of the CCSS-NCQ was converted into Japanese and culturally adapted following standard procedures, including forward and backward translation and expert review. Structural equation modeling (SEM) was employed to test the proposed four-domain structure of the questionnaire, consisting of Memory, Task Efficiency, Organization, and Emotional Regulation.

RESULTS

A total of 133 childhood cancer survivors (CCS) participated in the study. The mean [standard deviation] age of participants was 20.9 [8.4] years, with 51.1% male and 48.9% female. The mean age at diagnosis was 8.3 [4.7] years. Regarding cancer type, 50.4% were diagnosed with central nervous system tumors, 34.6% with hematological malignancies, and 11.1% with solid tumors. The Japanese version of the CCSS-NCQ demonstrated excellent fit in the confirmatory factor analysis (CFA), supporting the proposed four-domain structure (GFI = 0.992, AGFI = 0.961, RMSEA = 0.008, CFI = 1.000). The standardized path coefficients from the latent neurocognitive function factor to each domain were 0.935 for Memory, 0.839 for Task Efficiency, 0.742 for Organization, and 0.547 for Emotional Regulation, indicating a very strong positive association between each individual domain and overall neurocognitive function.

CONCLUSION

The Japanese version of the CCSS-NCQ retained the factor structure of the original North American version and demonstrated good reliability and content validity in this sample of Japanese CCS, supporting its use as a tool for systematic assessment of neurocognitive function in clinical follow-up settings. Future studies examining predictive ability between the CCSS-NCQ and direct cognitive assessment is planned.

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QoL/Rehabilitation

A QUALITATIVE EXAMINATION OF MENTAL HEALTH AMONG LATINO AND NON-LATINO PEDIATRIC CANCER SURVIVORS

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BACKGROUND-AIM

Compared with non-Latino childhood cancer survivors, Latino survivors have greater worry about late effects, psychological distress, and depressive symptoms, contributing to worse mental health-related quality of life. Latino survivors also more frequently endorse barriers to accessing specialty care. The aims of this qualitative study were to determine: 1) perceptions of survivor's mental health and psychological functioning and 2) experiences with mental health supports and care among Latino and Non-Latino childhood cancer survivors.

METHODS

A subset of survivors and parents of survivors participating in an epidemiologic study of cancer in childhood were recruited in-person or via telephone for this qualitative study. Nine audio recorded semi-structured focus groups were conducted in Spanish or English. Focus groups were conducted separately among participants from self-identified Latino and Non-Latino backgrounds. Audio-files of focus groups were transcribed, written transcripts were coded, and themes were developed by 3 analysts using thematic analyses.

RESULTS

Focus groups included 17 young adult pediatric cancer survivors (mean age = 24.9 y ± 7.0y; 45% Latino and 55% Non-Latino) and 16 parents of survivors ages 10-17 years (mean child age = 15.6y + 5.2y; 44% Latino and 56% Non-Latino). Latino participants described a range of concerns about survivors' mental health and psychological functioning, including depressive symptoms, learning difficulties, and anxiety, while non-Latino participants only reported concerns regarding anxiety. Some participants from both ethnic groups reported prior or current mental health care from psychiatrists, psychologists, and/or therapists or counselors. Yet, only Latino survivors and parents reported a lack of interest in mental health services after receiving a referral. Participants from both ethnic groups reported relying on family and friends, support groups, and camps to promote positive mental health, while spiritual and religious coping strategies were reported only by Latino participants.

CONCLUSION

Findings underscore published literature on the critical gap between referral to mental health services and engagement among Latino childhood cancer survivors, who demonstrated greater lack of interest in services despite reporting more diverse mental health concerns. Notably, Latino survivors and their parents more frequently endorsed spiritual coping as a primary strategy for psychological well-being. These results suggest the need for responsive models of care that integrate spiritual and community-based strengths while addressing barriers to formal service utilization.

Funding
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QoL/Rehabilitation

ASSOCIATIONS BETWEEN FATIGUE AND CLINICAL, SOCIODEMOGRAPHIC AND LIFESTYLE FACTORS IN AN INTERNATIONAL COHORT OF ADOLESCENT CHILDHOOD CANCER SURVIVORS: OUTCOMES FROM THE PACCS STUDY

K.E. Thornton [1], S.H. Johansen [2], W. Hang Deng [2], M.H. Larsen [2], C.S. Rueegg [10], M. Bratteteig [9], M. Grydeland [9], L. Thorsen [3], E.H. Larsen [2], P.M. Lähteenmäki [5], M. Götte [11], H.B. Larsen [8], C. Schindera [7], I.K. Torsvik [4], E. Ruud [6], S.A. Anderssen [9], H.C. Lie [2]

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BACKGROUND-AIM

Fatigue is a common, late effect among childhood cancer survivors (CCS), but remains poorly understood, especially in young CCS. We therefore assessed the associations between fatigue and multiple clinical, sociodemographic, health, and lifestyle factors in adolescent CCS.

METHODS

Our international sample included 495 CCS, aged 9-18 years, from Norway, Finland, Denmark, Germany and Switzerland through the international Physical Activity in Childhood Cancer Survivors (PACCS) study. Fatigue was measured using PedsQL multi-dimensional fatigue scale (0-100, higher score=less fatigue). Clinical variables (diagnosis, time since treatment, relapse) were collected from patient records. Sociodemographic (age, sex, parental education), and perceived health and lifestyle factors (body mass index, physical activity, sedentary time, sleep, screen use) were collected via self-report. Physical activity (PA) was additionally measured using accelerometers (ActiGraph). Associations between fatigue and these factors were explored with sequential, multivariable linear regression models.

RESULTS

We included 495 CCS with a mean age of 12.2 (SD 2.2, range 9-18 years); 51% were Norwegian, 48% female, and 46% were diagnosed with Leukemia. Mean fatigue score was 74.9 (SD 15.5). Lower fatigue scores were associated with younger age at study (β= -1.29, 95% CI, -1.90 - -0.67, P<0.001), sleeping within recommended range during weekdays (β=4.19, 95% CI,1.25 - 7.12, p=0.005) , and "Good/very good" self-rated health (β=20.16, 95% CI,13.76 - 26.57, p<.01). There was also a tendency for higher moderate-to-vigorous levels of PA to be associated with lower fatigue (β=0.07, 95% CI,-0.00 - 0.15, p=0.056). The model accounted for 19% of the variance in fatigue scores.

CONCLUSION

Our study helps understand the relationship between fatigue and numerous clinical, health- and lifestyle factors, including modifiable ones such as sleep and PA. However, our comprehensive model explained only a modest amount of variance in fatigue, urging further studies to identify high risk populations and modifiable factors to include in interventions.

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QoL/Rehabilitation

ASSOCIATIONS BETWEEN PHYSICAL FITNESS AND FATIGUE IN ADOLESCENT CHILDHOOD CANCER SURVIVORS: THE PACCS STUDY

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BACKGROUND-AIM

Fatigue is a prevalent and distressing late effect among childhood cancer survivors (CCSs), yet its physiological determinants remain unclear. This study examined the associations between key domains of physical fitness, physical activity, and fatigue in adolescent CCSs and explored whether these associations differ from those observed in healthy controls.

METHODS

This cross-sectional analysis was part of the international multicenter Physical Activity and Fitness in Childhood Cancer Survivors (PACCS) study. Physical fitness was evaluated by cardiopulmonary exercise testing (VO2peak), isometric muscular strength (knee extension, chest press, and handgrip) and 1-minute sit-to-stand test. Physical activity was measured by accelerometry. Associations between physical fitness, physical activity and fatigue were examined using multivariable mixed-effects linear regression models.

RESULTS

A total of 123 CCSs (mean age 13.5±2.5 years, 6.7±3.5 years post-treatment)
and 99 controls (mean age 13.1±2.6 years) were included. Higher VO2peak (β=0.66, 95% CI 0.14-1.17, p=0.012) and greater muscular strength (β=5.85, 95% CI 0.63-11.08, p=0.028) were associated with less fatigue in CCSs, whereas activity levels were not associated with fatigue. No significant differences were observed in the association between physical fitness or physical activity measures and fatigue between CCSs and controls.

CONCLUSION

Fatigue in adolescent CCSs is associated with physical fitness rather than physical activity level, and the relationships between fitness and fatigue are similar in survivors and healthy controls. These findings highlight the relevance of physical fitness assessment in survivorship research and warrant further investigation of fitness-targeted approaches to fatigue in adolescent CCSs.

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QoL/Rehabilitation

CHRONIC PAIN, PSYCHOSOCIAL, COGNITIVE AND SOMATOSENSORY FUNCTION IN ADOLESCENTS FOLLOWING CHILDHOOD HAEMATOLOGY MALIGNANCIES

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BACKGROUND-AIM

Chronic pain is reported by 11-44% of childhood cancer survivors (CCS), but highlighted areas of need include: multidimensional pain assessment; clinical screening tools; understanding relationships between pain, psychological function and comorbidities; and identifying points for intervention.[1] Pain has also been associated with risk of impaired neurocognition in CCS[2, 3]. Neuropathy assessments (Pediatric-modified Total Neuropathy Scale, Ped-mTNS) [4] and quantitative sensory testing (QST)[5-8] have identified alterations related to prior chemotherapy. Relationships with type and distribution of pain require further evaluation.
Aims:
- report incidence, type, and intensity of pain
- explore relationships between pain and psychosocial and cognitive function
- quantify altered somatosensory function and associations with Ped-mTNS score

METHODS

Adolescents (14-18yrs) >5 years post treatment were recruited from the Haematology Late Effects Clinic, Great Ormond Street Hospital.
Following parental and participant consent/assent, evaluation included:
• pain history
• validated questionnaires: quality of life; multidimensional fatigue, pain catastrophizing, anxiety, and resilience; parental report (child pain intensity, quality of life, parental catastrophizing)
• neuropathy screening: Ped-mTNS
• NIH Toolbox Cognition Battery: executive function, processing speed
• somatosensory function: QST (static thermal & mechanical thresholds, dynamic allodynia; hand, foot ± pain site)[8]
NHS Ethics ID:18/LO/0533 Approval:24/4/2018 & 04/09/2024
Protocol: doi.org/10.1186/ISRCTN64983308

RESULTS

Preliminary data include 65 adolescents (60% male; mean 16.7, sd 0.9yrs; family-reported ethnicity 62% White) with prior haematological malignancies (72% ALL).
Recurrent pain was reported by 69%, with higher incidences compared to an English school survey[9] of: backache 34% vs 6.2%; headache 28% vs 12.3%; and multisite pain 35% vs 17.8%. Lower limb pain was reported by 25%, and 20% felt pain was related to prior treatment. Questionnaires reflected moderate-severe levels of: average pain intensity (VAS >4/10) in 21%; reduced quality of life (PedsQL<70) in 32%; fatigue in 68%; trait anxiety (STAI>18) in 50%; and pain catastrophising (PCS-C>15) in 39% of adolescents and 50% of parents. Higher pain intensity correlated with reduced quality of life, and increased pain catastrophizing and anxiety.
NIH Toolbox Cognitive Battery data (subset n=17) was mostly within the normative range. However, processing speed scores were lower, negatively associated with pain intensity, and this association was mediated by poor sleep function.
A Ped-mTNS score of 5 and above suggested neuropathy in 31%, and was associated with higher pain intensity, and reduced mechanical detection and vibration sensitivity. Sensitivity to pressure pain was reduced compared to controls.[8] Dynamic cool and/or brush allodynia on the hand/foot was reported by 10-16%.
Data collection and analysis, including associations with prior treatment, is ongoing.

CONCLUSION

Chronic pain, impaired quality of life, anxiety, and fatigue were common and inter-related co-morbidities in adolescents with prior haematological malignancies. Symptoms and signs suggestive of neuropathy were reported by over one-quarter, and ongoing analysis is evaluating associations with type of pain and prior treatment. Earlier recognition and interventions for pain, sleep disturbance, psychosocial and cognitive difficulties, may improve longer-term outcome.

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References

1. Schulte, F.S.M., et al., *Pain in long-term survivors of childhood cancer: A systematic review of the current state of knowledge and a call to action from the Children's Oncology Group.* Cancer, 2021. **127**(1): p. 35-44.
2. Tonning Olsson, I., et al., *Pain and functional outcomes in adult survivors of childhood cancer: A report from the St. Jude Lifetime Cohort study.* Cancer, 2021. **127**(10): p. 1679-1689.
3. Partanen, M., et al., *Neuropathic pain and neurocognitive functioning in children treated for acute lymphoblastic leukemia.* Pain, 2022. **163**(6): p. 1070-1077.
4. Kandula, T., et al., *Pediatric chemotherapy induced peripheral neuropathy: A systematic review of current knowledge.* Cancer Treat Rev, 2016. **50**: p. 118-128.
5. Tutelman, P.R., et al., *Long-term alterations in somatosensory functioning in survivors of childhood cancer.* Pain, 2022. **163**(6): p. 1193-1205.
6. Lieber, S., et al., *Small-fiber neuropathy and pain sensitization in survivors of pediatric acute lymphoblastic leukemia.* Eur J Paediatr Neurol, 2018. **22**(3): p. 457-469.
7. Ruscher, V., et al., *Long-term small-fiber neuropathy and pain sensitization in survivors of pediatric acute lymphoblastic leukemia after stem cell transplantation.* J Cancer Res Clin Oncol, 2020. **146**(8): p. 2143-2152.
8. Verriotis, M., et al., *Phenotyping peripheral neuropathic pain in male and female adolescents: pain descriptors, somatosensory profiles, conditioned pain modulation, and child-parent reported disability.* Pain, 2021. **162**(6): p. 1732-1748.
9. Gobina, I., et al., *Prevalence of self-reported chronic pain among adolescents: Evidence from 42 countries and regions.* Eur J Pain, 2019. **23**(2): p. 316-326.

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QoL/Rehabilitation

CO-CREATING PSYCHOSOCIAL INFORMATION AND SUPPORT RESOURCES WITH CHILDHOOD, ADOLESCENT, AND YOUNG ADULT CANCER SURVIVORS (CAYACS), THEIR SUPPORT NETWORK MEMBERS, AND THE HEALTHCARE PROFESSIONALS WHO WORK WITH THEM

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BACKGROUND-AIM

With the number of childhood, adolescent, and young adult cancer survivors (CAYACS) growing rapidly, there is a pressing need for accessible tools to support psychosocial health and well-being during survivorship. While physical late effects are often managed in survivorship care, psychosocial needs and support remain largely unmet. Personalized digital tools, such as phone apps, can help bridge this gap and better meet these identified needs by providing accessible, tailored information and resources. We aimed to 1) identify CAYACS' psychosocial information and support needs, to guide development of resources that address them and 2) co-create the framework for how CAYACS will interact with a new digital tool, including prioritization of tailored resources based on their self-reported needs.

METHODS

The project's user panel (CAYACS, their support network members, and healthcare professionals) engaged in a series of four virtual co-creation workshops. Across workshops, the panel was prompted to provide input on which psychosocial topics are most important to address, what the application should look like, and mechanisms through which the application could tailor the information and resources provided to the individual user.

RESULTS

User panel participation fluctuated and the number of participants ranged from 15 to 35 across workshops. Preliminary analyses showed that fatigue, relationships, fertility, sexual health, cognition, and psychosocial health were identified as key topics to include in the app. CAYACS also indicated needs for information about what these late effects are, how to manage them, and support for explaining their experience of these late effects to other people. Initial analyses also showed that CAYACS' identified needs and preferences differed across subgroups of the user panel (e.g., indicated needs from CAYACS differed from that of healthcare providers). Narrative analysis, with attention to similarities and differences across stakeholder groups, will be used to expand on the initial themes identified and results will be discussed.

CONCLUSION

Co-creation is a feasible and highly valuable method for developing digital tools to support the growing CAYACS population. This work highlights the importance of including people with lived experience in the development of tools meant to support them.

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QoL/Rehabilitation

CO-CREATION OF WEB-BASED INFORMATIONAL CONTENT FOR SUPPORT NETWORK MEMBERS OF CHILDHOOD, ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS: THE E-QUOL PROJECT

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BACKGROUND-AIM

Support network members of childhood, adolescent, and young adult cancer survivors (CAYACS)—including parents, siblings, partners, grandparents, and close friends—report substantial unmet information and support needs. These needs extend across several areas, such as cancer-related health information, psycho-emotional support, follow-up care, finances, education, and sexuality. Despite this, in Europe, there is currently no centralized and tailored resource available to address these needs. As part of the European e-QuoL (Equality in Quality of Life) initiative, this project's objective is to develop multilingual, evidence-based online informational content for support network members, co-created with them to support their long-term well-being.

METHODS

The project follows a four-phase co-creation process. Phase 1 involved identifying key topics through systematic reviews and a cross-sectional European e-QuoL Needs Study among CAYACS and their support network members. Phase 2 included drafting informational content by experts in pediatric oncology, psychosocial care, and survivorship, written in accessible language. Phase 3, currently ongoing, uses focus groups with support network members (N = 13) to evaluate the relevance, clarity, completeness, and usefulness of preliminary content. Eligible participants are aged ≥16 years, English-speaking, and living in Europe. Phase 4 will consist of a Delphi study with English-speaking international experts and support network members aged ≥16 years to iteratively refine the content until ≥75% consensus on relevance, clarity, completeness, and credibility of information is reached. Quantitative data will be analysed using descriptive statistics, and qualitative data using qualitative content analysis.

RESULTS

Qualitative content analysis of focus group data will provide insights into participants' perceptions of the preliminary content and inform its tailored refinement. Through iterative rounds, the Delphi study is expected to achieve consensus on the final content, integrating the perspectives of support network members and the expertise of the expert panel.

CONCLUSION

This project addresses the unmet needs of CAYACS' support network members by co-creating a central, multilingual, evidence-based online informational content. The co-creation approach enhances the relevance and quality of the information. Dissemination through the PanCare website in multiple languages will promote accessibility across Europe and thereby support survivorship care by amplifying the voices of support network members who play an important role in survivors' long-term well-being.

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QoL/Rehabilitation

EARLY ADAPTED PHYSICAL ACTIVITY (APA) INITIATION AS A KEY PREDICTOR OF POST-TREATMENT CONTINUATION IN ADOLESCENT AND YOUNG ADULT(AYA) CANCER SURVIVORS : A RETROSPECTIVE STUDY OF THE HOPAYA DAY HOSPITAL EXPERIENCE

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BACKGROUND-AIM

Adolescents and young adult cancer survivors (AYACS) face a heightened risk of physical and psychosocial sequelae, necessitating tailored care from the end of treatment. In 2022, the Léon Bérard Centre (CLB) launched the HOPAYA day hospital, a multidisciplinary program designed to assess AYACS' needs six months post-treatment and refer them to targeted care, particularly adapted physical activity (APA). HOPAYA combines medical and psychological consultations with an APA assessment, followed by referral to a local network (gyms, associations) or internal CLB care for nearby patients. This program aims to detect early sequelae and structure APA pathways, acting as a motivational lever for long-term engagement.
To retrospectively analyze the APA follow-up of patients included in HOPAYA, assessing their participation in APA before and after treatment, factors associated with continuing APA post-treatment (distance, pathology, sequelae, socioeconomic constraints), the impact of referral to local facilities or CLB care, and barriers to participation.

METHODS

This single-center retrospective study included 86 AYACS (aged 15–25) treated for cancer and followed at HOPAYA between 2022–2024. Data were extracted from medical records, focusing on APA follow-up during treatment, completion of an APA assessment during the day hospital, continuation of APA post-treatment (CLB or partner network).
Recorded data were clinical (cancer type, early sequelae), social (school/work schedules) and geographical (distance to CLB) characteristics.

RESULTS

Of the 86 patients, 78 (91%) underwent an APA assessment at HOPAYA, among them 38 (49%) had prior APA follow-up during treatment and 40 (51%) were introduced to APA at HOPAYA.
16 patients (21%) continued APA post-treatment, exclusively among those with prior APA follow-up (16/38 vs. 0/40, $p<0.001$). Barriers to APA continuation included geographical distance, lack of prior APA experience during treatment and socioeconomic constraints

CONCLUSION

This study highlights three critical insights:
- Early APA integration during treatment is decisive for post-treatment adherence, preventing physical deconditioning and loss of movement habits.
- HOPAYA acts as a motivational lever: The structured day hospital visit reinforces APA engagement by formalizing referrals and raising awareness of its benefits.
- AYA-specific barriers (e.g., school/work conflicts, limited local APA programs) underscore the need for tailored solutions (extended-hour APA sessions, digital APA programs or tele-rehabilitation

HOPAYA demonstrates that systematic, early APA integration—coupled with a structured day hospital assessment—significantly improves post-treatment adherence. Future steps include expanding local partnerships to reduce geographical barriers, piloting remote APA evaluations (e.g., via questionnaires) to assess distant practice levels and advocating for AYA-specific APA programs, systematically offered from diagnosis to survivorship.
This approach could transform long-term outcomes for AYACS by embedding APA as a cornerstone of cancer care.

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QoL/Rehabilitation

EFFECTS OF SOCIAL DETERMINANTS OF HEALTH ON ENTRANCE AND RETENTION OF A SURVIVORSHIP CLINIC

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BACKGROUND-AIM

Primary Children's Hospital (PCH) cares for a pediatric cancer population living in an extremely large geographical catchment area of approximately 400,000 square miles across six states in the Intermountain West. This population encompasses children and families who live in vastly different communities and are exposed to varying social determinants of health (SDOH). SDOH may influence access to essential healthcare for this population, including annual follow-up in our childhood, adolescent, and young adult cancer survivorship clinic (SVC). In this study, we describe the rates of entrance and retention to our clinic as they relate to SDOH.

METHODS

The code status of variables of race/ethnicity, rural-urban commuting area (RUCA), child opportunity index (COI) (defined as low, moderate, or high), language, sex, insurance type (public, self-pay, private), and distance to PCH (< 100 miles vs > 100 miles) were compared between pediatric oncology patients seen at PCH between 2020-2025 (n=7772) and patients seen in the SVC from 2022-2025 (n=637) to assess entrance rates. Retention rates and associations with SDOH variables were also compared between the cohort of patients who had a single SVC visit (n=385) vs. multiple SVC (2+) visits (n=263). Statistical evaluation was completed using chi-square analysis.

RESULTS

All patients entering the SVC were less likely to have a low COI compared to moderate and high COI (5.0% vs 7.8% and 8.8%, $p < 0.001$), public insurance compared to self-pay or private (4.9% vs 8.2% and 9.2%, $p<0.001$), or live farther away (6.3% vs 8.6%, $p<0.01$). However, COI ($p=0.78$), insurance ($p=0.88$), and distance ($p=0.45$) did not affect retention rates. RUCA status, race/ethnicity, language, and sex did not appear to have an impact on entrance or retention rates to the SVC. Disease-specific populations also exhibited differences among SDOH groups and entrance to the SVC. Patients with public insurance were less likely to enter the SVC with diagnoses of leukemia (20% vs 33% and 34%, $p<0.001$), lymphoma (17% vs 38%, $p<0.01$), sarcoma (1.3% vs 4.8% and 6.4%, $p=0.001$), and Wilms tumor (6.2% vs 7.7% and 15.9%, $p=0.03$). Those who lived farther away were less likely to enter with diagnoses of brain tumors (0.4% vs 6.4%, $p<0.001$), leukemia (22% vs 32%, $p<0.01$), and lymphoma (18.9% vs 37.4%, $p=0.02$). Patients with lymphoma also were less likely to enter SVC if they had low COI (3.6% vs 31.7% and 37.3%, $p<0.001$). Patients with sarcoma who identify as other than non-Hispanic White were also less likely to enter SVC ($p=0.04$). RUCA status, language, and sex did not appear to have an impact on entrance to the SVC when considering primary cancer diagnosis. No variables of SDOH in this study were found to significantly affect retention when assessed by primary cancer diagnosis.

CONCLUSION

SDOH, particularly COI, distance to treating facility, and insurance type, can impact entrance into SVC and may result in a significant barrier to accessing care for childhood cancer survivors. However, retention has not shown to be definitively affected by SDOH, indicating patient commitment to the clinic once entered and the value of the services being provided in SVC for these patients and families. This study underscores the need for further studies to evaluate interventions to mitigate the effects of SDOH on entrance to survivorship for this population.

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QoL/Rehabilitation

EMOTIONAL AND BEHAVIORAL ISSUES AND QUALITY OF LIFE IN PEDIATRIC SUBJECTS WITH A HISTORY OF ACUTE LYMPHOBLASTIC LEUKEMIA

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BACKGROUND-AIM

Survival in pediatric ALL has markedly improved, shifting clinical attention toward long-term cognitive and psychosocial outcomes. International literature reports heterogeneous findings, frequently describing higher vulnerability in females and in children diagnosed at younger ages. The aim of this cross-sectional observational study was to evaluate cognitive functioning, psychiatric/emotional profile and quality of life in a local cohort of pediatric ALL survivors, with specific focus on comparative analyses across subgroups defined by sex, age at evaluation and age at ALL diagnosis.

METHODS

Twenty-three subjects aged 6–17 years, off therapy for at least one year and followed at Spedali Civili of Brescia, were enrolled. Standardized tools were administered: Wechsler scales for cognitive assessment; K-SADS interview, CBCL and YSR for psychiatric and emotional screening; PedsQL for perceived quality of life; Body Uneasiness Test or Human Figure Drawing for body image. Data were analyzed descriptively and comparatively across sex, age at evaluation, and age at diagnosis.

RESULTS

Mean global IQ was within the normal-to-high range, contrary to numerous studies that show an IQ within normal range but slightly lower than healthy controls. No substantial cognitive differences emerged between subgroups.
Internalizing symptoms were more frequent than externalizing ones. Anxiety disorders represented the most common findings, particularly separation anxiety in younger children and generalized or social anxiety in adolescents, who more often presented with subthreshold symptoms. Depressive traits, although mostly subclinical, were more common in adolescents. Unlike many literature reports, externalizing disorders and PTSD were absent.
In self-administered questionnaires, parents of school-aged children reported more symptoms than parents of adolescents, but adolescents themselves reported more symptoms than their parents. Comparative analyses highlighted a higher prevalence of internalizing symptoms in subjects with an early ALL diagnosis and in in males, differing from much of the literature that often reports greater female vulnerability. Across almost all subgroups, adolescents reported more symptoms than their parents, indicating partial divergence between external observation and self-perception.
Body image concerns were generally non-clinical in adolescents, whereas projective drawings in younger children often suggested insecurity and inhibition.
Overall PedsQL scores indicated unsatisfactory quality of life, with lower values in emotional and school domains. Both parent- and self-reports showed poorer perceived quality of life among males and early ALL diagnosis.

CONCLUSION

Although cognitive functioning was globally preserved, a meaningful proportion of pediatric ALL survivors displayed emotional vulnerabilities and reduced perceived well-being. Subgroup comparisons revealed patterns partially divergent from existing literature, particularly a higher prevalence of symptoms in males and in subjects who received an early diagnosis. Differences between parent and patient perceptions underline the importance of multi-informant assessment. These findings support the systematic integration of psychological evaluations into oncological follow-up programs to promote individualized and comprehensive survivorship care. Further multicenter studies are needed on larger case series, including different types of cancer and treatment protocols.

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QoL/Rehabilitation

EMOTIONAL WELL-BEING AND EDUCATIONAL EXPERIENCES IN ADULTHOOD AFTER CHILDHOOD CANCER: A POPULATION-BASED STUDY.

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BACKGROUND-AIM

Late effects of childhood cancer treatment may affect emotional well-being and academic achievement later in life. Educational disruptions during and after treatment may have lasting consequences for adult functioning. This population-based study aimed to describe emotional well-being and educational outcomes among adult survivors of childhood cancer (CCS) in Iceland.

METHODS

The study included CCS aged ≥18 years diagnosed before age 18 between 1981 and 2011 and treated with chemotherapy and/or radiotherapy within the pediatric oncology service in Iceland (N=121); 115 met the inclusion criteria. Hospital records were combined with self-reported data from an online questionnaire. Data were collected between 2016 and 2019. Emotional well-being was assessed using the Depression, Anxiety and Stress Scale – 21 Items (DASS-21). Educational experiences were assessed using self-reported data. Descriptive statistics and cross-tabulations examined associations between emotional well-being and educational variables.

RESULTS

Of 100 individuals who agreed to participate, 88 completed the DASS-21 (37 [42%] females), with a mean age of 29.8 years (SD = 7.5; range 19–48). Over one-third were diagnosed before 5 years of age. Most participants reported emotional symptom levels within the normal range; however, elevated symptoms (mild or higher) of depression, anxiety, and stress were reported by 35.2%, 30.7%, and 28.4%, respectively. No significant differences in emotional well-being were observed across age at diagnosis or age at assessment. Learning difficulties following treatment were reported by 52.3%. There was a statistically significant association between learning problems following treatment and DASS-21 subscales results, with higher levels of educational problems associated with an increased likelihood of elevated DASS-21 scores (all $p < .001$; 2 missing values).

CONCLUSION

Emotional distress and self-reported learning difficulties are common among adult CCS. These findings underscore the importance of ongoing follow-up, including systematic assessment of emotional well-being and learning-related challenges and timely referral to appropriate support services.

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QoL/Rehabilitation

EVALUATION OF THE IMPACT OF AN EXERCISE AND PHYSICAL ACTIVITY THERAPY SERVICE FOR ONCOLOGY AND HAEMATOLOGY PATIENTS

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BACKGROUND-AIM

Children treated for cancer are at risk of significant treatment related morbidity such as cardiovascular disease, diabetes, depression and secondary cancers. Being physically active and participating in sport and exercise, something often taken for granted, are essential components of normal life for children and young people. However, evidence indicates that over 60% of childhood cancer survivors do not meet recommended UK exercise guidelines. We introduced the role of an Exercise and Physical Activity Therapist to a large Oncology Unit to support and enable this patient group to engage in physical activity, with benefits both during treatment and long term. An evaluation study of the first twelve months of the service was conducted to demonstrate the impact of the role on levels of physical activity and health benefits with the aim of supporting continuation of the role.

METHODS

A mixed methods study used a quantitative and qualitative approach:
• Review of the literature
• Research interviews with clinicians who had experience of the role
• Analysis of secondary anonymised quantitative patient data including demographics, pre and post assessment of functional testing and Paediatric Quality of life (PedQL) questionnaires.

RESULTS

143 patients (92 boys, median age 13-18 years, age range 7 - 18 years) were seen in the first year. Service users were seen for active support, remote support or advice and guidance. 36% of patients had a malignant haematology diagnosis. 58% who received active support had a neuro-oncology diagnosis. Patients were at various stages of their clinical journey. 49% of patients were referred to the service to improve mobility and general quality of life or increase their exercise tolerance and conditioning.
The evaluation showed statistically significant improvement in physical strength and stamina using functional testing ($p = <0.05$) and quality of life from the PedQL scores ($p = <0.01$). Participation in PE at school and compliance with government guidelines for physical activity doubled during the duration of therapy.
The service complimented that delivered by physiotherapists but was shown to attend to unmet need in the patient population.

