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Survivorship passport as a new clinical paradigm in pediatric oncology: An exploratory observational study

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Abstract

Introduction: Advances in pediatric oncology have increased survival rates of patients. To support the long-term care of these survivors, the Survivorship Passport (SurPass) provides a personalized, portable summary of their diagnosis, treatments, and potential sequelae.

Objective: This study investigates the correlation between SurPass use and long-term knowledge gains among survivors, as measured by its impact on the accuracy of treatment recall and awareness of potential long-term effects.

Methods: This observational study included long-term survivors classified into two arms: Those with SurPass (Arm A) and those without (Arm B). A structured questionnaire assessed recall of diagnosis, chemotherapy, radiotherapy, and awareness of late effects. Responses were scored for accuracy, and between-group comparisons were performed.

Results: Survivors with SurPass, who are typically followed up in specialized centers, demonstrated markedly higher recall accuracy than those without it. Correct recollection of radiotherapy and chemotherapy was higher in Arm A by 64% (p=0.05) and 48% (p=0.03), respectively. Awareness of late effects and adherence to structured follow-up were also greater within Arm A. The SurPass mitigated the expected decline in recall accuracy over time, particularly for survivors treated at younger ages.

Conclusion: Preliminary findings suggest that SurPass may support patient engagement and continuity of care in survivorship settings; however, longitudinal studies are needed to confirm these exploratory findings.

Keywords: Pediatric oncology; Cancer survivors; Survivorship passport; Exploratory observational study

1. Introduction

Globally, cancer remains a leading cause of morbidity and mortality, with over 19 million new cases and nearly 10 million deaths annually.[1] In Italy, approximately 380,000 new cases are diagnosed each year, highlighting the persistent public health burden despite advances in prevention and therapy.[2] Over the past few decades, advances in oncological research, early diagnosis, and increasingly effective therapies have substantially improved the prognosis for children and adolescents diagnosed with cancer.[3] Each year, approximately 400,000 children and adolescents (aged 0–19) develop cancers, including leukemias, brain tumors, lymphomas, and neuroblastoma. In high-income countries, over 80% are cured, whereas in low- and middle-income countries, fewer than 30% survive, with limited access to essential cancer medications (29% vs. 96%).[4] These individuals, known as childhood cancer survivors (CCS), represent a growing population whose care must extend far beyond the conclusion of acute therapy. Survivorship is not equivalent to being disease-free. Many survivors face physical and psychosocial complications that persist or emerge years after treatment.[5-7] Studies have shown that CCSs are at a higher risk of developing adverse health outcomes and experiencing a diminished quality of life compared with their peers.[8] These complications are closely associated with previous oncological therapies and are commonly referred to as late or delayed effects.[9] Because such effects may develop years or even decades after treatment, a long-term follow-up is essential and should be tailored to both the treatment received and the characteristics of each survivor. Follow-up guidelines vary across survivor populations and take into account factors such as the type of cancer, the treatment modalities employed, and their intensity.[10-12] Importantly, the degree of risk for developing late effects varies across survivors and depends on multiple variables. These include age at diagnosis, gender, history of cancer-related surgical procedures, and cumulative exposure to chemotherapeutic agents and radiation.[13] Given the variability and complexity of these factors, effective communication and shared decision-making between healthcare professionals and survivors are essential. However, several challenges persist.

Many survivors, having undergone treatment at a very young age, lack detailed knowledge or memory of their diagnosis and therapy.[14] This hampers their ability to participate actively in their own long-term care, and, more broadly, in chronic care management.[15-17] In addition, the limited familiarity among some clinicians with the natural course of late effects further restricts accurate risk stratification and appropriate surveillance.[18] Another critical issue is the safe and consistent transmission of essential medical information during the transition from pediatric to adult services, particularly when follow-up occurs in different geographical locations or healthcare systems.[19] To address these issues, the Survivorship Passport (SurPass) was developed as part of several collaborative European initiatives, including the European Network for Child and Adolescent Cancer Research,[20] the PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies project,[21] and the European Reference Network of Paediatric Oncology Experts for Diagnosis and Treatment.[22] Available in both digital and paper formats, the SurPass provides a structured, personalized summary designed to improve survivors' quality of life.[23] It empowers patients to take an active role in their own care while equipping healthcare providers with a reliable platform for delivering evidence-based, long-term follow-up.[24-27]

