



Use of Patient-Centered Technology and Digital Interventions in Pediatric and Adult Patients with Hematologic Malignancies

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Abstract

Purpose of Review As society continues to advance in technology, it is important to address how this advancement can impact and enhance patient care. The purpose of this review is to identify patient-centered technology currently available for adult and pediatric patients with and those having survived hematologic malignancies. Given that patients with hematologic malignancies often have to adhere to strenuous medication regimens, coordinate care with many different providers, manage symptoms associated with treatment, and manage late effects associated with survivorship, they would benefit greatly from patient-centered technology aimed at decreasing these burdens.

Recent Findings This review found various available digital interventions for this patient population and focuses on an overview of commercially available smartphone applications, patient portals, and technology for remote monitoring.

Summary In summary, many digital interventions exist for use in the medical care of oncology patients. The incorporation of these interventions can allow for more personalized medical care, better organization of treatment plans by caregivers at home, and easy delivery of accurate medical information.

Keywords Digital interventions · Mobile · Mobile health · mHealth · Technology · Behavior · Patient-centered · Leukemia · Lymphoma · Myeloma · Hematological malignancies · Cancer

Introduction

As cancer remains extremely prevalent with 1.6 million people diagnosed in 2020 [1], it has become imperative to utilize our advancements in technology to assist patients to improve symptom management and coordinate care. Hematologic malignancies are among the most common cancer diagnoses with B-cell acute lymphoblastic leukemia being the most common cancer diagnosis in pediatric patients with a remission rate of greater than 90% [2]. Therefore, we will focus this review on the role for patient-centered technology specifically for patients actively being treated

for or having previously survived hematologic malignancies. We will highlight the need for digital interventions to promote healthy lifestyles, medication adherence, and improved patient-provider communication among this population. Of note, we will not include examining artificial intelligence and its applications including large language models as it is out of scope for this review.

Uptake of Technology

Over the course of the last several decades, advancements in technology have expanded exponentially. For adults and children, the usage of internet and smartphone plays a substantial role in their everyday lives, with many children interacting with digital technology at increasingly younger ages. Most young children interface with various technological devices: approximately 73% of parents report that their children ages 9–11 use a computer, 80% play on a tablet, and 67% utilize a smartphone [3] with growing access across disease conditions [4–8].

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The COVID-19 pandemic further accelerated these pre-existing trends. Within several months from the introduction of the novel coronavirus in January 2020, COVID-19 became a global pandemic. With governmental mandates to practice social distancing and stay at home, individuals became more reliant on digital technology for communication, work, education, and health care. Digital-based technology is commonly used and widely available with promising effectiveness data [9•, 10–12], giving medical providers diverse opportunities to further connect with their patients and offer additional support outside medical institutions.

Defining Digital Interventions

In this review, we explore the use of patient-centered digital technology in pediatric and adult patients with hematologic malignancies. Digital technology used in healthcare is divided into two major categories: eHealth and mHealth. Healthcare services provided electronically, or information technology used in the prevention and management of healthcare is referred to as eHealth. eHealth includes the internet, virtual reality, and electronic medical records. Alternatively, mobile and wireless applications to deliver medical care, such as social media, text messaging, smartphone apps, and wearable devices, are referred to as mHealth. We will explore digital interventions such as commercially available web-based and smart device applications, remote monitoring devices, and patient portals for disease self-management. Specific healthcare system technologies such as electronic health medical records and telemedicine are more physician-centered and, therefore, outside of the scope of this review.

We conducted a focused literature search in PubMed Central using terms related to digital health, mobile health (mHealth), technology-based interventions or tools that were investigated in patient populations with a diagnosis of any hematological malignancies, such as acute lymphoblastic leukemia, acute myeloid leukemia, multiple myeloma, Hodgkins lymphoma, and non-Hodgkins lymphoma. We prioritized including original research studies, and we only included studies that were in the English language.

The use of eHealth and mHealth is growing in various medical specialties, and patients with chronic medical conditions are more frequently utilizing these technologies [13]. Often described benefits of using digital interventions in medicine include breaking down socioeconomic barriers such as difficulty accessing in-person healthcare services and reducing the cost of travel expenses. Digital interventions such as smartphone apps allow for personalizing medical information and symptom management specific to each patient and family. This personalization allows for the evolution of treatment as the needs of patients change over time.