CONCLUSION

This study demonstrates the importance of embedding physical exercise (early) in the clinical journey of patients undergoing treatment for childhood cancer. The introduction of a structured exercise programme has the potential to improve both stamina and strength and double a patient's participation in exercise related activity. Such improvements are likely to impact the long-term morbidity associated with childhood cancer, benefiting both the individual and global health economy. These results are a powerful justification for continuation of the role.

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QoL/Rehabilitation

FROM SURVIVORSHIP TO EMPLOYMENT: A MIXED-METHODS EVALUATION OF A VOCATIONAL INTEGRATION PROGRAM FOR CAYAC SURVIVORS

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BACKGROUND-AIM

Childhood, adolescent, and young adult cancer (CAYAC) survivors often experience long-term physical, cognitive, and psychological late effects that can hinder workforce entry, increasing the risk of unemployment, underemployment, health-related absenteeism and reduced financial autonomy. Recent evidence-based guidelines emphasize incorporating occupational monitoring and support within multidisciplinary follow-up care. Vocational integration programs are recognized as key components of survivorship care, with potential to enhance psychosocial well-being.
This study aimed to describe the implementation of a multidisciplinary vocational integration program for CAYAC survivors in Turin (Italy) and to explore participants' perceptions of its impact on employment integration, including perceived barriers and facilitating factors.

METHODS

The multidisciplinary intervention included individualized career guidance based on vocational profiling and functional assessment, soft-skills training, structured paid internship placement, and workplace integration, followed by outcome evaluation and support for employment transition. A mixed-methods approach was employed, combining the SF-12 (12-Item Short Form Health Survey) questionnaire to assess health-related quality of life with semi-structured thematic interviews.

RESULTS

Between January 2021 and January 2025, 23 CAYAC survivors participated in the projects, of whom thirteen joined the study (mean age at diagnosis: 12.9 years; mean age at interview: 27.2 years). Participants reported over 40 late effects, mostly of moderate severity. SF-12 revealed reduced physical (mean 45.2) and mental (mean 43.5) component scores. A three-words reflection task indicated that the program was rewarding (11/13) and stimulating (10/13), while a minority described it as demanding (3/13) or limiting (1/13), highlighting a generally positive experience.
Thematic analysis identified eight macro-themes: 1) Motivations and expectations: gain work experience, develop skills, desire for autonomy and financial independence; 2) Impact of cancer on workability: physical and cognitive late effects created barriers to professional engagement and occupational choice, sometimes resulting in employment loss due to physical impairments; 3) Accessibility and task adequacy: individualized tasks matched skills and physical limitations, promoting job stability; 4) Self-esteem and self-efficacy: participation fostered personal growth, confidence, and independence; 5) Value of vocational support: career guidance and skill-building were perceived as impactful and novel; 6) Social support and workplace integration: relationships with tutors, peers, and supervisors enhanced autonomy and belonging; 7) Double-edged peer/family support: support was helpful but overprotection could limit autonomy; 8) Critical aspects of social support: structured guidance and relational support were key to positive outcomes; lack thereof hindered self-efficacy.
Overall satisfaction was high (mean 8.3/10), with participants highlighting motivation, confidence, employability, and the central role of social support and flexibility.

CONCLUSION

This pilot study provides preliminary evidence that a tailored, multidisciplinary vocational intervention is feasible and valued by CAYAC survivors. Such programs may support the transition to employment, address psychosocial challenges, and enhance overall health-related quality of life. Larger, longitudinal studies are needed to confirm these findings.

Table 1: Socio-demographic and medical characteristics of participants.

	No.	%
Sex		
Female	6	46.2
Male	7	53.8
Age at diagnosis		
0–4	2	15.4
5–9	0	0.0
10–14	6	46.2
≥15	5	38.4
Age at the interview		
20–24	5	38.4
25–29	6	46.2
30–34	1	7.7
≥35	1	7.7
Off-therapy		
<2000	1	7.7
2000–2009	2	15.4
2010–2014	4	30.8
≥2015	6	46.2
Education		
Middle school	4	30.8
High school	8	61.5
University	1	7.7
Diagnosis		
Acute Leukaemia (Myeloid or lymphoblastic)	5	38.4
CNS Tumours	4	30.8
Others *	4	30.8
Chemotherapy	12	92.3
Radiotherapy	6	46.2
Neurosurgery	4	30.8
Hematopoietic stem cell transplantation	2	15.4
Disease Relapse	1	7.7
Late effects **		
Patients with ≥ 1 LE	12	92.3
Grade 1	7	17.5
Grade 2	25	62.5
Grade 3	8	20.0
Second Neoplasm	2	15.4

**Ewing Sarcoma, Immature Teratoma, Nasopharyngeal Rhabdomyosarcoma, and Epstein-Barr Virus-Associated Hemophagocytic Lymphohistiocytosis.*
***According to the National Cancer Institute's Common Terminology Criteria for Adverse Events (CTCAE) version 4.03.*

Table 1: Socio-demographic and medical characteristics of participants.

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QoL/Rehabilitation

GLOBAL PRIORITIZATION OF SURVIVORSHIP SYMPTOMS BY HEALTHCARE PROVIDERS TO INFORM A STANDARDIZED PRO ASSESSMENT TOOL

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BACKGROUND-AIM

We recently developed a 141-item symptom instrument, the Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events for Childhood Cancer Survivors (PRO-CTCAE-SCC). This study aims to identify survivorship-relevant, clinically-manageable, and assessment-important symptoms rated by healthcare providers across 21 countries on 4 continents to inform the global use of the PRO-CTCAE-SCC.

METHODS

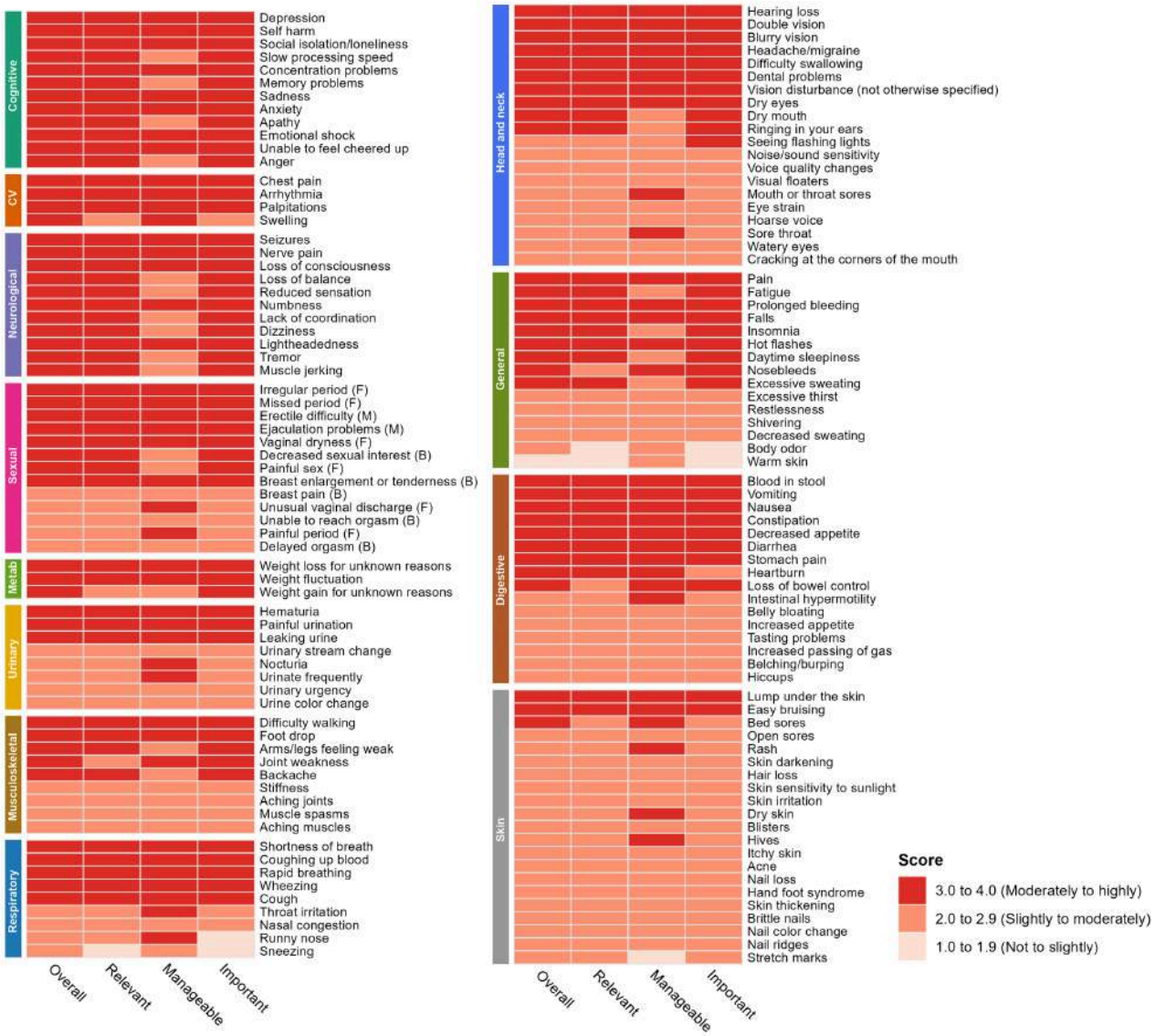
Participants included 232 providers involved in childhood cancer survivorship care, recruited from ISLCCC meeting attendees and the St Jude Global Alliance database. We grouped 141 symptoms into 12 domains (cardiovascular, digestive, head/neck, musculoskeletal, sexual, cognitive/psychological, respiratory, neurological, urinary, metabolic, skin, general). Two survey forms were used, each including approximately 70 items across six domains. Providers were randomly assigned to complete one form, rating each symptom across 3 dimensions (survivorship relevance, clinical manageability, assessment importance) using a 4-point ordinal scale. A dimension-specific score for each symptom was calculated as the mean of all provider responses. An overall score was derived by averaging the scores of 3 dimensions. Providers reported personal characteristics, including attained age, sex, practice type (oncologists, primary care physicians [PCPs], nurses), practice years, and practice focus (more research vs clinical care). Country-level factors from the 2019 WHO dataset included age-standardized all-cancer mortality, physician density, and out-of-pocket expenditure as a % of total health expenditure (OOP%). Associations between each symptom rating and personal and country factors were assessed using chi-square tests.

RESULTS

The response rate was 71%. Respondents were predominantly oncologists (67%), followed by nurses (22%) and PCPs (9%). Most providers practiced in high-income countries (87%), countries with age-standardized cancer mortality >100 per 100,000 population (86%), and health systems with ≤20% OOP% (74%). Across symptoms, survivorship relevance and assessment importance dimensions received consistently higher scores than clinical manageability (see Figure). The highest-scoring domains were cognitive/psychological (3.4), cardiovascular (3.4), and neurological (3.4). The top-rated symptoms included depression (3.7), self-harm (3.7), and social isolation/loneliness (3.5) in cognitive/psychological domain; chest pain (3.6), arrhythmia (3.5), and palpitations (3.4) in cardiovascular domain; and seizures (3.7), nerve pain (3.6), and loss of consciousness (3.6) in neurological domain. Most symptoms were rated consistently across physician (85-94%) and country (75-86%) factors. Symptoms showing significant associations across 2-3 dimensions were uncommon (1.4-3.5% by provider and 2.1-8.5% by country factors). Cardiovascular symptoms were emphasized in higher-mortality or lower-resource settings, whereas symptoms from head/neck, musculoskeletal, and sexual domains were prioritized in lower-mortality or higher-capacity health systems ($P<0.05$).

CONCLUSION

Provider and country factors had limited influence on symptom prioritization across survivorship relevance, clinical manageability, and assessment importance. The largely consistent prioritization across providers, with expected context-specific variation, provides key evidence for the next phase of clinical validation of the PRO-CTCAE-SCC tool for global survivorship care.



Notes:

1. CV: Cardiovascular; Metab: Metabolic; Relevant: Survivorship Relevance; Manageable: Clinical Manageability; Important: Assessment Importance.
2. The heatmap displays descriptive ratings and does not indicate statistical significance.
3. Each cell represents an individual symptom.
4. Overall represents the mean of the three dimension-specific scores for each symptom.
5. Dimension-specific scores were calculated as the mean of provider responses per symptom.
6. Symptom domains are ranked by the overall scores of all symptoms within each domain. Individual symptoms of each domain are ranked according to their overall scores.
7. Similar color intensity across symptoms indicates consistency in provider ratings.

Figure: Provider ratings across three dimensions (survivorship relevance, clinical manageability, and assessment importance) of 141 symptoms spanning 12 symptom domains

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QoL/Rehabilitation

HEALTH-RELATED SOCIAL NEEDS IN A SINGLE-CENTER COHORT OF CHILDHOOD CANCER SURVIVORS

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BACKGROUND-AIM

Childhood cancer survivors (CCS) face a high burden of late effects, with marked poverty-associated disparities in health outcomes and adherence to survivorship guideline-based care. To eliminate these disparities, clinically modifiable poverty measures beyond the conventional proxies of public insurance or low-income ZIP code must be identified. Health-related social needs (HRSN), including food, housing, transportation, or utility insecurity, are specific, modifiable poverty measures that represent potential targets for intervention to improve survivorship outcome disparities. The burden of HRSN in pediatric survivorship is unknown; here, we aim to characterize the prevalence of HRSN among a regional cohort of CCS.

METHODS

Cross-sectional survey of pediatric (<18-year-old) or adult (≥18-year-old) CCS who completed cancer-directed therapy ≥2 years prior at 7 Northeastern US centers. We report preliminary data from participants enrolled at the lead site—a large academic pediatric cancer center—from April to December 2025. We initially conducted sequential recruitment of all eligible participants at in-person clinic visits. Interim analysis of the first 100 patients identified underrepresentation of historically marginalized groups, aligned with prior literature demonstrating disparities in survivorship care access. The study was amended to add remote recruitment via text message, email, or phone, using a quota sampling strategy to match racial, ethnic, and language demographics of patients treated at our center. Adult CCS or parents/guardians of pediatric CCS consented and electronically completed a single-timepoint Household Survey in English, Spanish, Portuguese, or any language with an interpreter, including validated measures of HRSN. Diagnosis, treatment, and late effects were abstracted from the medical record.

RESULTS

Among 223 eligible patients, 152 (68%) consented to participate; consent rate was 98% for in-person approaches and 29% for remote approaches. Our analytic cohort consisted of 150 participants who contributed surveys (119 in-person and 31 remotely), with 147 (98%) providing complete HRSN data. Pediatric CCS (n=48) had a mean age of 12.5 years and adult CCS (n=102) 26.0 years. Mean time from end of therapy was 11.6 years (7.2 years for pediatric CCS and 13.6 years for adult CCS). A majority (60%, n=90) of participants had a history of hematologic malignancy; 51% (n=76) were female; self/parent-identified race and ethnicity included 5% (n=8) Asian, 8% (n=12) Black, 18% (n=27) Hispanic, and 64% (n=96) White; and 12% (n=17) with a primary language other than English, matching the demographics of children with cancer treated at our center.
One-quarter (25%, n=37) of participants reported at least one HRSN. The most common HRSN domains were food insecurity (18%, n=27) and housing insecurity (11%, n=17). HRSN were more frequently reported by patients recruited remotely (52%, n=16/31) than in-person (18% n=21/119).

CONCLUSION

Our findings demonstrate that over a decade from the end of therapy, one in four CCS reports modifiable HRSN—exposures linked with adverse health outcomes in the general population. This study is ongoing at 6 regional survivorship centers; when fully accrued, we will test associations between HRSN and 1) treatment-related late effects, 2) cardiovascular risk conditions, and 3) survivorship care engagement, to identify specific outcomes and care delivery metrics amenable to HRSN-targeted intervention to improve equity in survivorship.

Table 1. Sociodemographic, disease, and treatment characteristics of a single-center childhood cancer survivorship cohort.

	N = 150[a]
Approach Method[b]	
Email	6 (4%)
In-person	119 (79%)
Text Message	25 (17%)
Age Cohort	
Pediatric (<18 year old) CCS	48 (32%)
Adult (≥18 year old) CCS	102 (68%)
Age (years)	21.68 (9.36)
Sex	
Female	76 (51%)
Male	71 (48%)
Nonbinary	2 (1%)
(Missing)	1
Race/Ethnicity	
Asian	8 (5%)
Black or African-American	12 (8%)
Hispanic or Latino	27 (18%)
More than one race/ethnicity	6 (4%)
White	96 (64%)
(Missing)	1
Primary Language	
English	127 (85%)
More than one language	6 (4%)
Other	3 (2%)
Portuguese	1 (1%)
Spanish	13 (9%)
Insurance Type	
Any private insurance	101 (68%)
Sole public insurance	31 (21%)
Other insurance (military/other)	9 (6%)
Don't know	8 (5%)
(Missing)	1
Annual Household Income as Percentage of Federal Poverty Level (FPL)	438.05 (385.97)
(Missing)	18
Annual Household Income <200% FPL	35 (27%)
(Missing)	18
Number of Individuals in Household	3.30 (1.44)
Diagnosis Type	
Heme Malignancy	90 (60%)
Neuro Oncology	14 (9%)
Solid Tumor	46 (31%)
Time Off Therapy (years)	11.55 (7.66)
Intensity of Treatment 3.0 Rating Score[c]	
1	3 (2%)
2	56 (38%)
3	74 (50%)
4	16 (11%)
(Missing)	1
Presence of Any Treatment-Related Late Effects	131 (87%)

[a] n (%); Mean (SD)

[b] In-person participants were approached sequentially at oncology clinic visits. Remotely recruited participants were randomly sampled within demographic quotas to ensure the overall cohort matched the racial and ethnic and primary language demographics of patients treated at our cancer center.

[c] Kazak et al, *Pediatric Blood and Cancer* 2012.

Sociodemographic, disease, and treatment characteristics of a single-center childhood cancer survivorship cohort.

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QoL/Rehabilitation

INFORMATION AND SUPPORT NEEDS OF SUPPORT NETWORK MEMBERS OF CHILDHOOD, ADOLESCENT, AND YOUNG ADULT CANCER SURVIVORS ACROSS EUROPE: RESULTS FROM THE E-QUOL PROJECT

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BACKGROUND-AIM

Members of the social support network of childhood, adolescent, and young adult cancer survivors (CAYACS) — including relatives and other close ones — often face unmet information needs, which can negatively affect quality of life and create long-term psychological burden. Most research to date has focused on the immediate family in Western countries. This study aims to assess the prevalence of information and psychosocial support needs among the broader support network across Europe and to examine disease-related and personal characteristics associated with these needs.

METHODS

This study used data from the cross-sectional e-QuoL Needs Study among CAYACS and their support networks. Support network members completed an adapted version of the Childhood Cancer Survivor Study–Needs Assessment Questionnaire (CCSS-NAQ) available in 15 languages and covering 12 domains: psycho-emotional consequences, health system concerns, cancer-related health information, general health, survivor care and support, surveillance, coping and life perspective, fiscal concerns, relationships, sexuality, services, and spirituality. Logistic regression analyses were used to identify disease-related and personal characteristics associated with the needs.

RESULTS

In total, 580 support network members from 19 European countries who completed ≥50% of items in at least one CCSS-NAQ domain were included in the analysis (78% parents, 9% siblings, 5% friends, 3% grandparents, 3% partners, 3% other relatives and professionals). Most were female (83%), half were aged ≥46 years, and 30% were close to a survivor who was >10 years post-diagnosis. Most participants reported at least one need in every domain except spirituality. The most prevalent needs were regarding cancer-related health information (89% indicated a need), psycho-emotional consequences (89%), and health system concerns (84%). Females were most likely to report unmet needs in psycho-emotional (OR 2.80; 95% CI 1.51–5.18), health system concerns (OR 1.90; 95% CI 1.05–3.43), surveillance (OR 2.92; 95% CI 1.69–5.04), coping (OR 2.04; 95% CI 1.17–3.56), and relationship (OR 2.47; 95% CI 1.37–4.46) domains. Individuals close to a survivor with neuro-cognitive late effects showed higher odds of unmet needs in psycho-emotional (OR 2.42; 95% CI 1.03–5.67), health system concerns (OR 3.56; 95% CI 1.56–8.11), cancer-related health information (OR 2.93; 95% CI 1.19–7.19), general health (OR 4.47; 95% CI 2.14–9.36), survivor care and support (OR 3.01; 95% CI 1.53–5.93), surveillance (OR 2.54; 95% CI 1.24–5.23), coping (OR 2.48; 95% CI 1.22–5.01), fiscal concerns (OR 3.81; 95% CI 1.83–7.94), relationships (OR 3.29; 95% CI 1.56–6.97), and services (OR 2.32; 95% CI 1.18–4.56) domains.

CONCLUSION

Broad informational and psychosocial support needs persist among members of CAYACS' support networks long after diagnosis. Future initiatives should address these needs by developing tailored, accessible tools that provide reliable, evidence-based information for support network members.

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QoL/Rehabilitation

NARRATIVE RECONSTRUCTION (NR) THERAPY FOR PARENTS OF CHILDHOOD CANCER SURVIVORS: A TRAUMA FOCUSED PROTOCOL

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BACKGROUND-AIM

Parents of childhood cancer survivors (CCS) frequently experience persistent psychological distress during survivorship. We have recently shown that nearly one-third of parents in our survivorship clinic screened positive for PTSD or reported trauma-related symptoms, highlighting the need for targeted trauma-informed interventions. Parental trauma in pediatric oncology is often prolonged and cyclical, shaped by ongoing medical follow-up and fear of recurrence, leading to fragmented narratives and emotional ambivalence. We aimed to describe the adaptation of Narrative Reconstruction (NR) therapy for parents of CCS and to demonstrate its feasibility through an illustrative clinical case from our initial case series.

METHODS

NR is a structured trauma-focused intervention integrating gradual exposure, affect labeling, and narrative reorganization. The protocol was adapted to address parental identity, ambivalent relationships with medical staff, and chronic uncertainty in survivorship. The intervention consisted of 16 weekly sessions delivered within a pediatric Hemato-oncology setting. We present a case of a mother of an adolescent CCS who completed the adapted NR protocol. Psychological distress was assessed pre-treatment, post- and three months follow-up, using the PROMIS depression and anxiety measures and the PC-PTSD and PCL-5 screening tool. The effect of the intervention was further assessed using the Narrative Emotional Integration Interview (NEII) semi-structured interview.

RESULTS

The adapted NR intervention enabled gradual integration of a focal trauma memory within the broader autobiographical narrative. Therapy focused on reconstructing the memory of the trauma event, facilitating exposure, affect labeling, and meaning-making processes. Findings from the NEII reflected a shift from fragmented and intrusive recollections toward increased acceptance, reduced self-blame, and enhanced reflective capacity. A central clinical marker of change involved transformation of pre-sleep trauma imagery: initially experienced as recurrent nightly flashbacks, the imagery evolved into internally guided narrative processing during therapy and was no longer reported by treatment completion, suggesting improved containment and integration of the traumatic memory.
Preliminary quantitative measures supported these clinical observations. Trauma-related symptoms decreased substantially, with PCL-5 scores declining from 18 at baseline to 4 post-treatment and 2 at three-month follow-up, and PC-PTSD scores decreasing from 2 at baseline to 0 at follow-up. Depressive and anxiety symptoms showed transient increases during therapy, followed by partial stabilization at follow-up, consistent with emotional activation during trauma processing.

CONCLUSION

Adapting NR therapy for parents of CCS may offer a promising trauma-focused approach within survivorship care. Embedding narrative-based interventions in pediatric oncology settings may help address the chronic and relational nature of medical trauma while supporting long-term psychological adjustment among parents.

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QoL/Rehabilitation

OCULAR LATE EFFECTS AMONG SWISS CHILDHOOD CANCER SURVIVORS

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BACKGROUND-AIM

Childhood cancer survivors (CCS) are at risk of developing delayed ocular late effects, but little is known about their impact on health-related quality of life (HRQOL). In this nationwide study, we report the prevalence of ocular late effects in CCS and study the associations of ocular late effects with HRQOL.

METHODS

This study included CCS from the Swiss Childhood Cancer Survivor Study (SCCSS), who were registered in the Swiss Childhood Cancer Registry, diagnosed before the age of 21 years, resident in Switzerland, and alive and aged ≥16 years at the time of the study. Siblings of the CSS served as a control group. We retrieved HRQOL (SF-36), ocular late effects (blindness in any eye, glaucoma, cataract, retinal disorder, dry eye disease, and eye movement disorder) and sociodemographic information using questionnaires. Data on cancer diagnoses and treatment originated from the Swiss Childhood Cancer Registry. We ran t-tests to test for differences in prevalence of ocular conditions between CCS with different tumor types (retinoblastoma, CNS tumors, other cancers) and siblings. We fitted multivariable linear regression models including CCS and siblings, using weights to account for the underrepresentation of siblings. All models were adjusted for sociodemographic factors (age at study, sex, parental education, region). For CCS only, we also adjusted for clinical factors (age at cancer diagnosis, cancer type) to quantify treatment-related risks in CCS.

RESULTS

With an overall response rate of 59%, we included 2419 participants (48% women; median age 25 [IQR 20-31]) with data on HRQOL and ocular conditions. Nineteen percent (456/2419) of CCS and ten percent of siblings (82/796) reported at least one ocular condition (p<0.001). CCS had more often dry eye disease (9%, n=211 vs 7%, n=53), followed by blindness (8%, n=193 vs 3%, n=26), eye movement disorder (4%, n=96 vs 1%, n=9), cataract (3%, n=72 vs 0%, n=0), retinal disorders (<1%, n=23 vs <1%, n=3) and glaucoma (<1%, n=19 vs <1%, n=2) than their siblings. Ocular conditions were most frequent among CCS of retinoblastomas (79%, 30/38), followed by CNS tumors (38%, 138/363) and other tumors (14%, 288/2012), with higher prevalence across all tumor types compared with siblings (all p<0.01). Mental and physical HRQOL scores were lower among both CCS and siblings with ocular conditions than those without ocular conditions (mean difference in physical HRQOL -2.2, 95%CI -3.3 to -1.1; mental HRQOL -2.3, -3.5 to -1.1). In multivariable logistic regression, radiation therapy (OR 1.45, 1.18 to 1.78), surgery (OR 1.39, 1.11 to 1.73) and hematopoietic stem cell transplantation (OR 3.41, 1.79 to 3.62) were associated with ocular late effects in CCS. Several ocular conditions, including blindness (-2.0, -3.6 to -0.4), glaucoma (-6.5, -11.2 to -1.9), cataract (-4.8, -7.2 to -2.4), retinal disorder (-6.1, -10.2 to -2.0), dry eye disease (-4.5, -5.9 to -3.1) and eye movement disorder (-4.0, -6.2 to -1.9) were associated with lower physical HRQOL in CCS, while only dry eye disease (-3.4, -4.7 to -2.0) was associated with lower mental HRQOL.

CONCLUSION

We observed reduced physical HRQOL among CCS with ocular late effects, such as cataracts, retinal disorders, dry eye disease and eye movement disorders. CCS who experience ocular complications should be counseled about possible therapeutic measures during follow-up care.

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QoL/Rehabilitation

PARENTS' EXPERIENCES OF A SUPPORT INTERVENTION FACILITATING (RE)INTEGRATION INTO DAYCARE FOR PRESCHOOL CHILDREN DURING PEDIATRIC CANCER TREATMENT: A QUALITATIVE INTERVIEW STUDY

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BACKGROUND-AIM

Due to cancer treatment, preschool children experience disruptions to everyday life, including withdrawal from daycare, which can affect early development. Following changes in isolation guidelines in Denmark, preschool children are now allowed to attend daycare during cancer treatment. Accordingly, a daycare support intervention was developed to facilitate (re)integration during cancer treatment to support preschool children's social development and well-being. The aim of this study was to explore parents' experiences of (re)integrating preschool children into daycare during cancer treatment following a daycare support intervention.

METHODS

A qualitative interview study exploring parents' experiences of a daycare support intervention facilitating (re)integration into daycare during pediatric cancer treatment. The multimodal intervention included: (1) An initial meeting involving parents, daycare staff, and hospital professionals to prepare all parties for the (re)integration process; (2) Education of daycare staff about childhood cancer and related care needs; and (3) Weekly supportive telephone calls to parents over a 12-week period. Data consisted of semi-structured interviews with 21 parents of preschool children (aged 0–6 years) (re)entering daycare during cancer treatment. Interviews were analyzed using a thematic approach.

RESULTS

The findings comprise three main themes: (1) Sharing the responsibility for (re)integration, (2) Collaboration with the daycare, and (3) Everyday life in daycare during cancer treatment. Hospital involvement was experienced as central to preparing daycare staff, legitimizing parents' concerns related to their child's (re)integration during cancer treatment, and fostering trust among both parents and daycare staff. Parents described the (re)integration process following the intervention as characterized by shared responsibility. When the child reentered daycare, clear and responsive communication with daycare staff was central to parents' sense of safety, whereas inconsistent communication undermined parental trust. Furthermore, a key challenge for parents concerned whether agreed-upon adaptations were consistently implemented in everyday daycare practice. Some parents related these challenges to staffing constraints within daycare settings. Adhering to cancer treatment imposed a need for parents to remain flexible and make day-to-day decisions regarding their child's daycare attendance. Despite disrupted attendance, parents described that their child spoke enthusiastically about friends, play, and daycare as a motivating part of their everyday life. Although (re)integration required considerable parental effort, parents viewed returning to daycare during treatment as a worthwhile investment in their child's development and well-being.

CONCLUSION

With appropriate support, preschool children can attend daycare during cancer treatment. The findings highlight parents' experiences of (re)integration into daycare during cancer treatment and contribute knowledge on how (re)integration can be supported for preschool children and their families.

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QoL/Rehabilitation

QUESTION PROMPT LISTS REGARDING POST-TREATMENT FERTILITY IN ADOLESCENT AND YOUNG ADULT PATIENTS WITH CANCER.

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BACKGROUND-AIM

Fertility issues are a major issue for adolescent and young adult (AYA) patients with cancer. Some patients are uncertain about how and to whom they should direct questions related to fertility. To address this gap, we aimed to create question prompt lists (QPLs) to support AYA patients in asking fertility-related questions in advance during consultations with medical professionals (MPs).