The SurPass, also known as the "passport of the cured," was launched in Italy in 2017 as a pilot project resulting from a collaboration between Gaslini Hospital in Genoa and Pausilipon Hospital in Naples.[28] It serves as a digital repository of essential health information, facilitating transition to adult care by preserving treatment history and making it accessible across clinical contexts. The platform features a web-based interface with a pseudo-anonymization system, ensuring encryption and adherence to the highest data protection standards.[29] The SurPass, available in multiple languages, is issued to each child or adolescent on completion of therapy and provides a detailed summary of the disease and treatments received.[23] Based on this information, the system generates personalized screening recommendations using integrated algorithms. The tool benefits both survivors and providers by importing data directly from medical records, supporting clinical decision-making with evidence-based

recommendations, and allowing monitoring of symptoms associated with late effects.[20-23,29]

The objectives of this study were to explore the association between the use of SurPass and improvements in long-term survivors' knowledge of their disease history, and to assess the impact of SurPass on treatment recall accuracy and awareness of potential long-term effects. The study aimed to answer the following questions: (i) Is there a relationship between the use of SurPass and the level of disease history knowledge in long-term survivors? and (ii) Does SurPass enhance survivors' recall of treatment history and awareness of potential long-term effects?

2. Materials and methods

2.1. Study design

An exploratory observational (cross-sectional) study was conducted to achieve the study's objectives. The study adhered to the Strengthening the Reporting of Observational Studies in Epidemiology guidelines for reporting (Table S1).[30]

2.2. Setting

Participants were recruited from G. Gaslini Hospital in Genoa. This center specializes in diagnosis, observation, and prevention following oncological therapy and routinely provides SurPass to eligible patients. Pediatric survivors are managed by a multidisciplinary team of physicians and nurses, who collaborate closely with the oncologists involved in the patient's initial treatment. Recruitment was conducted between January and April 2021.

2.3. Eligibility criteria and sample

The cohort was recruited among survivors attending the clinic through online communities dedicated to children and adolescents who had recovered from pediatric cancer, or through direct administration of a digital questionnaire to long-term survivors attending outpatient follow-up at G. Gaslini Hospital in Genoa. The study was based on a convenience sample of survivors attending follow-up at the center during the study period. It was not possible to define a comprehensive pool of potential participants, as some subjects were contacted via online communities; consequently, a precise response rate cannot be calculated. All participants who completed the digital questionnaire or attended follow-up at our center were included in the analysis, and all available data are reported to promote transparency. No formal sample size calculation was performed, as the primary aim of the study was exploratory. The study population was divided into two arms: Arm A, which received SurPass, and Arm B, serving as the control group. Regarding participant flow, all contacted subjects were documented, indicating those who completed the questionnaire and those who were excluded or did not respond. Any missing data in the responses were handled by reporting the number of missing values for each variable and using a complete-case analysis approach, which allowed for a transparent presentation of the analyzed data.

2.4. Tools

2.4.1. SurPass

The collection and archiving of clinical data within the SurPass system adhered to internationally recognized standards, enabling the semi-automated generation of the passport. Cancer diagnoses were classified according to the International Classification of Childhood Cancer 3rd Edition,[31] while therapeutic agents were coded using the Anatomical Therapeutic Chemical classification.[32] This ensured consistency across drugs, including those with multiple commercial names (e.g., cyclophosphamide, Endoxan, Cytoxan). When standardized coding was not feasible, a free-text field was provided to capture important clinical details relevant to long-term care, such as complications during treatment (e.g., seizures, Intensive Care Unit admissions) or specific interventions. SurPass generation began with entering the survivor's personal information to create an individual record. Treatment data were then entered using pre-defined templates in the web-based platform. Once the treatment summary was complete, built-in algorithms generated evidence-based recommendations, and the electronic document was issued to survivors upon completion of their primary treatment.[23] Following SurPass generation and issuance of recommendations by a healthcare professional, a personal account was created for each survivor. This allowed access to the digital platform, where users may view or print their treatment summaries, educational brochures, and other documents in multiple available languages. These materials can be shared with any healthcare provider, supporting communication and continuity of care. Importantly, SurPass data may only be modified by authorized clinicians with access credentials. In the event of relapse or a subsequent diagnosis of a malignant neoplasm, the SurPass may be updated accordingly as soon as new clinical data are available. The updated SurPass will then integrate new treatment details and generate revised screening recommendations. Survivors may also access their own portal to upload additional information regarding follow-up visits, tests, and clinical outcomes. The SurPass serves a dual purpose: (i) to provide survivors with a personalized, guideline-based follow-up document, and (ii) to standardize clinical data entry for SurPass generation, multilingual translation, and predictive algorithm integration. These algorithms stratify individual risk for late

effects such as cardiomyopathy, gonadal toxicity, thyroid cancer, or subsequent malignant neoplasms. Each screening recommendation is color-coded to indicate its strength: green indicates a strong recommendation, yellow indicates a moderate recommendation, orange indicates a weak recommendation, and red indicates a recommendation not advised due to an unfavorable harm–benefit ratio.