Technology-based interventions allow close home monitoring of medication adherence and enable patients to keep medical information such as treatment plans and follow-up appointments well-organized. Finally, eHealth and mHealth applications, such as social media platforms and chat rooms, allow patients and families to connect with others undergoing similar medical journeys, creating a sense of community.

Use of Technology in Hematologic Malignancies

Pediatric and adult patients with cancer are a unique group that could benefit significantly from adding digital interventions to their treatment and follow-up plans. The CDC estimated that about 1.6 million adults were diagnosed with invasive cancer in 2020 [14], and it is estimated that roughly 15,000 children are diagnosed with cancer yearly in the USA [15]. Due to advances in treatment, pediatric patients diagnosed with various types of cancer have 5-year survival rates approaching 80% [16]. Treatment regimens, including chemotherapy, surgery, and radiation, are rigorous and prolonged, sometimes spanning the course of several years with additional years of surveillance. Both during and after treatments, patients face many physical and psychosocial challenges. Additionally, long-term survivors are at risk for various late effects secondary to their cancer treatments requiring extensive screening throughout their lifetime [17]. The addition of technology-based interventions, particularly for children and young adults raised in the era of technology, could be a positive adjunct to their long and challenging clinical course, not only during treatment but also during survivorship as well.

There exist many reasons that hematologic malignancies lend themselves to using technology-based interventions. As aforementioned, the extended duration of therapy generates both physical and psychosocial challenges. Common physical side effects of cancer treatment include fatigue, pain, nausea, and weakness. These physical symptoms, the stress of treatments, and the uncertainty of outcome can further lead to anxiety, depression, and decreased quality of life [18, 19]. Due to the prolonged course and frequent follow-up appointments and hospitalizations, cancer treatment disrupts the everyday lives of patients and their families. The treatment course and the symptoms associated with treatment impair the patient's ability to participate in work, school, and activities. Therefore, the resulting disruption in school attendance along with the intensive treatment regimens for the malignancy itself leads to an increased risk for developing neurocognitive impairment not only during treatment but also in survivorship [20–22]. Technology-based interventions can be helpful for these patients to track their symptoms outside

of the office, providing clinicians with real-time data to personalize their medical care. eHealth and mHealth can provide mental health services, cognitive rehabilitation, and social support for patients and families in a more accessible structure than in a medical office setting.

Advances in oncology allow most treatment to occur in outpatient settings and at home. While this development offers many benefits, it also places a considerable burden of stress and responsibility on the family and caregivers. Many families find it challenging to manage multiple medications and frequent follow-up appointments. Studies have shown that patients who miss doses of oral chemotherapy have higher relapse rates [23]. Digital technology such as smartphone apps can be utilized for medication adherence and the organization of medical information.

Chemotherapy and radiation given to treat hematologic malignancies cause both short and long-term side effects. Cancer survivors need to understand their diagnosis and previous treatment regimens to effectively screen for late effects throughout the rest of their lives. Survivorship is another area that digital interventions can play a role in keeping medical information organized and educating survivors on their individualized needs for follow-up and screening.

Finally, the incorporation of technology allows for enhancing the patient-physician relationship in oncology patients. Using applications to track daily physical and psychosocial symptoms outside of the office enables clinicians to better understand their patients' daily struggles and personalize treatment plans accordingly. Technology allows medical providers to check in on their patients outside medical institutions. Applications tied to electronic medical records, such as MyChart, enable clinicians to share results and convey information with patients and

families readily. Figure 1 (created in Microsoft PowerPoint) highlights the relationships between patient-centered digital interventions with internet applications and remote monitoring.

The use of digital technology in healthcare is rapidly expanding, and the field of oncology has unique attributes making the field prime for the addition of eHealth and mHealth options to treatment courses. With an aging population and predicted shortage of oncologists in the USA, it is becoming imperative for cancer centers to incorporate more technology adjuncts into their practices. The rest of this article will focus on the currently available digital interventions for childhood and adult oncology, focusing on commercial apps for smart devices, remote monitoring, and disease self-management.

Overview of Commercially Available Apps

Many medical applications for smart devices already exist for various medical conditions and are being utilized by patients and families. The number of available medical apps continues to grow, with over 65,000 apps available to Android users at the end of 2022 and almost 54,000 available to Apple users at the end of 2020 [24, 25]. Companies developed many of these apps without professional healthcare input. Research to evaluate the quality and effectiveness of medical apps is expanding, particularly in oncology.