METHODS

Semi-structured interviews lasting 30-60 minutes were conducted between Aug. 2023 and Mar. 2024, with patients aged <40 years diagnosed with cancer at aged < 25 years. Explanatory documents were mailed in advance, and written informed consent was obtained. Patients were also asked to provide information regarding diagnosis, treatment details, age at diagnosis, whether fertility preservation information was provided before treatment, and whether fertility preservation was performed. Before each interview, the study purpose was re-explained and consent was reconfirmed. Interviews were conducted online and focused on fertility-related informational needs and barriers to accessing information. All interviews were audio-recorded after confirmation from participants, and qualitative content analysis was performed. Qualitative content analysis was performed by extracting units of meaning and classifying them based on shared elements. These findings were used to develop the QPL

RESULTS

Sixteen patients who had completed treatment participated in this study (male/female: 8/8; solid tumor /hematologic tumor: 8/8). Data were organized into four major categories: (1) specific fertility-related informational needs, (2) methods for obtaining information, (3) readiness to receive information (e.g., disease status, age, and partner status), and (4) issues emerging after treatment (e.g., post-treatment sexual life, late effects, financial issues, work-life balance, etc.). Based on these findings, diagnosis and treatment, related content was added, and narratives were converted into a 37-item questionnaire. The final QPL comprised seven sections presented as follows: A. About consultation B. Fertility/Pregnancy, C. Fertility testing, D. Sexual life during/after treatment, E. Treatment for infertility, F. Responses to being informed that having children is difficult, and G. Use of preserved sperm/eggs. Usage instructions were added to the pamphlet. The final version was reviewed by six survivors with treatment experience and 11 MPs.

CONCLUSION

Although QPLs have been developed for various diseases and have demonstrated usefulness, some patients hesitate to ask questions. Barriers include difficulty identifying appropriate MPs, insufficient MP knowledge, and inadequate preparation for fertility-related discussions. The developed QPL is currently being evaluated in an observational study involving survivors who are more than five years post treatment. Its effectiveness and remaining challenges will be assessed.

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QoL/Rehabilitation

SETTING UP A PEER DISCUSSION GROUP FOR AYAS IN REMISSION FROM CANCER : FEEDBACK AND OUTLOOK

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BACKGROUND-AIM

The post-cancer period, as a continuation of the illness and treatment journey, represents a phase of increased vulnerability, with well-documented psychosocial and mental health challenges, particularly among young adults. Completion of cancer treatment is associated with multiple transitions, including physical and psychological recovery, management of late effects, identity- and meaning-related concerns, and re-engagement with social, familial, educational, and professional roles. In response to the need for tailored post-cancer care, we aimed to evaluate the implementation of peer discussion groups as a psychotherapeutic support intervention complementary to individual therapy.

METHODS

Since 2023, two discussion group programs have been offered on a voluntary basis to cancer survivors aged 18–30 years. One program targeted survivors in the early post-treatment phase (within five years of treatment completion), while the second was designed for long-term survivors (more than five years post-treatment). All groups were facilitated by a psychologist. Each program consisted of cycles of five 90-minute sessions, held monthly. Evaluation focused on feasibility, participant engagement and satisfaction, and identification of key themes emerging from group discussions. An exploratory comparative analysis between the two group formats was also conducted.

RESULTS

Eight group cycles were conducted, involving a total of 63 participants (mean 7.9 participants per cycle). Participant engagement was high, and the intervention was generally perceived as beneficial, particularly in terms of emotional support, normalization of shared experiences, and the development of a sense of belonging within a peer group. Practical aspects of the intervention (format, duration, frequency, and setting) were rated positively. Core themes included experiences of illness and treatment, physical and cognitive late effects (e.g. fatigue, disability, memory and attentional disorders), relational changes and feelings of being out of sync with peers, identity-related concerns, body image and intimacy issues (premature ageing, others' perceptions, sexuality, fertility), redefinition of life goals, fear of relapse and long-term risks, and medical follow-up. Both commonalities and specific differences were observed between the two programs.

CONCLUSION

Peer discussion groups for young adult cancer survivors are feasible and appear to meet a clear need for psychotherapeutic support in the post-cancer period, both shortly after treatment completion and in long-term survivorship. This group-based approach represents a valuable complement to individual supportive care in oncology.

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QoL/Rehabilitation

SEXUAL HEALTH RELATED QUALITY OF LIFE OUTCOMES IN ADULT SURVIVORS OF CHILDHOOD CANCER USING EUROPEAN ORGANISATION FOR RESEARCH AND TREATMENT OF CANCER–QUALITY OF LIFE QUESTIONNAIRE SEXUAL HEALTH (EORTC QLQ-SH22)

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BACKGROUND-AIM

Childhood cancer survivors (CCS) are at risk of a wide spectrum of chronic health conditions. Despite advancements in understanding of these chronic health conditions, there is limited data available regarding sexual functioning of adult survivors of childhood cancers.

METHODS

Participants were adult survivors (>18years) of childhood cancers enrolled in After Completion of Treatment (ACT) Clinic, Tata Memorial Hospital . Survivors enrolled on the study were administered 22-item European Organisation for Research and Treatment of Cancer–Quality of Life Questionnaire Sexual Health (EORTC QLQ-SH22) between October 2024 and December 2025. Data regarding demographics, treatment exposures, pubertal and menstrual history, relationship status, sexual practices and dysfunction, and fertility outcomes were collected from the patient records. Individual domain and composite scores of SHQ22 were calculated. A linear regression model was used to examine the association between the natural logarithm transformation of the scores and the independent variables of interest.

RESULTS

178 survivors were enrolled on the study, 153 (85.9%) men and 25 (14%) women, median age of 24 (18 – 41) years. Diagnoses in 118(66.2%) was haematolymphoid malignancy and 60(33.8%)solid tumours. 36(19.5%) are married, 29(15.7%) are in a committed relationship, 120(64.9%) identified themselves as single. 5(2.7%) survivors had endocrine dysfunction , 60(32.4%) had met high-risk criteria of developing gonadotoxicity of which 13 reported inability to sire a pregnancy . Composite SHQ score for the entire cohort is 28.2 (Mean SD 14.5). Females reported higher SHQ score [33.6(18.4) vs 27.3(13.6), p=0.045]. Survivors of solid malignancies had higher scores than haematolymphoid cancers [32 (15.3) vs 26.3(13.4), p=0.01]. Age at diagnosis, chemotherapy exposure and pelvic radiation did not have significant impact on sexual health.

CONCLUSION

Significant sexual dysfunction is common in adult survivors of childhood cancer. A better understanding of association of sexual dysfunction and physical and psychological risk factors in adult survivors of childhood cancer is needed.

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QoL/Rehabilitation

SHAPED - HEALTH BEHAVIOUR INTERVENTIONS TO SUPPORT CHILDREN AND YOUNG PEOPLE POST-CANCER TREATMENT: A RAPID SCOPING REVIEW

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BACKGROUND-AIM

Children and young people (C&YP) who have undergone cancer treatment may exhibit decreased physical activity (PA) levels (Braam, 2016), increased risk of malnutrition ranging from undernutrition to obesity (Revuelta Iniesta, 2019) and worsened mental health (Friend et al., 2018). Despite the reported benefits of promoting health behaviour in C&YP post-treatment to improve physical and mental health, and reduce the reoccurrence of secondary cancers, support is not offered as part of routine paediatric care (Zhang et al, 2017). As such, C&YP report unmet psychosocial needs (Lewandowska et al., 2021) and worries around returning to 'normal life' (Kleinlugtenbelt et al., 2025). Therefore, the aim was to conduct a scoping review to examine literature on health behaviour interventions for C&YP aged 0-18 following cancer treatment to identify key characteristics and effectiveness of existing interventions and highlight gaps to inform future intervention design.

METHODS

A rapid scoping review was conducted in accordance with JBI guidelines and PRISMA-ScR reporting guidelines. Seven academic and seven grey literature databases were searched for eligible studies published between 2000 and 2025. Inclusion criteria included any intervention targeting a health behaviour (e.g. PA, diet, mental wellbeing) for C&YP age 0-18 who were post-cancer treatment. Data were extracted relating to the content of the intervention, behaviours focused on, population, effectiveness, and feasibility.

RESULTS

In total, 5253 studies were screened with 20 meeting the inclusion criteria. Most interventions were PA-focused (n = 15/20; 75%) and used either a randomised controlled trial (RCT) design (n = 11/20; 55%) or a single-arm pre-post feasibility design (n = 8/20; 40%). There were limited examples of multi-modal interventions integrating PA alongside diet (n = 3/20; 15%) or psychosocial support (n = 2/20; 10%). Most studies exploring acceptability or feasibility reported figures above 70%. Improvements in PA (e.g., MVPA, step count), physical health (e.g., aerobic fitness, physical functioning), and psychosocial outcomes (e.g., quality of life, self-efficacy) were most commonly reported. Strengths of the studies included the use of theory in 60% of interventions, the integration of social support opportunities with families and peers, and using a technology-enhanced delivery mode including websites, apps, and activity monitoring. Authors of the included interventions recommended future practice to use a multi-disciplinary team to co-design multi-modal programmes that are tailored to C&YP and involve families and peers. Future research studies are recommended to use theory-based frameworks, deliver multi-site interventions with more diverse groups, collect long-term follow-up data, conduct cost-effectiveness analyses, and further explore the effectiveness of gamification and digital-focused interventions for C&YP post-cancer treatment.

CONCLUSION

The rapid scoping review identified that health behaviour interventions are feasible for C&YP during survivorship and can support improvements in physical and psychological wellbeing. However, more evidence on the impact of multi-modal interventions, integrating PA alongside other health behaviour support, is needed in the future. Co-designed, theory-driven, individually tailored interventions are needed in the future to improve multiple health behaviours for C&YP post-cancer treatment.

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QoL/Rehabilitation

SHAPED - SERVICE DEVELOPMENT OF A HEALTHY BEHAVIOURS PROGRAMME FOR CHILDREN AND YOUNG PEOPLE POST CANCER TREATMENT

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BACKGROUND-AIM

Approximately 1,900 children (0-14 years old) and 2,300 young people (15-24 years old) are diagnosed with cancer each year in the UK (Cancer Research UK, 2025). The use of complex treatments (e.g., chemotherapy, radiotherapy) has led to paediatric cancer survival rates doubling since the 1970s (Cancer Research UK, 2024). However, cancer treatment for children and young people (C&YP) can negatively impact health and future chronic conditions (Oeffinger et al., 2006). Interventions to support physical activity (PA) and nutrition in C&YP can positively influence physical and mental health (Demers et al., 2021). Nevertheless, some C&YP and their families report insufficient support post-treatment (Wakefield et al., 2013). This aligns with the top 10 research priorities for childhood cancer (CCLG, 2023) and guided the development of this project. The SHAPED project aims to co-design a multi-modal health behaviours programme for C&YP aged 0-19 years who have completed their cancer treatment to support physical and mental health and wellbeing. An overview of the SHAPED project methodology will be presented.

METHODS

The project consists of five interlinked work packages (WP's):
WP1: Scoping review of existing post-cancer health behaviours programmes for C&YP.
WP2: Online survey and interviews with healthcare professionals (HCPs) to understand current experiences and future preferences for post-cancer support for C&YP.
WP3: This WP will involve sending C&YP 'ideas kits' where participants will be asked to draw, use stickers, or make an item to represent activities they currently do, what they would like to do in the future, and how they can be supported to engage in healthy behaviours. Follow-up interviews with C&YP and their parents or carers will be conducted to explore their ideas kit creations in more detail. Parents and carers will also have the opportunity to complete a separate online survey to understand their specific support needs and any challenges they have faced.
WP4: Interviews with community stakeholders (e.g. teachers, sports coaches) with experience of supporting C&YP during and after cancer treatment will be carried out to understand how they currently provide support, preferences for future changes, and barriers to engagement.
WP5: The findings from WP's 1-4 will then inform three workshops to be held with C&YP, their families, HCPs, and community stakeholders to co-design a new support programme. These workshops will cover topics such as: (1) Health behaviour priority; (2) Overcoming barriers; (3) Programme outcomes; (4) Delivery; (5) Accessibility; (6) Programme name and presentation.

RESULTS

As the project is ongoing, an overview of the SHAPED methodology will be discussed, in reference to the five WPs. Within this, insights will be provided on project progress, preliminary findings, and data collection challenges so far.

CONCLUSION

The SHAPED project will combine findings from five WPs to co-design a multimodal support programme for C&YP post-cancer treatment, to support their physical and mental health. A logic model for a new support programme will be developed and included within a future funding application for Phase 2 of the project, to pilot and evaluate the co-designed service for C&YP post-cancer treatment.

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QoL/Rehabilitation

SHAPED: HEALTHCARE PROFESSIONALS' ROLE IN SUPPORTING CHILDREN AND YOUNG PEOPLE TO ENGAGE WITH HEALTH BEHAVIOURS POST-CANCER TREATMENT

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BACKGROUND-AIM

Children and young people (C&YP) diagnosed with cancer experience increased survival rates due to advances in treatment (Cancer Research UK, 2024; 2025). However, treatment can result in physiological and psychological challenges that extend into adulthood (Wong et al., 2025; Lee et al., 2023). Despite receiving extensive care during treatment, C&YP often experience insufficient post-treatment support, with families reporting unmet needs and limited awareness of available resources (Wakefield et al., 2013; Paul et al., 2025). Many C&YP with cancer express interest in physical activity (PA), weight management, and diet support (Pugh et al., 2017), which may improve C&YP's mental and physical health (Fletcher et al., 2018; Singh et al., 2023). Families report having positive relationships with their HCPs during cancer treatment (MacKay et al, 2025) and evidence suggests HCPs are well placed to promote health behaviours post-cancer treatment (Hardcastle et al, 2018). Guided by the COM-B model (Michie et al, 2014), this study aimed to explore HCPs perceptions about supporting C&YP to engage in health behaviours after cancer treatment.

METHODS

A mixed method approach was conducted using an online survey of 79 paediatric oncology HCPs and semi-structured follow-up interviews with 15 HCPs working in the UK. The 17-item survey explored HCPs experience working in paediatric oncology, current health behaviour support provided, and gaps for future support. Quantitative data were analysed descriptively with qualitative survey responses analysed using content analysis. The interviews explored these topics in further detail and were analysed using Framework Analysis.

RESULTS

Over 50% of participants had 10+ years of experience working in paediatric oncology. Respondents worked across six broad job roles. Mental health support was the only health behaviour that over half of participants reported delivering often, typically by HCPs who were more experienced (10+ years' experience). Support was mostly delivered using referrals to other specialists or charities, or though families. Participants reported a lack of support to promote physical activity, diet, mental wellbeing, and peer support post-treatment. The interviews identified four higher-order themes and 10 lower-order themes relating to barriers faced by HCPs and perceived barriers for C&YP's engaging with health behaviours. Key influences of behaviour were the need to acknowledge the physical and psychological impact of cancer treatment on C&YP, limited resources for HCPs, and challenges of undoing negative health habits developed during treatment. HCPs aimed to support C&YP to return to their normal activities using family-centred multi-modal care.

CONCLUSION

This research identified that health behaviour support is currently lacking or delivered inconsistently and is dependent upon a HCP's experience and confidence. Future support programmes need to be family-centred, offering options around when and how support is provided. Support needs to consider the impact of cancer treatment on families and acknowledge how this influences engagement with support. Future research needs to explore C&YP's perspectives on what a health behaviour support programme should look like, and how it should be delivered. Using co-design to develop a support programme is required to ensure C&YP and HCPs engage with the programme.

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QoL/Rehabilitation

UNDERSTANDING AND ADDRESSING LATE EFFECTS IN AYA CANCER SURVIVORS: THE LATE-AYA EUROPEAN PROJECT

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BACKGROUND-AIM

Adolescents and young adults (AYAs) who survive cancer often face long-lasting physical, psychological, and social late effects (LE) that significantly impact their quality of life (QoL), despite increasing survival rates. Traditional survivorship models tend to prioritize disease- and treatment-related outcomes, while underrepresenting broader dimensions of QoL such as daily functioning, psychological well-being, and life engagement. To better capture the heterogeneity of survivorship experiences, LATE-AYA focuses on two AYA subgroups: individuals diagnosed with cancer between 15–25 years and those diagnosed between 26–39 years of age. Innovative, holistic approaches are needed to systematically capture the multidimensional nature of QoL and to guide supportive care interventions aimed at improving QoL throughout the survivorship trajectory.

METHODS

LATE-AYA is a multidisciplinary project involving 19 partners and 7 patient recruitment centres across Europe. The project aims to develop a digitally supported, holistic model of survivorship care with a primary focus on QoL in AYA cancer survivors. Digital tools are used for the longitudinal collection of patient-reported outcomes and QoL indicators across physical, emotional, social, and functional domains. These tools are embedded within a broader intervention framework designed to identify QoL challenges, support personalized follow-up, and facilitate timely supportive care. Data from digital assessments are combined with clinical and qualitative inputs to provide a comprehensive understanding of QoL determinants and their evolution over time. Patient and stakeholder engagement is central to the project to ensure that QoL priorities are defined from the survivor perspective. The study follows a two-stage design: Stage 1 will model LE and QoL trajectories using clinical and patient-reported data, while Stage 2 will evaluate a personalized, digitally supported intervention through a randomized controlled trial.

RESULTS

LATE-AYA is expected to improve the identification of QoL challenges and unmet needs that are often under-recognized in routine follow-up. Anticipated outcomes include enhanced patient engagement, more responsive and needs-based survivorship care, and improved QoL trajectories. Based on Stage 1 data, the project will establish a benchmark for evaluating future implementations of the intervention tools in Stage 2, contributing to the definition of QoL-relevant indicators for AYAs and informing the development of targeted interventions aimed at improving long-term well-being.

Moreover, the personalized intervention is expected to generate indirect psychoeducational effects on the survivor's social environment—including family, school, workplace, and peer networks—by strengthening communication skills and providing tools to facilitate the expression of needs, emotions, and challenges related to the cancer experience. This process aims to promote more effective reintegration into everyday social contexts.

CONCLUSION

By placing QoL at the core of survivorship care and leveraging digital tools within a holistic framework, LATE-AYA seeks to advance the understanding and management of late effects in AYA cancer survivors. This approach has the potential to support more meaningful, patient-centred outcomes and to inform future QoL-focused survivorship models at an international level.

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Subsequent Malignant Neoplasms (SMN)

ARE CLINICALLY DETECTED SUBSEQUENT BENIGN NEOPLASMS ASSOCIATED WITH AN INCREASED RISK OF SUBSEQUENT MALIGNANT NEOPLASMS?

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BACKGROUND-AIM

Childhood cancer survivors (CCSs) are at risk of developing multiple subsequent neoplasms with increasing age. Subsequent benign neoplasms (SBNs) may serve as markers of an increased risk for subsequent malignant neoplasms (SMNs). Clinically detectable SBNs are frequently identified during routine follow-up of cured patients. The primary aim of this study was to evaluate the association between clinically detectable SBNs and the risk of SMNs. The secondary objective was to compare clinically detectable SBNs with imaging-detected SBNs.

METHODS

A cohort of 4,348 CCSs followed at the Long-Term Follow-Up Clinic Prague (LCP) was analyzed. Patients had been treated for lymphomas (23%) or solid tumors (77%). Within the cohort, 162 patients developed at least one SBN and 249 patients developed at least one SMN. All SBNs were histologically confirmed, and patients with known genetic cancer predisposition syndromes were excluded. The proportions of clinically detectable versus imaging-detected SBNs were evaluated, along with SMN occurrence in each group.

RESULTS

In the LCP Subsequent neoplasm cohort 188 SBNs were identified. 60 (32%) of these were clinically detectable SBNs and 128 (68%) imaging-detected SBNs. The median time since first cancer treatment to diagnosis was 10.5 years (IQR 5.3–14.9) for clinically detectable SBNs and 18.2 years (IQR 12.7–24.9) for imaging-detected SBNs. The most common clinically detectable SBNs were lipomas (n=13, 24%) and fibroadenomas (n=10, 18%). Among imaging-detected SBNs, the most frequent diagnoses were meningiomas (n=29, 27%) and thyroid adenomas (n=23, 21%). In 37 patients (23%) with SBNs, a SMN was diagnosed; of these, 11 patients had a clinically detectable SBNs. This proportion is higher than in the overall LCP CCS cohort, where the occurrence of SMNs was 5.7%.

CONCLUSION

Imaging modalities most frequently detected anticipated SBNs as part of recommended post-radiotherapy surveillance. Palpable lesions are often not indicated for biopsy due to their clearly benign characteristics on imaging, such as lipomas and fibroadenomas. Nevertheless, patients with these benign findings may still have an increased risk of developing SMNs and therefore require closer follow-up. In a future LCP Subsequent neoplasm study, we plan to evaluate the association between benign lesions detected exclusively by imaging and the risk of SMN development.
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Subsequent Malignant Neoplasms (SMN)

IS BREAST CANCER SURVEILLANCE STILL NEEDED AFTER MODERN RADIOTHERAPY FOR WILMS TUMOR?

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BACKGROUND-AIM

Contemporary treatment of Wilms tumor (WT) achieves cure rates approaching 90%. However, long-term survivors remain at increased risk of secondary malignancies, partly attributable to the late effects of radiation therapy (RT) and specific chemotherapeutic agents. Female survivors of childhood, adolescent, and young adult (CAYA) cancers who received RT involving breast tissue are known to have a substantially increased risk of early-onset breast cancer (BC). The cumulative incidence of BC among childhood cancer survivors has been reported to range from 13% to 20% by 40–45 years of age and is associated with higher BC-related mortality compared with women diagnosed with sporadic breast cancer. Data from historical cohorts of children treated for WT indicate that RT delivered to high abdominal fields extending above the diaphragm—approximately corresponding to the anatomical level of the prepubertal nipple—is associated with an increased risk of subsequent BC. This association has been corroborated by additional studies, particularly among WT survivors, providing level B evidence supporting an elevated BC risk following irradiation of upper abdominal fields.
Given the substantial evolution of RT techniques, we performed a retrospective analysis to estimate radiation dose to the nipple/breast region in patients treated with contemporary RT and to evaluate whether BC surveillance remains justified.

METHODS

Patients with WT of any age and sex who received abdominal RT according to the SIOP-RTSG 2016 Umbrella protocol at the IRCCS Istituto Nazionale dei Tumori (Milan) between 2019 and 2025 were included. All patients underwent CT simulation, and treatment plans were generated using volumetric modulated arc therapy (VMAT) with the Eclipse planning system (version 15.6, Varian Medical Systems). Prescribed doses ranged from 14.4 to 25.2 Gy, delivered in daily fractions of 1.8 Gy.
For each patient, nipple position was identified on simulation CT images, and the corresponding radiation dose was extracted from treatment plans, with particular attention to doses ≥1 Gy.

RESULTS

Fourteen patients were analyzed (7 males and 7 females), with a mean age of 7 years (range 2–27 years) at the time of RT. Treatment was delivered in accordance with protocol guidelines, targeting either the flank or the whole abdomen while excluding the residual kidney. Thirteen patients received flank irradiation and one received whole-abdominal irradiation. In all but two patients, the radiation dose to the nipple was 0 Gy. In two patients aged 4 and 5 years, the nipple received a dose of 1 Gy.

CONCLUSION

Current breast cancer surveillance recommendations for WT survivors are largely based on cohorts treated before 2000. The 2019 guideline update issued a moderate recommendation for BC surveillance in survivors exposed to upper abdominal RT involving breast tissue at a young age. Our findings suggest that individualized breast cancer surveillance decisions may be appropriate for patients treated with modern radiotherapy techniques, rather than applying uniform screening recommendations based on historical cohorts. Detailed dosimetric assessment of actual breast tissue exposure should be incorporated into survivorship care planning.

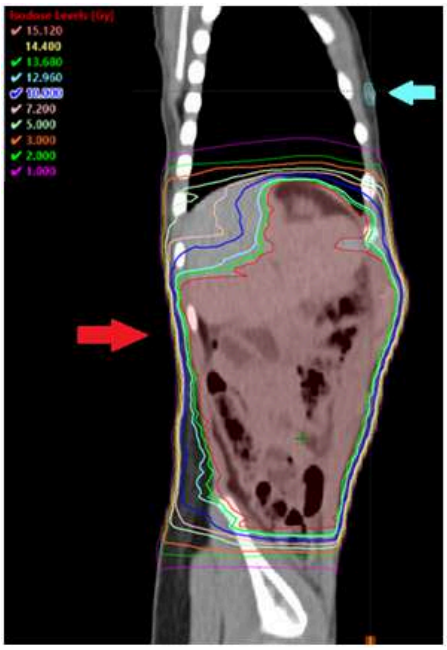

Fig.1 - Sagittal image from simulation CT scan showing dose distribution in treatment of the left flank (total dose 14.4 Gy) in a 3-year-old patient. The nipples are outlined in light blue and marked with an arrow of the same colour. The distribution of low doses is represented by the 1 Gy (pink), 2 Gy (green) and 3 Gy (orange). The volume of the PTV (Planned Target Volume) is represented by the red area and marked with an arrow of the same colour.

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Subsequent Malignant Neoplasms (SMN)

LONG TERM RISK OF SUBSEQUENT THYROID CANCER IN SURVIVORS OF CHILDHOOD AND ADOLESCENT CANCER IN EUROPE: A COHORT STUDY WITHIN PANCARESURFUP CONSORTIUM

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BACKGROUND-AIM

Subsequent thyroid cancer occurring after childhood and adolescent cancer (CAC) has been the subject of extensive research. However, most of what is known about the incidence of subsequent thyroid cancers and their risk factors comes from studies with follow-up periods covering young adulthood. and very little is known about this incidence in

older adults. We sought to study the evolution of risk into advanced adulthood, particularly in patients treated with chemotherapy.

METHODS

We studied the long-term risk of thyroid cancer in a large-scale pan-European cohort of 68,142 five-year CAC survivors from 13 European countries, more than 15,000 of whom were followed for over 30 years. We estimated the Relative Risk (RR) and the Relative Excess Risk (RER) of thyroid cancer, compared with that observed in the general population, adjusting for sex, age at CAC, year of CAC diagnostic, attained age, radiation therapy and chemotherapy.

RESULTS

The cumulative thyroid cancer incidence reached 1.8% (95%CI: 1.6 - 2.2%), at age 60 years. Overall, compared to the general population, thyroid cancer risk was 14.1 (95%CI: 12.0-16.5) times higher among male CAC survivors, and 7.4 (95%CI: 6.5-8.4) times higher among female CAC survivors, 2.1 (95%CI: 0.9-4.2) times higher if treated by surgery alone, 11.2 (95%CI: 8.4-14.6) times higher if treated with radiotherapy, 7.0 (95%CI: 5.0-9.6) times higher if treated by chemotherapy, and 16.4 (95%CI: 14.2-18.8) times higher if treated with radiotherapy and chemotherapy. We observed a plateauing in adjusted RR and an increase in RER with increasing attained age in survivors who received radiation therapy alone: the adjusted RR were, respectively 1.1 (95%CI: 0.5-2.6), 0.7 (95%CI: 0.3-1.8), and 1.2 (95%CI: 0.5-3.2) times higher at age 30-39, 40-49 and 50 years or more than at age 20-29 years. At the opposite, survivors who received chemotherapy experienced an increase in both RR and RER, without a plateau, the corresponding RR being 0.8 (95%CI: 0.3-2.0), 2.6 (95%CI: 0.8-8.4), and 13.0 (95%CI: 1.9-90.6) after chemotherapy alone and 0.7 (95%CI: 0.5-1.0), 1.5 (95%CI: 0.9-2.4), and 3.2 (95%CI: 1.5-6.9) after chemotherapy and radiotherapy.

CONCLUSION

The high risk of thyroid cancer observed in young adults having survived from a childhood cancer remains in older adults beyond 50 years. Our findings show also that not only children who have undergone radiotherapy, but also those who have undergone chemotherapy, are at increased risk for thyroid cancer until late adulthood. Further research is needed to identify which types of chemotherapy are associated with thyroid cancer risk

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Subsequent Malignant Neoplasms (SMN)

RISK OF SUBSEQUENT PRIMARY NEOPLASM IN NEUROBLASTOMA IN A COHORT OF 3123 FIVE-YEAR SURVIVORS OF CHILDHOOD AND ADOLESCENT CANCER IN EUROPE: THE PANCARESURFUP SIOPEN STUDY

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BACKGROUND-AIM

Survivors of neuroblastoma (NBL) are at risk of developing subsequent primary neoplasms (SPNs), but previous risk estimates were typically based on small studies and therefore were often not robust. The aim of our study was to quantify the risk, associated risk factors, and temporal trends of SPNs in five-year neuroblastoma survivors in the PanCareSurFup (PCSF) cohort.

METHODS

Among the 69460 PCSF cohort members, 3123 individuals had been diagnosed with neuroblastoma between 1948 and 2008 and survived for at least 5 years. Risks of SPNs were quantified using standardized incidence ratios (SIR), absolute excess risks (AER) relative risk (RR) and cumulative incidence (CumInc). Risks were stratified by four treatment eras (<1970, 1970-1979, 1980-89, 1990-2008).

RESULTS

Among the 3123 NBL survivors, in 134 developed a total of 159 SPNs. SIR for developing any SPN is 3.5 (95%CI: 2.9-4.2). The CumInc of developing any SPN was 5.3%, 9.9%, and 13.8% by attained age 40, 50 and 60, respectively.
The greatest SIRs were observed for connective and soft-tissue sarcoma (SIR =30.5, 95%CI: 17.4,49.5), thyroid carcinoma (SIR=13.9, 95%CI: 8.3,22.0) and bone sarcoma (SIR=9.9, 95%CI: 3.6,21.5). Overall, 58.9% of SPNs developed within the presumed radiation field. Use of radiotherapy increased the risk nearly 4-fold RR=3.8 (95% confidence interval (CI): 1.7-8.4), but chemotherapy did not increase risk RR=1.6 (95% CI: 0.7-3.7). SIRs and AERs for developing SPNs were similar across treatment eras (P heterogeneity=0.40).

