

D2.1 - Report of review of literature

E-health tools and identification of unmet needs



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Abbreviations

AR: Augmented Reality

CBT: Cognitive and Behavioural Therapy

EHRs: Electronic Health Records

LTFU: Long-Term Follow-Up

VR: Virtual Reality



Project partners

Number	Short name	Partners' names
1	HUGO	GCS HOPITAUX UNIVERSITAIRES GRAND OUEST
1.1	CHUA	CENTRE HOSPITALIER UNIVERSITAIRE D'ANGERS
1.2	ICO	INSITUT DE CANCEROLOGIE DE L'OUEST
2	HUPON	MAGYAR GYERMEKONKOLOGIAI HALOZAT - MAGYAR GYERMEKONKOLOGUSOK ES GYERMEKHEMATOLOGUSOK TARSASAGA
3	UNIOSL	UNIVERSITETET I OSLO
4	CHUSE	CENTRE HOSPITALIER UNIVERSITAIRE DE SAINT ETIENNE
5	IGG	ISTITUTO GIANNINA GASLINI
6	RESILIENCE	RESILIENCE
7	OUH	OSLO UNIVERSITETSSYKEHUS HF
8	AUH	AARHUS UNVERSITETSHOSPITAL
9	AU	AARHUS UNIVERSITET
10	TUCH	VARSINAIS-SUOMEN HYVINVOINTIALUE
11	HUS	HUS-YHTYMA
12	ISGLOBAL	FUNDACION PRIVADA INSTITUTO DE SALUD GLOBAL BARCELONA
13	KDBZ	KLINIKA ZA DJEČJE BOLESTI ZAGREB
14	CLB	CENTRE DE LUTTE CONTRE LE CANCER LEON BERARD
15	CINECA	CINECA CONSORZIO INTERUNIVERSITARIO
16	UKESSEN	UNIVERSITAETSKLINIKUM ESSEN
17	CCBL	JAVNA ZDRAVSTVENA USTANOVA UNIVERZITETSKI KLINICKI CENTAR REPUBLIKE SRPSKE
18	ONKO-I	ONKOLOSKI INSTITUT LJUBLJANA
19	EPICONCEPT	EPICONCEPT
20	ALP	ASOCIATIA LITTLE PEOPLE ROMANIA
21	CUSL	CLINIQUE UNIVERSITAIRE SAINT-LUC ASBL
22	AP-HP	ASSISTANCE PUBLIQUE HOPITAUX DE PARIS
23	UMC-MAINZ	UNIVERSITAETSMEDIZIN DER JOHANNES GUTENBERG-UNIVERSITAET MAINZ
24	PANCARE	PANCARE
25	UNILU	UNIVERSITAT LUZERN
26	IGR	INSTITUT GUSTAVE ROUSSY
27	ERINTETTEK	ERINTETTEK EGYESULET
28	AGUERRIS	ASSOCIATION LES AGUERRIS
29	YCE	FUNDATIA YOUTH CANCER EUROPE
30	RMH	THE ROYAL MARSDEN NATIONAL HEALTH SERVICE TRUST

Key findings

Needs of Children, Adolescents and Young Adults

PHYSICAL NEEDS

Necessity: children require palliative and supportive care to manage symptoms like pain, nausea and fatigue, with a focus on improving their quality of life.

Digital tools: apps and wearable devices are recommended for tracking symptoms, enabling healthcare providers to adjust care plans promptly.

EMOTIONAL / MENTAL / PSYCHOLOGICAL NEEDS

Necessity: there is a critical need for care addressing emotional suffering and distress, using creative and relaxation techniques.

Digital tools: mental health apps and VR environments can provide accessible support and distraction, aiding in anxiety reduction and coping strategies.

DEVELOPMENTAL NEEDS

Necessity: addressing age-dependant developmental, emotional and psychosocial needs is crucial, with an emphasis on education and socialisation.

Digital tools: educational apps and platforms should be utilised to ensure continuous education and engagement.

REHABILITATION NEEDS

Necessity: support in physical activity restoration, cognitive difficulties and psychosocial reintegration is vital.

Digital tools: apps for physical therapy and AR for engaging activities can support rehabilitation effectively.

INFORMATION NEEDS

Necessity: delivering age-appropriate information and effective communication about medical history and treatments is essential.

Digital tools: patients portals and educational websites can provide crucial information, enhancing understanding and decision-making.

MEDICAL NEEDS

Necessity: tailored follow-up, health promotion, and transition programs are required for long-term care and independence.

Digital tools: EHRs with patient portals and telehealth services can streamline communication and ensure coordinated care.

INTEGRATIVE APPROACHES AND INTERACTIVE TOOLS

Necessity: an integrated care approach that encompasses physical, emotional, and developmental needs is needed.

Digital tools: comprehensive care management platforms can offer a centralized hub for managing healthcare needs and community support.

Families' needs

Information needs: systematic reviews identified significant unmet information needs among families, covering treatment, coping, and everyday life.

Barriers and facilitators: effective communication and information provision depend on healthcare professionals' approach, communication settings, and personal factors of the relatives.

Preferences: the form, sources, and timing of information provision vary, highlighting the need for personalized communication strategies.

The work highlights the complexity of caring for children with cancer and their families. It underscores the importance of a multidisciplinary approach to address the diverse needs through both traditional and digital means. The focus on digital tools across various aspects of care reflects an understanding of the role technology can play in modern healthcare, offering innovative solutions to support patients, survivors, and their families in navigating the challenges posed by cancer.

Introduction

The FormIT methodology emphasizes the importance of the initial explore phase in the concept design cycle. Accordingly, **WP2 conducted several systematic reviews to establish the state-of-the-art (SoA)** in areas such as: needs related to childhood and young adult cancer survivors' quality of life (CAYACS) for which existing resources exist or need development; gaps, hurdles, factors, and situations impeding the implementation of current tools and technologies; and best practices and key success factors for achieving the project's objectives. **Studies were searched in at least two databases (Medline/PubMed and Embase) and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) standards.**

A **global core group, with regular virtual meetings, was established** to foster results and successful collaboration. This included three subgroups focusing on different literature aspects to address concerns regarding project timelines. A feedback loop was established for continuous assessment and improvement of e-health tools and interventions, based on the evolving needs of the target population and technological advancements.

The focus of the 3 subgroups have been defined based on their expertise: **HUPON: needs of children with cancer**, defining the specifications for potential interventions to consider future collaborative projects for younger patients. **CLB: needs of adolescents and young adults** concerning supportive care, QoL, and digital tools. **UNILU: families' needs.**

HUPON: needs of children (0-15 yo) with cancer, defining the specifications for potential Interventions to consider future collaborative projects for younger patients.

To provide a cohesive summary that combines the needs of childhood cancer patients and survivors (age ≤ 15 yo) and the methods for measurement and outcomes associated with addressing these needs, we structured the information as follows:

Physical needs

Need: palliative and supportive care for symptoms like pain, nausea, and fatigue, and improvement of quality of life.

Measurements methods: symptom inventory questionnaires by nurses, age-related assessments for optimal palliative care, and screening for organ dysfunction.

Outcomes: alleviation of physical suffering, optimization of function, and enhanced quality of life at all disease stages.

Digital tools: symptom tracking apps and wearable devices for real-time monitoring of physical symptoms like pain, fatigue, and sleep quality.

Usage: patients and caregivers can input daily symptoms, which healthcare providers can review to adjust care plans promptly.

Emotional / Mental / Psychosocial needs

Need: care for emotional, social, and spiritual suffering, and relieving distress through various creative and relaxation techniques.

Measurements methods: ALTE07C1 assessment battery for evaluating cognitive, social, emotional, and behavioral functioning, and the QLIC-ON PROfile for detailed psychological evaluations.

Outcomes: improved coping skills, reduced distress/fear, enhanced patient engagement, and preservation of the child's identity.

Digital tools: mental health apps offering cognitive-behavioral therapy (CBT), mindfulness, and relaxation exercises; virtual reality (VR) environments for distraction during procedures.

Usage: to provide accessible mental health support and therapeutic distraction, helping reduce anxiety and improve coping strategies.

Developmental needs

Need: managing developmental, emotional, and psychosocial needs in an age-dependent manner, including socialization and educational aspects.

Measurements methods: prospective investigations for changes in function/abilities, and ongoing management post-discharge with early intervention.

Outcomes: achievement of milestones of independent living, psychological and academic benefits from continued education, and early social integration.

Digital tools: Educational apps and platforms tailored to various developmental stages, offering personalized learning experiences even during hospital stays.

Usage: facilitate continuous education and developmentally appropriate engagement, ensuring minimal disruption to the child's educational progress.

Rehabilitation needs

Need: support in restoring physical activity, addressing body image issues, improving cognitive difficulties, and facilitating psychosocial and educational reintegration.

Measurements methods: measures to evaluate improvements in physical activity, body image perceptions, cognitive improvements, and learning disabilities.

Outcomes: enhanced reintegration into everyday life, improved physical and psychological well-being, and support for educational advancement.

Digital tools: physical therapy apps and online platforms for guided exercises, and augmented reality (AR) for engaging physical activities.

Usage: support physical rehabilitation and encourage participation in exercises designed to improve mobility and strength in a fun, engaging way.

Information needs

Need: age-appropriate information delivery and effective communication strategies regarding medical history, treatment effects, and informed consent.

Measurements methods: evaluation of the effectiveness of communication methods and the provision of information tailored to age and developmental level.

Outcomes: improved understanding of medical conditions, treatment procedures, and overall empowerment of patients and families through knowledge.

Digital tools: patient portals and educational websites providing age-appropriate information about cancer, treatments, and health literacy; interactive storybooks and games for younger patients.

Usage: enhance understanding of medical conditions and treatments, empower patients and families with knowledge, and facilitate informed decision-making.

Medical needs

Need: tailored long-term follow-up and surveillance, health promotion, and transition programs for adolescent and young adult cancer patients.

Measurements methods: monitoring health outcomes through LTFU surveillance, assessing the impact of patient-controlled electronic personal health records, and evaluating patient activation and quality of life.

Outcomes: enhanced health literacy, effective management of health post-treatment, and successful transition to normal life and independence.

Digital tools: electronic health records (EHR) with patient portals for easy access to medical history and treatment plans; telehealth services for consultations and follow-ups.

Usage: streamline communication between healthcare providers and patients, ensuring continuous, coordinated care and facilitating long-term follow-up and surveillance.

Integrative approaches and interactive tools

Need: comprehensive care that integrates physical, emotional, and developmental needs through multidisciplinary teams and innovative technologies.

Measurements methods: utilization of interactive tools like web-based programs, smartphone-based telehealth systems, and electronic patient-reported outcomes for continuous monitoring and tailored support.

Outcomes: Strengthened resilience, improved mental health and patient engagement, and a supportive environment that facilitates healing and recovery.

This integrated summary underscores the holistic approach required to address the multifaceted needs of childhood cancer patients and survivors, outlining the specific methods for measuring these needs and the expected outcomes from interventions designed to enhance their quality of life.

Digital tools: comprehensive care management platforms integrating various aspects of care; social networking sites and forums for peer support; mobile apps for resilience and mental training.

Usage: offer a centralized hub for managing healthcare needs, providing community support, and delivering personalized interventions to enhance overall well-being.

Specific examples of potential digital tools

Symptom tracking app: "PainSquad" for pain management and symptom reporting.

Mental Health support: "Headspace" for mindfulness and stress reduction; "SuperBetter" for resilience building through gameful living.

Educational engagement: "Khan Academy Kids" for personalized learning experiences.

Physical rehabilitation: "Physitrack" for guided physical therapy exercises.

Patient information: "MyChart" for accessing patient portals and medical information.

Electronic health records: platforms like "Epic" that include patient portals for comprehensive medical history review and appointment scheduling.

Telehealth services: "Teladoc" for accessing healthcare professionals remotely.

Community support: online forums such as "CancerCare" for peer support and advice.

By leveraging these digital tools, healthcare providers can offer more personalized, efficient, and effective support to childhood cancer patients and survivors, addressing their complex needs in a holistic and integrative manner.

Methodology

SEARCH STRATEGY

We conducted a comprehensive search in various electronic databases including PubMed, and Embase/Central. Additionally, manual searches were performed using the bibliographies of relevant studies. We aim to gather quantitative, qualitative, and mixed-method studies published until February 2024. The specific search approach for PubMed and Embase/Central are detailed in Appendix 1. Our study design adheres to the PRISMA 2020 guidelines and the protocol will be registered with PROSPERO.