2.4.2. Surveys

To conduct the study, a three-section survey was performed: (i) Socio-demographic data collection; (ii) data collection regarding the clinical situation and the received treatment; and (iii) data collection on perceptions and degree of satisfaction regarding different aspects (follow-up, complications, SurPass utility).

A specific analysis was conducted on survivors' self-perceived memory of treatments received during the initial period of care. A six-point Likert scale (0 = no recollection, 5 = maximum recollection) was adopted. The same scale was used to assess participants' perceived awareness (0 represented no awareness, 5 represented maximum awareness) of post-treatment complications and their satisfaction with subsequent follow-up (0 = not at all satisfied, 5 = totally satisfied). The survey was developed as a bilingual (Italian/English) digital questionnaire and distributed to the entire eligible population through the Google Forms platform.

2.5. Statistical analysis

To evaluate the potential role of the SurPass in supporting survivors' knowledge of their cancer diagnosis, treatments, and long-term follow-up recommendations, descriptive statistics were applied. A univariate analysis was conducted to compare subgroups of survivors with and without the SurPass. Continuous variables were assessed for normality using the Shapiro–Wilk test, and, if normally distributed, were reported as mean (M) ± standard deviation (SD) and compared between groups using independent samples *t*-tests. Categorical variables were reported as frequencies and percentages and compared using Chi-square or Fisher's exact tests, as appropriate. Survey responses based on Likert-type items were treated as continuous variables to facilitate group comparisons, while acknowledging that Likert scales are ordinal and that non-parametric approaches could also be appropriate. Given the exploratory nature of the study, the simplicity of the statistical methods, and the relatively small size of some subgroups, the findings should be interpreted with caution and without implying causal conclusions. All analyses were conducted using Jamovi software (version 2.3), with *p*-values below 0.05 considered indicative of possible exploratory associations.

2.6. Ethical consideration

The study received ethical approval from the Regional Ethics Committee of Liguria, with the PanCareFollowUp protocol (Protocol Number: Registro CER Liguria 295/2020 – ID 10632). Data were collected anonymously and processed by the authors in full compliance with applicable Italian regulations on clinical research[33] as well as relevant European legislation, and in accordance with the principles of the 1964 Declaration of Helsinki and its subsequent amendments.[34]

3. Results

3.1. Sample characteristics

A total of 125 survivors were enrolled, of whom 83 (66.4%) were female and 75 (60%) were Italian. A total of 51 subjects (40.8%) were followed as outpatients in the recruiting center and therefore possessed SurPass, while 74 (59.2%) were long-term survivors who did not possess SurPass.

3.2. Group comparisons

Baseline characteristics were compared between participants with SurPass (n = 51) and those without SurPass (n = 74). Continuous variables were assessed for normality using the Shapiro–Wilk test, and assumptions of homogeneity of variances were evaluated with Levene's test. Normally distributed variables with equal variances were analyzed using the independent samples *t*-test. Categorical variables were presented as frequencies and percentages and compared using the Chi-square test or Fisher's exact test, as appropriate. No significant differences were observed between groups in terms of age (t [123] = −1.27; p=0.208; Cohen's d = −0.23; 95% confidence interval [CI]: −0.59, 0.13) or age at diagnosis (t [123] = −0.36; p=0.718; Cohen's d = −0.07; 95% CI: −0.42, 0.29). Gender distribution (χ^2 = 0.127; p=0.721), knowledge of the diagnosis (χ^2 = 0.459; p=0.498), nationality (χ^2 = 9.78; p=0.369), and main treatment (χ^2 = 4.25; p=0.235) were also comparable between groups. Table 1 summarizes the group comparison.

3.3. Long-term survivors' knowledge about their disease history

Of the 51 subjects who possessed a SurPass, 37 (72.55%) showed diagnostic accuracy, compared to 40 (54.05%) of those who did not possess it (p=0.001). A total of 50 out of 75 (66.67%) Italian nationality subjects showed adequate accuracy compared to 27 out of 50 foreigners (54.0%) (p=0.032). The other variables did not significantly influence participants' knowledge about their own clinical condition. Table 2 and Figure 1 provide a summary of these data.