CONCLUSION

Neuroblastoma survivors previously treated with radiotherapy are at a markedly increased risk for developing SPNs and our findings could be relevant for risk stratification in long-term follow-up

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Subsequent Malignant Neoplasms (SMN)

SECONDARY PANCREATIC DISEASES (PANCREATITIS, EXOCRINE DYSFUNCTION AND ADENOCARCINOMA) IN CHILDHOOD CANCER SURVIVORS : A REPORT FROM THE FRENCH CHILDHOOD CANCER SURVIVORS STUDY (FCCSS)

B. Fresneau [9], A. Folegatti [6], D. Rajaonera [9], R. Allodji [9], S. Bolle [8], C. Demoor [1], C. El-Fayech [9], N. Haddy [9], N. Journy [9], C. Khouri [9], L. Lenez [9], N. Sellami [8], V. Souchard [9], C. Veres [9], G. Vu-Bezin [9], C. Alapetite [5], F. Doz [4], H. Pacquement [4], M. Boussach [3], P. Fayoux [2], C. Dufour [6], V. Minard-Colin [6], I. Diallo [10], T. Pudlarz [7], F. De Vathaire [9]

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BACKGROUND-AIM

Long-term childhood cancer survivors (CCS) face increased risks of late effects, including second malignant neoplasms (SMNs). While several SMNs are well described, the risk of secondary pancreatic ductal adenocarcinoma (PDAC)in CCS remains poorly characterized, as well as the risk of other pancreatic diseases (pancreatitis and exocrine dysfunction).

METHODS

We analysed data from the French Childhood Cancer Survivors Study (FCCSS), which includes 7,670 five-year CCS diagnosed before age 21 between 1945 and 2000. Incidence of secondary PDAC and benign pancreatic disease (pancreatitis and exocrine dysfunction) was assessed through cohort linkage with National Hospital and Medical Insurance Database (SNDS) and medical records. Multivariable logistic regression models were applied to evaluate associations between treatment-related exposures and the risk of pancreatitis and/or pancreatic exocrine dysfunction. For secondary pancreatic adenocarcinoma, Fine and Gray competing risks models were used to account for death as a competing event.

RESULTS

With a median follow-up of 33 years (IQR=26-41), we identified 14 cases of PDAC and 100 cases of pancreatitis/exocrine dysfunction. PDAC occurred exclusively >20 years after the first cancer, predominantly between ages 40 and 60, with a male predominance (71%) and poor prognosis (78% mortality). Both conditions were more frequent in patients exposed to combined chemotherapy and radiotherapy. Abdominal irradiation significantly increased the risk of pancreatitis/exocrine dysfunction (RR=3.54, 95%CI=2.17–5.75), with risk evident at doses ≥1 Gy (RR=2.76, 95%CI=1.62-4.69, for patients with ≥50% of the pancreas that received ≥1 Gy compared to non-exposed patients), but no dose–response gradient (RR=3.81, 1.68 and 3.71 for patients exposed to a mean dose to the entire pancreas of 1-4.99, 5-19.99 and ≥20Gy, respectively). For PDAC, a strong positive interaction was observed between abdominal irradiation and actinomycin D (p=0.007), the sHR being 27.1 (95%CI=13.6–54.2) in patients who received both modality, and 2.2 (95%CI=0.87-4.56) in all the other patients together. We did not identify any dose-response relationship between pancreas exposure to RT and the risk of PDAC. Other chemotherapy agents were not associated with the risk of PDAC. The cumulative incidence of PDAC observed in the FCCSS cohort in patients exposed to abdominal irradiation and actinomycin was very similar to those observed in CDKN2A mutation carriers (Figure-1).

CONCLUSION

CCS are at risk of both benign and malignant pancreatic late effects decades after therapy. Abdominal irradiation is a key determinant of pancreatitis, while the interaction between irradiation and actinomycin D may drive PDAC development resulting in similar risk compared to patient with genetic conditions such as CDKN2A mutations. These findings emphasize the need for lifelong surveillance and risk-adapted follow-up strategies to enable early detection and prevention in high-risk survivors.

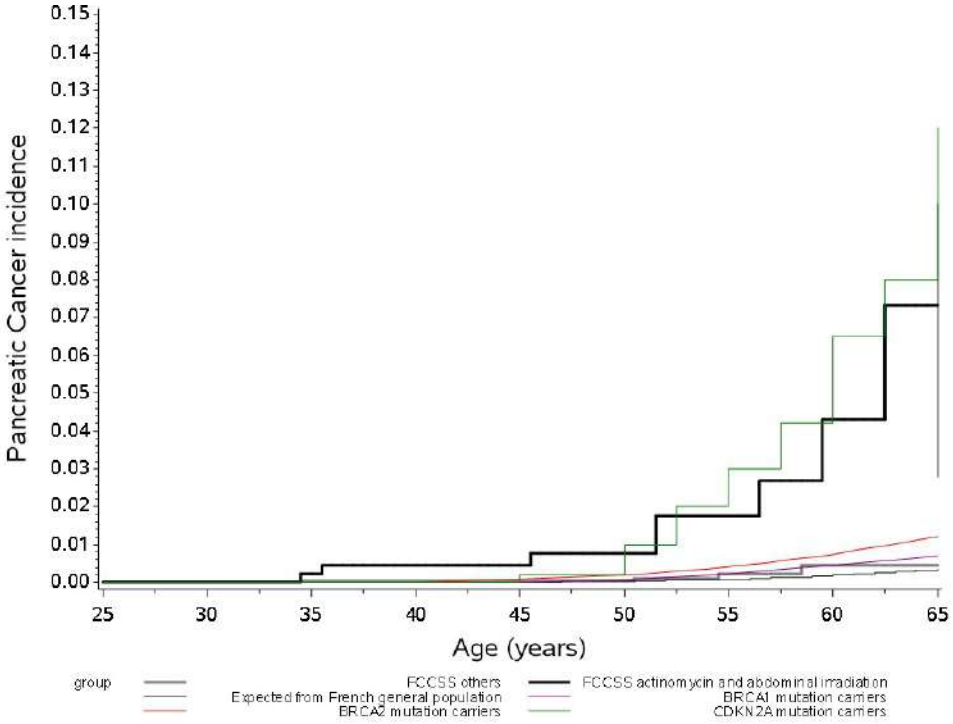

Figure-1: cumulative incidence of PDAC observed in the FCCSS cohort according to exposure of abdominal irradiation and actinomycin, compared with that expected in the general French population (French cancer registry), and in carriers of pathogenic constitutional mutations in BRCA1, BRCA2 (Katona, 2024) and CKN2A (Klatte, 2024) genes.

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Subsequent Malignant Neoplasms (SMN)

SUBSEQUENT MALIGNANT NEOPLASMS (SMNS) AMONG 56,000 CHILDHOOD CANCER SURVIVORS WITH INDIVIDUAL PATIENT DATA (IPD): THE INTERNATIONAL IPD-SMN STUDY

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BACKGROUND-AIM

Childhood cancer survivors face an elevated risk of developing subsequent malignant neoplasms (SMNs). Insufficient statistical power associated with limited participant numbers in individual cohorts preclude addressing knowledge gaps on risks and risk factors for specific SMNs. Because of this, pooling data from well-established cohorts worldwide is crucial. For some of the most common SMNs, such as breast cancer, sarcomas, and colorectal cancers, substantial knowledge on treatment-related risks already exists and/or international efforts are underway to further investigate those risks. However, for several other important types of SMNs international collaboration is needed to gather sufficient data to address knowledge gaps. This study aims to investigate risks and risk factors for three types of SMNs: subsequent lung cancer, thyroid cancer, and melanoma using internationally pooled data.

METHODS

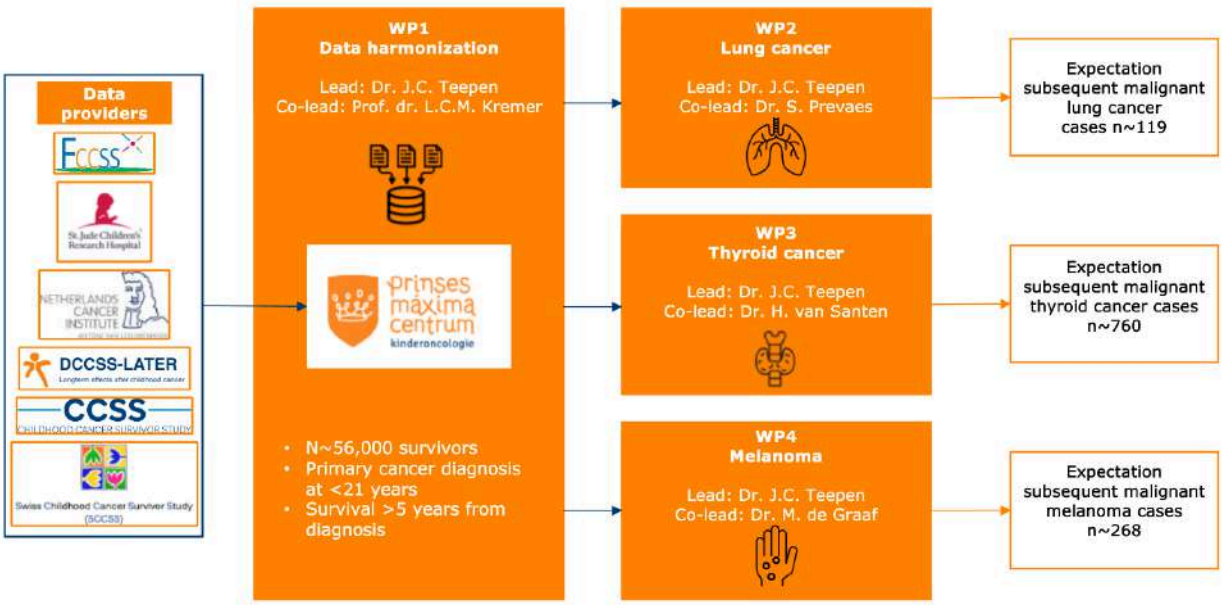
We will pool and harmonize data on childhood cancer treatment, sociodemographics, lifestyle behaviors, and SMNs from six childhood cancer survivor cohorts in North America and Europe into a single database at the Princess Máxima Center. This effort will leverage infrastructure previously established for studying breast cancer risk in female childhood cancer survivors by including the following cohorts: the Dutch Childhood Cancer Survivor Study-LATER cohort, the North American Childhood Cancer Survivor Study, the St. Jude Lifetime Cohort Study, the French Childhood Cancer Survivor Study, the Swiss Childhood Cancer Survivor Study, and the Dutch Hodgkin Late Effects Study. These cohorts all have detailed information available on cancer treatment, such as details on radiotherapy fields and doses, specific chemotherapy agents and doses, hematopoietic stem cell transplantation, and on SMNs. We will estimate long-term relative and absolute risks of the three SMN subtypes, as well as treatment-related risk factors. For lung cancer, we will evaluate risks associated with chest radiotherapy field and dose, specific chemotherapy agents, smoking, and the interaction between treatment and smoking. For thyroid cancer, we will determine risks associated with chemotherapy among survivors not treated with radiotherapy, and chemotherapy-related risks in addition to radiotherapy. For melanoma, we will determine risks associated with radiotherapy, chemotherapy, hematopoietic stem cell transplantation, and family history of melanoma. Experts in the field of late effects, (pediatric) oncology, radiation oncology, pulmonology, endocrinology, and dermatology will be closely involved during the project. We will conduct time-to-event analyses.

RESULTS

We expect to include approximately 56,000 survivors, with currently reported minimum counts of 119 subsequent lung cancers, 760 subsequent thyroid cancers, and 268 subsequent melanomas across participating cohorts. Due to the unique international data, we anticipate significant new results with both scientific and clinical impact.

CONCLUSION

The expected results of the IPD-SMN study will provide relevant input for childhood cancer treatment protocols and survivor surveillance protocols. Findings on subsequent thyroid cancer can, for example, be used to update the IGHG thyroid cancer surveillance guideline. Moreover, the dataset will serve as a robust source of childhood cancer survivor data for elucidating other knowledge gaps on SMNs.



Overview of the IPD-SMN study

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Subsequent Malignant Neoplasms (SMN)

SUBSEQUENT MALIGNANT NEOPLASMS AFTER CHILDHOOD, ADOLESCENT, AND YOUNG ADULT CLASSICAL HODGKIN LYMPHOMA ACROSS TREATMENT ERAS: A SEER ANALYSIS

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BACKGROUND-AIM

Survivors of childhood, adolescent, and young adult (CAYA) classical Hodgkin lymphoma (cHL) experience elevated risks of subsequent malignant neoplasms (SMNs), which remain a leading cause of late morbidity and mortality. SMN risk is strongly influenced by treatment exposures—particularly radiation and cytotoxic chemotherapy—while sociodemographic factors may further modify risk. Over the past five decades, cHL therapy has evolved toward risk-adapted approaches and modern radiation techniques aimed at reducing late toxicities. Population-based data from cancer registries and large cohort studies provide a unique opportunity to examine SMN incidence across treatment eras by quantifying SMN burden, characterizing high-risk subgroups, and informing survivorship care and surveillance strategies.

METHODS

We conducted a population-based cohort study of cHL CAYA survivors (diagnosed at 0–39 years) using the National Cancer Institute Surveillance, Epidemiology, and End Results (SEER) registries (1975–2024). Survivors were defined as individuals alive ≥12 months after cHL diagnosis. Incidence and SMN burden analyses collated data from SEER 8, 12, 17, and 21 registries. Analyses were stratified by approximate treatment era, with 1975–1989 representing the "combined modality" era, 1990–2015 representing the "risk adapted" era, and 2016–present representing the "modern" era, consistent with published results of large therapeutic studies and accepted treatment paradigms for cHL. Age group (childhood: diagnosed 0-14 years; AYA: diagnosed 15-39 years), sex, race/ethnicity, and radiation receipt were assessed as covariates. Multiple primary–standardized incidence ratio (MP-SIR) analyses were performed in SEER*Stat using SEER 8 only. All data processing and descriptive analysis were conducted in R. Patient characteristics were summarized overall and by era. Categorical variables were compared across eras using Pearson's Chi-Square tests, and effect size was quantified using Cramer's V. Continuous variables were compared across eras using ANOVA, with pairwise comparisons performed when relevant.

RESULTS

Among 48,854 individuals diagnosed with cHL, 45,526 met inclusion criteria and comprised the analytic cohort. Median age at cHL diagnosis was 26 years (IQR 20–32); 49% were female, 82% White, and 19% Hispanic. Overall, 2,986 survivors (7%) developed ≥1 SMN, and 382 (1%) developed ≥2 SMNs. The proportion with ≥1 SMN declined across eras (24% in 1975–1989; 6% in 1990–2015; 1% in 2016–present). Median latency to first SMN was 190 months (IQR 104–283). In MP-SIR analyses using only SEER 8 data, survivors experienced an overall twice-fold increased SMN risk compared with the general population (SIR 2.68, 95% CI 2.47–2.90; excess risk 49 per 10,000 person-years). Elevated risks were observed across treatment eras, age at diagnosis, sex, and race/ethnicity. SMN risk was higher among survivors treated with radiation versus not, regardless of treatment era.

CONCLUSION

Across five decades of cHL treatment evolution, survivors continue to experience significantly elevated SMN risk, including those treated in the modern era. While the absolute burden of SMNs has declined over time, there are signals that excess risk may persist for all CAYA cHL survivors and across demographic subgroups. These findings underscore the need for continued long-term, risk-adapted survivorship care and highlight the importance of continued treatment refinement and individualized late-effects counseling for CAYA cHL survivors.

Table 1: Cohort Description and Standardized Incidence Ratios for SMN Development Compared to the General Population

	Overall Cohort (n = 45,526)	Combined Modality Era (1975-1989) (n = 4,787)	Risk-Adapted Era (1990-2015) (n = 31,173)	Modern Era (2016-Present) (n = 9,566)	*p*-value
Age at HL diagnosis, mean (SD)	25.46 (7.74)	24.92 (7.35)	25.54 (7.83)	25.48 (7.59)	< 0.001
Age at HL diagnosis, median (IQR)	26 (20, 32)	25 (20, 30)	26 (20, 32)	26 (20, 31)	< 0.001
Age group at cHL diagnosis, *n* (%)					0.03
Diagnosed during childhood (0-14 years)	3609 (8)	367 (8)	2539 (8)	703 (7)	
Diagnosed as an AYA (15-39 years)	41917 (92)	4420 (92)	28634 (92)	8863 (93)	
Sex, *n* (%)					< 0.001
Female	22330 (49)	2224 (46)	15332 (49)	4774 (50)	
Male	23196 (51)	2563 (54)	15841 (51)	4792 (50)	
Race, *n* (%)					< 0.001
White	37516 (82)	4409 (92)	25670 (82)	7437 (78)	
American Indian/Alaska Native	193 (0)	9 (0)	133 (0)	51 (1)	
Asian or Pacific Islander	2254 (5)	106 (2)	1467 (5)	681 (7)	
Black	5087 (11)	244 (5)	3629 (12)	1214 (13)	
Unknown	476 (1)	19 (0)	274 (1)	183 (2)	
Ethnicity, *n* (%)					< 0.001
Non-Hispanic (Non-Latine)	37078 (81)	4522 (94)	25201 (81)	7355 (77)	
Hispanic (Latine)	8448 (19)	265 (6)	5972 (19)	2211 (23)	
Survival months after HL, median (IQR)	151 (73, 237)	399 (206, 455)	176 (119, 238)	45 (27, 64)	< 0.001
Vital status, *n* (%)					< 0.001
Alive	38745 (85)	2070 (43)	27292 (88)	9383 (98)	
Dead	6781 (15)	2717 (57)	3881 (12)	183 (2)	
Mean age at first SMN	50	53.34	44.38	30.44	
≥1 SMN, *n* (%)					
Yes	2986 (7)	1121 (24)	1785 (6)	80 (1)	
No	41871 (93)	3509 (76)	28925 (94)	9437 (99)	
≥2 SMNs, *n* (%)					
Yes	382 (1)	231 (5)	149 (0)	2 (0)	
No	44442 (99)	4386 (95)	30542 (100)	9514 (100)	
SMN Standardized Incidence Ratios (95% CI; excess risk per 10,000 person-years)*	2.68 (2.47-2.9; 49)	2.73 (2.46-3.01; 68.18)	2.48 (2.14-2.87; 30.36)	5.88 (3.21-9.86; 41.26)	
Diagnosed during childhood (0-14 years)	4.84 (3.24-6.95; 31.16)	5.66 (3.66-8.35; 53.68)	2.6 (0.71-6.67; 7.34)	0	
Diagnosed as an AYA (15-39 years)	2.62 (2.41-2.84; 50.94)	2.63 (2.37-2.92; 69.89)	2.48 (2.13-2.87; 32.71)	5.96 (3.26-10; 44.47)	
Female	2.79 (2.45-3.17; 55.2)	3.04 (2.57-3.56; 80.26)	2.42 (1.92-3.02; 34.8)	2.86 (0.78-7.31; 20.34)	
Male	2.61 (2.34-2.89; 45.5)	2.56 (2.25-2.91; 61.75)	2.53 (2.07-3.07; 27.77)	10.18 (4.88-18.72; 58.66)	
Non-Hispanic White	2.62 (2.39-2.87; 50.49)	2.68 (2.4-2.98; 67.73)	2.44 (2.04-2.89; 30.86)	4.54 (1.82-9.35; 32.13)	
Non-Hispanic Black	2.61 (1.93-3.47; 42.37)	2.28 (1.39-3.52; 50.45)	2.69 (1.74-3.96; 35.93)	10.92 (2.25-31.92; 67.56)	
Non-Hispanic American Indian/Alaska Native	5.50 (1.13-16.06; 64.01)	3.36 (0.08-18.7; 65.84)	8.38 (1.01-30.27; 69.13)	0	
Non-Hispanic Asian or Pacific Islander	4.61 (2.85-7.04; 53.5)	6.91 (3.68-11.82; 123.21)	2.78 (1.12-5.73; 23.12)	6.21 (0.16-34.58; 36.25)	
Hispanic (All Races)	2.77 (1.96-3.8; 39.19)	3.01 (1.84-4.64; 70.38)	2.25 (1.26-3.71; 21.71)	7.59 (1.57-22.19; 56.62)	
Radiation: None/Unknown	2.14 (1.87-2.45; 32.64)	2.05 1.7 2.45 45.58	2.07 1.65 2.57 21.85	6.77 3.5 11.83 49.27	
Radiation: Yes	3.13 (2.81-3.46; 64.2)	3.20 2.83 3.61 82.36	2.93 2.38 3.58 40.42	3.65 3.65 0.44 13.19 21.65	

** Calculated using SEER 8 database only*

Table 1: Cohort Description and Standardized Incidence Ratios for SMN Development Compared to the General Population

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Subsequent Malignant Neoplasms (SMN)

SUBSEQUENT MALIGNANT NEOPLASMS AFTER NEUROBLASTOMA. A REPORT FROM THE ITALIAN NEUROBLASTOMA REGISTRY (RINB)

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BACKGROUND-AIM

Subsequent malignant neoplasms (SMN) are among the possible late complications in neuroblastoma (NB) patients. Alkylating agents or epipodophyllotoxins (AA/EPI) and/or radiotherapy (RT) treatment are the main risk factors for this occurrence. We reviewed the data collected over >40 years by the Italian Neuroblastoma Registry (RINB).

METHODS

All NB cases enrolled in the RINB between January 1979 and December 2020 were eligible for analysis. Patients without follow-up were excluded. For each patient, RINB collects info on demographic, tumor characteristics, and treatment information including that of relapse/progression if any. Follow-up on NB status and/or SMN occurrence is through the treating institution or census bureaus. The risk of developing a SMN was estimated by using the cumulative incidence function (CIF), treating death from any cause as competing event. The association between NB characteristics and the risk of a SMN were assessed using the Fine-Gray competing risk model and reported as subdistribution hazard ratio (sHR) with 95%-CI.

RESULTS

Among 4,849 patients enrolled in the RINB, 3,752 were eligible with a median follow-up since diagnosis of 6.6 years (IQR 2.2-14). Among them, 55 developed a SMN, however one, who died for an Ewing sarcoma with unknown date of SMN incidence, was excluded. Among the 54 evaluable patients, 19 (35%) developed a hematologic SMN at median time of 2.4 years (IQR 1.5-10.3) and 35 (65%) a solid SMN at median time of 14.5 years (IQR 8.6-17.0); p<0.0001 (Table). A further SMN, respectively affecting gastrointestinal trait, lung, CNS, thyroid, pancreas and 1 AML, was reported in 6 patients after a median time since the first SMN of 3 years (IQR 0.8-10.8).
The cumulative incidence of SMN at 20 and 30 years after NB diagnosis, was respectively of 2.7% (95%-CI: 1.9-3.4) and 3.4% (95%-CI: 2.2-4.5). In particular, the CIF at 20 and 30 years for hematologic SMN remains stable at 0.7%, indicating a plateau over time; on the contrary, that for solid SMN increases from 2.0% to 2.7%.
Among the 19 patients with hematologic SMN, treatment included only AA/EPI in 11 (58%); while in further 5 (26%) it was based on AA/EPI and RT. Surgery alone was given to 3 (16%) patients.
Among the 35 patients with a solid SMN, 13 (37%) received only AA/EPI; in further 21 (60%) AA/EPI were associated to RT and the affected organ was within the RT field in 16 of them (76%) (11 thyroid, 3 sarcomas, 1 kidney carcinoma and 1 skin cancer); 1 (3%) patient was only surgically treated.
Considering the whole RINB cohort, the risk of developing a SMN did not correlate with sex and age at NB diagnosis. Compared to stage L1, those with L2, M or Ms were at higher risk of SMN (sHR 2.1, 3.4, 2.4, respectively).
Compared to untreated patients, there was no difference in the hazard of developing a hematologic SMN for patients either exposed to AA/EPI with or without RT. On the contrary the sHR for solid SMN was significantly higher for those exposed to AA/EPI (5.7 (95%-CI 0.7-43.4)) and AA/EPI + RT (23.2 (95%-CI 3.1-172.5)), p<0.0001.

CONCLUSION

We confirm that SMN are possible late complications after NB with hematologic SMN being less frequent and occurring earlier but not increasing over time, while solid tumors continue to increase without reaching a plateau.
The occurrence of 4 SMN among only surgically treated patients deserves further investigation on possible genetic predisposition.

	Subsequent Malignant Neoplasm (SMN)					
	Solid		Hematologic			
Neuroblastoma chracteristics	**N (%)**		**N (%)**		**Total**	**p**
Total	**35 (100.0)**		**19 (100.0)**		**54 (100.0)**	
	Thyroideal carcinoma	15 (42.9)	AnLL	8 (42.1)		
	CNS neoplasm	8 (22.9)	MDS	4 (21.1)		
	Soft tissue sarcoma	5 (14.3)	CML	2 (10.5)		
	Bone sarcoma	1 (2.9)	ALL	2 (10.5)		
	Non-melanoma skin cancer	3 (8.6)	NHL	2 (10.5)		
	Carcinoma (kidney, ovary)	2 (5.5)	HL	1 (5.3)		
	NOS	1 (2.8)				
Interval NB diagnosis—SMN, years						<0.0001
Median, IQR	14.5 (8.7-17.0)		2.4 (1.5-10.3)		10.4 (4.3-15.4)	
Gender						0.492
Male	15 (42.9)		10 (52.6)		25 (46.3)	
Female	20 (57.1)		9 (47.4)		29 (53.7)	
Age at diagnosis (months)						0.793*
0-18	15 (42.9)		7 (36.9)		22 (40.7)	
19-59	15 (42.9)		10 (52.6)		25 (46.3)	
≥60	5 (14.2)		2 (10.5)		7 (13.0)	
Stage INRG						0.097
L1	9 (25.7)		1 (5.3)		10 (18.5)	
L2	20 (57.1)		13 (68.4)		33 (61.1)	
M	4 (11.4)		1 (5.3)		5 (9.3)	
Ms						
Overall treatment						0.035*
AA/EPI only	13 (37.1)		11 (57.9)		24 (44.4)	
AA/EPI+RT	21 (60.0)		5 (26.3)		26 (48.2)	
None (surgery only)	1 (2.9)		3 (15.8)		4 (7.4)	
RT						0.217*
Metabolic MIBG	4 (19.1)		1 (20.0)		5 (19.2)	
Metabolic MIBG+external beam tumor site	2 (9.5)		2 (40.0)		4 (15.4)	
External beam: tumor site	8 (38.1)		2 (40.0)		10 (38.5)	
External beam: TBI	7 (33.3)		0		7 (26.9)	

*Fisher exact test

AnLL: Acute non-Lymphoblastic Leukemia; ALL: Acute Lymphoblastic leukemia; MDS: Myelodysplastic Syndrome; CML: Chronic Myeloid Leukemia; CNS: Central Nervous system; AA/EPI: alkiylating agents/epipodophillotoxins; RT: Radiotherapy; MIBG: MetaIodoBenzylGuanidine; TBI: total body irradiation

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Subsequent Malignant Neoplasms (SMN)

SUBSEQUENT SALIVARY GLAND CANCERS AFTER CHILDHOOD CANCER: A MONOCENTRIC CASE SERIES

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BACKGROUND-AIM

Childhood Cancer Survivors (CCS) are at increased risk of Subsequent Malignant Neoplasm (SMN). Data on the occurrence of salivary gland cancers (SGC) in CCS are limited, with reported percentages from large series ranging between 0.006 and 0.06% . Ionizing radiation with or without combination with AA is the main reported risk factor.
Aim
Describe SGC prevalence as SMN among CCS followed at our institute.

METHODS

Retrospective analysis of CCS in follow-up at our clinic between 1995 and 2025. CNS tumor survivors excluded. Screening for original cancer recurrence is based on clinical recommendations of the therapeutic clinical trial; that for SMN is based on IGHG/PanCare guidelines. In case of SMN whole exome sequencing (WES) genetic testing for cancer predisposition (CPS) screening is offered.
Data on tumor type, age at diagnosis of first and SMN as well on cumulative doses of chemo and radiotherapy were collected from the institutional database. The radiation dose received by the salivary glands were measured using the ARIA and ECLIPSE software.

RESULTS

Among 1552 evaluated CCS (703 hematological, 849 solid cancers), four cases (0.26%) of SGC were diagnosed in as many survivors (2 with Hodgkin lymphoma (HL), 1 ALL and 1 soft tissue sarcoma (STS). In one HL patient (#1), the SGC was the third SMN following two different sarcomas. All the SGC were low-grade parotideal muco-epidermoid carcinomas occurring after 6.2, 9.8, 10.1 and 17.5 years from the end of therapy. In 2 CCS the imaging was indicated by clinical suspect whereas in the remaining asymptomatic 2 it was performed because clinical recommendations of the therapeutic clinical trial.
All the patients had received AA-based chemotherapy, with a cumulative Cyclophosphamide Equivalent Dose respectively of 3.1, 4.3, 16.1, 16.5 g/m2. Only 3 patients (2 HL and 1 STS) were treated with radiotherapy (RT) and the calculated dose to the affected parotid was of 2.1, 12.0 and 12.0 Gy. The RT doses received by the contralateral not affected parotid were always higher except for the case #1 who received TBI. WES was performed in three patients and was informative in two: in the case with HL (#1) who developed multiple SMN, a cancer genetic predisposition (ATM mutation) together with a mutation in the ITK immune-regulatory gene. The second patient also with HL (#4) carried a mutation in the TACI immune-modulating gene.
All SGC were surgically treated with superficial parotidectomy. Oncologic TNM stage was pT2N0M0 for the three patients with available information. No further treatment was performed and all survivors are cancer free respectively after 6.8, 0.9, 0.7, 8.4 years since parotidectomy.

CONCLUSION

In our small cohort the SGC frequency is much higher than that reported in larger series. This incidence is still high even if the two asymptomatic cases incidentally observed during cancer screening are excluded.
Among irradiated CCS the calculated RT dose received by the affected parotid was lower than that received by the contralateral organ. This observation is in contrast with a dose-response effect reported in the literature. Although numbers are limited in our series, we hypothesize that the “paradox” effect described for the thyroid were high RT doses to the gland have a killing effect which does not lead to SMN, might apply to the parotid gland too. In addition to treatment, genetic predisposition either linked to CPS or to imuno-regulatory genes might play a role in SGC occurrence. Studies in larger series are needed.