INCLUSION AND EXCLUSION CRITERIA

Eligible studies must meet the following criteria: 1) publication date between February 2014 and February 2024; 2) publication in a peer-reviewed journal; 3) study type includes experimental, quasi-experimental, descriptive, exploratory, or observational; 4) investigation of digital health tools as a primary or secondary focus; 5) inclusion of, aged under 15, previously treated for cancer; 6) participants have completed oncology treatment, regardless of the time elapsed since treatment completion; 7) reliance on self-reports or reports from former patients; 8) publication in English. We will exclude meta-analyses, systematic reviews, and case studies.

STUDY SELECTION AND DATA EXTRACTION

Initial screenings of titles and abstracts were independently conducted by two reviewers using Zotero software. Full texts of potentially relevant articles were thoroughly examined to confirm their suitability for inclusion. Any disagreements will be resolved through consultation with a third reviewer. Data to be collected includes study title, authors, publication year, journal, study design, study country, and participant demographics such as disease site, age, measures used, participant numbers, and primary and secondary outcomes. A standardized table was used to extract data pertinent to the efficacy of digital health tools in enhancing quality of life and well-being.

QUALITY ASSESSMENT

The quality of included studies were assessed by two reviewers using the GRADE system, as proposed by Guyatt et al. in 2008.

CLB: needs of adolescents and young adults concerning supportive care, QoL and digital tools.

Digital tools used to enhance the quality of life and well-being of adolescent and young adult cancer survivors: a systematic scoping review of the literature.

Aim of the review

Access to the internet and personal technology (e.g., smartphones and other electronic devices) is growing rapidly, as are innovations in digital health technology (or 'e-'). Digital health can be broadly defined as the use of technology in the promotion, prevention, treatment, and maintenance of health and health care. Digital health includes electronic health (eHealth), mobile health (mHealth), health information technology, wearable devices, telehealth, and telemedicine (see table 1). These technological solutions are an essential tool for supporting and improving healthcare and support services and have the potential to significantly enhance users' quality of life and well-being.

Compared with the general population, adolescent and young adult cancer survivors represent a vulnerable population with an increased risk of health problems (late effects) and functional deficiencies. There is a recognized need to implement effective and efficient models of follow-up care from the end of treatment through to long-term survival. Digital health is particularly relevant for adolescents and young adults (AYA), who are ubiquitous users of technology. In the general population, 93% of teenagers aged 13 to 17 and 99% of young adults aged 18 to 29 use the internet. Most connect to the Internet using mobile devices; 88% of teenagers and 98% of young adults use a smartphone or mobile phone. In addition, the vast majority of teenagers (89%) and young adults (90%) say they use at least one social media site (e.g., Facebook, Instagram, Snapchat, Twitter) (Devine et al., 2018).

The aim of this review is to provide an inventory of digital tools used to enhance the quality of life and well-being of adolescent and young adult cancer survivors and to gather empirical evidence of their effectiveness.

CLB table 1

Main digital health interventions for AYA cancer survivors (Devine et al., 2018)

Modality	Definition	Examples
Internet interventions	Early applications of digital health interventions included static Web sites or CD-ROMs. More recent applications incorporate sophisticated elements of engagement within Web sites (e.g., interactive tools, media, and gamification) or other digital health components (e.g., text or short messaging service) delivered in conjunction with Web sites.	Web sites Asynchronous forums Chat/instant message Electronic health records
MHealth applications	mHealth interventions have used text messaging/short messaging service or mobile applications (apps) to deliver interventions targeting a variety of health outcomes.	Text messaging Smartphone applications Wearable devices (e.g., fitness trackers)
Social media	Social media platforms can be used in health behavior interventions to reach diverse groups without geographic restrictions, provide a forum for information dissemination and exchange, and enable provision of support from peers, family, and health professionals.	Facebook Twitter Instagram Snapchat
Telehealth	Telehealth is the use of technology such as videoconferencing to connect two or more individuals (e.g., AYA survivor and health care provider) in replacement of an in-person connection.	Videoconferencing Remote delivery of group intervention Online counseling
Emerging digital health Intervention	Emerging areas include the use of digital storytelling, video gaming, and virtual reality to address psychosocial and health care utilization concerns of AYA survivors.	Video narratives Digital scrapbooks Active video games for exercise or physical activity Games related to memory or cognitive rehabilitation Headset to play distracting game during medical procedure

Methodology

SEARCH STRATEGY

A search was carried out in several electronic databases (PubMed, PsycINFO, Science Direct, Cochrane) and by a manual search based on the bibliographies of the selected studies. Quantitative, qualitative and mixed studies conducted since April 2014 were retrieved. The search strategy for PubMed is presented in Appendix 1. This study design complies with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA 2020) guidelines. The protocol was registered on PROSPERO.

INCLUSION AND EXCLUSION CRITERIA

Studies were included if they: 1) were published between April 2014 and April 2024 (which is a period of ten years, plus a search to update the results before publication of the article); 2) were published in a peer-reviewed journal; 3) were experimental, quasi-experimental, descriptive, exploratory or observational studies; 4) investigated digital health tools as a primary or secondary variable; 5) included AYA participants aged 15-25 at the time of the study, previously treated for cancer; 6) included participants who had completed oncology treatment (without taking into account the time since end of treatment); 7) included only self-reports or reports directly from former patients themselves; 8) were written in English or French.

Meta-analyses, systematic reviews and case studies were not be considered.

STUDY SELECTION AND DATA EXTRACTION

Titles and abstracts of articles extracted from the initial search were independently reviewed by two reviewers using Zotero software. The full papers of the selected articles will then be reread to determine whether they included in the review. Discrepancies were discussed with a third reviewer until agreement was reached.

General information was collected for each study selected: title of the study, authors, year, journal, study design, country, as well as the socio-demographic characteristics of the participants: site of the disease, age of the population, measures used, number of participants, primary and secondary outcomes, dependent and independent variables. With regard to our objective, the main results concerning the effectiveness of digital health tools used to improve quality and well-being were extracted. The data was extracted using a standardised table.

QUALITY ASSESSMENT

The quality assessment of the selected studies was carried out by two reviewers using the GRADE (Grading of Recommendations, Assessment, Development, and Evaluations) system (Guyatt et al., 2008).

REFERENCES

- Devine, K. A., Viola, A., Coups, E. J., & Wu, Y. P. (2018). Digital Health Interventions for Adolescent and Young Adult Cancer Survivors. *JCO Clinical Cancer Informatics*, 2, 1-15. <https://doi.org/10.1200/cci.17.00138>
- Guyatt, G., Oxman, A. D., Vist, G. E., Kunz, R., Falck-Ytter, Y., Alonso-Coello, P., & Schünemann, H. J. (2008). GRADE : an emerging consensus on rating quality of evidence and strength of recommendations. *BMJ. British Medical Journal (Clinical Research Ed.)*, 336(7650), 924-926. <https://doi.org/10.1136/bmj.39489.470347.ad>

UNILU: families' needs concerning supportive care, QoL and digital tools.

To provide a cohesive summary that combines the families' needs the methods for measurement and outcomes associated with addressing these needs, we structured the information as follows:

The aim is to systematically summarize the current evidence on unmet needs of families of childhood cancer patients and survivors and adult survivors of childhood, adolescence, and young adulthood cancers. Two systematic reviews were conducted to assess the unmet information needs of families of childhood cancer patients and survivors. These reviews originated from the same database search. The first publication (Appendix 1) included a systematic assessment of the qualitative evidence and has been completed and published. The second publication (Appendix 2) included the review of quantitative evidence and is currently under review. The third systematic review (Appendix 3) is ongoing to identify the information needs of adult survivors of childhood, adolescence, and young adulthood cancers.

Review 1: Qualitative systematic review of the information needs of relatives of childhood cancer patients and survivors

PURPOSE

To summarize and describe qualitative research on:

- 1) the self-reported (unmet) information needs of relatives of children who were diagnosed with cancer;
- 2) their perceived barriers and facilitators to appropriate information acquisition; and
- 3) their preferences for information provision.

RESULTS

The review included 27 publications, with most research focusing on parents or primary caregivers. Five areas of information needs were identified: treatment, medication, and care; general information about cancer; coping and support; follow-up, late effects, and rehabilitation; and parenting and everyday life. Appropriateness of information depended on health care professionals' aptitude, message characteristics, communication setting, and relatives' personal factors. Preferences for form, sources, and timing for information provision varied.

REFERENCE

Ilic, A., Sievers, Y., Roser, K., Scheinmann, K., & Michel, G. (2023). The information needs of relatives of childhood cancer patients and survivors: A systematic review of qualitative evidence. *Patient Education and Counseling*, 114, 107840.

<https://doi.org/10.1016/j.pec.2023.107840>

Review 2: Quantitative systematic review of the information needs of relatives of childhood cancer patients and survivors

PURPOSE

This systematic review aims to:

- 1) summarize the quantitative evidence on the information needs of relatives and close friends of childhood cancer patients and survivors; and
- 2) identify factors associated with these needs.

RESULTS

Of 5810 identified articles, 45 were included. Information needs were classified as unmet, met (satisfied), and unspecified and categorized into five domains: medical information, cancer-related consequences, lifestyle, family, and support. Most unmet information needs concerned cancer-related consequences (e.g., late effects), while information needs on support were generally met. Migration background and higher education were associated with higher information needs among parents. Siblings had lower information needs than parents and their needs decreased only long after diagnosis.

REFERENCE

Sievers, Y., Roser, K., Scheinemann, K., Michel, G., & Ilic, A. [under review]. The information needs of relatives of childhood cancer patients and survivors: A systematic review of quantitative evidence. *Patient Education and Counseling*.

Review 3: Systematic review of the information needs of survivors of CAYA cancers

PURPOSE

This review aims to:

- 1) assess the information needs of adult survivors of childhood, adolescence and young adulthood cancer;
- 2) identify factors associated with these needs; and
- 3) describe any differences in reported needs between different groups of survivors.

RESULTS

This systematic review is ongoing, and the first results will be available in April 2024.

REFERENCE

Bertolini, E., Michel, G., & Ilic, A. (2024). The information needs of adult survivors of childhood, adolescence and young adulthood cancer: A systematic literature review. PROSPERO 2024 CRD42024505031 Available from:

https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42024505031

HUPON APPENDIX 1

PubMed and Embase / Central search strategy (February 8th, 2024)

Date of search: 08-FEB-2024

Original pool: 60,980

After automatic duplicate removal: 50,341

After manual duplicate removal: 47,596

Search keys

PUBMED

("childhood cancer" OR "pediatric cancer" OR "paediatric cancer" OR "child* with cancer" OR "pediatric oncology" OR "paediatric oncology" OR "childhood leukemia" OR "childhood leukaemia" OR "pediatric leukemia" OR "paediatric leukemia" OR "childhood malignan*" OR "pediatric malignan*" OR "paediatric malignan*" OR "childhood tumo*" OR "pediatric tumo*" OR "paediatric tumo*") AND ((**patient*** OR "Patient-reported") AND (**outcomes** OR need OR needs OR requirement OR requirements OR want OR wants OR preference OR preferences OR "information needs" OR "health needs" OR "health concerns" OR prefer* OR motivation* OR expectation* OR attitude* OR experience* OR necessit* OR support* OR "Health Services Needs and Demand"[Mesh] OR "Needs Assessment"[Mesh] OR "Patient Preference"[Mesh] OR "Attitude to Health"[Mesh] OR "Consumer Behavior"[Mesh] OR "Motivation"[Mesh] OR "Delivery of Health Care"[Mesh]))

EMBASE / CENTRAL

('childhood cancer' OR 'pediatric cancer' OR 'paediatric cancer' OR 'child* with cancer' OR 'pediatric oncology' OR 'paediatric oncology' OR 'childhood leukemia' OR 'childhood leukaemia' OR 'pediatric leukemia' OR 'paediatric leukemia' OR 'childhood malignan*' OR 'pediatric malignan*' OR 'paediatric malignan*' OR 'childhood tumo*' OR 'pediatric tumo*' OR 'paediatric tumo*') AND (**patient*** OR 'patient-reported') AND (**outcomes** OR need OR needs OR requirement OR requirements OR want OR

wants OR preference OR preferences OR 'information needs' OR 'health needs' OR 'health concerns'
OR prefer* OR motivation* OR expectation* OR attitude* OR experience* OR necessit* OR support*
OR 'health services needs and demand' OR 'needs assessment' OR 'patient preference' OR 'attitude to
health' OR 'consumer behavior' OR 'motivation' OR 'delivery of health care')

CLB APENDIX 1

PubMed search strategy (April 2nd, 2024)