3.4. SurPass recall

Familiarity with the SurPass was limited; of the 74 subjects who did not possess it, only 19 had heard of it at the time of the survey (25.68%). The impact of SurPass use on the ability of long-term survivors to accurately recall treatments received during the primary care period was investigated. Participants were asked to report the type of treatment, its duration, and the number and type of medications administered. The median scores of subjects who possessed the passport (median: 2.5; range: 2–3) showed an increased ability to recall compared to those who did not possess it (median: 1.5; range: 1–1.5) (p=0.010). The other variables did not show a significant influence on the degree of recall (Table 3).

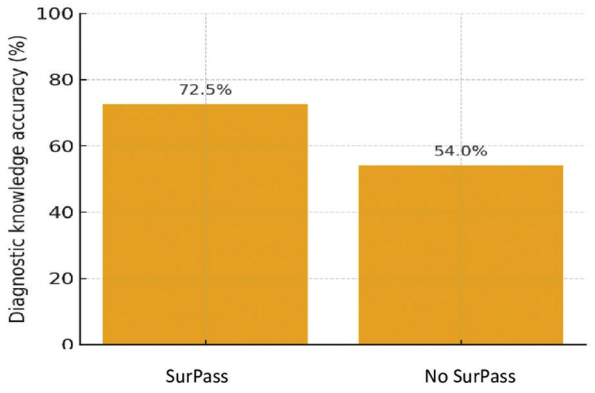

Figure 1. Diagnostic knowledge between groups

Table 1. Group comparison

Variable	SurPass (n=51)	No SurPass (n=74)	p-value
Age in years (mean±SD)	21.6±1.44	21.3±1.65	0.252[a]
Age at diagnosis in years (mean±SD)	14.0±2.23	13.9±2.02	0.725[a]
Gender, *n* (%)			0.721[b]
Female	38 (74.5)	53 (71.6)	
Male	13 (25.5)	21 (28.4)	
Knowledge of diagnosis, *n* (%)			0.498[b]
Yes	49 (96.1)	69 (93.2)	
No	2 (3.9)	5 (6.8)	
Nationality, *n* (%)			0.369[b]
Italian	28 (54.9)	50 (67.6)	
Russian	6 (11.8)	2 (2.7)	
Canadian	3 (5.9)	3 (4.1)	
Lebanese	3 (5.9)	3 (4.1)	
English	3 (5.9)	4 (5.4)	
American	0 (0.0)	5 (6.8)	
Brazilian	2 (3.9)	1 (1.4)	
French	2 (3.9)	2 (2.7)	
Indian	2 (3.9)	2 (2.7)	
German	2 (3.9)	2 (2.7)	
Main treatment, *n* (%)			0.235[b]
Monoclonal antibodies	10 (19.6)	10 (13.5)	
Chemotherapy	15 (29.4)	18 (24.3)	
Surgery	10 (19.6)	27 (36.5)	
Radiotherapy	16 (31.4)	19 (25.7)	

Note: [a]Independent sample t-test; [b]Chi-square test.
Abbreviations: SD: Standard deviation; SurPass: Survivorship passport.

3.5. Awareness of possible treatment complications

Table 4 summarizes the results obtained on awareness regarding possible treatment complications. Italian nationality and SurPass possession were associated with higher levels of awareness, suggesting that the SurPass has

Table 2. Participants' knowledge of their clinical conditions

Variable	Category	*n* (%)	p-value
Years after diagnosis	<5 years	16 (55.2)	>0.05
	≥5 years	61 (63.5)	
Gender	Female	51 (61.5)	>0.05
	Male	26 (61.9)	
Nationality	Italian	50 (66.7)	0.032
	Foreigner	27 (54.0)	
Survivorship passport possession	Yes	37 (72.6)	0.01
	No	40 (54.1)	
Main treatment	Chemotherapy	27 (65.9)	>0.05
	Radiotherapy	21 (60.0)	
	Monoclonal antibodies	10 (66.7)	
	Surgery	19 (55.9)	