Table 1:

Patient #	**1**	**2**	**3**	**4**
Gender	M	F	M	M
Age at the diagnosis (y)	12.8	2.7	6.1	12.8
First cancer	HL	RMS	ALL	HL
Alkylating agents (AA)	Yes	Yes	Yes	Yes
AA cumulative dose CED ^(g/m^2)	16.5	16.1	3.1	4.3
Radiotherapy (RT)	Yes	Yes	No	Yes
Rt dose to the right SG, Gy (Mean, max-min)	12.0 (TBI)	50.0 (56.4-23.0)	/	2.1 (4.2-1.3)
Rt dose to the left SG, Gy (Mean, max-min)	12.0 (TBI)	12.0 (19.0-6.8)	/	9.1 (20.2-1.8)
HSCT	Yes (auto)	No	No	No
SGC	MEC *	MEC	MEC	MEC
Pathology grade	Unknown	Low grade	Low grade	Low grade
Laterality	Left	Left	Right	Right
Latency (y) °	17.5	9.8	10.1	6.2
Treatment of SGC	Superficial Parotidectomy	Superficial Parotidectomy	Superficial Parotidectomy	Superficial Parotidectomy
Stage (TNM)g	/	pT2N0M0	pT2N0M0	pT2N0M0
Genetic features (germinal)	*ATM (c.1033C>T) + ITK* (c8395_8404del)	Not available	Negative	*TACI* (TNGRSF13B c.311G>A)
Alcohol consumptio	Never	Never	Never	Never
Smoking habit	Never	Never	Never	Never

Abbreviations: ALL, Acute lymphoblastic leukemia; HL, Hodgkin Lymphoma; RMS, Rhabdomyosarcoma; SG Salivary Gland; SGC Salivary Gland Cancer; HSCT Hematopoietic Stem Cells Transplantation; MEC Mucoepidermoid carcinoma

^ CED = Cyclophosphamide Equivalent Dose

*= following 2 other sarcomas as SMN

°= Since the first elective end of therapy

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Other 2

APPLICATION OF PATIENT-GENERATED HEALTH DATA FROM WEARABLES AND ELECTRONIC PATIENT-REPORTED OUTCOME TOOLS IN ONCOLOGY: A SYSTEMATIC REVIEW

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BACKGROUND-AIM

Oncology care increasingly uses digital technologies, with growing reliance on patient-generated health data (PGHD) collected via wearable sensors and electronic patient-reported outcome (ePRO) platforms. PGHD streams, defined as continuous, high-frequency data generated outside clinical visits, enable real-time assessment of physical activity, physiology, symptoms, and functional status. This systematic review aims to synthesize the evidence on the clinical use and translational impact of PGHD across the oncology care continuum.

METHODS

PubMed, Web of Science, and Scopus were searched for English-language studies published from 1/1/2005 to 5/13/2025 in oncology. Data were extracted using a PRISMA-guided framework capturing study characteristics, PGHD collection modalities, clinical purposes, outcomes, and limitations. Given substantial heterogeneity in PGHD sensor types, analytic methods, and outcome reports, results were synthesized using narrative and thematic methods.

RESULTS

Of 1,410 records identified, 31 met inclusion criteria after title/abstract and full-text review, representing wearable PGHD from more than 2,200 cancer patients and survivors. Included studies comprised prospective observational studies (n=18, 58%), non-randomized interventional trials (n=6, 19%), randomized controlled trials (n=4, 13%), and secondary data analyses (n=3, 10%), either evaluating wearable sensor data alone or in combination with ePROs. Sample sizes ranged from 10 to 214, with monitoring durations ranging from a single clinical session to a 9-month home-based assessment. Feasibility and adherence thresholds were consistently met (n=21), with ≥70-90% of planned valid wear days achieved across chemotherapy, radiotherapy, surgical, and survivorship cohorts. Sustained engagement was reported during intensive treatment periods (chemotherapy or radiotherapy; n=17) and within specific patient populations (e.g., older or postoperative cohorts; n=5). PGHD-based activity metrics (i.e., step count, cadence, sedentary time, moderate-to-vigorous physical activity) were significantly associated with self-reported performance status, symptom burden, and quality of life (n=18). Significant associations between PGHD-based activity measures and survivorship outcomes, including overall and progression-free survival, were reported in lung cancer, head and neck cancer, and mixed solid tumor cohorts (n=5). Wearable-guided exercise or rehabilitation interventions (n=3) demonstrated significant improvements in objective physical activity, functional recovery, and patient-reported outcomes, including fatigue, dyspnea, and sleep quality. In proof-of-concept studies (n=4), machine-learning models incorporating PGHD achieved up to 90% classification accuracies for symptom severity and functional status, and area under the curve of 0.76-0.83 for hospitalization or mortality prediction, outperforming clinical variable-only models. PGHD integration into patient-facing dashboards or electronic medical record workflows showed high usability per the System Usability Scale (n=4).

CONCLUSION

Wearable-derived PGHD have been reported to be feasible, clinically informative, and responsive to interventions across the cancer care continuum. To maximize clinical impact, future research is needed to prioritize standardized analytic approaches, rigorous validation of digital biomarkers, equal access to wearable technologies, and scalable integration into clinical workflows.

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Other

BRIDGING THE GAP BETWEEN PRACTICE AND PREFERENCES: A SURVIVOR-LED STUDY ON LONG-TERM FOLLOW-UP CARE

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BACKGROUND-AIM

With increasing survival after childhood cancer, structured long-term follow-up care (LTFU) is essential to detect late effects and address psychosocial needs. In Germany, LTFU structures remain heterogeneous, and survivor perspectives are rarely systematically integrated into service development. This survivor-led study aimed to assess current LTFU practice, survivors' preferences for future care, and the prioritization of key follow-up components.

METHODS

A nationwide, online survey was conducted among 212 childhood and adolescent cancer survivors in Germany whose cancer diagnosis was made before the age of 18 years, initiated and led by Survivor Deutschland e.V. The questionnaire assessed current LTFU settings, preferred care structures, unmet needs, and the perceived importance of different LTFU components. Descriptive and quantitative analyses were performed, complemented by analyses of open-ended exploratory questions. Likert-scale items (1–10) are reported as medians with interquartile ranges (IQR).

RESULTS

After the age of 18, follow-up care most frequently took place with office-based oncologists or other specialists (43.9%, n=43), in paediatric oncology outpatient clinics (14.3%, n=14), or in specialized LTFU centres (28.6%, n=28). Notably, 6.12% reported receiving no follow-up care at all. In contrast, survivors' preferences strongly favoured specialized survivorship care. Multiple responses were allowed: 54.7% (n=116) wished for follow-up in a specialized LTFU centre, 31.6% (n=67) preferred follow-up with office-based specialists, and 15.6% (n=33) additionally indicated a preference for psychological support (also shown in figure 1). The perceived importance of follow-up care was very high (median 10/10, IQR 8–10), while satisfaction with current follow-up care was substantially lower and heterogeneous (median 4.5/10, IQR 0–8).The highest-rated aspects of care included comprehensive coverage of follow-up-related costs (median 10, IQR 9-10), adequate consultation time (median 10, IQR 9-10), a single point of contact for all medical late effects (median 10, IQR 8-10), timely communication of test results and recommendations (median 10, IQR 8-10), and easy access on the treating team (median 9, IQR 8-10). Lower priority was given to geographic proximity to the current place of residence (median 7, IQR 5–9) and appointment reminders (median 5, IQR 2–8). Importantly, the medical discipline providing follow-up care was of comparatively low relevance, with similar ratings for adult medicine specialists (median 6, IQR 4–8) and paediatric oncology teams (median 4, IQR 1–7). Regarding preferred travel distance for follow-up care, most survivors were willing to travel considerable distances: 65.6% (n=139) indicated willingness to travel 21–150 km, and a further 19.8% (n=42) reported willingness to travel more than 150 km, including 11.8% (n=25) who would travel over 300 km if needed. In contrast, only 14.6% (n=31) preferred travel distances of up to 20 km.

CONCLUSION

This survivor-led study reveals a substantial gap between current LTFU practice and survivors' preferences in Germany. Survivors strongly favour specialized, multidisciplinary follow-up care with sufficient consultation time, expert knowledge on late effects, and clear communication. Despite the high perceived importance of LTFU, satisfaction with current care remains low, highlighting the need for structured, accessible, and survivor-centred care models that integrate medical, psychosocial, and organizational aspects.

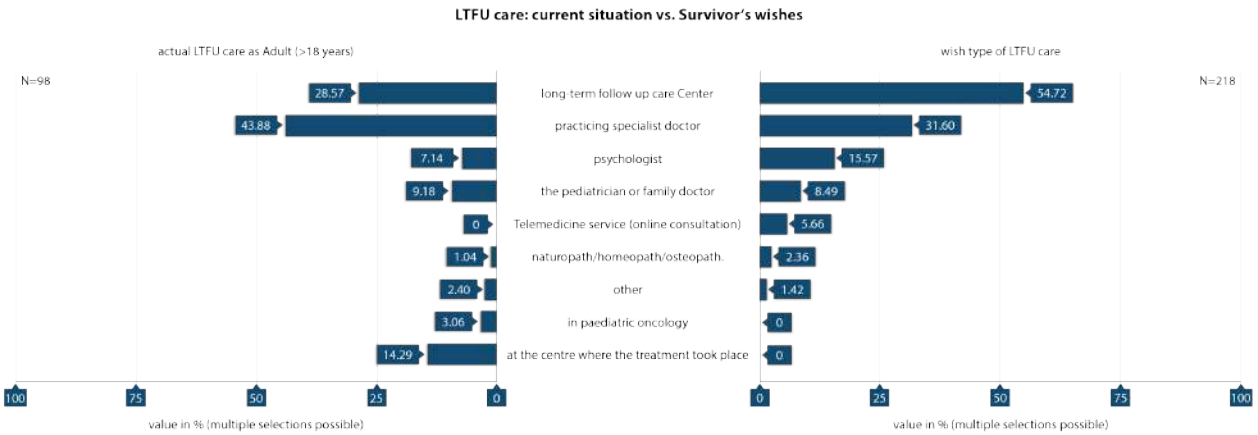

Figure 1: Mismatch between current long-term follow-up (LTFU) care and survivors' preferences. Current LTFU care in adulthood (>18 years) is compared with preferred care structures (multiple responses allowed). Survivors predominantly favour specialized LTFU centres and additional psychological support, contrasting with current care mainly provided by office-based specialists.

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Other

COMPARISON OF EXCESS RISK OF LATE MORTALITY AND SUBSEQUENT MALIGNANT NEOPLASMS (SMNS) AFTER HODGKIN LYMPHOMA (HL): A CHILDHOOD CANCER SURVIVOR STUDY (CCSS) AND DUTCH HODGKIN LYMPHOMA SURVIVOR STUDY COLLABORATION

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BACKGROUND-AIM

HL survivors are at increased risk for cancer treatment associated late morbidity and mortality. Few studies have compared outcomes across countries with differing treatment patterns and population health, and none, to our knowledge, have included treatment exposures. We compared rates of late mortality and SMNs, events occurring >5 years from diagnosis, among survivors of HL in the United States and Netherlands, including associations with HL treatment exposures.

METHODS

This retrospective analysis used the CCSS and the registry-based Dutch Late-Effects HL Study to evaluate 5-year survivors of HL diagnosed at ages 15-20 years between 1970-1999. Age, diagnosis year, and sex were used to create inverse probability weighting with robust standard error estimates for the CCSS cohort to account for non-participation among potentially eligible cases. Cancer treatment (yes/no) available in each cohort included exposure to radiation (chest, abdomen, pelvis) and chemotherapy (anthracycline, procarbazine, alkylating agents, bleomycin, etoposide, platinum, vinca alkaloids). Crude and standardized rates of mortality and SMNs as well as absolute excess risks (AER) were estimated relative to the age- and sex-matched general population in each country. Adjusted rate ratios (ARR) for cohort-specific standardized mortality and SMNs were estimated using multivariable piecewise-exponential models adjusting for attained age, year of diagnosis, sex, and cancer treatment.

RESULTS

2,116 eligible CCSS (1,488 participants) and 720 Dutch survivors were included, with respective median (IQR) follow-up times of 26.9 (20.8-35.1) and 25.3 (19.4-29.7) years from HL diagnosis. Crude all-cause late mortality rates were comparable between cohorts (death per 1000 person-years [95% confidence interval (95%CI)]: CCSS=15.1 [95%CI:14.1-16.1]; Dutch=13.2 [95%CI:11.5-15.1]). The standardized all-cause mortality ratio was lower among CCSS (6.1 [95%CI:5.7-6.5]) compared with Dutch survivors (12.1 [95%CI:10.5-13.8]). AER of death per 1000 person-years was comparable (CCSS=12.6 [95%CI:11.6-13.7]; Dutch=12.1 [95%CI:10.4-14.0]). The crude incidence rate of SMNs was comparable between cohorts (rate per 10,000 person-years: CCSS=111.8 [95%CI:103.2-120.9]; Dutch=122.6 [95%CI:104.8-142.6]), while the standardized SMN incidence ratio was lower among CCSS (5.9 [95%CI:5.4-6.4]) compared with Dutch survivors (8.6 [95%CI:7.3-9.9]). AER of SMN was comparable between cohorts (rate per 10,000 person-years: CCSS=92.8 [95%CI:84.1-101.9]; Dutch=108.3 [95%CI:90.4-128.3]). In multivariable analyses comparing the standardized mortality and SMN risk among CCSS vs. Dutch survivors, CCSS survivors had a 25% lower standardized rate of SMNs (ARR=0.74 [95%CI:0.61-0.89]) and a 50% lower standardized rate of mortality (ARR=0.49 [95%CI:0.41-0.58]). After adjusting for treatment exposures, ARRs decreased for both SMN (ARR=0.66 [95%CI:0.55-0.80]) and mortality (ARR=0.40 [95%CI:0.33-0.48]) in CCSS survivors when compared to Dutch survivors.

CONCLUSION

Despite comparable crude rates, standardized rates for mortality and SMNs differed between cohorts, reflecting variation in background population risk. These findings suggest that excess risk of death and SMNs due to HL treatment may be similar for HL survivors despite differences in country-level population health, supporting ongoing global initiatives to improve survivor health and lifespan.

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COMPUTATIONAL APPROACHES TO AID IN SURVIVORSHIP CARE PLAN GENERATION USING ELECTRONIC HEALTH RECORD DATA

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BACKGROUND-AIM

Manually creating treatment summaries for survivorship care plans (SCPs) is labor intensive and error prone. Computational approaches using electronic health record (EHR) data can improve accuracy and reduce provider workload. We aimed to develop methods to semi-automate treatment summary generation from EHR data.

METHODS

Demographics, problem lists, medication records, clinical notes, diagnostic reports, and other cancer-related data were obtained from our Epic Clarity data warehouse for pediatric cancer and hematopoietic stem cell transplantation (HSCT) patients diagnosed from 1/1/2011 to 12/31/2021. We developed a custom pipeline using Python to ascertain treatment with anti-neoplastic agents, MIBG, and I-131. Using large language model (LLM) prompting techniques on a secure version of ChatGPT 4.0 with post-processing logic, we determined receipt of HSCT and chimeric antigen receptor T-cell (CART) therapy. Results were validated against a preexisting, manually abstracted dataset of 1120 patients diagnosed from 1/1/2012 to 12/31/2016 followed by review of discrepancies by pediatric oncologists.

RESULTS

Across 53 chemotherapies, our pipeline yielded a mean 99.9% correct match on exposures with ≥99.5% for 51/53 agents, 99.2% for ATG, and 99.1% for vincristine. Discrepancies (n=82) were mostly due to abstracted data errors (39.0%), treatment at outside centers (37.8%), and receipt for non-oncologic reasons (13.4%). For 4 anthracycline, 6 alkylating, and 2 platinum agents, the pipeline error rate for lifetime dosages (>5% discrepancy) was 5.2% (88/1686 administrations) after correction of abstraction errors in 5.8%. For anthracyclines, the remaining errors (n=26/722 administrations) were mostly due to outside therapies (42.3%) and dosing in mg (38.5%). For steroids, our pipeline yielded a 93.5% match for prednisone and 94.0% for dexamethasone. Prednisone discrepancies were mostly due to abstracted data errors (79.5%) and receipt outside the therapy window (8.2%). For dexamethasone, discrepancies were mostly due to abstracted data errors (73.1%) and receipt for a non-therapeutic reason (19.4%). MIBG and I-131 exposures had no false positives.

In the cohort, 92 patients underwent 115 transplants. The LLM identified 97.8% of recipients, including 2 that were not in the validation dataset, and had 2 false positives. One of the missed transplants occurred at another center. The LLM missed 6 repeat transplants and incorrectly identified 35 extra transplants, while there was only 1 extra occurrence in the abstracted data. The HSCT source type (e.g., matched related, mismatched cord) was correct in 104/107 (97.2%) identified transplants with 5 errors in the abstracted data. The date of HSCT matched exactly in 96% with the remaining 4 correct within 30 days. The CART LLM correctly identified 2/2 recipients.

CONCLUSION

Computational summarization of cancer treatments using EHR data is feasible and may correct errors. LLMs show significant promise in extracting exposures from unstructured EHR data. Treatment received at other centers is a significant source of error, which requires a method to flag those patients. We are working to refine our pipeline for home, intrathecal, and steroid medications, and correct dosing errors. We are also refining the HSCT LLM and developing LLMs for radiation exposure and key surgeries. Future work includes real-world implementation at a single site to semi-automate SCP production followed by future expansion to other centers.

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Other

CUMULATIV LONG-TERM HEALTH PROBLEMS IN CHILDHOOD CANCER SURVIVORS: THE FIRST RESULTS OF A LONG-TERM FOLLOW-UP PROJECT IN VIENNA

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BACKGROUND-AIM

Childhood cancer survivors carry a significant risk of developing late health problems and long-term follow-up is essential. Follow-up care is a standardized routine in pediatrics. To provide transition into a long-term follow-up program after the age of 18 years, a public health care follow-up clinic called "Interdisciplinary Oncological Follow-up Clinic (IONA)" was recently established in Vienna. Herein we aim to quantify the frequency and spectrum of late effects in childhood cancer survivors, and to examine the association between treatment exposure and long-term morbidity.

METHODS

This long-term follow-up study focused on patients who had been treated at the "St. Anna Children's Hospital (SAK)" for pediatric cancer except brain tumors. Data were collected either at the SAK late effects clinic or, after transition of patients, from the IONA. Late effects were quantified using the "Cumulative Illness Rating Scale" (CIRS) score. Additionally, specific treatment-related complications were screened.

RESULTS

In 213 survivors, a median time of 12 years since end of therapy was documented. The mean overall CIRS score was 3.19 # 1.9 (median = 3; range 0-13), and 94.8% of survivors had at least one organ impairment (CIRS # 1). Moderate organ dysfunction (grade 2) was documented in 41.3% of participants, while severe organ impairment (grade 3-4) was rare (<1%). Late effects were most frequently observed within the endocrine (62.4%) and musculoskeletal (53.1%) systems. Among the additionally screened comorbidities, 74.2% of participants were diagnosed with at least one comorbidity, most commonly osteoporosis/osteopenia (31.9%). With Spearman correlation analysis, a significant positive association was documented between overall CIRS score and years since therapy (ρ = 0.17, p = 0.013). Chemotherapy exposure was associated with higher overall morbidity (mean CIRS 3.29 vs. 2.54 in non-exposed survivors). Participants treated with stem cell transplantation showed the highest overall CIRS scores (4.29 vs. 3.15). Exposure to platinum derivatives was associated with higher overall morbidity and higher prevalence of hearing impairment. Additionally, participants treated with platinum derivatives showed higher cardiac CIRS scores (p = 0.032) and higher arterial hypertension scores (p = 0.033). Analysis showed higher liver (p = 0.0499) and renal scores (p < 0.001) in patients exposed to dactinomycin. Anthracyclines were associated with cardiovascular late effects. Cumulative anthracycline doses showed positive associations with hypertension scores (ρ = 0.165, p = 0.039). A higher prevalence of hypothyroidism was observed in patients with neck irradiation (p = 0.01). Pelvis irradiation was associated with higher genitourinary CIRS scores (p = 0.03). Significantly higher hepatic CIRS scores in patients treated with radiotherapy exposing the liver (p = 0.04) were observed.

CONCLUSION

Survivors of childhood cancer face a high prevalence of late effects, highlighting the necessity of structured long-term follow-up care in specialized clinics as realized herein within the IONA project.

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Other 2

DENTO-FACIAL SIDE-EFFECTS IN CHILDHOOD CANCER SURVIVORS: THE SMILE CONSORTIUM

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BACKGROUND-AIM

Facial deformation is a common late adverse effect following radiotherapy for childhood head-and-neck tumours, yet knowledge of dose-response relationships for developing facial bones and dental structures remains limited. Age-adapted dose constraints and standardised clinical practices are lacking (1), complicating treatment optimisation and patient counselling.

METHODS

To address these gaps, we established the SMILE (MinimiSing long-terM Impact of dentition and faciaL dEformations) consortium, an international multidisciplinary collaboration including paediatric oncologists, dentists, radiologists, surgeons, physicists, and childhood cancer survivors. The consortium focuses on three priorities: (1) Investigate-building evidence through patient-reported outcomes and image-based models to establish age-adapted dose constraints; (2) Integrate - translating findings into standardised clinical practice; (3) Innovate - advancing patient-centred care through dedicated late-effect clinics and auto-contouring solutions.

RESULTS

Key Advances:
1. Consensus Atlas: We developed the first consensus atlas for paediatric facial structure delineation with experts from 16 institutions (13 countries), providing standardised guidelines for mandible, temporomandibular joint (TMJ), vomer, maxilla, nasal, orbital, and sphenoid bones (Fig 1). Validation with 9 clinicians demonstrated high confidence (≥3/5 Likert scale) for all structures and excellent agreement for mandible and TMJ (submillimetre). Mean manual contouring time was 2 hours.
2. Automated Segmentation: To facilitate translation to clinical practice, we are developing machine learning models (nnU-Net) to auto-segment atlas structures and teeth. Preliminary results are encouraging and models trained on small datasets (<20 patients) achieved submillimeter accuracy for many facial structures e.g. sphenoid, ethmoid and nasal bone. For dental structures, we validated an open-access model (TotalSegmentator), trained on adult data, on five patients (aged 1-12), achieving submillimetre accuracy on planning CT with primary/mixed dentition, with 90% of structures within 2 Gy of expert reference.
3. Outcome Assessment Tools: we developed and validated DENTALE, a radiographic scoring tool for orthopantomogram assessment, evaluating condylar morphology, mandibular ramus, alveolar processes, and tooth morphology with excellent inter-observer reliability (ICC: 0.857-0.939). Using a 16-point threshold, DENTALE achieved 100% sensitivity and 88.2% specificity for specialized dental care referrals in 102 rhabdomyosarcoma survivors.
4. Patient Perspectives: Two qualitative studies collect experiences of childhood cancer survivors (aged 12-20) and families to support personalisation of care.

CONCLUSION

SMILE aims to address major barriers to understanding and minimising dentofacial toxicity. Our tools support consistent dose evaluation across institutions and development of evidence-based, age-adapted dose constraints to inform treatment planning, improve patient counselling, and reduce life-altering dentofacial side-effects in childhood cancer survivors.

1. Davey A, et al. Clin Transl Radiat Oncol. 2023;43:100681.

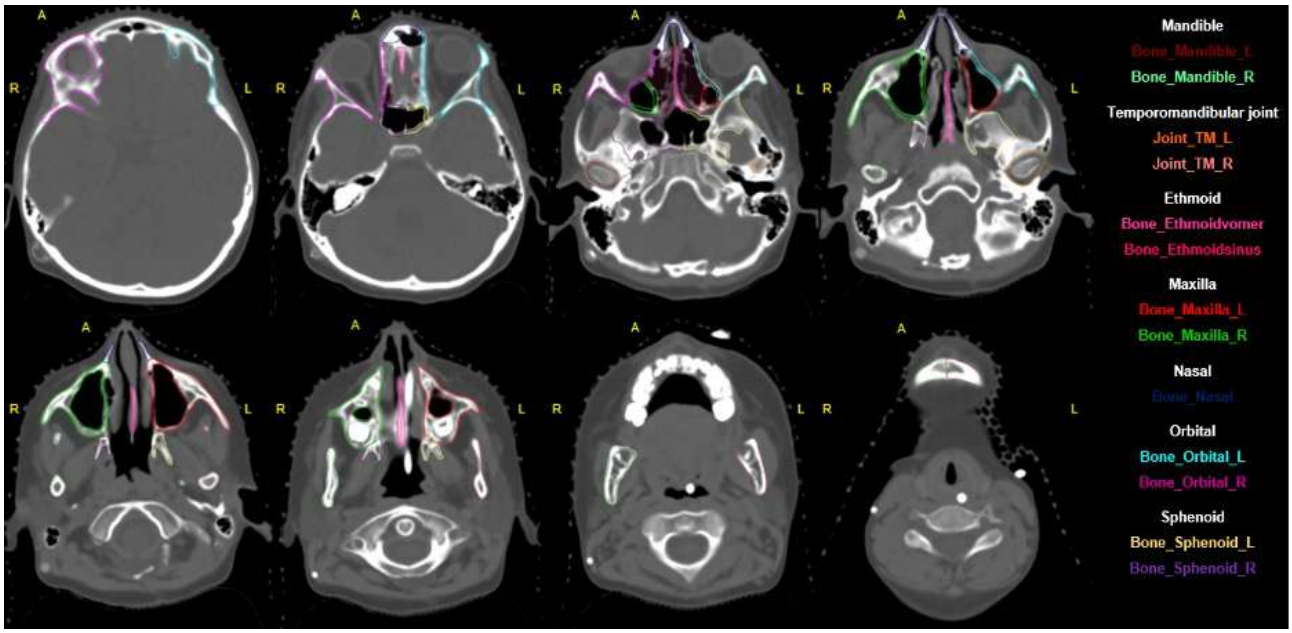

Fig 1: Final Consensus Paediatric Facial Structures Atlas

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DEVELOPING THE HARMONY TOOL: A PATIENT-CENTERED RAPID SCREENING INSTRUMENT FOR ANXIETY AND DEPRESSION IN PEDIATRIC AND AYA CANCER SURVIVORS

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BACKGROUND-AIM

Background: Anxiety and depressive symptoms are common among children, adolescents and young adult cancer survivors (CAYACS), yet psychological screening during follow-up remains inconsistent and often secondary to physical surveillance. Existing instruments are frequently too lengthy or insufficiently adapted to developmental stages, limiting their use in routine oncology care.
Aim: The HARMONY-Tool study aims to develop a brief, patient-centered screening instrument to identify anxiety and depressive symptoms in CAYACS and to prepare its validation for routine clinical use.

METHODS

We conducted an iterative qualitative study involving multiple stakeholders, following Boateng's best practices for developing and validating scales for health research.
First, semi-structured interviews were performed with 30 patients aged 7–25 years recruited from two French pediatric oncology and hematology departments. Data were analyzed using thematic analysis (Braun and Clarke's method), with a deductive framework combined to an inductive item generation. To reflect developmental differences and transitions, three age-specific versions were designed (7–10, 11–14, and 15–25 years).
Second, individual interviews were conducted with 10 healthcare professionals (pediatric hemato-oncologists, nurses, psychologists) to assess clinical relevance, clarity, and feasibility. In parallel, a multidisciplinary expert committee (psychiatry, pediatric oncology, psychology, methodology, and research engineering) reviewed interim findings and contributed to item selection and wording.
Third, cognitive interviews were conducted with 15 patients from the three age groups after completion of the questionnaire during routine follow-up consultations to assess comprehension, acceptability, emotional impact, and feasibility, and to refine items prior to validation.

RESULTS

Of 73 eligible patients contacted, 30 participated (41.1%). The main reasons for non-participation were lack of time, lack of concern, and reluctance to revisit illness-related experiences. The iterative integration of patient perspectives, professional feedback, and expert review resulted in a single 15-item French-language screening tool, designed as a common core and implemented in three age-specific versions with adapted wording for children aged 7–10 years, adolescents aged 11–14 years, and young people aged 15–25 years, capturing both subtle and severe manifestations of anxiety and depression. It reflects patients' lived experiences, with both internalizing and behavioral manifestations. The tool is brief, age-adapted to the three groups under study, and designed for hetero-administration during routine follow-up. This version has entered the pre-test phase.

CONCLUSION

The HARMONY-Tool represents the first patient-centered, age-adapted rapid screening instrument specifically developed for anxiety and depressive symptoms in children, adolescents and young adult cancer survivors (CAYACS). By facilitating early identification of psychological distress during follow-up, it has the potential to improve timely referral to specialized care in routine survivorship follow-up. Multicenter validation and comparison with reference scales are planned as the next steps

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EARLY ADAPTED PHYSICAL ACTIVITY (APA) INITIATION AS A KEY PREDICTOR OF POST-TREATMENT CONTINUATION IN ADOLESCENT AND YOUNG ADULT (AYA) CANCER SURVIVORS: A RETROSPECTIVE STUDY OF THE HOPAYA DAY HOSPITAL EXPERIENCE

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BACKGROUND-AIM

Adolescents and young adult cancer survivors (AYACS) face a heightened risk of physical and psychosocial sequelae, necessitating tailored care from the end of treatment. In 2022, the Léon Bérard Centre (CLB) launched the HOPAYA day hospital, a multidisciplinary program designed to assess AYACS' needs six months post-treatment and refer them to targeted care, particularly adapted physical activity (APA). HOPAYA combines medical and psychological consultations with an APA assessment, followed by referral to a local network (gyms, associations) or internal CLB care for nearby patients. This program aims to detect early sequelae and structure APA pathways, acting as a motivational lever for long-term engagement.
To retrospectively analyze the APA follow-up of patients included in HOPAYA, assessing their participation in APA before and after treatment, factors associated with continuing APA post-treatment (distance, pathology, sequelae, socioeconomic constraints), the impact of referral to local facilities or CLB care, and barriers to participation.

METHODS

This single-center retrospective study included 86 AYACS (aged 15–25) treated for cancer and followed at HOPAYA between 2022–2024. Data were extracted from medical records, focusing on APA follow-up during treatment, completion of an APA assessment during the day hospital, continuation of APA post-treatment (CLB or partner network).
Recorded data were clinical (cancer type, early sequelae), social (school/work schedules) and geographical (distance to CLB) characteristics.

RESULTS

Of the 86 patients, 78 (91%) underwent an APA assessment at HOPAYA, among them 38 (49%) had prior APA follow-up during treatment and 40 (51%) were introduced to APA at HOPAYA.
16 patients (21%) continued APA post-treatment, exclusively among those with prior APA follow-up (16/38 vs. 0/40, $p<0.001$). Barriers to APA continuation included geographical distance, lack of prior APA experience during treatment and socioeconomic constraints
This study highlights three critical insights:
-Early APA integration during treatment is decisive for post-treatment adherence, preventing physical deconditioning and loss of movement habits.
-HOPAYA acts as a motivational lever: The structured day hospital visit reinforces APA engagement by formalizing referrals and raising awareness of its benefits.
-AYA-specific barriers (e.g., school/work conflicts, limited local APA programs) underscore the need for tailored solutions (extended-hour APA sessions, digital APA programs or tele-rehabilitation

CONCLUSION

HOPAYA demonstrates that systematic, early APA integration coupled with a structured day hospital assessment significantly improves post-treatment adherence. Future steps include expanding local partnerships to reduce geographical barriers, piloting remote APA evaluations (e.g., via questionnaires) to assess distant practice levels and advocating for AYA-specific APA programs, systematically offered from diagnosis to survivorship.
This approach could transform long-term outcomes for AYACS by embedding APA as a cornerstone of cancer care.