#1	"adolescent"[MeSH Terms] OR "adolescen*"[All Fields] OR ("young adult"[MeSH Terms] OR ("young"[All Fields] AND "adult"[All Fields]) OR "young adult"[All Fields]) OR "AYA"[All Fields]	2,993,004
#2	"cancer*"[All Fields] OR "neoplasms"[MeSH Terms] OR "neoplas*"[All Fields] OR ("carcinoma"[MeSH Terms] OR "carcinom*"[All Fields]) OR ("sarcoma"[MeSH Terms] OR "sarcom*"[All Fields]) OR ("leukemia"[MeSH Terms] OR "leukem*"[All Fields] OR "leukaem*"[All Fields]) OR ("lymphoma"[MeSH Terms] OR "lymphom*"[All Fields]) OR ("multiple myeloma"[MeSH Terms] OR ("multiple"[All Fields] AND "myeloma"[All Fields]) OR "multiple myelom*"[All Fields] OR "myelom*"[All Fields])	5,333,922
#3	"survivors"[MeSH Terms] OR "survivor*"[All Fields] OR "survivorship"[MeSH Terms] OR ("cancer survivors"[MeSH Terms] OR ("cancer"[All Fields] AND "survivor*"[All Fields]) OR "cancer survivor*"[All Fields]) OR "follow-up"[All Fields] OR ("after"[All Fields] AND ("cancer*"[All Fields] OR "neoplasms"[MeSH Terms] OR "neoplas*"[All Fields])) OR ("aftercare"[MeSH Terms] OR "aftercare"[All Fields] OR ("after"[All Fields] AND "treatment"[All Fields]) OR "after treatment"[All Fields]) OR "post-treatment"[All Fields] OR "off-treatment"[All Fields] OR "post-cancer"[All Fields] OR ("late"[All Fields] AND "effect*"[All Fields]) OR "long-term"[All Fields] OR "remission*"[All Fields] OR "recover*"[All Fields] OR ("rehabilitation"[MeSH Terms] OR "rehabilitat*"[All Fields])	5,855,194
#4	"digital health"[MeSH Terms] OR ("digital"[All Fields] AND "health"[All Fields]) OR "digital health"[All Fields] OR ("digital"[All Fields] AND "health"[All Fields] AND "technology"[All Fields]) OR "digital health technology"[All Fields] OR ("digital"[All Fields] AND "tool"[All Fields] OR ("telemedicine"[MeSH Terms] OR "telemedicine"[All Fields] OR "ehealth"[All Fields]) OR "telehealth"[All Fields] OR "health information technology"[All Fields] OR ("mobile"[All Fields] AND "health"[All Fields]) OR "mobile health"[All Fields] OR "mhealth"[All Fields] OR ("text messaging"[MeSH Terms] OR ("text"[All Fields] AND "messaging"[All Fields]) OR "text messaging"[All Fields]) OR "app"[All Fields] OR ("wearable electronic devices"[MeSH Terms] OR ("wearable"[All Fields] AND "electronic"[All Fields] AND "device*"[All Fields]) OR "wearable electronic device*"[All Fields] OR ("wearable"[All Fields] AND "device*"[All Fields]) OR "wearable device*"[All Fields]) OR "digital"[All Fields] AND "game"[All Fields] OR ("virtual reality"[MeSH Terms] OR ("virtual"[All Fields] AND "reality"[All Fields]) OR "virtual reality"[All Fields]) OR ("robotics"[MeSH Terms] OR "robot*"[All Fields]) OR ("online"[All Fields] AND ("self help groups"[MeSH Terms] OR ("self help"[All Fields] AND "groups"[All Fields]) OR "self help groups"[All Fields] OR ("self"[All Fields] AND "help"[All Fields] AND "group"[All Fields]) OR "self help group"[All Fields])) OR "podcast"[All Fields] OR ("social networking"[MeSH Terms] OR ("social"[All Fields] AND "networking"[All Fields]) OR "social networking"[All Fields] OR ("social"[All Fields] AND "network"[All Fields]) OR "social network"[All Fields]) OR ("social media"[MeSH Terms] OR ("social"[All Fields] AND "media"[All Fields]) OR "social media"[All Fields])	238,499
#5	"quality of life"[MeSH Terms] OR ("quality"[All Fields] AND "life"[All Fields]) OR "quality of life"[All Fields] OR "well being"[All Fields]	677,885
#6	(#1 AND #2 AND #3 AND #4 AND #5)	178
#7	#6 AND (y_10[Filter])	153
#8	#7 AND (english[Filter] OR french[Filter])	152

Literature Review 2: supportive care needs of childhood, adolescent and young adult cancer survivors, a systematic mixed study review

Not for distribution, unpublished

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Keywords: childhood, adolescent and young adult cancer survivors; supportive care needs; unmet needs; follow-up; systematic review; quality of life

ABSTRACT

Problem identification: Supportive care needs (SCN) need to be better identified in childhood, adolescent and young adult (CAYA) cancer survivors.

Literature search: A systematic search was conducted on PubMed, PsycINFO, Cochrane and Science Direct on articles published between 2001 and 2023 exploring CAYA cancer survivors’ SCN. Of the 2,281 articles found, 34 were included.

Data evaluation/synthesis: Descriptive and quality analyses were conducted. SCN regarding medical, psychological, fertility, healthcare system, social and daily life domains were found in survivors. The most frequent SCN found across studies concerned information about late effects and follow-up, mental health counseling, and support regarding survivors’ fertility. Some evidence of an evolution of the type of needs over time was highlighted.

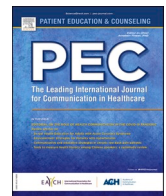
Conclusions: SCN persist long after treatment in CAYA cancer survivors. Further work is required to explore the evolution of SCN throughout survivorship.

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The information needs of relatives of childhood cancer patients and survivors: A systematic review of qualitative evidence

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ABSTRACT

Objectives: To synthesize qualitative research on the information needs of relatives of childhood cancer patients and survivors.

Methods: Systematic searches of PubMed, PsycINFO, CINAHL, and Scopus identified relevant literature. Extracted data were combined using thematic synthesis. Methodological quality was assessed using the JBI critical appraisal tool for qualitative research.

Results: The review included 27 publications, with most research focusing on parents or primary caregivers. Five areas of information needs were identified: treatment, medication, and care; general information about cancer; coping and support; follow-up, late effects, and rehabilitation; and parenting and everyday life. Appropriateness of information depended on health care professionals' aptitude, message characteristics, communication setting, and relatives' personal factors. Preferences for form, sources, and timing for information provision varied.

Conclusion: The review identified information needs, communication barriers, and preferences among caregivers and siblings of childhood cancer patients and survivors, highlighting areas requiring further research and clinical consideration in addressing the identified challenges.

Practice implications: Caregivers and siblings have unique but similar information needs regarding childhood cancer. To ensure that these needs are met, health care professionals could use eHealth and mHealth technologies, assess each family member's knowledge, and create a safe and supportive environment for questions and feedback.

1. Introduction

A cancer diagnosis in children is rare, and families rarely have any information or experience. Every year about 225'000 children are newly diagnosed worldwide [1], and many families are profoundly affected by the disease. A childhood cancer diagnosis disrupts family functioning [2, 3] and can mobilize a support system where people other than immediate family members get involved in the care of the affected child [4]. During this delicate period, parents' responsibilities escalate as they are responsible for decision-making and assume a central role in caring for their child. Furthermore, they strive to preserve everyday family life and be involved in the daily care of their other children [5]. Grandparents

might help their children with material, practical and emotional support to help preserve optimal family functioning [6]. Siblings are also profoundly affected by the disease and are often closely involved in their sibling's care [7]. In addition to the organizational changes caused by the disease, childhood cancer challenges the emotional well-being of the affected families. Especially in the first months after the diagnosis, anxiety, and feelings of uncertainty and fear for the outcomes of the affected child are common among parents [8,9], siblings [10], and grandparents [11]. Those feelings might persist after treatment completion [3,12], as childhood cancer survivors are at an increased risk for cancer recurrence, secondary cancers, and other severe late effects.

Obtaining information may allow for dealing with uncertainty and

Abbreviations: ALL, Acute lymphoblastic leukemia; AML, Acute myeloid leukemia; APL, Acute promyelocytic leukemia; CML, Chronic myeloid leukemia; CNS, Central nervous system; eHealth, Electronic health; HCPs, Health care professionals; mHealth, Mobile health.

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coping with disease [13,14]. In cancer care, providing adequate information to patients has been associated with a lower level of psychological distress throughout the disease and better coping with the illness and its consequences [15]. However, information needs have been reported as the most prevalent among the unmet needs of parents of children with cancer at diagnosis and during treatment [16]. Information needs were also common among parents of survivors, who still desired more information, especially on late effects and follow-up care [17]. Ormandy [18] describes a patient health information need as “[...] a recognition that your knowledge is inadequate to satisfy a goal that you have, within the context/situation that you find yourself at a specific point in the time” (p. 99). In line with this definition, four dimensions are central to the understanding of patient information needs [18]: 1) the purpose the patient has for obtaining information (e.g., take a decision); 2) the specific context in which the person is located (e.g., sociodemographic characteristics); 3) the situation that prompted the need (e.g., a disease diagnosis); and 4) the specific timepoint at which the need arises. For this systematic review, Ormandy’s definition of patients’ information needs [18] will be used to understand relatives’ information needs, as a specific definition for the latter group is not yet available.

The information needs of relatives of adult cancer patients have been summarized in a systematic literature review [19]. Nevertheless, this study did not include relatives of children diagnosed with cancer and relatives of adult childhood cancer survivors. Considering the necessity to understand information needs from the perspective of the involved individuals and in light of their specific circumstances, the current review will focus on qualitative research, which allows for a more comprehensive and in-depth exploration of the context and meaning of participants’ experiences [20]. We aimed to summarize and describe qualitative research on: 1) the self-reported (unmet) information needs of relatives of children who were diagnosed with cancer; 2) their perceived barriers and facilitators to appropriate information acquisition; and 3) their preferences for information provision.

2. Methods

2.1. Protocol and registration

The current review is organized according to the PRISMA statement [21], and its protocol has been registered on the PROSPERO database (Registration number: CRD42022347283).

2.2. Search strategy

We systematically searched peer-reviewed research concerning the information needs of relatives of childhood cancer patients and survivors published until July 25, 2019, in PubMed, PsycINFO, CINAHL, and Scopus. A search update applying the same criteria was conducted on July 19, 2022. Four blocks with several free and thesaurus terms on “childhood”, “cancer”, “family members” and “information needs” were designed for each database (Appendix A). All the databases were searched using their default settings, but to reduce the number of irrelevant results, the “humans” filter was selected when possible. Additionally, a citation search of the reference lists of the included publications was conducted to identify any missed research.

2.3. Inclusion and exclusion criteria

Studies were eligible if they applied qualitative methods to assess relatives’ self-reported information needs related to childhood cancer. Qualitative results from studies applying mixed methods were included if they reported results separately for quantitative and qualitative analyses. To include only the research referring to the contemporary and relevant information setting, studies were excluded where: 1) the focus was not on self-reported information needs of relatives of children who

received a childhood cancer diagnosis according to the International Classification of Childhood Cancer, third edition (ICCC-3) [22] (also excluding studies where children were older than 18 at diagnosis or diagnosed with other diseases, the focus was on other aspects or needs than information, on patients’ or survivors’ own information needs, or not self-reported needs of relatives); 2) only quantitative methods were used to assess and/or analyze information needs; 3) duplicate records; 4) publication was before 2007; 5) the report used languages other than English, German, French, Italian, Spanish, Dutch, Serbo-Croatian, and Romanian; and 6) other reasons (not an empirical research article, information needs assessment was not among the aims of the study, other reviews). Publications applying only quantitative methods and quantitative results of studies applying mixed methods for the analysis of relatives’ information needs will be synthesized in an upcoming separate review.

2.4. Selection of studies and data extraction

All the references identified through the database searches were imported into an EndNote X9 (first search) or EndNote 20 (second search) library, and duplicates were excluded using the automatic function of the software. The references were then imported in an Excel file (first search) or into the Rayyan [23] online software for systematic reviews (second search). Two reviewers (AI and KR, GM, or YS) independently screened titles and abstracts of all potentially relevant publications applying the inclusion and exclusion criteria described in Section 2.3. All the articles that were included by at least one reviewer were subjected to full-text screening. The same two reviewers completed full-text screening applying the same exclusion criteria. Discordance about inclusion was solved through discussion until consensus was reached or by involving a third reviewer.