Table 3. Memory recall scores

Variable	Category	Median (range)	p-value
Years after diagnosis	<5 years	2.5 (2–3.5)	0.022
	≥5 years	1.5 (1.5–2)	
Gender	Female	2 (2–3)	>0.05
	Male	2 (1.5–3)	
Nationality	Italian	2 (1.5–3.5)	>0.05
	Foreigner	2 (1–3)	
Survivorship passport possession	Yes	2.5 (2–3)	0.01
	No	1.5 (1–1.5)	
Main treatment	Chemotherapy	2 (1.5–2.5)	>0.05
	Radiotherapy	2 (2–3)	
	Monoclonal antibodies	2 (2–2.5)	
	Surgery	2.5 (2–3)	

Table 4. Awareness regarding treatment complications

Variable	Category	Median (range)	*p*-value
Years after diagnosis	<5 years	2.5 (2–3.5)	>0.05
	≥5 years	3 (2.5–3.5)	
Gender	Female	3 (2–4)	>0.05
	Male	3 (2–4)	
Nationality	Italian	3.5 (3–4)	0.03
	Foreigner	2 (1–3)	
Survivorship Passport possession	Yes	4 (3–4.5)	0.01
	No	2.5 (1.5–3.5)	
Main treatment	Chemotherapy	3 (2.5–3.5)	>0.05
	Radiotherapy	2.5 (2–3.5)	
	Monoclonal antibodies	2.5 (2–3)	
	Surgery	3 (2–4)	

the potential to be a valuable tool for empowering CCS regarding their health and well-being by increasing their awareness of treatment-related late effects.

3.6. Follow-up

The follow-up program was conducted at a specialized center for nearly all participants with a SurPass (48; 94.12%) and for 51 participants (68.92%) without a SurPass; those not included were followed by various medical specialists. Although the differences were not statistically significant (p=0.089), a higher proportion of SurPass participants reported a high level of satisfaction (>3 on a 0–5 Likert scale) with the proposed follow-up program compared to participants without SurPass (38 [74.51%] vs. 49 [66.22%]). Overall, 49 (96.08%) SurPass users agreed or strongly agreed that receiving SurPass was beneficial for managing their clinical care.

4. Discussion

This observational study suggests that the SurPass may support long-term survivors' ability to retain knowledge and recall details about their previous diagnosis, therapeutic interventions, and potential late effects. In terms of awareness, the benefit observed among survivors equipped with a SurPass was statistically significant (p=0.010). Moreover, Italian nationality was also associated with a significant positive effect among CCSs (p=0.030). Recall ability and patient knowledge were higher among CCSs in the SurPass group compared to those without the tool (p=0.010), indicating an association that warrants further investigation. It should be noted that all data were collected from a single center and a convenience sample, which limits the generalizability of the results. Therefore, these observations should be interpreted with caution.

4.1. SurPass and survivor knowledge retention

The data collected are in line with international evidence emphasizing the positive role of individualized survivorship care plans in increasing patient knowledge, promoting self-management, and enhancing communication with healthcare providers.[35] The SurPass was helpful in mitigating the expected decline in recollection over time, which is often pronounced in survivors treated at very young ages, a group especially vulnerable to memory gaps due to their developmental stage at diagnosis. Without a structured, portable document, survivors frequently present fragmented recollections of their treatment history, reflecting a systemic gap in education and continuity of care.[36] Furthermore, data from this study indicate that Italian nationality and SurPass possession were associated with a higher degree of awareness of treatment-related late effects, though these findings should be interpreted cautiously given the cross-sectional design and convenience sampling approach. This aligns with broader evidence suggesting that comprehensive, patient-centered documentation, mainly in electronic formats, strengthens long-term self-efficacy and confidence in navigating post-treatment healthcare.[37] Beyond these quantitative improvements, the SurPass can also be understood as a bridge between past experiences of illness and future health trajectories. By providing survivors with a concise yet comprehensive record of their therapeutic journey, the document not only supports memory but also fosters a sense of ownership and continuity that can reduce anxiety about potential late effects.[38] This psychological dimension is particularly relevant for young survivors, for whom uncertainty about long-term risks can represent a significant burden. Having an accessible and reliable source of medical information reduces dependence on fragmented recollections or family memory, thereby enhancing autonomy in the transition from pediatric to adult care.[39] The SurPass functions as a facilitator of communication, not only between patients and their healthcare providers, but also across multidisciplinary teams and different levels of the healthcare system. While promising, these observations should be treated as preliminary and limited to the setting of this single-center study. In contexts where survivors may relocate, change providers, or transition between pediatric and adult oncology services, SurPass should help minimize the risk of data loss and ensure that critical therapeutic information remains consistently available. This continuity might be crucial for designing follow-up programs tailored to individual risk profiles and for avoiding redundant or inappropriate diagnostic interventions.[23,40] Moreover, the