One group of researchers, Narrillos-Moraza et al. [26••], performed an observational, cross-sectional descriptive study of commercially available apps on Android and iOS platforms for patients with both benign and malignant hematologic conditions. In this study, the quality of the apps was independently evaluated by two reviewers using

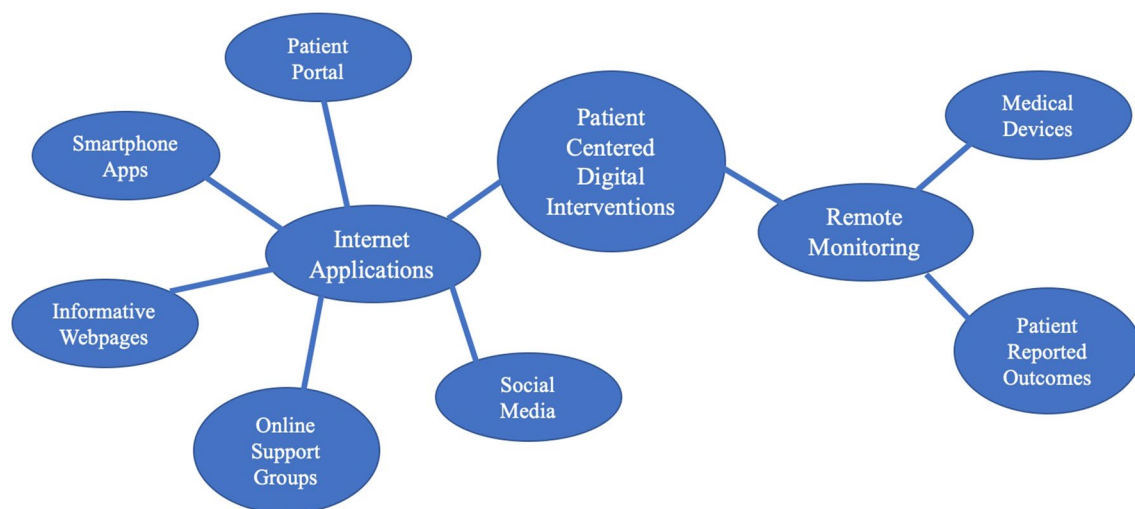


Fig. 1 Components of patient-centered digital interventions

the Mobile Application Rating Scale (MARS), a validated grading scale. MARS focuses on five domains: engagement, functionality, aesthetics, information quality, and subjective quality. In this study, researchers found that the caliber of available apps widely ranges, with more than half of the apps not meeting acceptable criteria for quality and content. Most apps targeted patients with anemia and other benign hematologic conditions. However, 26 of the 88 (roughly 30%) evaluated did specifically target those with hematological malignancies. Some of the apps that rated the highest in this study included oncology apps such as Multiple Myeloma Manager, Hodgkin Lymphoma Manager, Focus on Lymphoma, ALL Manager, and CLL manager. These apps scored exceptionally high in the engagement and functionality domains. Researchers found that the features that defined these top-scoring apps were active patient participation with options for treatment and symptom monitoring, reminders, and scheduling. This study additionally demonstrated that few available apps (approximately 26%) were created in collaboration with healthcare professionals and that most health-related apps are free and accessible for everyone. Therefore, the lack of consultation with healthcare experts raises concerns about the content validity in these apps.

A systematic review conducted by McCann et al. [27••] assessed various digital health interventions targeting oncology patients ages 13–39 years, focusing on symptom

management, medication adherence, self-care, and mental health. They used an adapted version of the MARS grading scale in addition to the Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (QualSyst) tool to summarize a methodological quality score for both quantitative and qualitative studies. Based on the QualSyst tool, the mean quality scores of these studies were greater than 68%. Patients overall reported positive experiences with digital interventions when asked. (However, it should be noted only a little over half of the studies inquired about patient experiences with the digital health intervention.) Negative experiences reported by the patients included technical difficulties, simplistic website designs, and the concern that while these platforms provided peer support, it was not equivalent to in-person interactions. Of the 38 studies reviewed, only 8 had expert recommendations or a steering committee included for advisement (21%). In addition, of these studies reviewed, 18 interventions focused on those in active treatment and 20 focused on those in survivorship, thus emphasizing a role of these technological interventions both during treatment and in survivorship. This systematic review also included not only apps, but also websites, video games, social media, virtual reality, and wearable physical activity trackers.