Descriptive data about the included publications were extracted in an Excel table by the first author (AI) and validated by a second author (GM, KR, or YS). We extracted descriptive data about the study (author (s), title, year, country/countries of data collection, study design, method of data analysis, time point(s) of data collection), the population of interest (kinship or relationship with patient/survivor, sample size, gender) and childhood cancer patients/survivors (sample size, diagnosis). Qualitative results about the outcomes addressed in the current review were coded by the first author (AI). To ensure consistency in the coding and interpretation of data, a second author (YS) independently coded a random sample of 20% of the included publications (n = 6). The two authors discussed the assigned codes and agreed on the coding strategy to be applied to the remaining articles. When the included publications comprised information on individuals other than relatives and extended family members, these were not extracted to keep the current review’s focus on relatives’ personal and self-reported information needs and preferences. Extracted information included participants’ direct quotations and authors’ interpretations of results that were labeled as “results” or “findings” in the original article [24]. Data extraction was facilitated by using the ATLAS.ti 22 software for qualitative research. Two reviewers (AI and YS) independently appraised the methodological quality of all included publications. Interrater reliability was assessed using Cohen’s Kappa, and discordances about scoring criteria were solved through discussion until consensus was reached.

2.5. Quality assessment

The publications’ methodological quality was assessed using the Joanna Briggs Institute JBI Critical appraisal checklist for qualitative research [25], which was described as a coherent instrument to evaluate the validity of qualitative research [26]. The checklist consists of ten items that assess bias in study design, conduct, and analysis. Each item can be evaluated as “yes”, “no”, “unclear” or “not applicable”. The quality appraisal has been used to assess the overall strength of the results. None of the included publications were excluded from the current

review because of their methodological quality.

2.6. Data synthesis

Qualitative data on relatives' information needs have been integrated by the first author (AI) using thematic synthesis [24]. Thematic synthesis is a transparent and systematic method for synthesizing qualitative evidence recommended by Cochrane [27]. The synthesis method comprises three separate stages: 1) free "line-by-line" coding of primary authors' statements and participants' quotes in the result section of the included publications; 2) the grouping of similar "free codes" and the development of data-driven "descriptive themes"; and 3) the interpretation of primary research findings through the development of theory-driven "analytical themes" which include interpretations, explanations, and hypotheses formulated by the review authors [24]. Detailed subgroup analyses were conducted based on the timing of information needs along the cancer continuum (grouped as: diagnosis and active treatment; survivorship; multiple stages), the relationship between relatives and the child with cancer (grouped as: parents/primary caregivers; siblings; mixed kinship), and the World Bank classification of Gross National Income [28] of the country/countries of data collection (grouped as: high-income; upper-middle-income; lower-middle-income; or mixed-income levels). Data synthesis was facilitated by using the ATLAS.ti 22 software for qualitative research.

3. Results

The search identified 5190 records, of which 572 were automatically recognized as duplicates, and 4618 were subjected to title and abstract screening. After title and abstract screening, 184 potentially relevant publications were eligible for full-text screening. One additional publication was identified using citation searching of the reference lists of the included publications that were retrieved through the database searches. The current review included 27 articles reporting the results of

27 studies. For further details on the inclusion process, see Fig. 1.

3.1. Characteristics of included studies

Most included studies applied qualitative methods only (n = 21), and six used mixed methods. Most included studies (n = 20) were conducted in high-income countries, five in upper-middle-income countries, and two in lower-middle-income countries. Two studies included multiple data-collection countries, one of which included two high-income countries, and the other included four countries with different income levels. Participants were mainly parents and other primary caregivers (e.g., grandparents, aunts, adult siblings) whose role was similar to that of parents (n = 24). Hereafter, the term "caregivers" will refer to this group. Two studies addressed siblings' information needs specifically, and one included the perspectives of both parents and siblings. We did not identify any study describing the experiences of grandparents. The majority of included studies focused on information needs during the period of diagnosis and active treatment (n = 17) or survivorship (n = 6), and four studies addressed multiple stages along the cancer continuum, of which one also included bereavement. Most of the publications assessed general information needs (n = 15), but some studies investigated the information needs relating to: late effects, follow-up, and survivorship issues (n = 5); a specific cancer diagnosis (n = 3); specific treatments, care, and their side-effects (n = 3), and genetic testing (n = 1). A minority of the publications addressed specifically unmet information needs [38,42,46,48,50,51,53–55], and only three studies defined information needs [39,43,47]. Detailed characteristics for each included publication are presented in Table 1.

3.2. Data synthesis

Our analysis identified 189 free codes, organized into 22 descriptive themes, encompassing five analytical themes. Further details about the studies reporting different themes and direct quotations (Q) from the

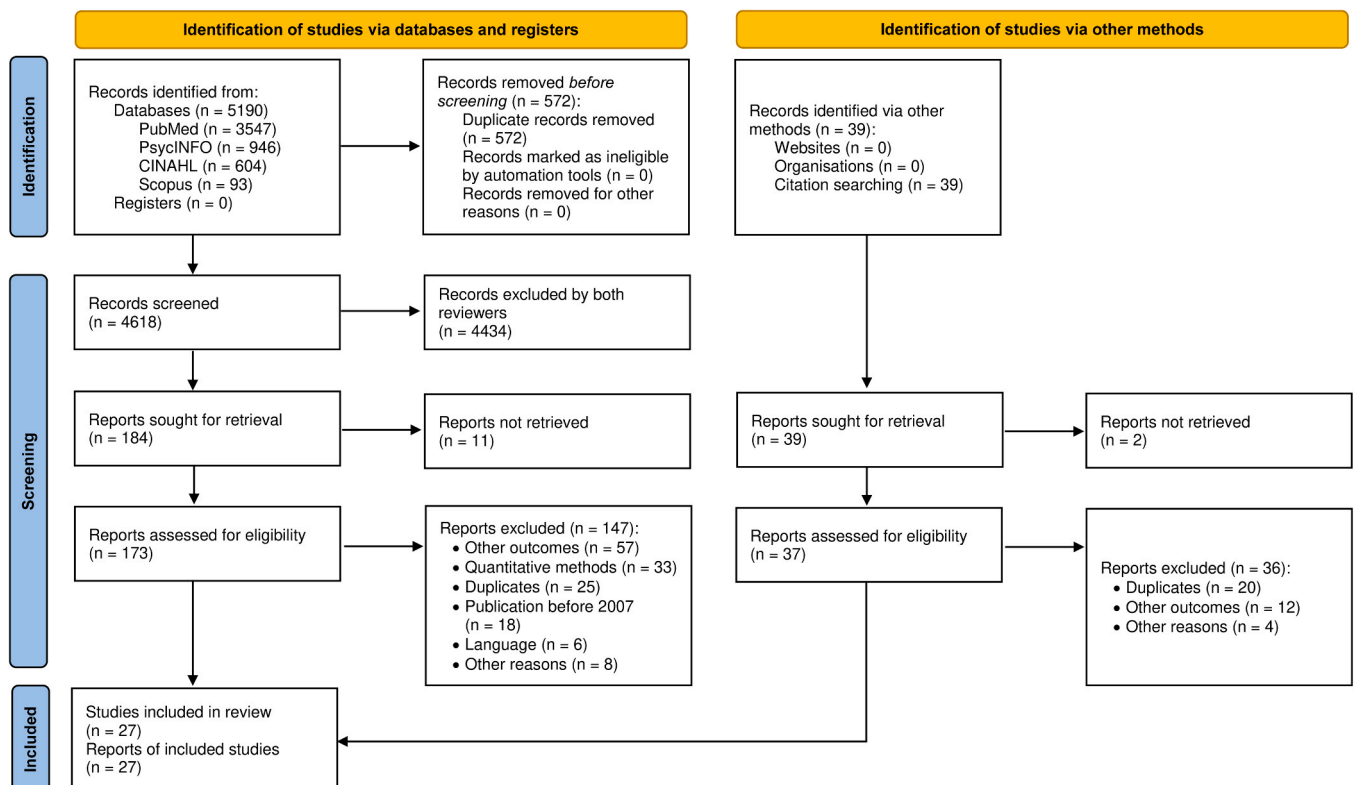


Fig. 1. Overview of the selection process (PRISMA 2020).

Table 1
Characteristics of the included studies.

Frist author, year Country/countries of data collection (World Bank classification)	Title	Area of assessed information needs ^a Timing of information needs along the cancer continuum ^b	Methodology Assessment tool ^c Analysis method ^d	Participants	Childhood cancer diagnoses
Aburn, 2014 [29] New Zealand (High-income)	Education given to parents of children newly diagnosed with acute lymphoblastic leukemia: The parent's perspective	Acute lymphoblastic leukemia Diagnosis and active treatment	Qualitative Semi-structured interviews (n = 12) Grounded theory	Parents: n = 12 Mothers: n = 9	ALL: n = 12
Ahmadnia, 2021 [30] Iran (Lower-middle-income)	Survivor and parent engagement in childhood cancer treatment in Iran	Not specified Active treatment	Qualitative Interviews (n = 4) and focus groups (n = 1; n = 5 parents) Content analysis	Parents: n = 9/10* Mothers: n = 6/7* The study also included survivors (n = 19/20*)	Not reported
Cheng, 2009 [31] Hong Kong (High-income)	Oral mucositis: A phenomenological study of pediatric patients' and their parents' perspectives and experiences	Chemotherapy-induced oral mucositis Active treatment	Qualitative Semi-structured interviews (n = 22) Inductive content analysis	Parents: n = 22 Mothers: n = 20 Fathers: n = 1 Grandmother: n = 1 The study also included patients (n = 22)	ALL: n = 9 Lymphoma: n = 4 Osteosarcoma: n = 7 Others: n = 2
Doulavince Amador, 2018 [32] Brazil (Upper-middle-income)	The strength of information on retinoblastoma for the family of the child	Retinoblastoma Diagnosis and active treatment (outpatient)	Qualitative Semi-structured interviews (n = 10) Qualitative content analysis	Families: n = 10 Mothers: n = 9 Grandmothers: n = 1	Retinoblastoma Unilateral: n = 5 Bilateral: n = 5
Greenzang, 2018 [33] USA (High-income)	Parent perspectives on information about late effects of childhood cancer treatment and their role in initial treatment decision making	Late effects Active treatment	Qualitative Semi-structured interviews (n = 12) Thematic analysis	Parents: n = 12 Female: n = 9	Hematologic malignancy: n = 5 Brain tumor: n = 2 Extracranial solid tumor: n = 5
Hobbie, 2010 [34] USA (High-income)	Identifying the educational needs of parents at the completion of their child's cancer therapy	Not specified Treatment completion and early survivorship	Mixed methods Focus groups (n = 2/3*; n = 10 families) The study also included questionnaires (n = 15) Content analysis	Parents: n = 10 Mothers: n = 7 Fathers: n = 3	ALL AML Hodgkin disease Ewing sarcoma Brain tumor Osteosarcoma Brain tumor
Jackson, 2007 [35] Australia (High-income)	Pediatric brain tumor patients: Their parents' perceptions of the hospital experience	Brain tumors Diagnosis and active treatment	Qualitative Open-ended answers to interview question "How has your experience with the hospital been so far?" at four timepoints (T): T1: diagnosis T2: 6 months after diagnosis T3: 1 year after diagnosis T4: 2 years after diagnosis Thematic analysis	Parents: n = 73 T1: n = 53 T2: n = 41 T3: n = 38 T4: n = 45	Brain tumor
Kästel, 2011 [36] Sweden (High-income)	Parents' views on information in childhood cancer care	Not specified Diagnosis and active treatment	Qualitative Interviews at 5 timepoints during the first year after the diagnosis (n = 40) Content analysis	Relatives: n = 8 Participants changed at each timepoint but included mothers, fathers, or siblings (in substitution of parents) Parents: n = 10	Leukemia Solid tumors
Keats, 2019 [37] Canada (High-income)	After childhood cancer: A qualitative study of family physician, parent/guardian, and survivor information needs and perspectives on long-term follow-up and survivorship care plans	Long-term follow-up and survivorship care plans Survivorship	Qualitative Semi-structured interviews (n = 10) Deductive/inductive content analysis*	The study also included survivors (n = 8) and family physicians (n = 6)	ALL: n = 5 Osteosarcoma: n = 1 Lymphoma: n = 1 Nephroblastoma: n = 1 Germinoma: n = 1 Embryonal rhabdomyosarcoma: n = 1
Kelly, 2018 [38] USA (High-income)	The why behind the questions: Question-asking in parents of children newly diagnosed with cancer - A report from the Children's Oncology Group	Not specified Diagnosis and active treatment	Qualitative Interviews (n = 20) Constant comparative analysis	Parents: n = 20 Mothers: n = 16 Fathers: n = 4	Leukemia: n = 12 Rhabdomyosarcoma: n = 3 Osteosarcoma: n = 2 Ewing sarcoma: n = 1 Non-Hodgkin Lymphoma: n = 1 Wilms' tumor: n = 1

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Table 1 (continued)