present findings invite reflection on the role of digital integration. While the current SurPass format provides significant benefits, future developments could involve linking the document with electronic health records, mobile applications, and telemedicine platforms, thereby strengthening the coordination and continuity of chronic care.[41] Such integration would not only preserve the individualized and portable nature of the SurPass but also enhance its interactivity, providing survivors with real-time updates, educational resources, and reminders for follow-up care. The combination of structured medical information and digital tools could further reinforce survivors' active participation in their long-term health management, paving the way for a new generation of dynamic and adaptive survivorship care instruments.[42]

An additional finding of our study is the significant difference in knowledge and awareness between Italian and foreign survivors. This result warrants careful consideration, as it may reflect broader disparities in survivorship care. However, given the exploratory design, these findings should be confirmed in larger and more diverse cohorts. Several factors may contribute to this gap. First, language barriers can play a crucial role: Non-native speakers may struggle to fully understand medical terminology or nuanced explanations, resulting in reduced comprehension and recall of complex treatment details. This challenge may be further amplified when survivors transition from pediatric to adult care, where communication often becomes more technical and less mediated by family members. Second, differences in health literacy and familiarity with the healthcare system may influence survivors' ability to interpret, retain, and apply clinical information. Prior research has shown that inadequate health literacy is associated with poorer understanding of late effects and reduced adherence to follow-up recommendations in cancer survivorship and chronic care contexts, according to Vetsch *et al.*[8] and Hickmann *et al.*[43] Third, access to structured follow-up programs may vary between Italian and foreign survivors, particularly for those who received part of their care outside specialized centers. Fragmented care pathways, administrative barriers, or less frequent contact with multidisciplinary teams may result in incomplete transmission of essential clinical information, ultimately affecting survivors' long-term knowledge and awareness.[37] These disparities have important implications for clinical practice. They highlight the need to develop culturally sensitive survivorship tools and educational strategies that actively account for linguistic and cultural diversity. The SurPass itself, already available in multiple languages, represents a promising step in this direction, but its dissemination and use should be systematically reinforced. Supplementary resources, such as multilingual patient brochures, simplified communication formats, and visual aids, may further support comprehension across heterogeneous populations. Moreover, integrating professional interpreters, digital translation resources, and targeted health literacy interventions into survivorship care can help reduce inequities and promote inclusiveness. Such efforts are essential to ensure that every survivor, regardless of their background, can benefit equally from structured follow-up, fully understand their treatment history, and actively participate in managing their long-term health.

4.2. Follow-up, engagement, and care management

The findings suggest that SurPass may have a notable impact on survivors' engagement with their ongoing healthcare, extending well beyond the passive retention of treatment information.[44] By providing a tangible and structured reference, it encourages survivors to take an active role in follow-up programs, fostering a sense of responsibility and empowerment over their own health.[43] Engagement is reinforced not only through scheduled visits but also by promoting continuous self-awareness, reflection on health status, and timely reporting of symptoms or concerns. This active participation contributes to a collaborative patient–provider relationship, where survivors are no longer passive recipients of care but informed partners in the decision-making process.[43-45] A key element of the SurPass is its ability to enhance communication at multiple levels. For survivors, it serves as a consistent tool to document questions, observations, and experiences, which can then be discussed during clinical encounters. For healthcare providers, it consolidates patient-reported information in a structured format, facilitating efficient and focused consultations while reducing misunderstandings and omissions.[46] The SurPass also supports communication across multidisciplinary teams, providing a shared reference point for oncologists, primary care physicians, nurses, and allied health professionals, thereby strengthening coordination of care and continuity between services.[46,47] Furthermore, engagement is amplified by the interactive potential of the SurPass. Survivors can use it to track personal health metrics, record side effects, and set reminders for follow-up activities, creating a feedback loop that integrates self-monitoring with professional oversight.[23,46,47] This fosters a proactive, rather than reactive, approach to long-term survivorship, encouraging survivors to recognize early signs of potential late effects and seek timely interventions. The structured documentation also enhances the survivor's confidence in communicating with healthcare providers, ensuring that questions and concerns are conveyed clearly and addressed appropriately.[46-48] By emphasizing active involvement and communication,

the SurPass transforms follow-up care from a series of discrete appointments into a continuous, participatory process. Survivors become more engaged, informed, and confident in navigating their healthcare, while providers gain a reliable, concise resource to guide individualized care plans. In this way, the SurPass functions not merely as a record of past treatments but as a dynamic tool for fostering ongoing dialogue, collaboration, and mutual accountability in long-term survivorship.[46-49]