Tables 1, 2, 3, 4, 5 and 6 summarize several selected eHealth and mHealth websites and applications that

Table 1 Selected eHealth and mHealth websites and applications for oncology: cancer education

Area of use	Title	Website or platform	Description
Cancer education	ALL Xplained (MedicineX)	Apple Store	Descriptive story based on a real patient that explains ALL (diagnosis, condition, treatment) to users without use of medical jargon
	Blood Cancer Tips (Free Apps for Everyone)	Google Play	Provides medical information and explanation for various types of childhood and adult hematologic malignancies
	Childhood Leukemia: A Preventable Disease (FreeCreativity2019)	Google Play	Provides information about healthy lifestyle choices for childhood, recognizing symptoms of childhood leukemia, and treatment regimens
	Children's Oncology Group	http://childrensoncologygroup.org	Provides patients and families with reliable information to guide them through all the phases of childhood cancer; includes information about clinical trials, coping, and community support
	National Cancer Institute	http://www.cancer.gov	Contains reliable information about all types of childhood and adult cancers; provides resources for patients and caregivers
	Cure Search	www.curesearch.org	Provides medical information about cancer and clinical trials from an organization aimed at driving research to provide more treatment options for childhood cancer; app is designed as a cancer care assistant with the ability to organize medications, appointments, and symptom tracking

Table 2 Selected eHealth and mHealth websites and applications for oncology: coping and support

Area of use	Title	Website or platform	Description
Coping and support	Beyond the Cure	http://beyondthecure.org	Program from The National Children’s Cancer Society to help childhood cancer survivors integrate the cancer experience into their new life and to celebrate survivorship; provides information, community resources, and academic scholarships
	Stupid Cancer	http://stupidcancer.org	Mission to empower everyone affected by adolescent and young adult cancer by ending isolation and building community; provides age appropriate resources to help navigate treatment and survivorship
	SuperSibs!	http://www.supersibs.org	Support for siblings of children with cancer; provides age appropriate coping skills and community resources
	LivingWith	http://thisislivingwithcancer.org Apple Store	Platform allows user to invite family and friends to join app; can request help with daily tasks like meal prep or transportation

Table 3 Selected eHealth and mHealth websites and applications for oncology: disease self-management — adherence

Area of use	Title	Website or platform	Description
Disease self-management — adherence	CML Today (Leukemia Patient Advocates Foundation)	Apple Store Google Play	Allows user to track intake of medication, set reminders for medication, track laboratory results, connect with local support groups
	MyMedSchedule Plus	MedActionPlan.com Apple Store Google Play	Medication reminder app that allows the user to input their medication schedules, set reminders, track medication taken, reminders for refills, and get updates from healthcare provider
	MyMeds	http://my-meds.com/	Medication organization website where users can import their meds, set reminders, read news about their health conditions, talk to pharmacist, identify better prices for meds
	CareZone	http://carezone.com Apple Store Google Play	Provides medication and appointment management; calendars and notes to document symptoms and track progress

have been used in oncology, including hematological malignancies.

Remote Monitoring

Remote patient monitoring is a way to observe patient clinical information from a distance. Remote monitoring of vital signs, laboratory values, and patient-reported outcomes can be valuable adjuncts to ongoing medical treatment of hematologic malignancies. Digital technology can be utilized to monitor side effects of medications and other patient-reported outcomes remotely to alter treatment plans as needed. Devices such as blood pressure cuffs, pulse oximeters, electrocardiogram applications, and glucometers can be used remotely. The generated data is then stored securely and efficiently accessed by healthcare professionals.

Web-based systems and wearable sensors to monitor cancer patients’ health data improve symptom management and decrease acute care utilization [28]. Biometric data monitoring can be used with standard care to supplement

home-based care. One study investigated temperature monitoring through a skin patch in oncology patients who were admitted to the hospital and found that this method of continuous monitoring could detect a fever quicker than standard routine monitoring [29]. This may inform future studies to investigate continuous vital sign monitoring while at home for at risk patients.

Hooke et al. explored one form of wearable technology and patient monitoring [30]. In this study, they investigated the Fitbit tracker and daily coaching use to increase physical activity and decrease fatigue in children during the maintenance phase of ALL treatment. They also looked at this in conjunction with corticosteroid treatment during the maintenance phase which often leads to worsening fatigue. The results were limited by a low sample size of 16; however, they did find a significant correlation with less reported fatigue associated with increased physical activity (measured in median number of steps per day) during the time of receiving corticosteroids. There was not a significant difference in fatigue or physical activity overall between the baseline measurement and the post-intervention time-point.