Frist author, year Country/countries of data collection (World Bank classification)	Title	Area of assessed information needs ^a Timing of information needs along the cancer continuum ^b	Methodology Assessment tool ^c Analysis method ^d	Participants	Childhood cancer diagnoses
Kerr, 2007 [39] Canada (High-income)	Understanding the supportive care needs of parents of children with cancer: An approach to local needs assessment	Not specified Diagnosis and active treatment	Mixed methods Semi-structured interviews (n = 3) The study also included surveys (n = 15) Content analysis	Parents: n = 3 Mothers: n = 3	No information on the children of the n = 3 interviewed mothers
Kilicarslan-Toruner, 2013 [40] Turkey (Upper-middle-income)	Information-seeking behaviours and decision-making process of parents of children with cancer	Not specified Diagnosis and active treatment	Qualitative Semi-structured interviews (n = 15) Inductive content analysis	Parents: n = 15 Mothers: n = 13 Fathers: n = 2	ALL: n = 6 Neuroblastoma: n = 4 Wilms' tumor: n = 2 Non-Hodgkin lymphoma: n = 1 CML: n = 1 Rhabdomyosarcoma: n = 1 Not reported
Lövgren, 2016 [41] Sweden (High-income)	Bereaved siblings' advice to health care professionals working with children with cancer and their families	Not specified Multiple stages, including end-of-life care and bereavement	Qualitative Open-ended answers (n = 108) survey question "What advice would you give to HCPs working with children with cancer and their siblings?" Content analysis	Siblings: n = 108 Female: n = 69 Male: n = 39	Not reported
Lyu, 2019 [42] China (Upper-middle-income)	Unmet family needs concerning healthcare services in the setting of childhood hospitalization for cancer treatment in Mainland China: A qualitative study	Not specified Active treatment (hospitalization)	Qualitative Semi-structured interviews (n = 19) Inductive content analysis	Parents: n = 19 Mothers: n = 14 Fathers: n = 5	ALL: n = 16 Malignant lymphoma: n = 1 Neuroblastoma: n = 1 Malignant rhabdomyoma: n = 1
Maree, 2016 [43] South Africa (Upper-middle-income)	The information needs of South African parents of children with cancer	Not specified Active treatment	Qualitative Interviews (n = 13) and one follow-up interview (for purpose of clarification) Inductive thematic analysis	Parents: n = 12/13* Mothers: n = 8 Fathers: n = 2 Grandmother: n = 1 Aunt: n = 1	Leukemia: n = 7 Kidney cancer: n = 4 Optic nerve glioma: n = 1
Masika, 2020 [44] Tanzania (Lower-middle-income)	Concerns and needs of support among guardians of children on cancer treatment in Dar es Salaam: A qualitative study	Not specified Diagnosis and active treatment	Qualitative Focus groups (n = 3; n = 22 guardians) Thematic content analysis	Guardians (parents, grandparents, uncles and aunts, other persons who live and provide care for the child): n = 22 Female: n = 15 Male: n = 7	Leukemia: n = 5 Eye cancer: n = 5 Cancer of the glands: n = 5 Kidney cancer: n = 2 Stomach cancer: n = 1 Thyroid cancer: n = 1 Liver cancer: n = 1 Not reported
McCann, 2019 [45] El Salvador (Lower-middle-income), Guatemala (Upper-middle-income), Mexico (Upper-middle-income) and Panama (High-income)	Identifying and prioritizing family education needs at pediatric oncology centers in Central America and Mexico	Not specified Diagnosis and active treatment	Qualitative Semi-structured interviews (n = 71, including all participants) and focus groups (n = 4, including all participants). Separate data for families only were not available. Thematic analysis	Families (mothers, fathers, adult siblings, grandparents): n = 28 The study also included HCPs (n = 52) and communication professionals (n = 11)	Not reported
Patterson, 2011 [46] Australia (High-income)	The development of an instrument to assess the unmet needs of young people who have a sibling with cancer: Piloting the Sibling Cancer Needs Instrument (SCNI)	Not specified Multiple stages	Mixed methods Focus group (n = 1; n = 4 siblings) and telephone interviews (n = 7) The study also included a staff survey (n = 26) and a survey with siblings (n = 71) Thematic analysis and triangulation	Siblings: n = 11 Female: n = 5 The study also included staff (n = 26)	Bone/muscle: n = 4 Brain: n = 3 Lymphoma: n = 1 Leukemia: n = 1 Hodgkin's: n = 1 Non-Hodgkin's: n = 1
Ringnér, 2011 [47] Sweden (High-income)	Parental experiences of information within pediatric oncology	Not specified Multiple stages	Qualitative Focus groups (n = 4; n = 14 parents) and individual interviews	Parents of n = 11 children: n = 14 Mothers: n = 10 Fathers: n = 4	Leukemia: n = 5 Brain tumor: n = 2 Solid tumor: n = 4

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Table 1 (continued)

Frist author, year Country/countries of data collection (World Bank classification)	Title	Area of assessed information needs ^a Timing of information needs along the cancer continuum ^b	Methodology Assessment tool ^c Analysis method ^d	Participants	Childhood cancer diagnoses
Rodgers, 2016 [48] USA (High-income)	Processing information after a child's cancer diagnosis - how parents learn: A report from the Children's Oncology Group	Not specified Diagnosis and active treatment	(n = 4) Qualitative content analysis Qualitative Semi-structured interviews (n = 20) Constant comparative analysis	Parents: n = 20 Mothers: n = 16 Fathers: n = 4"	ALL: n = 10 AML: n = 1 APL: n = 1 Non-Hodgkin lymphoma: n = 1 Rhabdomyosarcoma: n = 3 Osteosarcoma: n = 2 Ewing sarcoma: n = 1 Wilms' tumor: n = 1 No information on the children of the n = 7 interviewed parents
Schaefer, 2022 [49] USA (High-income)	"Giving the gift of life twice": Understanding the lived experiences of parent donors and nondonors in pediatric haploidentical hematopoietic cell transplantation	Hematopoietic cell transplantation Active treatment (donation and transplant)	Qualitative Interviews (n = 7; with the purpose to inform the development of the questionnaire) and questionnaires with open-ended questions (n = 136) Framework method	Parents: n = 136 Mothers: n = 88 Fathers: n = 44 Other: n = 4 No information on the n = 7 interviewed parents	CNS tumor: n = 15
Schuele, 2019 [50] USA (High-income)	Information needs regarding cognitive late effects of caregivers of central nervous system tumor survivors	Cognitive late effects Survivorship	Qualitative Semi-structured interviews (n = 15) The study also included interviews with HCPs (n = 8) Grounded theory	Families/caregivers: n = 15 Female: n = 14 Male: n = 1 The study also included HCPs (n = 8)	Not reported: n = 22
Stub, 2021 [51] Norway (High-income)	Communication and information needs about complementary and alternative medicine: A qualitative study of parents of children with cancer	Complementary and alternative medicine Active treatment	Qualitative Semi-structured interviews (n = 22) Not specified	Parents of n = 22 children: n = 24 Female: n = 20 Male: n = 4	ALL: n = 3 AML: n = 2 Osteosarcoma: n = 2 Pontine glioma: n = 2 Hepatoblastoma: n = 1 Neuroblastoma: n = 1 Germ cell tumor: n = 1 Lymphoma: n = 1 No information specific to the children of the n = 31 interviewed parents
Tan, 2022 [52] Malaysia (Upper-middle-income)	Information needs of Malaysian parents of children with cancer: A qualitative study	Not specified Multiple stages	Qualitative Semi-structured interviews (n = 13) Thematic analysis using elements of Grounded theory	Parents of n = 13 children: n = 14 Mothers: n = 9 Fathers: n = 5 This study also included HCPs (n = 8)	ALL: n = 3 AML: n = 2 Osteosarcoma: n = 2 Pontine glioma: n = 2 Hepatoblastoma: n = 1 Neuroblastoma: n = 1 Germ cell tumor: n = 1 Lymphoma: n = 1 No information specific to the children of the n = 35 interviewed parents
Vetsch, 2017 [53] Australia (High-income)	"Forewarned and forearmed": Long-term childhood cancer survivors' and parents' information needs and implications for survivorship models of care	Late effects Survivorship	Mixed methods Semi-structured interviews (n = 31) This study also included self-administered questionnaires with parents (n = 163) and survivors (n = 322) Content analysis supplemented with the methodology described by Miles and Huberman (1994)	Parents: n = 31 A subsample of parents who responded to the questionnaire were interviewed. Separate data on interview participants were not provided. This study also included survivors (n = 39 were interviewed; n = 322 responded to the questionnaire)	No information specific to the children of the n = 35 interviewed parents
Vetsch, 2020 [54] Australia (High-income) and New Zealand (High-income)	Genetics-related service and information needs of childhood cancer survivors and parents: A mixed-methods study	Genetics Survivorship	Mixed methods Interviews (n = 35) This study also included questionnaires with parents (n = 218) and survivors (n = 404) Qualitative thematic analysis	Parents: n = 35 A subsample of parents who responded to the questionnaire were interviewed. Separate data on interview participants were not provided. This study also included survivors (n = 52 were interviewed; n = 404 responded to the questionnaire).	No information specific to the children of the n = 35 interviewed parents

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Table 1 (continued)

Frist author, year Country/countries of data collection (World Bank classification)	Title	Area of assessed information needs ^a Timing of information needs along the cancer continuum ^b	Methodology Assessment tool ^c Analysis method ^c	Participants	Childhood cancer diagnoses
Wakefield, 2012 [55] Australia (High-income)	Family information needs at childhood cancer treatment completion	Transition after treatment Early survivorship	Mixed methods Semi-structured telephone interviews assessing both quantitative and qualitative data Inductive coding applying the framework of Miles and Huberman (1994)	Parents: n = 78 Mothers: n = 44 Fathers: n = 34 Siblings: n = 15 This study also included survivors (n = 19)	No information specific to the children of the interviewed n = 78 parents and n = 15 siblings

Notes:

All information as stated in the original manuscript.

Abbreviations: ALL, Acute lymphoblastic leukemia; AML, Acute myeloid leukemia; APL, Acute promyelocytic leukemia; CML, Chronic myeloid leukemia; CNS, Central nervous system; HCPs, Health care professionals.

^a Some studies addressed information needs in a specific area, while other studies addressed information needs in general without restricting to a specific area.

^b Some studies assessed information needs retrospectively and the timing along the cancer continuum might not correspond to the children's disease stage at the time of the study.

^c Unless specified differently, this only refers to qualitative data assessed in the study.

* Inconsistent information throughout the manuscript

included studies are summarized in Table 2. In the results section, we indicated example quotes from Table 2 that support the claims.

3.2.1. Relatives' information needs

3.2.1.1. Treatment, medications and care. The majority of publications described relatives' information needs about treatment, medications and care. These needs were especially prominent in the studies addressing needs earlier along the cancer continuum, among caregivers and siblings, and studies conducted in high- and upper-middle-income countries. Specific areas included information about current treatment and different treatment options [30,32,35,37,39–44,46,48–50,52,55], their side effects (Q1) [31,35,38,40,42,44,46,48,52], alternative medicine [51], and information about caring for the child at home [29,31,33,34,36,38,40,42,45,48,51,52]. Caregivers described that this information helps them better prepare to support the child (Q2) and relieve their suffering (Q1).

3.2.1.2. General information about cancer. Another area where relatives reported high information needs concerns general information about cancer, such as causes [43–45,52,55], characteristics [29,30,32,35,39–44,46,48,50–52,55], and early symptoms of cancer [32,44,52], prognosis and survival chances [32,35,39–43,45,46,52], and risks of cancer development for other family members (Q3) [54,55]. This need was common among all relatives and along the entire cancer continuum. While participants from studies conducted in high- and upper-middle-income countries reported desiring disease-specific information about cancer, those from studies conducted in lower-middle-income countries reported desiring information about the causes of cancer, their responsibility (Q4), and mortality. For instance, caregivers recognized that their lack of education about cancer might influence their child's health outcomes and felt guilty for their child's disease. Similarly, siblings described the desire to get more information on what has caused their sibling's cancer, prognosis, recovery chances, and their own risk of developing the disease.

3.2.1.3. Coping and support. Participants further reported information needs concerning coping and support. Coping and support refer to information about practical [34,35,38,42,45,52,55] and emotional [38,40,45,46,48,51,52,55] support services available for families of children

with cancer (Q5). This information was especially reported by caregivers from studies conducted in high- and upper-middle-income countries and was important for them to better organize and cope with future challenges. Information needs about coping and support were reported along the entire cancer continuum. Many participants from studies conducted in upper-middle-income countries described the need for practical support as opposed to psychological support (Q6).