4.3. Broader oncology implications

While the SurPass was initially developed for pediatric oncology, its principles of structured, patient-centered documentation and accessible health summaries are broadly applicable across oncology settings, including adult cancer care.[50,51] Survivorship across the cancer continuum often involves complex treatment histories, multiple therapeutic modalities, and prolonged follow-up, all of which can pose challenges to patient engagement, adherence, and self-management. Tools like the SurPass, by providing an organized and tangible record of diagnosis, interventions, and individualized recommendations, may facilitate continuity of care, enhance patient autonomy, and support proactive management of late effects.[52] In adult oncology, similar approaches can reinforce adherence to therapy transitions, such as opioid switching for pain management or transitioning from intravenous to subcutaneous therapies in chronic oncologic or inflammatory conditions.[53] Structured documentation helps patients and providers navigate these changes safely, ensuring that dosing, scheduling, and monitoring are clearly communicated. Moreover, integrating information on complementary or supportive treatments—commonly used in advanced cancer populations—can improve coordination of care and reduce the risk of unrecognized interactions, while empowering patients to actively participate in treatment decisions.[23,46-49] Beyond clinical management, survivorship tools also create opportunities for standardized data collection across heterogeneous populations. By capturing consistent information on treatment history, follow-up adherence, and symptom trajectories, these tools can inform research, guide policy, and provide benchmarks for quality improvement initiatives.[54] In this way, the SurPass model represents a scalable, adaptable framework that bridges pediatric and adult oncology, promotes patient-centered care, and strengthens evidence-based approaches to survivorship across diverse cancer types.[55]

4.4. Perspective for clinical practice

The results highlight the practical utility of the SurPass in routine clinical care, providing a structured and accessible summary of a survivor's medical history that promotes continuity of care and patient engagement.[23] By consolidating complex therapeutic information, the SurPass allows clinicians to rapidly assess past interventions, understand individualized risk profiles, and tailor follow-up schedules.[20-23] Its consistent use supports a proactive approach to long-term survivorship, contributing to the timely identification of potential complications or late effects.[23] From an organizational perspective, the SurPass facilitates care coordination as a shared reference across multidisciplinary teams.[23] Nurses play a key role in maintaining and updating the document, monitoring patient-reported outcomes, and acting as a liaison between survivors and other healthcare settings, particularly in chronic care.[56] Structured nursing involvement enables systematic symptom tracking, early identification of potential adverse events, and consistent reinforcement of self-management strategies.[57] In this way, the SurPass becomes not only a medical record but also a practical tool to organize care pathways, schedule interventions, and optimize resource use within outpatient and inpatient oncology services.[20-23] The tool can also support educational and behavioral interventions, providing survivors with clear, actionable information on their treatment history, potential late effects, and recommended follow-up activities, thereby encouraging active engagement and self-monitoring.[58] Nurses and allied health professionals can leverage the SurPass to deliver personalized education, guide adherence to screening protocols, and reinforce healthy behaviors, including lifestyle modifications that may mitigate long-term risk.[59] The integration of advanced digital technologies, such as predictive tools and remote monitoring devices, could potentially further enhance support, although additional evidence is needed to confirm their actual impact.[60-63] The use of predictive models and Internet of Things sensors may provide additional information to optimize follow-up, but these applications remain conceptual and speculative at present. Similarly, the adoption of artificial intelligence-integrated digital tools in the context of the SurPass may suggest more personalized care scenarios, but it does not constitute established evidence of effectiveness.[62-65] In summary, the SurPass represents a structured survivorship tool with potential applications in both pediatric and adult oncology. The potential of digital technologies remains promising but should be regarded as hypothetical and requires confirmation through future studies.