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EARLY-ONSET CHRONIC AND METABOLIC MORBIDITY AMONG SURVIVORS OF CHILDHOOD ACUTE LYMPHOBLASTIC LEUKEMIA: EVIDENCE FROM MIDDLE-EASTERN REAL-WORLD DATA

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BACKGROUND-AIM

Survivors of childhood acute lymphoblastic leukemia (ALL) are at increased risk of long-term morbidity; however, limited data describe the early onset of metabolic and chronic conditions in contemporary cohorts or their association with treatment intensity in real-world settings. Existing evidence largely reflects European or North American populations, historical treatment eras, and fragmented healthcare systems. Data from Middle Eastern populations, particularly within a national health insurance framework enabling longitudinal follow-up across childhood and adulthood, are scarce. This study addresses these gaps by evaluating early-onset metabolic and chronic morbidity among childhood ALL survivors treated across multiple therapeutic eras within Israel's integrated healthcare system

METHODS

We conducted a retrospective cohort study using electronic health records from Clalit Health Services, Israel's largest integrated payer–provider healthcare system. Five-year survivors of childhood ALL (diagnosed <19 years between 1980–2018) were matched 1:6 to cancer-free controls by age and sex. Chronic conditions were ascertained longitudinally using validated diagnosis codes. Multivariable Cox and logistic regression models estimated associations between ALL survivorship and chronic health outcomes. Among survivors, additional analyses examined associations with treatment intensity, treatment protocol era, and cranial radiation exposure (dose-specific)

RESULTS

The cohort included 437 childhood ALL survivors and 2,622 matched controls; survivors were 74.6% Jewish, 18.3% Arab, and 7.1% other ethnicities. Compared with controls, ALL survivors had significantly increased risks of central nervous system conditions (HR 3.65, 95% CI 1.71–7.80), thyroid disorders (HR 2.18, 95% CI 1.55–3.05), cardiovascular disease (HR 2.09, 95% CI 1.35–3.22), diabetes (HR 1.83, 95% CI 1.05–3.21), obesity (HR 1.58, 95% CI 1.31–1.91), and metabolic syndrome (OR 2.09, 95% CI 1.53–2.80). No ethnic differences were found across all chronic conditions. Excess morbidity occurred within the first 2-years of survivorship and persisted through 5- years, except for endocrine that became apparent later. Higher treatment intensity, earlier treatment protocols, and hematopoietic stem cells were associated with greater burden.

CONCLUSION

Childhood ALL survivors experience early and disproportionate accumulation of chronic conditions, at young ages. Leveraging real-world data, this study provides novel evidence that treatment intensity and protocol era strongly shape early survivorship risk; unrelated to type of healthcare or ethnicity. These findings highlight the need for early, risk-adapted surveillance and targeted metabolic prevention strategies in contemporary childhood ALL survivorship.

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EXCELLENT SURVIVAL, SUBSTANTIAL TOXICITY: SEVERE TOXICITY-FREE SURVIVAL FOLLOWING CHILDHOOD ACUTE LYMPHOBLASTIC LEUKEMIA

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BACKGROUND-AIM

Survival rates for most childhood cancers have improved significantly, but the growing population of survivors experience serious, long-term, treatment-related complications. This burden is overlooked by traditional outcome measures. Severe Toxicity-event-free survival (ST-EFS) is a recently introduced, consensus-based outcome that integrates severe, treatment-related toxicities with traditional event-free survival (EFS) to improve outcome evaluation. This first trans-consortium study of ST-EFS in pediatric patients with acute lymphoblastic leukemia (ALL) aims to characterize the incidence and risk factors for Severe Toxicities (STs) and to facilitate ST-EFS as an international standard for treatment outcome evaluation.

METHODS

The cohort study included 3,063 pediatric patients (1–17 years) with Philadelphia chromosome-negative ALL, diagnosed from 1998 to 2019 across Australia, the Nordic and Baltic countries, and the United States. The occurrence of 21 predefined STs was assessed by medical record review and, for two participating cohorts, by initially screening comprehensive toxicity databases. Time-to-event analyses estimated ST-EFS and the cumulative incidence of STs. Cox models explored ST risk factors, adjusting for age, sex, and relapse status, and stratifying by risk group and cohort.

RESULTS

Of 3,063 children, 253 (8.3%) experienced at least one ST. Five-year EFS was 85.8%, whereas ST-EFS was 79.6%. The most frequently observed STs were severe osteonecrosis, disabling paralytic and neuropathic conditions, and severe psychiatric disorders. Older age at diagnosis and female sex were associated with an increased risk of STs (HR 2.1 (1.5–2.9) for 5–9 years, 3.6 (2.6–5.1) for 10–17 years vs 1–4 years, and 1.5 (1.1–1.9) for females), partially driven by osteonecrosis. Relapse was also associated with an increased risk of STs with an HR of 3.7 (2.5–5.6). ST occurrence varied across cohorts, most pronounced in one center with higher rates of STs, mainly psychiatric disorders and osteonecrosis. Omitting individual cohorts in sensitivity analyses had a modest effect on the ST-EFS estimates (ranging from 76.8–80.7%). Most STs (77%) occurred within five years after ALL; among late STs (>five years) not preceded by relapse, psychiatric disorders predominated. Excluding psychiatric disorders and cognitive dysfunction as ST events slightly increased ST-EFS estimates to 80.2% at five years and from 75.3% to 77.1% at 10 years.

CONCLUSION

Although survival in childhood ALL is excellent, a substantial proportion of patients experience serious, long-term toxicities that compromise daily functioning. ST-EFS is a clinically meaningful outcome that integrates severe, treatment-related toxicity with traditional outcome measures. Our findings support the implementation of ST-EFS as a new standard alongside conventional endpoints in future studies to better balance efficacy against long-term harm, guide survivorship care, and enable both historical and international comparisons; an approach that will remain important as novel therapeutic strategies are introduced.

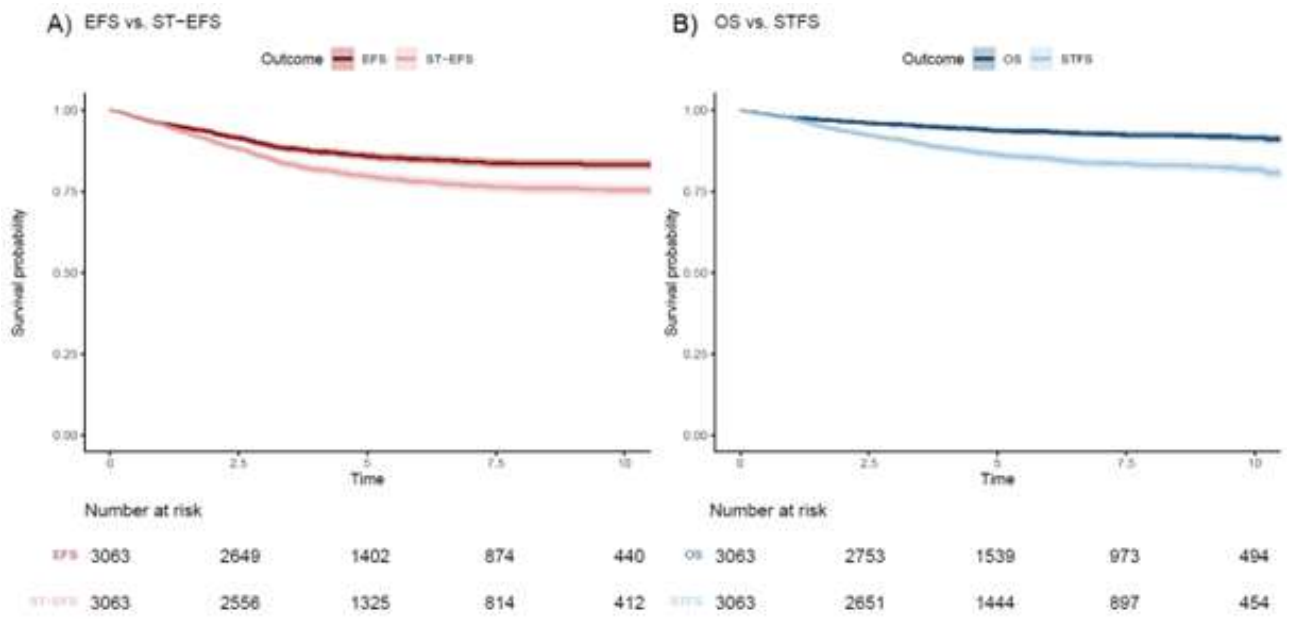

Figure 1. Kaplan-Meier curves showing A) event-free survival (EFS) and Severe Toxicity-event-free survival (ST-EFS); and B) overall survival (OS) and Severe Toxicity-free survival (STFS). EFS events comprised resistant disease, relapse, second malignant neoplasm, or death. ST-EFS included the same events with the addition of Severe Toxicities (STs), while STFS included STs in addition to OS. Patients without events were censored at last follow-up.

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FEASIBILITY OF THE PANCAREFOLLOWUP EHEALTH LIFESTYLE INTERVENTION TO PROMOTE THE ADOPTION OF SUSTAINABLE CHANGES IN LIFESTYLE BEHAVIOURS: A PANCAREFOLLOWUP STUDY

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BACKGROUND-AIM

A low level of physical activity and unhealthy dietary habits increase the risk of late effects among childhood, adolescent, and young adult cancer survivors. To fit survivors' daily lives, lifestyle interventions must be person centred and require minimal travel. Within the PanCareFollowUp project, an eHealth intervention was developed and demonstrated to support survivors in adopting sustainable improvements in physical activity and diet. To enable integration into routine care, insight into the feasibility of the intervention is needed. This study therefore aimed to assess the feasibility of the PanCareFollowUp Lifestyle intervention with survivors and healthcare professionals (HCPs).

METHODS

The PanCareFollowUp Lifestyle intervention consisted of 1-6 person centred screen to screen sessions with a certified lifestyle coach knowledgeable in late effects. A single arm feasibility study was conducted at two clinics in the Netherlands. Fifty eight participants were recruited who were diagnosed with cancer before age 25, were ≥5 years post treatment, aged 16-55 years at inclusion, and had low physical activity and/or unhealthy dietary intake reflected by overweight. Feasibility was assessed using coaching reports and questionnaires completed by survivors four months after the final session, and by HCPs (coaches and late effects physicians) at study end. Outcomes, using the Bowen framework, included demand, attrition, adherence, acceptability, practicality, integration and implementation. attrition.

RESULTS

Of the 114 eligible survivors, 58 participated in the lifestyle intervention (50.9%) (demand). Five participants (8.6%) discontinued prematurely, and one remaining participant did not adhere to all scheduled sessions (adherence). Overall, 13.4% of study measurements were missing (attrition). Survivors (n=42) and HCPs (n=8) rated the intervention highly (8.1±0.9 and 7.6±1.2, 1-10 scale), and most would recommend it to others (survivors: 8.7±1.2; HCPs: 75%) (acceptability). There was a strong preference for screen-to-screen delivery, with over three quarters of survivors and both coaches indicating they would prefer online above face-to-face coaching in the future. Nearly all survivors appreciated being able to participate from home (97.7%). Both coaches reported they could deliver the intervention as intended (practicality). Key facilitators included strong coach-survivor relationships, personalized support, survivors' intrinsic motivation, and the structured, time efficient format. Barriers were mainly survivor related, including low motivation, limited self discipline, mental or physical health challenges, and non stimulating social environments. Additional barriers included high BMI, underlying addictive behaviours, limited time, stress, and external factors such as weather or COVID 19 restrictions (integration and implementation).

CONCLUSION

The PanCareFollowUp Lifestyle intervention proved feasible and was well-received, with high demand, adherence, acceptability. Screen-to-screen, person-centred coaching was practical to deliver and supported engagement, while strong coach-survivor relationships emerged as key facilitators. Barriers were mainly survivor-related, including motivation, mental or physical health challenges, and non-stimulating environments. Overall, these findings support further refinement of the intervention and provide a strong rationale for evaluation in a full-scale trial prior to broader dissemination in survivorship care across Europe.

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GUT MICROBIOTA IN CHILDHOOD ACUTE LYMPHOBLASTIC LEUKAEMIA PATIENTS AND THEIR SIBLINGS DURING MAINTENANCE PHASE OF TREATMENT

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BACKGROUND-AIM

Childhood acute lymphoblastic leukaemia (ALL) survivors present metabolic and cardiovascular late effects such as overweight/obesity. Hypothesis is that the immune and metabolic phenotype co-evolve when affected by cancer. Gut microbiota (GM) plays a contributing role in these changes, but the underlying mechanisms remain poorly understood.

METHODS

We compared the gut microbiota composition of over one-year-old ALL patients (n=13) during the maintenance phase of treatment with healthy siblings (n=13) from faecal samples. DNA extraction and sequencing were performed, and species-level relative abundance of microbiota was estimated.

RESULTS

The study revealed significant differences in GM composition between ALL patients and their healthy siblings. ALL patients presented a lower overall species abundance measured with both species richness ($p=0.0023$) and Shannon index ($p=0.0051$). Significant differences in beta diversity dispersion were observed for treatment (all p-values < 0.01), suggesting higher inter-individual variability within the treatment group. Additionally, multiple bacterial species, exhibited significant differences in abundance between the study groups. For example, Bacteroides uniformis presented a significantly lower abundance in ALL patients, whereas several species belonging to the Firmicute phylum were more abundant in the patient group.

CONCLUSION

Our study identified several significant differences within the GM composition between healthy siblings and ALL patients during treatment. This provides a new direction for future studies, aiming to further understand the role of GM in the development of late effects after ALL treatment.

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IMPLEMENTATION OF A GERMAN GUIDELINE ON LONG-TERM FOLLOW-UP CARE AFTER CHILDHOOD AND ADOLESCENT CANCER: RESULTS FROM AN ONLINE SURVEY

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BACKGROUND-AIM

Due to increasing evidence of long-term effects following childhood and adolescent cancer, lifelong, risk-adapted long-term follow-up care (LTFU) is recommended. LTFU usually starts 5 years after treatment focusing on surveillance and early diagnosis of late effects. In May 2025, the AWMF S2k guideline on long-term follow-up care for childhood cancer survivors (025-003) was published, representing the first evidence-based survivorship guideline in Germany.
We conducted an accompanying online survey to examine knowledge, experience and perceived needs regarding survivorship care in healthcare providers and scientific professionals in this field.

METHODS

The anonymous survey was distributed online via the guideline homepage and professional journals/networks. Participants provided demographic data, work field and experience with survivorship care. Further topics included: 1) use of survivorship care plans 2) perceived knowledge and competence 3) need for further information and preferred channels 4) perceived practical relevance of the new guideline. Analyses were descriptive and hypothesis-driven with non-parametric correlations.

RESULTS

By November 2025 the guideline had been downloaded 13.376 times and 274 participants had accessed the survey. After data preprocessing, n=226 data sets remained for final analysis. Participants (121 females, age M=49 years, SD=12.27) worked as physicians an average of 22 years (SD=11.69) and primarily in clinics. They treated only a few cancer survivors annually (10-50 cases). Survivorship care plans from various sources were used by 41 %. Although they felt informed about the frequency of late effects, risk factors, prevention, and treatment, they reported lacking information on specific LTFU procedures and felt only partially competent in survivorship care. There was a strong demand for further information, especially guidelines, accordingly the new guideline was considered as relevant, but also online resources and educational programs. Personal competence correlated significantly and moderately with the use of survivorship care plan and with the perceived relevance of the guideline.

CONCLUSION

Findings of this survey reveal the need for broader dissemination and implementation of structured, guideline-based LTFU, which will be further addressed in professional networks. A mixed-method study is currently being conducted in Germany to assess optimal cancer survivorship medical education programs for clinicians (CanEdu Study on Cancer Survivorship Care - Current Gaps in Medical Education). Overall aim is to define frameworks of providing theoretical and practical training in survivorship care in postgraduate clinicians.

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Other 2

IMPLEMENTING A GDPR-COMPLIANT DIGITAL SURVIVORSHIP PASSPORT TO ENABLE CROSS-BORDER SURVIVORSHIP CARE IN CHILDHOOD CANCER

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BACKGROUND-AIM

The increasing number of childhood cancer survivors highlights the need for coordinated long-term follow-up across different healthcare systems. Survivorship care is frequently disrupted when patients transition among centers or countries, due to limited access to complete treatment summary reports and non-structured follow-up practices. The Survivorship Passport (SurPass) is a European digital initiative designed to facilitate continuity of care by compiling standardized treatment summaries and providing personalized follow-up recommendations based on IGHG and PanCare guidelines. The clinical use of such a tool across borders requires strict compliance with the General Data Protection Regulation (GDPR).

METHODS

With the aim of addressing cross-border data protection, SurPass v2.0 underwent a structured evaluation of regulatory, technical, and organizational safeguards prior to and during clinical deployment. Data protection requirements were incorporated using a privacy-by-design approach, ensuring that GDPR principles were embedded into system functionalities and clinical workflows. The assessment process included mapping data flows across institutions, reviewing access management and authorization procedures, and conducting a Data Protection Impact Assessment (DPIA) focused on cross-border data exchange. Regular multidisciplinary meetings supported alignment between clinical users and technical teams.

RESULTS

The platform was deployed through a centralized European infrastructure (PanCareSurPass Platform-Central, CINECA,Italy) and implemented in six clinical centers from different countries. The evaluation confirmed robust compliance with GDPR requirements relevant to cross-border healthcare, including transparency, purpose limitation, data minimization, and safeguarding of patient rights. The process also highlighted opportunities for refinement, such as clearer definition of data retention timelines, inforcement of consent management procedures, and broader application of encryption and pseudonymization for sensitive clinical data. Further recommendations addressed access control policies, continuous staff training, and harmonized security practices among participating centers.

CONCLUSION

This cross-border implementation of SurPass v2.0 demonstrates that digital survivorship tools can support coordinated long-term follow-up for childhood cancer survivors while fully respecting European data protection standards. Embedding GDPR compliance within clinical workflows enables secure data sharing across healthcare systems and contributes to more consistent and personalized survivorship care.

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IMPROVING LIFE AFTER CANCER DIAGNOSIS - PREDICTING AND PREVENTING LATE EFFECTS IN ADOLESCENT AND YOUNG ADULT (AYA) CANCER SURVIVORS, WITH A FOCUS ON FERTILITY AND REPRODUCTIVE HEALTH

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BACKGROUND-AIM

Despite significant advances in cancer treatment and rising survival rates, adolescent and young adult (AYA) cancer survivors remain vulnerable to a wide spectrum of both physical and psychosocial treatment-induced late effects. Among these sequelae, gonadal toxicity, infertility, and impaired sexual health are particularly impactful, with long-term consequences on key developmental life phases and overall quality-of-life.
Current evidence on how to accurately predict, prevent, and optimally manage late effects among AYA remains limited. The rarity of large-scale cohorts, broad range of individual diagnoses, diversity of treatment exposures, and the latency before late effects emergence has slowed research efforts and highlighted the need for large-scale, collaborative research efforts to address these persistent gaps in knowledge. The PredictAYA project aims to advance understanding of the incidence, severity, and impact of late effects among AYA cancer survivors aged 15–39 years at diagnosis, and to develop predictive models for these outcomes, with a particular focus on gonadal toxicity.

METHODS

PredictAYA (Project 101214879) is an EU funded consortium linking 18 research partners and more than 50 clinical institutions across Europe. The project combines existing AYA cancer survivor cohorts with new data collections and employs four complementary methodological approaches:
1. Epidemiological analyses of large-scale, population-based registry data to robustly quantify risks and temporal patterns of late effects.
2. Clinical outcome assessments in both new and ongoing AYA cancer survivor cohorts, linking detailed treatment exposures with clinical outcomes and patient reported experiences.
3. Genetic modelling to identify genomic markers that predict susceptibility to late effects following cancer therapy.
4. In vitro experimental models to investigate biological mechanisms and underlying pathways involved in treatment-related organ toxicity.

RESULTS

Initiated in June 2025, PredictAYA will engage clinicians from 15 European countries (Austria, Belgium, Denmark, England, Estonia, France, Germany, Italy, Netherlands, Poland, Portugal, Scotland, Spain, Sweden, Switzerland) in assembling both population-based data and a clinical cohort of more than 8,000 AYA survivors. Patient-centered research, including qualitative and quantitative studies, stakeholder consultations, and direct survivor involvement, will supplement the clinical outcomes and capture experiences related to decision-making, fertility communication, unmet needs, and gaps in care.
The combination of large, diverse cohorts and integrated methodological approaches will enable robust assessment of rare conditions, new treatment modalities, and disparities in care across Europe to improve patient care and outcomes. Results will be disseminated throughout the five-year project, culminating in the development of prediction models for late toxicities and evidence-based, tailored guidelines on late-effects management.

CONCLUSION

The EU funded PredictAYA project will advance the quality of care and long term quality-of-life for AYA cancer survivors across Europe by identifying key predictors, mechanisms, and timing of late-effects, with a particular focus on gonadal toxicity and its lifelong impacts.

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Other

IMPROVING PASSPORT FOR CARE USER EXPERIENCE - IMPLEMENTATION OF CHILDREN'S ONCOLOGY GROUP PROTOCOL-BASED AUTOMATED TREATMENT ENTRY INTO SURVIVORSHIP CARE PLANS

T. Ghosh [7], M.C. O'Connor [2], B.A. Solis [2], C.S. Yun [4], J. Stepenske [1], L.E. Carmichael [5], M.A. Acquazzino [6], A. Devine [5], D.N. Friedman [3], M.J. Ehrhart [5], C.M. Fordis [2], M.M. Gramatges [2], K.L. Foster [2]

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BACKGROUND-AIM

Passport for Care (PFC) is a web-based clinician tool that facilitates the development of individualized survivorship care plans (SCP) for childhood, adolescent, and young adult cancer survivors based on the Children's Oncology Group (COG) Long-Term Follow-Up (LTFU) Guidelines. PFC was developed at Texas Children's Hospital with the Baylor College of Medicine Center for Collaborative and Interactive Technologies (CCIT), and in partnership with the COG. Clinicians report satisfaction with PFC as a support tool, but indicate that time required for data entry into the PFC system is a barrier to its use, which may also impact accuracy of data entry and subsequently generated guidelines. To address this, the CCIT team and the COG LTFU Clinical Care Translation Task Force (CCTTF) engaged in a collaborative effort to develop a protocol-based automated entry system to improve efficiency, accuracy, and user satisfaction with the PFC portal.

METHODS

COG protocol nurses abstracted relevant treatment data (protocol number, arm, therapeutic drug names, routes, and prescribed cumulative doses) for COG protocols with high enrollment or duration as standard of care treatment, utilizing a standardized entry form developed by the COG CCTTF. The submitted treatment summaries were then reviewed by CCTTF members to include only cumulative dosing relevant to accurately describe dose-dependent late effects risk and novel therapies for which late effect risk is currently unknown. The relevant treatment data (including specific doses for anthracyclines, alkylators, and novel agents), and possible radiation were included in the summaries provided to the CCIT team for the PFC build. Using the protocol summaries, the CCIT team developed a modified data entry workflow, providing a new tool whereby a specific treatment protocol and arm could be selected, and all protocol-based treatments and doses automatically populated. Entries remain editable by the clinician until accepted, allowing for individualization if known dose modifications or omissions occurred.

RESULTS

To date five protocols/arms have been populated into PFC and are ready for implementation by users (AALL0932 low-risk and standard-risk arms, AALL1131 high-risk, and AHOD1331 with either bleomycin or brentuximab). Five additional protocols are currently undergoing treatment abstraction, 12 have been submitted and are under review by CCTTF, and one is ready for input into PFC. Throughout this process, CCTTF has met quarterly to review and adjust the standardized entry form based on feedback from the protocol nurses. Designated CCTTF members meet with the CCIT team quarterly. Initial user assessment is underway to compare the protocol-specific automated treatment entry interface with the existing entry method for time, accuracy, and user experience.

CONCLUSION

We anticipate utilization of protocol-based, automated treatment entry will reduce the administrative burden of data entry and improve user satisfaction, while maintaining SCP output fidelity to guidelines. This has the potential to broaden PFC use and improve adherence to COG LTFU Guidelines not only for centers who enrolled patients on selected trials, but for the global network of centers actively treating patients according to selected standard of care regimens. We would like to acknowledge funding support from: NCTN Operations Center Grant U10CA180886, NCTN Statistics & Data Center Grant U10CA180899, St. Baldrick's Foundation, & NCORP Grant UG1CA189955.

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Other 2

LANDSCAPE OF CANCER SURVIVORSHIP IN EUROPE: FINDINGS FROM THE JANE2-WP7 SURVEY

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BACKGROUND-AIM

The European Joint Action Networks of Expertise (JANE2), aims to develop Networks of Expertise in priority areas of oncology, in which WP7 focus on Survivorship. In Task 7.2, a landscape analysis was conducted to map cancer survivorship programs for childhood (CCS), adolescent and young adult (AYA) and adult cancer survivors across Europe, including care models, research activities, and collaborative networks.

METHODS

We collected data through a structured questionnaire from 4 types of institutions: clinical and research centers, scientific societies, and patient advocacy groups. The questionnaire was developed on LimeSurvey platform and disseminated between May and August 2025. Following a general module, including the definition of “cancer survivor” used by respondents, 4 institution-specific modules addressed survivorship program and research activities. Three further modules explored survivorship networks, challenges and barriers to care, and health economic aspects. The initial sample comprised the 69 partner institutions of JANE2 WP7, with further expansion through snowball sampling.

RESULTS

Eighty-four institutions across 26 European countries provided 124 responses, allowing multiple entries per center. Italy and Belgium were most represented (n=29 responses), followed by Spain (n=8).
“Cancer survivor” was most frequently defined as “five years after diagnosis” (29%) or “at the end of treatment” (27%), followed by “since diagnosis” (24%).
Among 93 responding clinical centers, 56% reported having structured survivorship care programs, mainly pediatric; however, more than half reported the presence of dedicated multidisciplinary teams.
Core services included clinical follow-up, psychological support, rehabilitation, genetic counseling and fertility preservation. CCS had broader access to services than adult survivors. Key survivorship components were largely unavailable, including transition programs, peer support, financial counseling, and return-to-work services.
Of 36 research centers, 64% reported active survivorship research, mainly on psychosocial aspects, late-effects, palliative care and lifestyle interventions. 5 scientific societies and 8 patient advocacy groups also reported survivorship-related activities. Educational programs were limited, being offered by 33% of clinical centers and advocacy groups only.
Most guidelines in use were international, particularly in the pediatric field (PanCare, IGHG, COG) and in general oncology (ESMO, ASCO, NCCN).
Twenty-four survivorship networks were identified, evenly distributed between national/regional and international levels, with a predominance of networks covering all age groups and with a specific focus on CCS.
The main barriers to implementing survivorship programs were identified as limited financial resources, lack of trained staff and insufficient interdepartmental coordination.

CONCLUSION

Survivorship programs are more developed and accessible for CCS, than for AYA and adult survivors. Despite strong expertise within pediatric centers, important gaps persist in structured networks, educational programs and coordination across centers.
Given the heterogeneity in “cancer survivor” definition, JANE2 WP7 proposed the following working definition: individuals who have had cancer and have completed active anti-tumour treatment (excluding hormonal therapy).
Overall, this survey highlights the need of “network of networks” to strengthen continuity of care and survivorship services for all survivors across Europe.

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Other 2

MAPPING SYSTEMS OF SURVIVORSHIP CARE

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BACKGROUND-AIM

Adherence to survivorship guidelines remains poor even in well-resourced settings despite prior targeted interventions. We hypothesized that utilizing systems science and working alongside local providers to develop a qualitative model of survivorship care would identify upstream barriers currently impeding successful intervention and provide a framework for future studies to improve care.

METHODS

We conducted group model building (GMB) with multiprofessional provider teams to develop a qualitative model of survivorship care. Providers were recruited from the Louisiana State University Health Sciences Center, a St. Jude Affiliate site, selected because its resource availability is representative of many rural and small U.S. communities (e.g., it lacks a robust, established survivorship program). Iterative GMB sessions (1 virtual, 1 in-person,) were used to generate a causal loop diagram summarizing survivorship care processes in the Shreveport, LA area, which was refined using findings from individual interviews.

RESULTS

10 virtual and 13 in-person participants developed and refined a draft model and identified four major themes comprising local survivorship care (Figure). 1) Provider knowledge and prioritization: Infrequency of childhood cancer survivors in clinical practices is a barrier to providers gaining experience, leads to survivorship care rarely being top of mind, and results in less provision of survivorship care. 2) Coordination across providers: Survivorship care delivery is dispersed across multiple providers, requiring extensive communication to coordinate patients' histories and care needs. Coordination requires extensive resources and often depends on establishment of inter-provider relationship building, both exacerbated during key transitions (e.g., between pediatric and adult care and/or organizations) and when provider roles are not clearly delineated. 3) Loss to follow-up: Infrequent visits spread across multiple providers results in limited provider awareness of who is due for follow-up and/or if recommended surveillance is occurring. In limited resource settings, patients may be referred across health care systems and required to return multiple times for appointments, introducing additional points for patients to fall through the cracks. 4) Survivor engagement: Survivors who understand their risks of late-effects and need for survivorship care are better positioned to communicate concerns with providers and more likely to complete recommended monitoring. However, education about survivorship often starts at the end of treatment, when patients begin to feel "cured" and ready to regain a sense of normalcy. This reduces motivation to stay engaged in survivorship care, unless active late effects emerge and must be addressed. Strong patient-provider relationships can also help survivors stay engaged but are often interrupted by transitions from cancer center to community and/or pediatric to adult care providers.

CONCLUSION

We used systems science to generate a model of survivorship care delivery that highlights a set of tightly interconnected challenges across provider knowledge, coordination, survivor engagement, and loss to follow-up. This model can be used to inform design of interventions seeking to enhance survivorship care delivery.