3.2.1.4. Follow-up, late effects and rehabilitation. Information about follow-up [37,48,52], rehabilitation after cancer care [46], and late effects [32–35,37,39,40,42,43,50,51,53,55] was common in the studies assessing information needs after cancer treatment completion, among caregivers, and studies conducted in high-income countries, but was not reported in studies conducted in lower-middle-income countries. Participants desired information about late effects in general [32,34,35,43,50], or specifically on mental and physical health [32,33,37,39,40,51,53], including fertility [53,55], surveillance plans and how to prevent and recognize a possible cancer recurrence [34,42,43], which was essential for them to prepare for future challenges (Q7 and Q8).

3.2.1.5. Parenting and everyday life. Participating caregivers mentioned having information needs about parenting children with cancer [34,40,42,43,49,52] and their siblings (Q9) [43,45] and everyday life changes (Q10) [37,38,45,48,51,52]. Information needs in this area were especially mentioned during treatment and in the studies conducted in high- and upper-middle-income countries.

3.2.2. Barriers and facilitators to appropriate information acquisition

3.2.2.1. Aptitude of HCPs. The aptitude of health care professionals (HCPs) was described as an important feature that might facilitate (Q11) or impede (Q12) appropriate information acquisition among relatives. HCPs' aptitude includes their availability to interact with relatives [29,30,32,35,36,38,40,42,47,48], encourage and answer their questions [29,36,38,40,47,48,54], provide accurate and clear explanations [29,30,35,36,38,41,42,47,48], repeat information [31,34,37–39,47,48], and personal traits such as patience [36,38,47,48], sensitivity [30,36,47,51], expertise [35], honesty [32,35,42,47], and empathy [30,31,35,36,40,47,48]. The aptitude of HCPs was mentioned as an important factor in all studies.

Table 2
Overview of descriptive and analytical themes.

Aim	Analytical themes	Descriptive themes	Example quotation	References
1	Information needs (area)	Treatment, medications and care	Quotation (Q)1: "I needed the doctor to explain to us what it's like to have OM [oral mucositis], the severity of it, and the extent of oral ulceration, how serious it was. It'd reassure me" (Parent, p. 834) [31] Q2: "I feel sad when my child does not want to eat. I do not know how to feed her, and I often need information about her nutrition." (Parent, p. 180) [40]	[29–46, 48–52,55]
		General information about cancer	Q3: "...[I don't know] if potentially future generations can have - like if my grandchildren are going to have yolk sac tumours." (Mother, p. 12) [54] Q4: "Did I do something wrong? I had never left my children without food, I always tried to keep our home clean." (Mother, p. 4) [45]	[29,30,32, 35,39–46, 48,50–52, 54,55]
	Coping and support		Q5: "Finally, one of the most important educational themes echoed by parents and the health care team was the emphasis on psychosocial education, from family support (including parents and siblings) to stress relief and relaxation." (Authors, p. 5) [45] Q6: "Information on how to obtain practical support needs are needed to assist parents in balancing these other responsibilities with caregiving for their sick child. This may include childcare for siblings, financial aid for medical and living costs, arrangements for leave from work, and temporary accommodations for those staying far from the treatment centers." (Authors, p. 146) [52]	[34,35,38, 40,42,45, 46,48,51, 52,55]
		Follow-up, late effects and rehabilitation	Q7: "I wanna know what's gonna happen... What are we really facing down the road? What is her life really gonna be like?" (Parent, p. 2) [33] Q8: "I think that information [about late effects] and knowledge is always useful; knowing when not to have to panic or being prepared	[32–35,37, 39,40,42, 43,46,48, 50–53,55]

Table 2 (continued)

Aim	Analytical themes	Descriptive themes	Example quotation	References
2	Barriers and facilitators	Parenting and everyday life	if something does happen. You can say, well yeah I knew that might have been a risk. You're sort of almost prepared for it – forewarned and forearmed." (Parent, p. 359) [53] Q9: "Furthermore, many of the children had siblings who also needed their parents to explain the situation concerning their brother or sister. Many parents wanted guidance on how to approach the topic." (Authors, p. 14) [43] Q10: "What am I supposed to do about work? How am I supposed to go to work when she can't go to daycare? You know, who is going to take care of her?" (Mother, p. 25) [38]	[34,37,38, 40,42,43, 45,48,49, 51,52]
		Aptitude of HCPs	Q11: "The experience and sensitive ear from the informant seems quite vital, including the capacity to read the families and to individualize the information." (Authors, p. 293) [36] Q12: "If we asked questions to the resident, then they would usually say that the information was in our folder and we should read about it. So, it kind of puts you off about asking questions to them" (Mother, p. 27) [38]	[29–32, 34–42,47, 48,51,54]
		Message	Q13: "The doctor should be transparent and clear in announcing the illness. We usually do not understand what doctors say [medical jargon]. A doctor should talk to us in simple words according to and based on our level of knowledge and understanding." (Parent, p. 5) [30] Q14: "Some parents also expressed that it would be helpful to understand how the combination of therapies impacted their child's likelihood of late effects, instead of learning separately about the late effects associated with each individual treatment or chemotherapeutic." (Authors, p. 3) [33] Q15: "Several also voiced wanting resources	[29,30, 32–43, 46–48, 50–55]

(continued on next page)

Table 2 (continued)

Aim	Analytical themes	Descriptive themes	Example quotation	References
3	Preferred form of information	Setting	to be available on an “as-needed” basis.” (Authors, p. 163) [50] Q16: “Some parents wanted time to connect with team members before they felt comfortable asking questions [...]” (Authors, p. 24) [38] Q17: “Siblings felt that information should be given [...] both with and without their parents being present.” (Authors, p. 300) [41]	[30,35,36,38–41,47,48]
		Receiver’s personal factors	Q18: “. . . it’s like the lady [physician] was saying it. but I couldn’t hear it.” (Parent, p. 456) [48] Q19: “We believed that we shouldn’t bother doctors and not to cause them headaches. My wife and I believed in and had faith in our doctor. We accepted whatever he told us because he had graduated and was an expert in this field so we trusted him” (Father, p. 4) [30]	[29,30,35–40,45–48,50,51]
		Written (printed or online)	Q20: “An online resource might be nice because then you could look whenever you happen to think that you don’t remember what the plan is. [...] I think that would take the anxiety level down a little bit.” (Caregiver, p. 163) [50] Q21: “Parents described having information available in their educational materials when questions arose as reassuring, “It kind of helped control some of that [uncertainty]” [...]” (Authors and mother, p. 25) [38]	[29,30,33,36–40,43,47,48,50,51,54]
		Verbal	Q22: “It would be great to talk to the person who is dealing exactly with your child’s problem” (Mother, p. 91) [32] Q23: “They also wanted scheduled follow-up information meetings with the physician, where they could sit down and look at the treatment schedule together, and regular contact with HCPs while the child was back at home.” (Authors, p. 248) [47]	[29,32,39,47,54]
		Phone*	Q24: “Sometimes there is not enough time at the outpatient department, and certain information	[36]

Table 2 (continued)

Aim	Analytical themes	Descriptive themes	Example quotation	References
3	Preferred source of information	Activities and workshops	has to be given by phone. This particular situation is very unsatisfactory to the families. The experience of being listened to and confirmed became most important. “Information by phone - how serious is this? We become more and more critical and observant.” [...]” (Authors and father, p. 292) [36] Q25: “Siblings also suggested that activities could be used while talking about difficult things, rather than just sitting down and talking.” (Authors, p. 300) [41]	[41,47,54]
		Combination	Q26: “Other parents felt a combination of written and spoken information was beneficial. One said: They gave us a booklet. I had gone through the booklet myself that you know to check you know certain things that I, that weren’t really making any sense. And I highlighted those things and when she (the professor) came around I asked her based on what I saw from the. (booklet).” (Authors and parent, p. 14) [43]	[43,47,54]
		HCPs	Q27: “The nurse often has an interpreting function, is often under less stress and can confront the physicians in order to get details.” (Authors, p. 293) [36] Q28: “The parents missed meeting a primary nurse and physician responsible for informing them, which contributed to their perceived need be on guard.” (Authors, p. 248) [47]	[29,31,32,36,38,40,41,46–48,51,52]
		Integrated information system	Q29: “They wanted the company of someone in the healthcare centre just to guide them step by step in every phase.” (Authors, p. 7) [30]	[30]
		Societies and associations	Q30: “[...] wished for controlled, scientific information about CAM [complementary and alternative medicine] preferably from the Children’s Cancer Society [...]” (Parents, p. 8) [51]	[29,51]
		Other parents and internet**	Q31: “Other families’ own experiences of caring for an ill child, their knowledge of how	[29,30,38,40,47,52]

(continued on next page)

Table 2 (continued)

Aim	Analytical themes	Descriptive themes	Example quotation	References
			to manage at home, and their real-world example were often more useful than the more sweeping, abstract descriptions obtained from the HCPs.” (Authors, p. 247) [47] Q32: “Additionally, parents sought information on their own if they felt that there was other information out there, “Well I asked questions and if I didn’t like what I had to hear I would Google it” [...]” (Authors and father, p. 25) [38]	
Preferred timing of information	Continuity		Q33: “Having good continuity of HCPs was also a part of feeling safe and secure.” (Authors, p. 247) [47] Q34: “Why in the world would you want to know- hear about the effects after you’ve already started or if you’re done. I’d wanna know... what we’re getting into before we get into it.” (Parent, p. 3) [33] Q35: “Most spoke about the need for information at the time of the diagnosis. One parent commented, “When my child was diagnosed it would have been best to sit down with someone and take some time and say okay, here was where it was located and here is the danger.” [...]” (Authors and parent, p. 288) [39]	[36,37,41, 43,47,48]
		Before treatment completion	Q36: “Although parents stated they needed information before or at the end of therapy about discerning symptoms, more specific risk factors (eg, late effects of therapy) may need to be delayed because of their desire to establish a new normal within their lives before dealing with late effects of therapy.” (Authors, p. 193) [34] Q37: “Statements made by the parents indicated that the need for information did not end after the child’s treatment had finished.” (Authors, p. 288) [39]	[30,33,34, 39,50,52]
	After treatment completion	Q38: “The parents emphasized that their needs for information did not decrease as time passed—on the contrary, after some time new and	[33,34,39, 47]	
		Critical periods		[47]

Table 2 (continued)

Aim	Analytical themes	Descriptive themes	Example quotation	References
			recurring questions left them needing more information. This was especially the case in later phases of the treatment, when the families sporadically visited the ward or the patient only got radiotherapy a few minutes each day.” (Authors, p. 248) [47]	

Notes:

Abbreviations: HCPs, Health care professionals; Q, Quotation.

* Reported as not preferred.

** Reported as preferred mainly when other more knowledgeable information sources are not available.

3.2.2.2. *Message.* Participants reported a preference for structured information [36–38,47,48,52] that is provided without the use of medical jargon (Q13) [29,30,36,38,41,42,48,53,55]. Despite the need for simple messages, they further recognized the need for reliable and precise [35, 37,40,42,43,47,48,50], research-based [51], and up-to-date [29] information. A further aspect that emerged, especially among participants from studies conducted in high-income countries, concerned the preference for individualized information, which is in line with relatives’ cultural values and native language [36,43], relevant to their specific situation (Q14) [29,33,34,36,37,50,51,55], and provided in the requested amount and when needed (Q15) [29,30,32,33,35,36,39,41, 47,48,50,53,54]. Siblings added that HCPs should consider that they might have different information needs than their parents [41] and need different explanations that are in line with their age [46] and the information provided to other family members [41].

3.2.2.3. *Setting.* A calm setting [47,48], establishing a good relationship with HCPs [30,35,36,38,40,47], and their physical presence [35, 36,38,40,47,48], facilitated building a relationship of trust and feeling comfortable with HCPs (Q16). The passage of time had a dual effect on caregivers. First, caregivers gained experience and became familiar with HCPs [38,40]. Conversely, it made new informational needs arise and increased difficulty persisting with questions [36,47]. Similarly, caregivers reported that the presence of other family members has a dual effect on appropriate information acquisition. They recognized that the presence of third parties reassures them that they will not miss any important piece of information [38,39]. However, other family members can also move the focus of the discussion to other aspects that are not directly relevant to caregivers [38]. Furthermore, caregivers have described their sick child’s presence as a limitation due to their desire to protect them from unpleasant information [39,47]. Similarly, siblings reported the desire to sometimes talk with HCPs without their parents being present (Q17) [41].