Table 4 Selected eHealth and mHealth websites and applications for oncology: disease self-management — patient portal

Area of use	Title	Website or platform	Description
Disease self-management — patient portal	ALL Manager (Point of Care)	Apple Store	Health management app where the user can utilize daily journal, document health measures (quality of life, symptoms), keep track of healthcare appointments; provides medical information about ALL
	CLL Manager (Point of Care)	Apple Store	Health management app where the user can utilize daily journal, document health measures (quality of life, symptoms), keep track of healthcare appointments; provides medical information about CLL
	CLL Watch and Wait Tracker (Lymphoma Canada)	Apple Store Google Play	Provides medical information about CLL and SLL, allows user to track symptoms and well-being over time; user can input appointments into calendar
	Don't Walk Alone (Lymphoma Canada)	Apple Store	Provides medical information about CLL; health tracking inputs data from Health App; allows user to connect with local community support groups and events
	Focus on Lymphoma (Lymphoma Research Foundation)	Apple Store Google Play	Provides medical information to patients and caregivers with tailored content based on lymphoma subtype; provides symptom and lab tracking, appointment reminders, and connection to local community
	Hodgkin Lymphoma Manager (Point of Care)	Apple Store	Health management app where the user can utilize daily journal, document health measures (quality of life, symptoms), keep track of healthcare appointments; provides medical information about Hodgkin Lymphoma
	LLS CAR T (The Leukemia and Lymphoma Society)	Apple Store Google Play	Provides education on Car-T Therapy
	LLS Health Manager (The Leukemia and Lymphoma Society)	Apple Store Google Play	Monitor and analyze side effects to medication, monitor food intake, hydration; medication reminder and question lists for medical providers
	Multiple Myeloma Manager (Point of Care)	Apple Store	Health management app where the user can utilize daily journal, document health measures (quality of life, symptoms), keep track of healthcare appointments; provides medical information about Multiple Myeloma
	NCCN Patient Guides for Cancer (National Comprehensive Cancer Network)	Apple Store Google Play	Easy to understand resources for patients with various types of childhood and adult cancer; describes treatment options and provides questions to ask medical providers
	The Cancer App (Interactive Pharma solutions limited)	Google Play	Provides medical information and resources for various childhood and adult cancer; organizes appointments, medications, and contacts
	Transplant Guidelines (National Marrow Donor Program/Be The Match)	Apple Store Google Play	Provides checklists to help prepare for transplant, customized 6-month, 12-month, and 2-year annual checkup guidelines; GVHD symptom tracker; allows user to set reminders for appointments, medications, and exercise

Table 5 Selected eHealth and mHealth websites and applications for oncology: disease self-management — other

Area of use	Title	Website or platform	Description
Disease self-management — other	Pain Squad (The Hospital for Sick Children)	http://campaignpage.ca/sickkidsapp Apple Store	Electronic pain diary for children with cancer
	Passport For Care	http://www.passportforcare.org/	Users enter details about specific types of cancer treatments and a guideline-based algorithm generates specific risk for late effects from childhood cancer and recommendations for screening; users can share information with primary care and specialty care providers

Table 6 Selected eHealth and mHealth websites and applications for oncology: social networks

Area of use	Title	Website or platform	Description
Social networks	Caring Bridge	http://www.caringbridge.org/	Personal health journal website; user can create their own website with health updates for friends and family to follow along
	DailyStrength	http://www.dailystrength.org/	Social network centered on support groups; users provide one another emotional support by discussing struggles and successes

Disease Self-management

More and more hematologic malignancies are being managed in the outpatient setting which require patients and their families to utilize disease self-management skills to attend clinic appointments, manage side effects, administer medications, and participate in health-promoting behaviors. Disease self-management and monitoring behaviors using electronic interventions can help patients and families become more self-reliant at home.

Multiple apps designed by @Point of Care, a platform that designs and creates digital tools for patients and clinicians to allow sharing of data and is dedicated to improving health outcomes [31], are available for disease self-management for pediatric and adult cancer patients, including Multiple Myeloma Manager, Hodgkin Lymphoma Manager, ALL Manager, and CLL Manager. These apps enable the patient to input data on mood, pain, and other symptoms easily shared with medical providers. These apps additionally allow for the management of treatment regimens and appointments and provide educational information about the patient's specific cancer diagnosis. These apps were reviewed by Narrillos-Moraza et al. [26••] and determined to be among the highest rated apps, with exceptionally high ratings in the functionality and engagement domains.