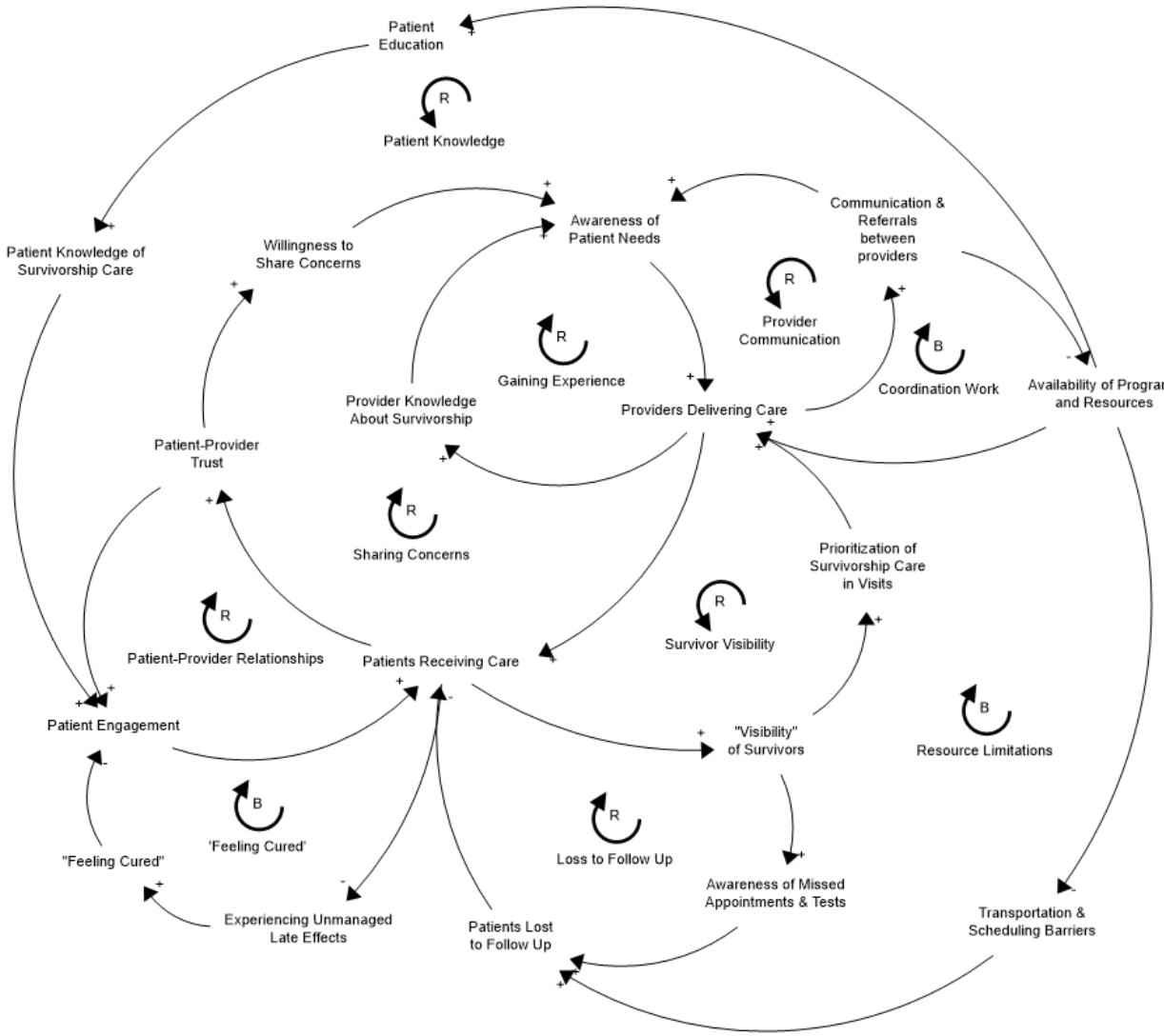

Figure. Survivorship care model generated by provider group model building. Arrows show causality. "+" variables move in the same direction. "-" variables move in opposite directions. Feeback loops - B=balancing, R=reinforcing.

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Other 2

OCCURRENCE OF AND RISK FACTORS FOR (PRE)FRAILTY IN CHILDHOOD, ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS: A SYSTEMATIC REVIEW

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BACKGROUND-AIM

(Pre)frailty is a state of reduced physiologic reserve, typically occurring in older people. However, survivors of childhood, adolescent and young adult cancer (CAYACS) are at risk for (pre)frailty at young or middle age. This may greatly impact their quality of life, but the occurrence and its associated risk factors are not yet clear. This is the first systematic review assessing this important topic, using evidence-based methods. Our aim was to provide an overview of the current evidence on the occurrence of (pre)frailty and associated risk factors in CAYACS.

METHODS

A systematic search was performed in PubMed/MEDLINE (21-03-2025) to identify studies on the occurrence of (pre)frailty and associated risk factors in CAYACS (diagnosed with cancer before 40 years of age, and survived at least 5 years since cancer diagnosis or at least 2 years after treatment completion). All definitions of (pre)frailty were eligible. Two reviewers independently performed study selection, data extraction and risk of bias assessment of the included studies.

RESULTS

Seventeen studies were included, with varying risk of bias. Across these studies, 9 prefrailty and 11 frailty definitions were used. Most definitions described prefrailty and frailty as the presence of two and at least three of five physical indicators, respectively (e.g. exhaustion, walking limitations, low energy expenditure, low lean muscle mass and muscle weakness). However, their operationalization varied widely. The occurrence of prefrailty and frailty, assessed after a minimum follow-up of 5 years after diagnosis, ranged between 10 and 57% (12 studies) and between 3 and 47% (17 studies), respectively. The occurrence increased with longer follow-up and was consistently higher than in controls of approximately similar age. Several risk factors for (pre)frailty were identified, although results varied across studies and definitions. These included older age at diagnosis, higher attained age, female sex, chronic conditions (e.g. neurologic and endocrine disorders), specific treatment modalities (e.g. cranial irradiation and alkylating agents), living in a resource-poor neighbourhood, and lifestyle behaviours (e.g. smoking and a sedentary lifestyle).

CONCLUSION

Although this systematic review suggests that CAYACS are at increased risk for developing (pre)frailty, high-quality studies using harmonized definitions of (pre)frailty are needed to obtain more precise estimates of occurrence, and to better identify associated risk factors.

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Other

OPTIMIZING REIMMUNIZATION IN SURVIVORS OF CHILDHOOD CANCER THROUGH QUALITY IMPROVEMENT METHODOLOGIES

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BACKGROUND-AIM

Background:
Childhood cancer survivors (CCSs) treated with immunosuppressive chemotherapy and hematopoietic stem cell transplants (SCT) are at increased risk for waning or loss of vaccine-induced immunity. Prior studies indicate up to 50% of CCSs may experience diminished or loss of serologic protection following therapy, highlighting the need for structured revaccination and immune monitoring. Ensuring optimal immunity to vaccine-preventable illnesses is therefore a critical component of survivorship care. The Children's Oncology Group (COG) Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers Version 6.0 (October 2023) recommend either measurement of antibody titers with targeted boosting or empiric boosters of all previously administered vaccine series after cancer treatment. The objective of this quality improvement project is to increase vaccine titer assessment and/or booster rates from approximately 0% of eligible patients to 60%.

METHODS

Methods:
This project was conducted in oncology and survivorship clinics at a freestanding academic children's hospital. The target population included patients at least 6 months post-chemotherapy for childhood cancer, excluding those who underwent SCT. A multidisciplinary team was assembled. Baseline measurement of patients undergoing titers and/or boosters between 6–18 months after therapy completion was collected using Hepatitis B titer and/or booster as the primary process measure. Gaps in care were identified through staff meetings, education on updated guidelines, and feedback on workflow barriers. Based on these findings, the team developed a Department Standard Resource (DSR) to provide education and process guidance. Cycles of change included department-wide education, pilot testing with a subset of providers, refinement of DSR resources, and clinic-wide rollout in November 2025. Outcomes were evaluated through intermittent post-intervention electronic medical record (EMR) review.

RESULTS

Results:
Following initial education in February 2025, the proportion of patients receiving titers and/or boosters did not change, indicating education alone was insufficient. Piloting the DSR with invested providers (N=6) identified the need for tools to simplify determination of required titers and streamline ordering. Supplemental resources were developed, including a quick-reference flow sheet, EMR order set, documentation phrase, and titer interpretation guide. After further piloting, the DSR was rolled out clinic-wide in November 2025 with establishment of a clinical project champion. In the three months following implementation, the proportion of patients receiving titer assessment and/or booster administration increased to 20%. Outcome measurement and process improvement are ongoing.

CONCLUSION

Conclusion:
With a target goal of 60% of CCSs receiving titer evaluation and/or booster administration by 12 months post-DSR implementation, current trends demonstrate progress. Additional quality improvement strategies may include audit and feedback, guidance from the clinical champion, and standardized order review. This initiative demonstrates a feasible approach to improving guideline-recommended immunologic assessment and booster vaccination in CCSs, with potential to enhance long-term protection against vaccine-preventable infections and treatment-related morbidity.

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Other

PATIENT-CENTRED, EVIDENCE-BASED LATE EFFECT SCREENING AND FOLLOW-UP CARE OF SURVIVORS OF ADOLESCENT AND YOUNG ADULT CANCER: THE PANCARE4AYA PROJECT

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BACKGROUND-AIM

Survivors of adolescent and young adult (AYA) cancer, age 15 to 39 years at diagnosis, are a unique population facing risk for health problems that impact their quality of life (QoL) in comparison to their peers without cancer. AYA cancer survivors have different needs than paediatric and adult cancer survivors as they develop different cancer types and treatment-related mortality and morbidity (late effects).
Late effects not only impact the quality of life of AYA cancer survivors, but also place significant societal and economic burden. The impact of late effects can be prevented or reduced through improved Survivorship Care, that combines long-term, systematic screening and follow-up care of AYA cancer survivors. While evidence-based guidelines for post-treatment cancer care exist for paediatric survivors, they are not yet adequately established for AYAs.
Survivorship Care enables early detection of treatable late effects and timely interventions to preserve health and improve QoL. The overall aim of the PanCare4AYA project is to improve the health and QoL of AYA cancer survivors across Europe by developing and evaluating Survivorship Care tailored for this unique population.

METHODS

The EU-funded PanCare4AYA project (Project 101213107) launched in April 2025 and is delivered by a consortium of 29 partners from 14 countries. PanCare4AYA will address current gaps in Survivorship Care. The project will develop an international long-term follow-up guideline for screening and follow-up specifically for AYA cancer survivors. The guideline will then be implemented via a novel, person-centred screening programme (AYA Cancer Survivor Screen programme).
The AYA Cancer Survivor Screen programme will be tested in an implementation study involving 1,000 AYA cancer survivors from 11 European countries (Croatia, Czech Republic, France, Germany, Italy, Lithuania, Netherlands, Norway, Sweden, Switzerland, United Kingdom). The study countries were selected to reflect the wide variations in current AYA cancer survivorship care across different European healthcare models to provide insights from variable settings that will support future programme uptake. The implementation study will evaluate the effectiveness of the AYA Cancer Survivor Screen programme through outcomes related to survivor empowerment, psychosocial functioning, physical and mental health and other QoL outcomes, as well as the care delivery and peer support. Innovative digital tools will be developed and implemented in France, Italy, Lithuania and the Netherlands. The experiences of both AYA cancer survivors and Health Care Professionals with the programme will be evaluated alongside feasibility.

RESULTS

The results of the implementation study will be finalized and published in the next five years. The future scale-up of the AYA Cancer Survivor Screen programme is vital to achieve sustainable real-world improvements to Survivorship Care for AYA cancer survivors. To support scale-up, a Replication Manual will be developed for the AYA Cancer Survivor Screen programme, including a Policy Outreach Strategy, guidance on digital survivorship care tool development, and a survivorship care initiation package. This will be made freely available after project completion.

CONCLUSION

PanCare4AYA aims to improve the health and QoL of AYA cancer survivors across Europe by developing, implementing and evaluating an AYA cancer specific Survivorship Care programme.

On behalf of the **PanCare4AYA** Consortium.

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On behalf of the PanCare4AYA Consortium

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Other

PSYCHOLOGICAL OUTCOMES OF PARENTS OF CHILDHOOD CANCER SURVIVORS – A SUMMARY OF FINDINGS FROM THE SWISS CHILDHOOD CANCER SURVIVOR STUDY–PARENTS

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BACKGROUND-AIM

Parents of childhood cancer survivors might face long-term psychological impact that may still persist decades after diagnosis. Evidence showed both adverse outcomes, such as distress and anxiety, and positive adaptation, such as growth and resilience. We synthesized our findings from the Swiss Childhood Cancer Survivor Study-Parents regarding their long-term psychological outcomes.

METHODS

Parents of survivors (CCS-Parents; child diagnosed with cancer ≤16 years, ≥20 years at study, ≥5 years post-diagnosis) were identified through the Swiss Childhood Cancer Registry and compared with parents with similar aged children as CCS-parents from a representative Swiss population sample (GP-Parents) from the Swiss Federal Statistical Office. We used validated instruments to assess post-traumatic stress (Impact of Event Scale Revised), worries (Worry and Anxiety Questionnaire), health-related quality of life (Short Form-36v2), post-traumatic growth (Post-Traumatic Growth Inventory), and resilience (Connor-Davidson Resilience Scale). Group differences were compared and associated factors among CCS-Parents were assessed using multivariable and multilevel regression models.

RESULTS

787 CCS-Parents participated (76% females; mean age=62.3 years, SD=6.9; mean time since cancer diagnosis=24 years, range: 7-40) and compared with 478 GP-Parents (57.7% females; mean age=62.1 years, SD=8.0). Psychological outcomes were as follows:
A - Illnesses/medical problems are the most stressful event that parents reported (CCS-Parents 49.5% vs GP-Parents 27.6%). The percentages of individuals with probable post-traumatic stress disorder were similar (CCS-Parents 4.8%, GP-Parents 6.7%, p=0.210). In CCS-Parents, lower education was associated with higher symptom levels.
B - About 50% of CCS-parents reported current cancer-related worries, which were higher in mothers, parents with one child, those experiencing ongoing disadvantages due to the child's illness, and those with support needs. General anxiety disorder was similar between groups (CCS-Parents 2.7%, GP-Parents 3.6%, p=0.536).
C - Physical and mental health-related quality of life was similar in CCS-parents and GP-parents, with slightly higher physical functioning in mothers of survivors. In CCS-Parents, lower mental health-related quality of life was associated with female sex, lower education, chronic conditions, migration background, and residence in French- or Italian-speaking regions.
D - Post-traumatic growth was higher in CCS-Parents than GP-Parents. CCS-Parents reported higher growth in the domains relating to others, spiritual change, and appreciation of life than GP-Parents. Higher growth was associated with female sex, older age, higher post-traumatic stress, and higher resilience.
E - Resilience was lower in CCS-Parents than GP-Parents. In CCS-Parents, better general health was linked to higher resilience, while higher depression and residence in French- or Italian-speaking regions were linked to lower resilience.

CONCLUSION

Parents of long-term childhood cancer survivors generally show similar levels of stress, anxiety, and health-related quality of life as parents from the general population decades after diagnosis. Nonetheless, cancer-related worries remain common, resilience is lower, and distinct subgroups show increased vulnerability. Long-term psychosocial care should focus on strengthening resilience and supporting parents with persistent worries or those with sociodemographic risk factors.

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Other

REDUCED PULMONARY FUNCTION AND ALTERED CEREBRAL BLOOD FLOW AMONG HODGKIN LYMPHOMA SURVIVORS.

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BACKGROUND-AIM

Long-term survivors of childhood Hodgkin lymphoma (HL) exposed to chest radiation and bleomycin are at increased risk for lung morbidities, which we previously found were associated with impaired visuomotor and visual processing speed outcomes among HL survivors. The mechanism linking lung morbidity and neurocognitive impairment is not well understood. This study aims to determine if HL survivors have altered cerebral blood flow associated with poor lung function compared to community controls.

METHODS

Lung function (FEV1, FEV1/FVC, DLCO), cardiopulmonary function (pkVO2, PkVCO2), and cerebral blood flow (CBF) were assessed in HL survivors (<21 years old at diagnosis, ≥ 18 years of age at assessment, >2 years post therapy, treated with chest radiation and/or bleomycin) and age matched community controls. Cardiopulmonary function was assessed with breath by breath gas exchange on a treadmill using the Bruce Protocol to maximal exertion endpoint, while simultaneously measuring CBF from the anterior and posterior circulation using a mobile, whole-head, near-infrared device (NIRsport2, NIRx). Optical density data were converted into changes in total hemoglobin concentration (ΔHbT) using the modified Beer–Lambert law. Whole head data in each stage was fitted using a linear model, and the absolute value of slope measured and compared between groups. To avoid outcome based selection bias, CBF correlations were calculated at the final stage (same for all participants) rather than the stage with maximum |slope|. This correlation coefficient (r) was compared between groups. Unpaired t-tests were used to compare the means of pkVO2 and pkVCO2.

RESULTS

Preliminary data from 46 HL survivors (n=25 females; mean[SD] age 40.3[8.6]) who were 26.1 [min-max: 19-42] years from diagnosis and 17 controls (n=10 females; 37.5[9.4]) showed female survivors had a lower pKVCO2 (1729.7[534.2] vs 2367.1[720.1], p=0.007), DLCOcor %predicted (88.8[14.4] vs 113.4[20.8], p=0.001), FEV1 %predicted (90.8[17.6] vs 103.9[11.3], p=0.048), and FVC %predicted (92.0[18.3] vs 107.0[8.7], p=0.027) compared to female controls. At peak exercise, 30% of survivors (n=14) showed anterior-posterior CBF anticorrelations vs. 18% of controls (n=3). This was driven by males: 47.6% (10/21) of male survivors exhibited r<0 vs. 16.7% (1/6) of male controls (p=0.077). Among male survivors, FVC (β=0.017, p=0.011) and FEV1/FVC (Figure 1; β=-0.045, p=0.006) were associated with the correlation between anterior and posterior CBF but not among females. Among female survivors, corrected DLCO was not significantly associated with the correlation between anterior and posterior CBF (β=0.015, p=0.052). No associations were found among pkVO2, pkVCO2, chest radiation dose, or bleomycin dose and negative correlation in anterior and posterior CBF.

CONCLUSION

Our results demonstrate associations between restrictive lung function patterns and disparities in anterior and posterior CBF changes in response to rising C02 levels. Additionally, our data suggests that interventions that target improving brain circulation in male survivors with impaired FVC or FEV1/FVC may be important for maintaining neurocognitive function.

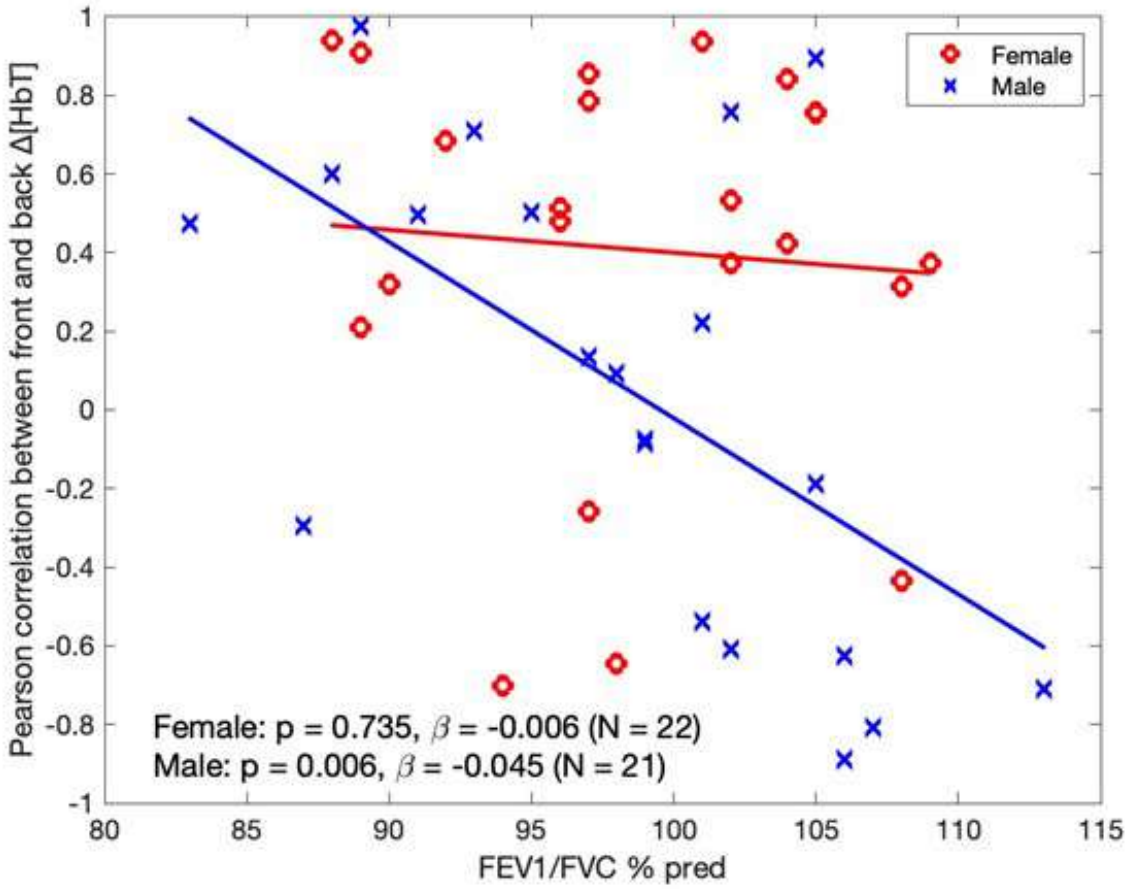

Figure 1. Association between FEV1/FVC % predicted and the correlation between the anterior and posterior circulation.

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Other

SEVERITY AND TIMING OF OTOTOXICITY IN SURVIVORS OF PAEDIATRIC CENTRAL NERVOUS SYSTEM AND SOLID TUMOURS TREATED WITH PLATINUM-BASED CHEMOTHERAPY: A RETROSPECTIVE COHORT STUDY.

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BACKGROUND-AIM

Ototoxicity is a common late complication among childhood cancer survivors treated with platinum chemotherapy. Our previous audit identified hearing loss as the most prevalent long-term morbidity in survivors of paediatric central nervous system (CNS) and solid tumours. While cumulative cisplatin dose is a recognised risk factor, the relative contributions of cisplatin and radiotherapy to hearing loss severity and timing remain unclear. This study evaluates factors associated with the risk, severity, and onset of hearing loss, with a focus on cisplatin dose and head and neck radiotherapy.

METHODS

Our study included childhood CNS and solid tumour survivors who were ≥2 years post-treatment, ≥5 years in remission, and attending long-term follow-up at KK Women's and Children's Hospital, Singapore (2017–2023). Ototoxicity was graded using the SIOP Boston Ototoxicity Scale. Logistic regression assessed factors associated with hearing loss. The hazard ratio for developing ototoxicity was estimated using survival curve analysis. Covariates adjusted for include age, sex and race.

RESULTS

Among 162 survivors (56 CNS, 106 solid tumours), hearing loss occurred in 42% of CNS and 20% of solid tumour survivors. Higher cumulative cisplatin dose increased the odds of hearing loss (OR 1.65 per 100 mg/m², 95% CI 1.35–2.22, p<0.001). Survivors receiving head and neck radiotherapy had higher odds of hearing loss (OR 3.21, 95% CI 1.39–7.40, p=0.006). Those receiving radiotherapy also tended to have higher cisplatin exposure, although this did not reach significance (p=0.065), suggesting partial overlap in treatment exposure. Survival curve analysis showed that both cisplatin dose and radiotherapy were independently associated with earlier hearing loss. Survivors receiving radiotherapy developed hearing loss earlier (HR 3.06, 95% CI 1.50–6.22, p=0.002), as did those exposed to >300 mg/m² cisplatin (HR 4.01, 95% CI 2.00–8.05, p<0.001). Among cisplatin-exposed survivors, those who also received radiotherapy developed hearing loss twice as early as those treated with cisplatin alone (HR 2.01, 95% CI 1.02–3.98, p=0.045).

CONCLUSION

Cumulative cisplatin exposure and head and neck radiotherapy are key determinants of both the risk and earlier onset of ototoxicity among childhood cancer survivors. While the risk of hearing loss increases progressively with higher cisplatin dose, the timing of onset appears more threshold-dependent, with earlier hearing loss observed particularly in survivors exposed to >300 mg/m². Our study also highlighted ototoxic interaction between radiotherapy and platinum therapy in affecting the timing of onset of hearing loss. These findings support risk-stratified audiological surveillance for survivors receiving combined modality treatment.

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Other

SOCIOECONOMIC OUTCOMES IN PARENTS OF CHILDHOOD CANCER SURVIVORS – A SUMMARY OF FINDINGS FROM THE SWISS CHILDHOOD CANCER SURVIVOR STUDY–PARENTS

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BACKGROUND-AIM

Childhood cancer can have a lasting socioeconomic impact on parents that extends into long-term survivorship. We synthesized our findings from the Swiss Childhood Cancer Survivor Study-Parents regarding parents' socioeconomic situation in terms of their support needs, partner relationships, and employment changes.

METHODS

Parents of survivors (child diagnosed with cancer ≤16 years, ≥20 years at study, >5 years post-diagnosis) were identified through the Swiss Childhood Cancer Registry and contacted by the former treating clinic. Using standardized questionnaires, we assessed perceived disadvantages (job-related, financial, social environment/friends, family, physical, psychological, or other) and support needs, use of support services, civil status and partner relationship quality (Relationship-specific attachment scale for adults), and employment changes during treatment and long-term professional and financial impact. Multivariable and multilevel regression models were used to identify factors associated with support needs, relationship security and dependency, and employment changes.

RESULTS

A total of 778 parents (mean age=62.3, SD=6.9; 76.5% females; 56.4% employed) of 513 survivors (44.4% females, 58.6% aged ≥30 years, 34.1% had leukemia; mean time since cancer diagnosis=24 years, range 7-40) participated. One fifth (19.2%) of parents reported current disadvantages and 7.1% reported ongoing support needs. Two-thirds (66.9%) wished they had received more support during treatment and 34.4% during long-term survivorship. Overall, 43.5% of parents used existing support services. Parents of survivors were less likely to be divorced or separated than comparison parents (9.0% vs 17.5%) and more often in a partner relationship (89.9% vs 85.0%). Relationship security was similar between groups and parents of survivors reported higher dependency within the relationship (p=0.032). During diagnosis and treatment, 21% of parents reported employment changes, most commonly: reduced working hours (52%), quitting work (27%), or unpaid leave (21%). Mothers were more likely than fathers to experience changes (OR=2.00; p=0.005), mainly due to childcare responsibilities (87% of parents with employment changes). Long-term professional and financial impacts were uncommon (each 5%) but more likely when survivors had late effects (financial impact OR=10.51), a relapse (OR=3.96), or were financially dependent on their parents (OR=3.64). Professional impact was associated with female sex (OR=3.26) and prior employment changes (OR=2.39).

CONCLUSION

Decades after the cancer diagnosis, most parents of long-term childhood cancer survivors function well socially, in their partner relationships, and professionally. However, a meaningful minority reported persistent disadvantages, support needs, or long-term work and financial impact, particularly when survivors have late effects or remain dependent. Sustained, visible, and targeted support may help parents during treatment but also throughout survivorship.
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Other

STANDARDIZING LATE-EFFECTS DATA CAPTURE IN CHILDHOOD CANCER SURVIVORSHIP: A FHIR-BASED FOLLOW-UP QUESTIONNAIRE

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BACKGROUND-AIM

Advances in paediatric oncology have raised survival rates, but childhood cancer survivors remain at high risk of late effects, including endocrine, cardiovascular, and neurocognitive complications. Structured and personalized long-term follow-up (LTFU) is essential to detect and manage these conditions, yet data collection practices vary widely, limiting interoperability and secondary use. Within the PanCareSurPass (PCSP) project, we aimed to standardize the follow-up questionnaire used in the Survivorship Passport (SurPass) and implement it as a computable artifact based on HL7 FHIR (Fast Healthcare Interoperability Resources).

METHODS

Clinically, we started from the Common Terminology Criteria for Adverse Events (CTCAE) and extended it to address survivorship-specific needs. Technically, the questionnaire was modelled using FHIR Questionnaire and QuestionnaireResponse resources and integrated into the PanCareSurPass FHIR Implementation Guide.

RESULTS

The standardized questionnaire supports first and subsequent visits, capturing consent, visit metadata, and clinical relevant pathological conditions with logic to differentiate new from existing conditions. To facilitate adoption, we developed a sandbox and published example instances.

CONCLUSION

This work delivers a robust foundation for interoperable LTFU data capture, supporting clinical care and research. Future steps include submission of m-CTCAE for community review and potential integration into future CTCAE survivor-specific releases.

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Other 2

TARGETED ORGAN-SPECIFIC LONG-TERM FOLLOW-UP POST HEMATOPOIETIC STEM CELL TRANSPLANTATION OF CAYA FANCONI ANEMIA PATIENTS: PRELIMINARY RESULTS FROM THE DOPO CLINIC

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BACKGROUND-AIM

Fanconi anemia (FA) is a rare inherited multisystem disorder caused by defects in the FA/BRCA DNA repair pathway, leading to bone marrow failure, congenital abnormalities and a high risk of malignancies, particularly of head and neck, requiring lifelong surveillance. Although hematopoietic stem cell transplantation (HCT) has improved survival of FA patients, it does not correct the non-hematological features of the disease and may increase the risk of late complications. Long-term data on chronic conditions (CC) after HCT in FA patients are limited. This study evaluates the prevalence and burden of CC in childhood, adolescent and young adult (CAYA) FA patients followed with a structured surveillance program.

METHODS

All CAYA FA patients who underwent allogenic HCT followed at the late effects clinic of the Gaslini Institute were included. For each patient, demographic, genetic, clinical and hematological data were collected together with donor type, conditioning regimen and acute/chronic Graft Versus Host Disease (GVHD). After HCT, patients underwent a targeted, organ-specific surveillance program according to the FA Research Fund (FARF) guidelines, including that for cancer and CC which were graded according to CTCAE v6.0.

RESULTS

Twelve transplanted CAYA FA patients were included (50% female; median age at diagnosis 6.1 years; FANCA mutations in 83%). HCT was performed at a median age of 8.5 years. Donor type (unrelated, related, $\alpha\beta$T-cell CD19#-depleted haploidentical) was evenly distributed across the cohort. Reduced-intensity conditioning regimens were used in all cases, most commonly cyclophosphamide plus fludarabine, with the addition of low dose of total body irradiation (200 cGy) in 3 patients. One patient developed acute GVHD (grade 2), while 4 (33%) developed chronic GVHD (2 limited, 2 extensive).

After a median of 12.5 years (IQR 10.6-15.9) post-HCT and at median age of 23 years (range 16–36), all patients developed at least one CC, median 2.5(IQR 1-6), for a total of 88 conditions (92% grade 1-2, 8% grade 3). The most frequently affected systems (Table 1B) were respiratory (restrictive or mixed lung disease, n=11), endocrine (thyroid dysfunction or hypogonadism, n=9), metabolic (obesity or insulin resistance, n=7) and hepatic (steatosis or steatohepatitis, n=7). The 6 grade 3 CC were observed in 5 patients and affected the eye (kerathopaty), esophagus (GERD), testes (azoospermia), teeth (agenesia) and immune system (1 post-HCT lymphoproliferative disease, 1 immune thrombocytopenia).