3.2.2.4. *Receiver’s personal factors.* A major theme that emerged among caregivers from studies conducted in high-income countries was their emotional burden shortly after the diagnosis [35,36,38,40,45,47,48, 51], when relatives recognized the inability to process any further information (Q18). They also mentioned that they receive most of the information at this time, and some caregivers reported feeling over-informed [29,35,36,38,48,50]. Participants, especially caregivers from studies conducted in high-income countries, reported that pre-existing knowledge affects further information acquisition [36,38, 48]. Some described not knowing enough to ask questions, but at the same time, they recognized that gaining knowledge helped them to ask more precise questions. Contrarily, the desire to avoid disagreement or

pressing HCPs with questions [30,36,47] were factors hindering question-asking (Q19) or were perceived to improve the quality of care received by the child. Positive feelings facilitating information acquisition included establishing a good relationship with HCPs that fostered reciprocity [35,47,48], feeling listened to and taken seriously [30,39,40,51], or being empowered and involved in important discussions [29,37,46].

3.2.3. Preferred form of information

The preferred form of information entails aspects of the channel used to deliver information. Studies conducted in lower-middle-income countries reported limited results on the preferred form of information among relatives.

3.2.3.1. Written (printed or online). Caregivers reported preferring receiving information in a written form, either paper-based (especially at diagnosis and active treatment) [29,30,33,36,39,43,47,48,51,54] or online (especially at survivorship; Q20) [37,50,51,54]. When information was available online, participants preferred online resources approved by their physicians [29,50,51]. Written resources allowed them to access the needed information at any time in specific situations [29,38,40] and helped them cope with emotional distress (Q21).

3.2.3.2. Verbal. Verbal information involves formal meetings with HCPs, which allow for remaining updated on the development of the disease and treatment, and clarifying any doubts (Q22 and Q23) [29,32,39,47,54]. Preferences for verbal information were reported mainly among caregivers. However, receiving information on the phone was not desirable among this group (Q24) [36].

3.2.3.3. Activities and workshops. Some participants reported that seminars and activities could be effective resources for getting information about cancer [41,47,54]. This preference was prevalent among siblings (Q25).

3.2.3.4. Combination. Some caregivers also mentioned a combination of different forms of information as the best way to obtain information (Q26) [43,47,54]. No studies reporting on siblings or from studies conducted in lower-middle-income countries have described this preference.

3.2.4. Preferred source of information

We have only found evidence on the preferred sources of information for other times than survivorship. Regarding the preferred sources of siblings, there was only limited evidence.

3.2.4.1. HCPs. The preferred sources participants mentioned were HCPs, mainly physicians and nurses (Q27 and Q28) [29,31,32,36,38,40,41,46–48,51,52]. Participants appreciated receiving information directly from the physician caring for the child but recognized this was often challenging because of time constraints. Therefore, they reported that nurses were essential in clarifying and directing their questions to the physician whenever they could not answer themselves (Q27).

3.2.4.2. Integrated information system. Among caregivers from studies conducted in lower-middle-income countries, some have also mentioned the need for an integrated information system and a reference person to guide them throughout the cancer journey (Q29) [30].

3.2.4.3. Societies and associations. A few studies conducted among caregivers from high-income countries mentioned external cancer societies or foundations as a valuable source of general information about cancer or complementary and alternative medicine at the time of cancer treatment (Q30) [29,51].

3.2.4.4. Other parents and internet. Some caregivers have mentioned other parents (Q31) [29,30,40,47,52] and self-identified internet web-pages (Q32) [30,38,40,47] as possible sources of information. They recognized the possibility of not receiving accurate information about their situation, but these two sources were helpful for participants when information was not provided by more knowledgeable sources. Other parents were also described as an important source for experience-based information, sometimes valued better than explanations provided by HCPs (Q31) [30,47,52].

3.2.5. Preferred timing of information

Participants, including especially caregivers, reported preferences for continuity (Q33) [36,37,41,43,47,48] in information provision along the entire cancer continuum, from diagnosis (Q34 and Q35) [30,33,34,39,50,52] to after treatment completion (Q36 and Q37) [33,34,39,47]. Some participants described these milestones as critical periods when they would have needed information but felt abandoned by HCPs (Q38) [47].

3.3. Quality appraisal

The results of the quality assessment are available in Table 3. The two reviewers agreed on 93% of the assigned scores, with Cohen's Kappa indicating substantial agreement ($k = 0.757$) [56]. The included publications showed an overall good methodological quality (mean number of "yes": 8.2; SD 1.2, range: 5–10).

4. Discussion and conclusion

4.1. Discussion

This review identified areas where relatives report diverse information needs, common barriers and facilitators to appropriate information acquisition, and preferences about form, source, and timing for information provision. Our results are based on a thematic synthesis of 27 publications reporting qualitative results of primary studies on relatives' information needs. Most publications focused exclusively on parents and other primary caregivers ($n = 24$) and high-income countries ($n = 20$). Only two studies addressed specifically siblings' information needs, and both were conducted in high-income countries. We have not identified any publication addressing grandparents' information needs or conducted in low-income countries. Five major information needs areas were: treatment, medication, and care; general information about cancer; coping and support; follow-up, late effects, and rehabilitation; and parenting and everyday life. We found that unmet information needs only occasionally are due to a lack of information provision from the HCPs. Instead, they result from a failure in the process of information acquisition. Our review showed that appropriate information acquisition is best reached when relatives perceive a favorable aptitude of HCPs, the message is simple, reliable, and tailored to their specific situation, the communication occurs in the desired setting, and when they feel to have established a satisfactory mutual relationship with HCPs. Relatives' self-reported preferences for information provision were described in terms of form, sources, and timing.

Caregivers mentioned a broad range of information needs, encompassing all five identified areas. Nevertheless, some differences were observed among caregivers from high- and upper-middle-income countries and caregivers from lower-middle-income countries. While caregivers from high- and upper-middle-income countries described information needs about their child's specific condition, caregivers from lower-middle-income countries reported desiring additional information, especially on the causes of the disease, their responsibility, and mortality risks. Information needs about coping and support, follow-up, late effects, and rehabilitation, and parenting and everyday life have mainly been observed among caregivers from high- and upper-middle-income countries. These differences may be due to the cultural and

Table 3

Results of the quality appraisal of included publications according to the JBI critical appraisal checklist for qualitative research.

First author, year	1	2	3	4	5	6	7	8	9	10	No. yes
Aburn, 2014 [29]	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	No	Yes	8
Ahmadnia, 2021 [30]	Yes	Unclear	Yes	Yes	Yes	Unclear	Unclear	Yes	No	Yes	6
Cheng, 2009 [31]	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	9
Doulavince Amador, 2018 [32]	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8
Greenzang, 2018 [33]	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	9
Hobbie, 2010 [34]	Unclear	Yes	Yes	Unclear	Yes	Unclear	No	No	Yes	Yes	5
Jackson, 2007 [35]	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8
Kästel, 2011 [36]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Keats, 2019 [37]	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	8
Kelly, 2018 [38]	Yes	Yes	Unclear	Yes	Yes	No	Yes	Yes	Yes	Yes	8
Kerr, 2007 [39]	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	8
Kilicarslan-Toruner, 2013 [40]	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	8
Lövgren, 2016 [41]	Unclear	Yes	Unclear	Yes	Yes	No	Yes	Yes	Yes	Yes	7
Lyu, 2019 [42]	Yes	Yes	Yes	Unclear	Yes	No	Yes	Yes	Yes	Yes	8
Maree, 2016 [43]	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	9
Masika, 2020 [44]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
McCann, 2019 [45]	Yes	Unclear	Yes	Unclear	Yes	No	No	Yes	Yes	Yes	6
Patterson, 2011 [46]	Yes	Yes	Yes	Yes	Yes	No	Unclear	No	Yes	Yes	7
Ringné, 2011 [47]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Rodgers, 2016 [48]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Schaefer, 2022 [49]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Schuele, 2019 [50]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Stub, 2021 [51]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9
Tan, 2022 [52]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Vetsch, 2017 [53]	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9
Vetsch, 2020 [54]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
Wakefield, 2012 [55]	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Yes	Yes	8

Notes:

- 1) Congruity between stated philosophical perspective and research methodology.
- 2) Congruity between research methodology and the research question or objectives.
- 3) Congruity between the research methodology and the methods used to collect data.
- 4) Congruity between the research methodology and the representation and analysis of data.
- 5) Congruity between the research methodology and the interpretation of results.
- 6) Is there a statement locating the researcher culturally or theoretically?
- 7) Is the influence of the researcher on the research, and vice-versa, addressed?
- 8) Are participants, and their voices, adequately represented?
- 9) Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
- 10) Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

societal stigma associated with childhood cancer in some lower-middle-income countries and misconceptions about its causes and treatments [57]. Differences were also observed regarding barriers and facilitators to appropriate information acquisition among different country income levels. We found caregivers from high- and upper-middle-income countries to report receiving more information than they could process. This can lead to a situation where caregivers feel overwhelmed by the amount of information they have to process and interpret, especially at the initial stage of the disease when they also experience intense emotional distress [58]. Our results showed that in lower-middle-income countries, caregivers were likely to rely on HCPs for information and guidance and were intimidated by the prospect of asking questions or seeking clarifications [57]. Regulations and uses on information provision to the parents of children with cancer may vary by country, with stricter regulations applied in high-income countries. Additionally, in lower-middle-income countries, the healthcare system may be less developed, and caregivers may have limited access to medical information and resources. In these contexts, caregivers may be less likely to ask questions or seek additional information out of respect for HCPs, or fear of appearing distrustful or demanding [57]. Caregivers reported a preference for written and verbal information, or a combination of both, provided that the information was trustworthy and approved by their HCP.

Siblings mentioned information needs similar to those of caregivers. However, they further stressed desiring additional information on the causes of cancer, their own risk of developing the disease, and the prognosis for their sick sibling. The main barriers to appropriate information acquisition reported by siblings concerned: not being involved

enough in discussions about their sibling’s disease, not receiving consistent information to that provided to parents, receiving unclear or vague information, and having the opportunity to talk with HCPs only with the presence of their parents. Siblings may feel that their parents’ presence hinders their possibility to speak honestly and freely about their feelings. They might be concerned about being judged or criticized by their parents or not being completely understood. Another possible explanation may be that sharing their concerns in front of their parents could further upset the latter [59], who are already burdened with responsibilities and fears for the sick child. Siblings described preferences for information provided through activities and workshops. Some examples of activities and workshops that may be helpful for siblings of children with cancer include support groups, art or music therapy, educational sessions, and camps or recreational activities [60]. These activities can provide siblings with a safe and supportive setting to learn and connect with other children who are going through similar experiences. By participating in these activities and workshops, siblings could better understand childhood cancer, improve their coping skills, and feel more connected and supported during a challenging time [61–63].

4.1.1. Strengths and limitations

Our results should be interpreted considering some limitations. First, most of the included publications have addressed caregivers’ information needs and information needs of relatives in high-income countries, and our results mainly apply to these specific groups of relatives. Further research is needed to consider the voices of siblings, grandparents, and relatives in low-income countries. Second, there was heterogeneity among the studies, with possible differences in how information needs

were defined and assessed. Most of the included publications did not define information needs or formally distinguish between met and unmet information needs. Finally, we acknowledge that some studies did not differentiate between reported past experiences with information and actual needs and preferences about information provision.

To our knowledge, the current review is the first to provide a qualitative summary of the self-reported information needs of relatives of children with cancer. We searched four major scientific databases in medicine and psychology and screened over 5'000 publications. Our results are drawn from 27 primary studies that showed good methodological quality, strengthening our results. We have included research conducted in both high- and middle-income countries and research including diverse relatives, childhood cancer diagnoses, and time points along the cancer continuum.

5. Conclusion

Our review identified different areas where relatives reported having information needs along the cancer continuum, the aspects of communication that may impede proper information acquisition, and their preferred ways to receive information on childhood cancer. Despite the challenge of identifying and providing the correct form and amount of information at the right time to each family member, our review identified some aspects that should be further considered in clinical practice and future research.

5.1. Practice implications

Our review showed that caregivers and siblings have similar yet unique information needs and preferences. Given the effects of information on relatives' and patients' psychosocial outcomes [53,64,65], it is vital to find solutions that accommodate these needs. HCPs could initially assess each family member's knowledge, understanding, and information needs related to the child's cancer diagnosis and treatment. This can help identify which family members require more information and what topics to focus on. Since individualized and attentive communication with each family member might be challenging for

HCPs, additional instruments for information acquisition should be used. Electronic health (eHealth) and mobile health (mHealth) technologies allow information to be tailored to specific situations and enable users to have access to information upon request [66]. Such technologies might provide extensive opportunities for education and information on childhood cancer among relatives [67] and in countries with lower income levels [68]. Additionally, especially in lower-middle-income countries, HCPs should create a safe and supportive environment where relatives feel comfortable asking questions and providing feedback. This should help identify areas where further information or support is needed and can also help build trust with caregivers.