A systematic review published in 2022 evaluated the current evidence on patient-centered digital health

records intended for patients with chronic health conditions, including oncology patients. This study concluded that the digital health record demonstrated positive effects in utilizing recommended or preventive health services, patient engagement, treatment adherence, and self-management [32]. Patient-centered digital health records enable patients to take a more active role in their care.

Due to the movement of oncology treatment towards more outpatient and at-home treatment regimens, the responsibility of the patients and families to successfully administer chemotherapeutic agents at home has increased over the years. Studies have shown that it is common for medication errors to occur when children and young adults receive medications at home [33]. Additionally, adherence to oral chemotherapy is critical to outcomes, as nonadherence to chemotherapy agents has been shown to lead to higher relapse rates [23]. Technology can be utilized to facilitate medication organization and administration. Technology can also track patterns and behaviors to provide interventions to combat barriers to adherence.

Many medication adherence apps are available, including MyMedSchedule and CareZone. These apps allow medical providers to input home medication regimens directly into patients' smartphones. The apps are also capable of sending reminders and demonstrating missed dosages. Digital technology can be utilized in this setting to organize medications, monitor missed dosages, and provide behavioral interventions to address difficulties with

adherence. This, in turn, can improve self-efficacy for following treatment plans.

Pediatric and adult patients undergoing chemotherapy and radiation treatment experience many symptoms including pain, nausea, and constipation. The use of electronic pain journals has been applied in different fields of medicine and is becoming increasingly utilized in the field of pediatric oncology. An example is an iPhone app called Pain Squad, which collects information on pain for adolescent patients with cancer. Data entered into the app can be shared with healthcare providers, leading to rapid and effective pain management.

Another area that digital apps and websites have positive potential in oncology is within the realm of promoting healthy lifestyle habits. Physical activity and nutrition apps have increased dramatically over the past decade. eHealth and mHealth technologies that enables healthy lifestyles and decreasing risky health behaviors, for example, tobacco use, could benefit both adolescent and adult oncology patients. Tobacco use contributes to the morbidity and mortality among the general population [34] and therefore can have devastating impacts on those who already have a history of cancer and are more susceptible to secondary malignancies. There is emerging literature on the predictors, outcomes, and interventions in engaging in risky health behaviors such as tobacco use among cancer survivors [35–37]. Included in these interventions are multiple web-based programs targeted toward not only improving health-promoting behaviors such as exercise but also discouraging risky health behaviors such as tobacco use. More research is needed to analyze the effectiveness of these types of digital interventions within the field of oncology and oncology survivorship.

Conclusions and Future Directions

The internet and smart devices are available to most children and families in this growing age of technology. Technology provides an opportunity to reach diverse populations of oncology patients to deliver support and treatment outside the walls of medical institutions. Digital interventions such as eHealth and mHealth technologies are quickly becoming integral to the medical care provided for these patient populations. Decentralizing care with digital interventions can provide patient-centered care with additional features of providing treatment and support while limiting exposure to nosocomial infections, reaching people in rural areas with limited access to transportation, and personalizing medical care based on patient-reported outcomes.

While technology provides many benefits to patients, digital-based interventions also come with challenges. These challenges include more responsibility placed on patients and caregivers as well as concerns for breach of

confidentiality. Challenges include the variability of health and technology literacy based on age and level of education. Some populations in rural areas or with low socioeconomic status may not have access to the internet and smart devices. Additionally, reimbursement can be challenging for remote patient monitoring programs due to lack of systematic data on outcomes.

As technology continues to expand, further research is necessary to assess the efficacy of digital interventions for hematologic malignancies. Studies have shown that very few commercially available apps are created with the input of medical professionals. Rarely do medical professionals oversee the information or educational material presented in eHealth and mHealth. Digital interventions could be more effective if patients, clinicians, and healthcare institutions become more involved with their creation and management. Studies have also shown that personalized digital interventions were the most effective for patients and families. Overall, pediatric and adult patients report positive attitudes and perceptions about using technology in their cancer care. Medical professionals should talk to patients and families to determine how best to incorporate eHealth and mHealth technologies into their oncology treatment plans.

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Data Availability No datasets were generated or analysed during the current study.

Compliance with Ethical Standards

Ethical Approval As this study is not a human and/or animal study, further statements are not applicable.

Conflicts of Interest The authors declare no competing interests.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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- Of importance
- Of major importance

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