Oncological screening identified oral precancerous lesions (leukoplakia) in 2 patients, successfully surgically treated; no malignant tumors were observed during the entire follow-up (FU) period. No significant differences in CC development were detected between patients receiving or not low dose TBI.

CONCLUSION

In this monocentric cohort, CAYA FA patients undergoing HCT experienced a substantial burden of CC, mostly mild, with predominant involvement of the respiratory, endocrine–metabolic and hepatic systems. No malignant tumors occurred. These apparently reassuring results might depend on the size and on the low median age of the cohort. Targeted surveillance enabled early identification and treatment of pre-cancer lesions. Despite the limited sample size, the long FU strengthens the importance of disease-specific surveillance programs in FA survivors. Larger studies including non-transplanted FA patients are needed to confirm findings and optimize long-term FU strategies.

Table 1. Clinical and transplant characteristics (A) and organ-specific chronic conditions after Hematopoietic stem Cells transplantation (B) in Childhood, Adolescent and Young Adults Fanconi Anemia patients

A

Gender, n (%)	Female	6 (50)
Age at FA diagnosis, years, median (IQR)		6.1 (2.5-6.7)
Genetic profile, n (%)	FANCA	10 (83)
	Other (FANCG, FANCL)	2 (17)
Extra-hematological manifestation at diagnosis, n (%)		9 (75)
	Kidney (agenesis, ectopia, reflux)	6
	Endocrine (failure to thrive)	4
	Gastro-intestinal (esophageal and duodenal atresia)	3
	Bone (radio hypoplasia)	2
	CNS vascular abnormalities	2
Transfusions, androgens pre-HCT, n (%)		8 (67)
Donor type, n (%)	HCT *Unmatched related donor*	4 (33)
	Matched related donor	4 (33)
	αβ T-cell CD19+-depleted haploidentical	4 (33)
Age at HCT, years, median (IQR)		8.5 (7.2-11.6)
Median time since diagnosis to HCT, years (IQR) (min-max)		3.6 (1.9-5.4) (0.4-11.5)
Conditioning regimen, n (%)	Cy (300 mg/mq/d, 4 days) + Flu (30 mg/mq/d, 4 days)	8 (67)
	Addition mini TBI (200 cGy)	3 (25)
	Other (Cy + abdominal RT 500 cGy)	1 (8)
GVHD prophylaxis, n (%)	ATG (5 mg/kg, 2 days) + CSA	3 (25)
	ATG (4 mg/kg, 4 days) + anti-CD20 (200 mg/mq, 1 day)	3 (25)
	CSA + anti-CD52 (0,2 mg/kg, 4 days) +/- MMF	3 (25)
	ATG (3,75 mg/kg, 4 days) + CSA + MTX (8 mg/mq/d, 3 days)	2 (17)
	CSA	1 (8)
Graft versus host disease, n (%)	Acute	1 (8)
	Chronic	4 (33)
Clinical status at last follow-up, n (%)	Alive	12 (100)
Age at last follow-up visit, median (IQR) (min-max)		23.1 (20.7-25.8) (16.5-36.3)
Median follow-up time after EoT, years (IQR) (min-max)		12.5 (10.6-15.9) (8.3-29.6)
Chronic conditions & complications, n, median (IQR)		88, 2.5 (1-6)
At least one chronic conditions & complications, n (%)	Yes	12 (100)
	Grade I-II, n (%)	82 (93)
	Grade III-IV, n (%)	6 (7)

Abbreviations: CAYA, Childhood, Adolescent, and Young Adult; FA, Fanconi Anemia; CNS, Central Nervous System; HCT, Hematopoietic stem Cells transplantation; Cy, Cyclophosphamide; mq, Flu, Fludarabine; TBI, Total Body Irradiation; RT, radiotherapy; GVHD, Graft Versus Host Disease; ATG, Anti-thymocyte globulin; CSA, ciclosporin; MMF, mycophenolate mofetil, MTX, Methotrexate; IQR, Interquartile Range; EoT, end of treatment; CMV, Cytomegalovirus; GERD, Gastro-esophageal reflux disease; DLCO, Diffusion capacity of the lungs for carbon monoxide.

B

SYSTEM/Organs		N (%)
AUDIOLOGICAL	Hearing loss	1 (8)
CARDIOVASCULAR	Hypertension	1 (8)
DENTAL		3 (25)
	Agenesia	2
	Altered enamel mineralization	1
ENDOCRINE		9 (75)
	Gonadal dysfunction (hypogonadism)	6
	Thyroid disease (nodules, hypothyroidism, thyrotoxicosis)	6
	Growth Hormone Deficiency	2
	Hyperprolattinemia	1
EYE		6 (50)
	Cataract	3
	Retinal abnormalities (CMV chorioretinitis sequelae)	2
	Punctate keratopathy (GVHD sequelae)	1
GASTRO-INTESTINAL	Esophageal disorders (dysmotility, GERD)	2 (17)
IMMUNE		4 (33)
	Hypogammaglobulinemia	2
	Immuno thrombocytopenia	1
	Post-transplant lymphoproliferative disease	1
REPRODUCTIVE		4 (33)
	Reduced/absent ovarian reserve	3
	Azoospermia	1
LIVER		7 (58)
	Fat liver/steatosis or Non-Alcoholic Fatty Liver Disease	5
	Liver function abnormalities (colestasis, hypertransaminasemia)	3
	Fibrosis (mild)	1
	Transient Hepatic Attenuation Differences	1
LUNG		11 (92)
	Obstructive disease	2
	Restrictive disease	4
	Mixed	5
METABOLIC		7 (58)
	Overweight	6
	Insulin resistance/Hyperinsulinism	3
	Dyslipidemia	3
NEUROLOGIC		2 (17)
	Epilepsy	1
	Ischemic cerebral lesion	1
ONCOLOGIC		3 (25)
	Precancerous lesions (oral)	2
	Benign skin cancer	2
PSYCHIATRIC	Depressive disorder	1 (8)
RENAL		3 (25)
	Chronic kidney disease (stage III)	1
	Other (lithiasis, simple renal cyst)	1
SKELETAL		6 (50)
	Low mineral density (osteoporosis)	4
	Other (exostosis, scoliosis	2

Clinical and transplant characteristics (A) and organ-specific chronic conditions after Hematopoietic stem Cells transplantation (B) in Childhood, Adolescent and Young Adults Fanconi Anemia patients

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Other 2

TELEHEALTH ELIGIBILITY CRITERIA FOR VIRTUAL PEDIATRIC SURVIVORSHIP CARE: A QUALITY IMPROVEMENT INITIATIVE

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BACKGROUND-AIM

The Children's Oncology Group (COG) Long-Term Follow-Up (LTFU) Guidelines offer recommendations for surveillance after childhood and adolescent cancer treatment. Screenings include history and physical exam as the primary assessment for late effects, with laboratory and imaging tailored to the treatment history.
While in-person visits after establishing survivor care have benefits for some long-term survivor (LTS) populations, financial, geographic and other barriers exist to accessing survivorship care. Limited data exist regarding the application of telehealth for delivery of pediatric survivorship services.

METHODS

Utilizing guidance from the COG LTFU guidelines, the American Medical Association Telehealth Implementation Playbook, and clinical expert opinion, we developed and implemented criteria necessitating in-person care for effective late effect surveillance at the Texas Children's Cancer and Hematology Center (TXCH) LTS Clinic.
TXCH LTS visits from July 1, 2025 through January 31, 2026 were reviewed for telehealth eligibility. Survivors of allogeneic transplant were excluded. To be eligible, survivors must have been seen by an LTS provider in the preceding 3 years and have a primary care provider (PCP). Children 17 years and younger must also meet treatment specific criteria (Table 1). Survivors ≥ 18 years of age were approached and consented to complete a 10-item survey on telehealth readiness, adapted from the National Center for Farmworker Health, Health Center Toolbox.

RESULTS

The TXCH LTS clinic completed 521 survivor visits (35 telehealth) between July 1, 2025 and January 31, 2026.
Among children <18 years old, 312 visits (18 telehealth, 6%) were conducted in leukemia (38%), lymphoma (8%), solid tumor (38%), brain tumor (13%), and histiocytic disorder (3%) survivors. By our criteria, 207 (66%) were eligible for telehealth. Most common reasons for ineligibility among those <18 years old were exposure to radiation (59%) and higher alkylating agent exposure without endocrinology care (46%), with some survivors meeting multiple exclusion criteria.
Of survivors 18 years and older, 209 visits (17 telehealth, 8%) were conducted in leukemia (31%), lymphoma (19%), solid tumor (31%), brain tumor (18%), and histiocytic disorder (1%) survivors. By our criteria, 145 (69%) were eligible for telehealth. 64 (31%) were not under the care of a PCP. 87 adult survivors completed the telehealth readiness survey: 80 (92%) understood how telehealth works and 58 (67%) were interested in survivorship by telehealth, all of whom had access to an internet-connected device.

CONCLUSION

Telehealth can improve access to survivorship care by reducing barriers associated with an in-person visit. About two-thirds of childhood cancer survivors in our clinic are telehealth eligible by these criteria, indicating underutilization of this care option. Most adult survivors indicate interest in telehealth-delivered care.
These findings suggest an opportunity to expand resources and infrastructure related to telehealth services for survivorship care. Future directions include additional refinement of telehealth criteria and evaluation of survivor and provider perceptions of the use of telehealth for long-term follow-up.

TABLE 1.

Telehealth exclusion criteria for survivors < 18 years of age
Receipt of radiation therapy*
Significant or high level of increased risk of infertility and not followed by endocrinology*
Survivors with a single kidney, not followed by nephrology**
Survivors with a known cancer predisposition syndrome

*Rationale: LTS receiving radiation and/or high doses of alkylating agent chemotherapy are at increased risk of disorders of growth and pubertal development and benefit from longitudinal monitoring of linear growth and pubertal tanner staging requiring in-person physical examination.

**Rationale: LTS with a single kidney warrant close blood pressure monitoring and need blood pressure assessment as part of the annual exam with an appropriately sized cuff for accurate measure.

Telehealth clinical exclusion criteria

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Other 2

THE PANCARESURPASS MULTI-COUNTRY IMPLEMENTATION STUDY – IMPACT OF A PERSONALIZED SURVIVORSHIP CARE PLAN ON PEOPLE-CENTRED FOLLOW-UP CARE FOR CANCER SURVIVORS

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BACKGROUND-AIM

Many Childhood Cancer Survivors (CCS) are unaware of their individual risk for late effects, which impairs self-management of follow-up care and wellbeing. The Survivorship Passport (SurPass) is a digital tool that provides a summary of each CCS prior cancer therapy, allowing for the creation of a personalized care plan for both CCS and health-care providers. The PanCareSurPass (PCSP) multi-country implementation study evaluated the implementation of SurPass in late-effects clinics in Austria, Belgium, Germany, Italy, Lithuania, and Spain and determined its impact on patient activation, empowerment, emotional well-being and quality of life of CCS. In addition, satisfaction with the SurPass was also assessed.

METHODS

A personalised SurPass was provided to each CCSs and/or their caregivers. Patient activation (primary outcome) was measured with the Patient Activation Measure (PAM); empowerment with the Health Education Impact Questionnaire (heiQ); and quality of life with the 5-level EuroQoL 5 Dimensions questionnaire (EQ-5D). All three instruments were administered before SurPass delivery (baseline) and again at least six weeks after delivery. Additionally, emotional impact was assessed with a study-specific questionnaire (PCSP-Q) and satisfaction with the digital SurPass tool with the Technology Acceptance Model (TAM) questionnaire, after SurPass delivery. Besides descriptive analyses multivariable logistic regression models examined whether the odds of improvement in each outcome differed between CCS who had received complex versus less complex treatment, adjusting for relevant confounders.

RESULTS

Implementation was successful in all six countries. 410 SurPass were handed over; all participants completed the baseline questionnaire and 348 completed the follow-up questionnaire. The analytic sample comprised 330 CCS and/or their caregivers (55.2% males, 36.7% leukaemias, 33.9% of CCS were between 1 and 4 years old at the time of diagnosis of the first tumour). No statistically significant improvement was observed for PAM, heiQ or EQ-5D after SurPass delivery. However, the PCSP-Q showed generally favourable experiences, especially high scores for perceived support in emotional reassurance (mean: 65.9, SD: 14.1) and shared decision making (mean: 78.9, SD: 19.3), indicating high perceived emotional support and shared decision making with no adverse emotional effects. CCS and their caregivers were satisfied with the technological utility of the SurPass tool (mean: 67.0, SD: 22.5).

CONCLUSION

The implementation of SurPass as a tool was technically successfull in late-effects clinics across several European countries and survivors were satisfied with the tool. While the SurPass was not effective increasing patients' activation, empowerment and quality of life it enhanced communication and engagement without causing emotional distress based on the PCSP-Q. This may reflect a cohort already well integrated into follow-up care and aware of potential long-term effects.

The tool's effectiveness might depend on integration into a comprehensive, interdisciplinary care pathway, and existing outcome measures may be insufficient to capture its full value for addressing the specific long-term needs of CCS.

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TRANSITION READINESS SCREENING IN CHILDHOOD, ADOLESCENT, AND YOUNG ADULT CANCER SURVIVORS

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BACKGROUND-AIM

Transition from pediatric to adult survivorship care is necessary for managing late effects in childhood, adolescent, and young adult (CAYA) cancer survivors. Ensuring CAYA survivors have the skills necessary to manage their healthcare is key to a successful transition, yet no standard practice for transition exists. To better understand our population's readiness for transition, screening using the Transition Readiness Assessment Questionnaire (TRAQ) was adopted as standard practice. Our objectives are to describe longitudinal changes in TRAQ scores and identify demographic and treatment exposures associated with transition readiness.

METHODS

A total of 108 survivors aged 14-26 years were screened with the TRAQ annually, from 2022-2026. Of them, 46 survivors completed at least two consecutive assessments. A paper version of the TRAQ was administered; data was transcribed into the electronic health record. The survivorship nurse and social worker delivered general transition education after initial screening. A retrospective chart review was conducted to extract participant sociodemographic and treatment characteristics. Survivors were required to have completed all items across TRAQ domains to be included in the analysis. Multivariable linear regression with 10,000 bootstrap replications was used to identify factors associated with subsequent TRAQ scores. The final model was refined for statistical stability and clinical relevance, adjusting for baseline readiness, sociodemographic, and treatment history.

RESULTS

Results from our analysis demonstrated a high treatment burden: 84% received systemic chemotherapy and 32% received radiation, with 28% having dual therapy. The cohort demonstrated a moderate level of transition readiness at baseline, with a mean overall TRAQ score of 3.12 (SD=1.00). On initial screening, 93 of the 108 (83%) reported a score $\geq$4 for the importance of managing their own future healthcare, while only 61 of the 108 (56%) expressed confidence in managing their own healthcare. Subsequent screening demonstrated a mean overall of 3.71 (SD=0.14), with 50% patients scoring $\geq$4 on subsequent screening. Of survivors who initially scored $\leq$3 on initial TRAQ, 17 (74%) continued to score $\leq$3 on second assessment. Older age at the initial assessment was a robust predictor of higher scores at follow-up (β=0.15, p=0.006). Additionally, female sex was associated with a substantial increase in readiness, with female survivors scoring over half a point higher than males (β=0.58, p=0.005). Survivors treated with systemic chemotherapy demonstrated significantly lower readiness scores at follow-up (β=−0.50, p=0.042) compared to those who did not receive systemic agents.

CONCLUSION

Initial TRAQ scores were highly predictive of subsequent readiness, revealing that skills rarely improve for high-risk survivors through age or standard education alone. This suggests that universal, "one-size-fits-all" approaches fail to meet the needs of those with the lowest baseline scores. Given the significant negative association between systemic chemotherapy and subsequent readiness, alongside the observed gender gap, a shift toward a risk-stratified model of care is essential. By utilizing screenings to implement differentiated, high-intensity support for survivors with higher treatment burdens, clinics can better ensure a successful transition to adult-centered care. Further analysis of subcategory scores may also aid in development of targeted interventions.

Table. Multivariable Longitudinal Analysis: Baseline Predictors of Subsequent Transition Readiness (TRAQ) Scores				
	Model 1 Coefficient [95% CI]	**Model 2** Coefficient [95% CI]	**Model 3** Coefficient [95% CI]	**Model 4** Coefficient [95% CI]
N	46	46	46	44
Baseline TRAQ Score 1-2	REF	REF	REF	REF
Baseline TRAQ Score 2-3	0.11 [-0.56, 0.77]	0.15 [-0.48, 0.79]	0.16 [-0.52, 0.85]	0.21 [-0.44, 0.86]
Baseline TRAQ Score 3-4	1.08** [0.44, 1.72]	1.24 [0.61, 1.87]**	1.11** [0.44, 1.77]	1.26*** [0.61, 1.90]
Baseline TRAQ Score 4-5	1.20*** [0.62, 1.78]	1.16 [0.63, 1.68]***	1.31*** [0.68, 1.93]	1.27*** [0.69, 1.84]
Age at Baseline TRAQ	0.13* [0.02, 0.24]	0.15 [0.04, 0.26]**	0.13* [0.01, 0.24]	0.15** [0.04, 0.26]
Female (REF: Male)	0.48* [0.07, 0.90]	0.52 [0.13, 0.91]*	0.54* [0.11, 0.97]	0.58** [0.17, 0.98]
Receipt of Any Radiation		-0.37 [-0.88, 0.14]		-0.35 [-0.84, 0.15]
Receipt of Any Systemic Chemotherapy			-0.52* [-1.00, -0.03]	-0.50* [-0.98, -0.02]
Adjusted R^2	0.4698	0.4847	0.4968	0.5095
*p-value<0.05 **p-value<0.01 ***p-value<0.001				

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VACCINATION PROGRAM AFTER ELECTIVE END OF TREATMENT IN CHILDHOOD CANCER SURVIVORS: A PROPOSAL

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BACKGROUND-AIM

Survival of childhood cancer patients now exceeds 80%, shifting the focus toward long-term survivorship care. However, post-treatment immunization remains inconsistent, and childhood cancer survivors (CCSs) frequently exhibit loss of vaccine-induced immunity following chemotherapy and hematopoietic stem cell transplantation (HSCT). Despite existing recommendations, implementation of standardized vaccination programs in pediatric hemato-oncology settings remains suboptimal. This project aimed to develop a comprehensive, pragmatic, and implementation-oriented vaccination program for CCSs after elective end of treatment (EOT) and HSCT.

METHODS

A multidisciplinary Working Group including pediatric hemato-oncologists, infectious disease physicians, and vaccinology experts was convened at a tertiary pediatric referral center. International guidelines (ECIL and others) and current immunological evidence were reviewed. A unified vaccination strategy was developed for CCSs treated for hematologic malignancies or solid tumors, with or without HSCT. The program addressed timing, vaccine selection, booster strategies, management of special conditions (e.g., asplenia, anti-CD20 therapy, travel to endemic areas), implementation pathways, and coordination with primary care and public health services. Routine pre-vaccination serological testing was discouraged, except when clearly indicated (e.g., HBV).

RESULTS

The Working Group developed structured vaccination schedules for two populations: HSCT recipients and CCSs treated without HSCT. Inactivated vaccines are recommended from 6 months post-HSCT (earlier in selected cases), while live attenuated vaccines are deferred until immune reconstitution is complete. For CCSs not undergoing HSCT, vaccination is resumed or restarted 3–12 months after EOT, regardless of prior vaccination status, without routine antibody titration. Additional recommendations address high-risk conditions, including asplenia and prolonged immunosuppression. Vaccination of household contacts is incorporated to provide indirect protection. The program emphasizes feasibility, flexibility across regional immunization systems, and integration into survivorship care plans.

CONCLUSION

This proposal provides a unified, evidence-informed, and implementation-oriented vaccination framework for CCSs after EOT and HSCT. By moving beyond fragmented, disease-specific recommendations, it supports standardization of post-treatment immunization as a core component of survivorship care. Prospective studies are warranted to evaluate immunogenicity, durability of protection, adherence, and clinical outcomes following real-world implementation.

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WHAT ARE EXPERIENCED BARRIES AND FACILITATORS TO IMPLEMENTING PERSON-CENTRED LONG-TERM SURVIVORSHIP CARE FOR CHILDHOOD CANCER SURVIVORS? INSIGHTS FROM THE PANCAREFOLLOWUP CARE INTERVENTION STUDY

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BACKGROUND-AIM

The PanCareFollowUp (PCFU) consortium developed the PCFU Care intervention for structured, person-centred, guideline-based long-term survivorship care for childhood cancer survivors (CCSs). This study explored barriers and facilitators encountered by healthcare professionals (HCPs) and project members during implementation in four European paediatric oncology clinics.

METHODS

The intervention comprised a pre visit Survivor Questionnaire, a Treatment Summary and Survivorship Care Plan completed by HCPs, a clinic visit guided by person-centred care, and a follow up call. A qualitative study was conducted using two semi-structured online focus groups with HCPs and project members, including patient advocates, involved in developing and/or delivering the intervention (n=13). Grol and Wensing's framework for implementation determinants guided analysis across innovation, professional, patient, social, organisational, and economic/political levels. Data were analysed using thematic analysis, combining inductive, axial and deductive coding. Findings were validated and prioritized in a reflection meeting.

RESULTS

At the innovation level, key barriers were the substantial time investment required from HCPs, particularly for completing the Treatment Summary and conducting follow-up calls. The length of the Survivor Questionnaire was considered burdensome for CCSs, and limited clinical capacity would make long-term follow-up difficult. At the professional level, HCPs sometimes struggled with shared decision-making. Some saw a shared care barrier in GPs avoiding health behaviour discussions with CCSs. At the patient level, psychological challenges, potential impaired decision-making capacity, and difficulty changing health behaviours were barriers. Social-level barriers included weak collaboration with non oncology specialists, referral difficulties, and limited knowledge of late effects among HCPs. Cultural differences in healthcare systems unfamiliar with person centred care would complicate implementation. Organizational barriers comprised insufficient staff and time, poor coordination, and limited access to psychosocial support. Participants highlighted the need for a coordinator to support transfer of care to GPs and noted that survivorship care was not equally established across cancer diagnoses. At the economic and political level, insufficient GP reimbursement and lack of sustainable national or insurer-based funding threatened long-term implementation of survivorship care.

Facilitators on innovation and professional level included the Treatment Summary, Survivorship Care Plan, guidelines, and Questionnaire, which were valued for structuring care and supporting a holistic, person-centred approach. Follow up calls and meaningful CCS-HCP interactions were considered essential. Shared decision making enhanced CCSs' empowerment, health awareness, self management, and engagement in healthy behaviours. Strong multidisciplinary collaboration, access to psychosocial support, web based tools, and supportive funding structures further promoted implementation (social, organizational and economic/political level).

CONCLUSION

The PCFU Care intervention was valued for its structured, person centred approach, care quality and potential to enhance survivor engagement and empowerment. However, addressing HCP time constraints, capacity limitations,

organizational challenges, and long term funding remains crucial for sustainable implementation across diverse healthcare systems.

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XE MRI DETECTS GAS-EXCHANGE ABNORMALITIES IN ADULT CHILDHOOD-CANCER SURVIVORS EXPOSED TO BLEOMYCIN

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BACKGROUND-AIM

Childhood-cancer survivors are at increased risk of drug-related long-term pulmonary complications. Inhaled hyperpolarized xenon-gas MRI (Xe MRI) is an emerging, sensitive modality to visualize and quantify regional lung function, and Xe gas-exchange MRI leverages the slight solubility of Xe gas in the pulmonary tissues to quantify regional ventilation (Xe within the alveolar airspace), membrane uptake (Xe within the alveolar-capillary membrane and blood plasma), and RBC transfer (Xe affiliated with the red blood cells). This pilot study aimed to evaluate the Xe gas-exchange MRI characteristics of adult childhood-cancer survivors who were exposed to bleomycin (~ 15 years ago), a common component of cancer-treatment regimens with known pulmonary toxicity.

METHODS

Xe gas-exchange MRI was performed in 14 childhood-cancer survivors and 29 age-matched healthy controls. Imaging was done during a <16-second breath-hold of hyperpolarized Xe gas (25-35% polarization; dosed at 1/6th predicted TLC) on a 3T Philips Ingenia MRI scanner using a flexible chest coil. An interleaved 3D-radial sequence was applied to acquire alveolar-gas and dissolved-phase signals simultaneously. One-point Dixon decomposition technique was applied to the dissolved-phase signal to separate the membrane-uptake and RBC-transfer components, generating quantitative maps of ventilation, membrane uptake, RBC transfer, and RBC:membrane ratio. Xe signal intensities in each map were categorized into six color bins based on ±1 standard deviation (σ) from a reference healthy population mean and further aggregated into Normal (-1σ to $+1\sigma$), Low ($< -1\sigma$), and High ($> +1\sigma$) categories and expressed as a percentage of the total lung volume. Pulmonary function tests (PFTs) were obtained concurrently with Xe MRI for the childhood-cancer survivors, and clinical data including chemotherapy indication and regimen, bleomycin dosing, and alternative cancer therapy like irradiation, were reviewed retrospectively from the electronic-medical record. Statistical comparisons were performed with Wilcoxon rank-sum test, with significance defined as $P < 0.05$.

RESULTS

Compared to healthy controls, childhood-cancer survivors had higher whole-lung median Xe membrane uptake (median: 8.8×10^{-3} vs 7.8×10^{-3} (arb unit), $P = 0.015$) as well as greater volume of lung with abnormally high membrane uptake ($Membrane_{High\%}$: 13.33% vs 0.88%, $P = 0.009$) (Figure). However, no significant differences were observed in ventilation and RBC transfer. PFTs in the childhood-cancer survivors were within normal limits. No significant associations were found between Xe gas-exchange metrics and bleomycin dosing, radiation exposure, or time since treatment exposure.

CONCLUSION

Xe gas-exchange MRI detected isolated elevated Xe membrane uptake in adult childhood-cancer survivors treated with bleomycin, despite normal PFTs, which may suggest subclinical pulmonary interstitial/alveolar-capillary membrane changes like fibrosis that would increase the amount of Xe gas within that gas-exchange compartment. Although the clinical significance remains unclear, this finding lays the groundwork for future prospective, longitudinal studies aimed at evaluating treatment-related pulmonary toxicities in cancer survivors using Xe MRI.

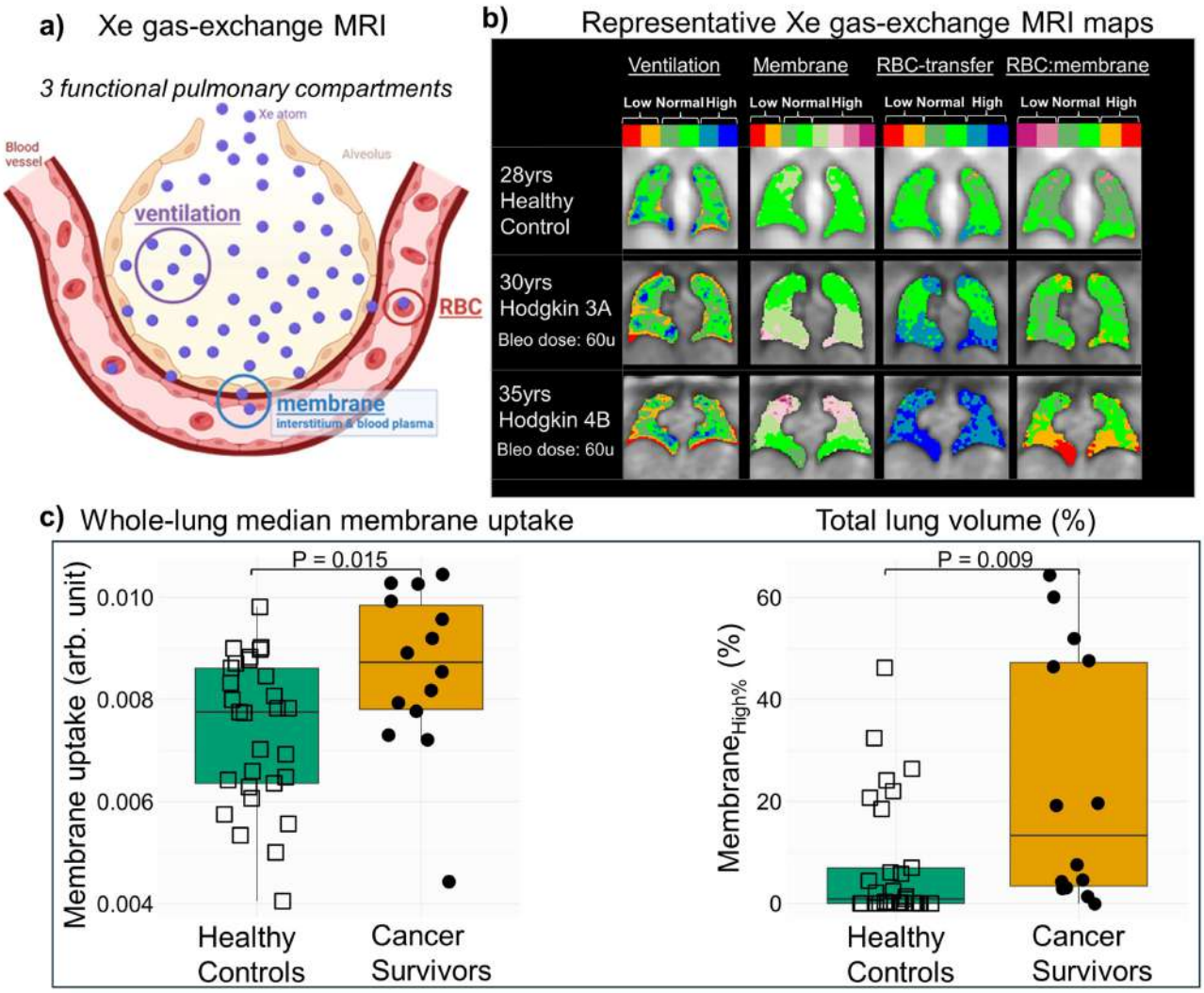

Figure: Xe gas-exchange MRI in healthy control subjects and childhood-cancer survivors. a) schematic representation of the 3 physiologic compartments (ventilation, membrane uptake, and RBC transfer) assessed with Xe gas-exchange MRI. b) representative Xe gas-exchange maps of a healthy control subject and two cancer survivors. c) comparison of membrane uptake between healthy control subjects and childhood-cancer survivors.

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