4.5. Study limitations and future directions

Several key limitations of the present study should be acknowledged. First, the sample size was relatively small, and recruitment occurred at a single outpatient clinic,

which may limit the generalizability of the findings. Since recruitment was based on convenience sampling, selection bias cannot be ruled out. Participants may not represent the wider population of CCSs, as those who agreed to participate could differ systematically in terms of motivation, health literacy, or engagement with survivorship care. This non-random selection restricts the external validity of the results. Second, the study relied heavily on self-reported data. Self-report introduces vulnerability to recall bias, as survivors may have inaccurately remembered details of their diagnosis or treatments, particularly if many years had passed since therapy. Social desirability bias may also have influenced participants to overstate their knowledge or engagement to appear more compliant with recommended follow-up. Together, these reporting biases could have inflated estimates of survivor knowledge and awareness in both groups. Third, the availability of SurPass in both digital and paper formats may have introduced performance bias linked to differential digital literacy. Survivors more familiar with digital tools may have been better able to access, navigate, and benefit from the electronic SurPass, while others with lower technological competence may have relied more passively on the paper version. As a result, observed differences may partially reflect disparities in digital competence rather than the intrinsic value of the SurPass itself. In addition, measures of patient engagement and adherence to follow-up schedules relied primarily on self-reported data. Objective measures, such as clinical verification of attendance at scheduled visits or electronic monitoring of SurPass use, were not available, which limits the reliability of the engagement outcomes reported here. Last, the cross-sectional design precludes conclusions about the durability of the SurPass's impact over time. Without longitudinal data, it remains uncertain whether improved recall and engagement persist years after the intervention or translate into meaningful clinical outcomes. Taken together, these sources of bias (selection, recall, social desirability, and performance bias) significantly limit the generalizability of the present findings but also provide a roadmap for future research. Future studies should address these issues through random sampling across multiple centers, larger and more heterogeneous cohorts, the use of validated objective outcome measures, and longitudinal follow-up to establish whether short-term improvements in knowledge and engagement persist over time. In particular, incorporating objective digital tracking systems, structured interviews, and integration with electronic health records could reduce reliance on self-report and provide more granular insights into patient engagement, adherence to scheduled follow-up, and symptom reporting. Advancements in digital platforms, such as mobile applications with reminders, interactive educational modules, and automated risk alerts, could optimize the SurPass for broader clinical implementation, creating a scalable model for both pediatric and adult oncology survivorship programs. Finally, in terms of statistical analysis, our approach was limited to basic tests (e.g., *t*-tests, chi-square). The absence of an a priori sample size calculation represents a further limitation, as the relatively small sample may reduce statistical power and the ability to detect smaller effect sizes. Moreover, some subgroups were small, which reduced statistical power and increased the risk of type II errors. These methodological constraints further limit the strength and robustness of our conclusions. Future studies with larger and more diverse samples will enable the use of more advanced statistical models, including multivariable analyses, to provide a more nuanced understanding of the observed associations.

5. Conclusion

In conclusion, the SurPass represents a potentially useful and pragmatic approach to survivorship care, aiming to enhance patient engagement, clinical efficiency, and structured data collection for research purposes. By providing survivors with a clear, comprehensive, and easily accessible record of their treatment history, the SurPass may help support health education, encourage self-management, and promote active participation in follow-up programs. Its dual format—both digital and paper-based—may facilitate continuity of care across different clinical settings, ensuring that essential information remains available when survivors transition between providers or regions. While our findings suggest possible advantages in the early recognition and management of treatment-related late effects, these should be regarded as preliminary observations rather than causal inferences. Further longitudinal studies will be needed to confirm these hypotheses over time. By consolidating relevant clinical information in a tangible and user-friendly format, the SurPass may assist healthcare providers in identifying needs and tailoring follow-up strategies to individual survivor profiles. Overall, the SurPass may serve as an example of a structured and personalized survivorship support tool that can be adapted for use across both pediatric and adult oncology contexts. Future multicenter, longitudinal studies will be essential to assess its long-term impact, generalizability, and scalability.

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Conflict of interest

The authors declare they have no competing interests.

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Ethics approval and consent to participate

The study received ethical approval from the Regional Ethics Committee of Liguria, under the PanCareFollowUp protocol (Protocol number: Registro CER Liguria 295/2020–ID 10632). Data were collected anonymously and processed by the authors in full compliance with applicable Italian regulations on clinical research (Legislative Decree June 24, 2003, No. 211 and Ministerial Decree December 17, 2004), as well as relevant European legislation, and in accordance with the principles of the 1964 Declaration of Helsinki and its subsequent amendments. Informed consent was obtained from all individual participants included in the study.

Consent for publication

Before accessing the questionnaire, participants were required to provide informed consent and consent for the processing and publication of their data. They were also provided with a specific information form detailing the study's purposes, methods, and consent for the publication of data findings.

Availability of data

The data supporting this research are available upon request from the corresponding author for data protection reasons.

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