Ethical approval

Ethical approval was not required.

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CRedit authorship contribution statement

Anica Ilic: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data curation, Writing – original draft, Writing – review and editing, Visualization, Project administration, Funding acquisition. **Yara Sievers:** Validation, Investigation, Writing – review & editing. **Katharina Roser:** Methodology, Validation, Writing – review & editing. **Katrin Scheinemann:** Writing – review & editing. **Gisela Michel:** Conceptualization, Methodology, Validation, Writing – review & editing, Supervision, Funding acquisition.

Declaration of Competing Interest

None to declare.

Appendix A. Database search blocks

	PubMed	PsycINFO	CINAHL	Scopus
Block 1: Child	child OR child* OR kid* OR baby* OR infant OR infant* OR newborn* OR neonat* OR neonat* OR pediatric* OR paediatric* OR girl* OR boy* OR toddler* OR "pre-schooler" OR preschooler* OR "pre schooler" OR "pre schoolers" OR adolescent OR adolescen* OR young* OR youth* OR teen*	child* OR kid* OR baby* OR infant* OR newborn* OR neonat* OR pediatric* OR paediatric* OR girl* OR boy* OR toddler* OR "pre-schooler" OR preschooler* OR "pre schooler" OR "pre schoolers" OR adolescent health OR adolescen* OR young* OR youth* OR teen*	child OR child* OR kid* OR baby* OR infant OR infant* OR newborn* OR neonat* OR pediatric* OR paediatric* OR girl* OR boy* OR toddler* OR "pre-schooler" OR preschooler* OR "pre schooler" OR "pre schoolers" OR adolescent health OR adolescen* OR young* OR youth* OR teen*	child OR child* OR kid* OR baby* OR infant OR infant* OR newborn* OR neonat* OR pediatric* OR paediatric* OR girl* OR boy* OR toddler* OR {pre-schooler} OR preschooler* OR {pre schooler} OR {pre schoolers} OR adolescent OR adolescen* OR young* OR youth* OR teen*
Block 2: Kinship	grandparents OR grandparent* OR "grand parent" OR "grand parents" OR grandmother* OR "grand mother" OR "grand mothers" OR grandfather* OR "grand father" OR "grand fathers" OR grandchild* OR "grand child" OR "grand children" OR granddaughter* OR "grand daughter" OR "grand daughters" OR grandson* OR "grand son" OR "grand sons" OR parents OR parent* OR mother* OR father* OR daughter* OR son* OR siblings OR sibling* OR brother* OR sister* OR spouses OR spouse* OR partner* OR husband* OR wife* OR	grandparents OR grandparent* OR "grand parent" OR "grand parents" OR grandmother* OR "grand mother" OR "grand mothers" OR grandfather* OR "grand father" OR "grand fathers" OR grandchild* OR "grand child" OR "grand children" OR granddaughter* OR "grand daughter" OR "grand daughters" OR grandson* OR "grand son" OR "grand sons" OR parents OR parent* OR mother* OR father* OR daughter* OR son* OR siblings OR sibling* OR brother* OR sister* OR spouses OR spouse* OR partner* OR husband* OR wife* OR	grandparents OR grandparent* OR "grand parent" OR "grand parents" OR grandmother* OR "grand mother" OR "grand mothers" OR grandfather* OR "grand father" OR "grand fathers" OR grandchild* OR "grand child" OR "grand children" OR granddaughter* OR "grand daughter" OR "grand daughters" OR grandson* OR "grand son" OR "grand sons" OR parents OR parent* OR mother* OR father* OR daughter* OR son* OR siblings OR sibling* OR brother* OR sister* OR spouses OR spouse* OR partner* OR husband* OR wife* OR	grandparents OR grandparent* OR {grand parent} OR {grand parents} OR grandmother* OR {grand mother} OR {grand mothers} OR grandfather* OR {grand father} OR {grand fathers} OR grandchild* OR {grand child} OR {grand children} OR granddaughter* OR {grand daughter} OR {grand daughters} OR grandson* OR {grand son} OR {grand sons} OR parent OR parent* OR mother* OR father* OR daughter* OR son* OR siblings OR sibling* OR brother* OR sister* OR spouses OR spouse* OR partner* OR husband* OR wife* OR

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(continued)

	PubMed	PsycINFO	CINAHL	Scopus
	wive* OR daughter* OR son* OR caregivers OR caregiver* OR carer* OR "care giver" OR "care givers" OR famil* OR relative* OR friends OR friend* OR "important other" OR "important others" OR "significant other" OR "significant others"	wive* OR daughter* OR son* OR caregivers OR caregiver* OR carer* OR "care giver" OR "care givers" OR famil* OR relative* OR friendship OR friend* OR "important other" OR "important others" OR "significant other" OR "significant others"	wive* OR daughter* OR son* OR caregivers OR caregiver* OR carer* OR "care giver" OR "care givers" OR famil* OR relative* OR friendship OR friend* OR "important other" OR "important others" OR "significant other" OR "significant others"	wive* OR daughter* OR son* OR caregivers OR caregiver* OR carer* OR {care giver} OR {care givers} OR famil* OR relative* OR friend OR friend* OR {important other} OR {important others} OR {significant other} OR {significant others}
Block 3: Information needs	Needs assessment OR "information need" OR "information needs" OR "need for information" OR "need of information" OR "health information" OR "information preference" OR "information preferences" OR "knowledge need" OR "knowledge needs" OR "wish for information" OR "wish of information" OR "desire for information" OR "desire of information" OR "request for information" OR "requests of information" OR "informational need" OR "informational needs" OR "informative need" OR "informative needs"	Needs assessment OR "information need" OR "information needs" OR "need for information" OR "need of information" OR "health information" OR "information preference" OR "information preferences" OR "knowledge need" OR "knowledge needs" OR "wish for information" OR "wish of information" OR "desire for information" OR "desire of information" OR "request for information" OR "requests of information" OR "informational need" OR "informational needs" OR "informative need" OR "informative needs"	Information needs OR "information need" OR "information needs" OR "need for information" OR "need of information" OR "health information" OR "information preference" OR "information preferences" OR "knowledge need" OR "knowledge needs" OR "wish for information" OR "wish of information" OR "desire for information" OR "desire of information" OR "request for information" OR "requests of information" OR "informational need" OR "informational needs" OR "informative need" OR "informative needs"	information demand OR {information need} OR {information needs} OR {need for information} OR {need of information} OR {health information} OR {information preference} OR {information preferences} OR {knowledge need} OR {knowledge needs} OR {wish for information} OR {wish of information} OR {desire for information} OR {desire of information} OR {request for information} OR {requests of information} OR {informational need} OR {informational needs} OR {informative need} OR {informative needs}
Block 4: Disease	neoplasms OR neoplasm* OR cancer* OR malign* OR tumor* OR tumour* OR oncolog* OR carcinoma* OR leukemia* OR leukaemia* OR lymphoma* OR medulloblastoma* OR sarcom* OR radiotherapy OR radiotherap* OR chemoradiotherapy OR chemotherapy , adjuvant OR induction chemotherapy OR consolidation chemotherapy OR maintenance chemotherapy OR chemotherap* OR surgical oncology OR "surgical oncology" OR "curative surgery"	neoplasms OR neoplasm* OR cancer* OR malign* OR tumor* OR tumour* OR oncolog* OR carcinoma* OR leukemia* OR leukaemia* OR lymphoma* OR medulloblastoma* OR sarcom* OR radiotherapy OR radiotherap* OR chemotherapy OR chemotherap* OR "surgical oncology" OR "curative surgery"	neoplasms OR neoplasm* OR cancer* OR malign* OR tumor* OR tumour* OR oncolog* OR carcinoma* OR leukemia* OR leukaemia* OR lymphoma* OR medulloblastoma* OR sarcom* OR radiotherapy OR radiotherap* OR chemoradiotherapy OR chemotherapy , cancer OR chemotherap* OR "surgical oncology" OR "curative surgery"	neoplasms OR neoplasm* OR cancer* OR malign* OR tumor* OR tumour* OR oncolog* OR carcinoma* OR leukemia* OR leukaemia* OR lymphoma* OR medulloblastoma* OR sarcom* OR cancer radiotherapy OR radiotherap* OR chemoradiotherapy OR cancer chemotherapy OR cancer surgery OR {surgical oncology} OR {curative surgery}

Note: Thesaurus/MeSH terms are reported in bold

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Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

Elsevier hereby grants permission to make all its COVID-19-related research that is available on the COVID-19 resource centre - including this research content - immediately available in PubMed Central and other publicly funded repositories, such as the WHO COVID database with rights for unrestricted research re-use and analyses in any form or by any means with acknowledgement of the original source. These permissions are granted for free by Elsevier for as long as the COVID-19 resource centre remains active.

Digital health and telehealth in cancer care: a scoping review of reviews



Kelly M Shaffer, Kea L Turner, Chelsea Siwik, Brian D Gonzalez, Rujula Upasani, Jillian V Glazer, Robert J Ferguson, Catherine Joshua, Carissa A Low



The COVID-19 pandemic necessitated remote cancer care delivery via the internet and telephone, rapidly accelerating an already growing care delivery model and associated research. This scoping review of reviews characterised the peer-reviewed literature reviews on digital health and telehealth interventions in cancer published from database inception up to May 1, 2022, from PubMed, Cumulated Index to Nursing and Allied Health Literature, PsycINFO, Cochrane Reviews, and Web of Science. Eligible reviews conducted a systematic literature search. Data were extracted in duplicate via a pre-defined online survey. Following screening, 134 reviews met the eligibility criteria. 77 of those reviews were published since 2020. 128 reviews summarised interventions intended for patients, 18 addressed family caregivers, and five addressed health-care providers. 56 reviews did not target a specific phase of the cancer continuum, whereas 48 reviews tended to address the active treatment phase. 29 reviews included a meta-analysis, with results showing positive effects on quality of life, psychological outcomes, and screening behaviours. 83 reviews did not report intervention implementation outcomes but when reported, 36 reported acceptability, 32 feasibility, and 29 fidelity outcomes. Several notable gaps were identified in these literature reviews on digital health and telehealth in cancer care. No reviews specifically addressed older adults, bereavement, or sustainability of interventions and only two reviews focused on comparing telehealth to in-person interventions. Addressing these gaps with rigorous systematic reviews might help guide continued innovation in remote cancer care, particularly for older adults and bereaved families, and integrate and sustain these interventions within oncology.

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Introduction

Before the COVID-19 pandemic, digital health and telehealth were uncommon in standard, global oncology care. Within clinical research, there has been over a decade of interest on leveraging technology to increase care accessibility, scalability, and cost-effectiveness. Delivering interventions by telephone and internet—via phone calls, videoconferencing, mobile applications, and web pages—can reduce the time burdens of cancer treatment¹ and extend access to evidence-based interventions for cancer prevention and control, surveillance, supportive care, treatment decision making, and more. As research in remote cancer-care delivery has grown rapidly over the past decade, with an abrupt acceleration during the pandemic, we sought to characterise the current state of the evidence by synthesising and summarising existing literature reviews in this field.

There are multiple formal definitions of both digital health and telehealth that often overlap. Digital health is defined as using “digital technologies for health, such as the internet of things”,² and “computing platforms, connectivity, software, and sensors for health care and related uses”.³ Telehealth has been defined by the US Health Resources and Services Administration as “the use of electronic information and telecommunications technologies to support long-distance clinical health care, patient and professional health-related education, public health, and health administration”.⁴ Although this definition is inclusive of digital health, telehealth is often used more narrowly to describe synchronous interactions between health-care providers and patients (eg, an appointment done via encrypted videoconferencing). In this Review, the terms digital health and telehealth are

used together to represent the full spectrum of remotely delivered, technology-supported, health-care interventions.

For a comprehensive summary of the science on remote cancer care, this scoping review extends the previous findings from an overview of reviews on telehealth interventions for post-treatment cancer survivors⁵ in three ways. First, the previous overview of reviews suggests that future research specifically addresses cancer prevention and health promotion. This scoping review addresses this need by summarising review literature on the use of telehealth across the cancer trajectory, from cancer prevention to end of life and bereavement. Second, this scoping review also provides the first compilation of reviews of digital health in cancer, which is important given the expansion of reimbursement coverage to include asynchronous electronic communication (ie, via patient portals) during the pandemic.⁶ Moreover, digital health practices are rapidly evolving and hold considerable promise for scaling interventions to be more accessible and cost-effective by reducing reliance on health-care personnel. The third extension of previous reviews is that this scoping review includes interventions for cancer health-care providers and family cancer caregivers. Digital health and telehealth practices hold promise for facilitating more collaborative care across health-care disciplines, and for overcoming many of the barriers family caregivers face to accessing their own health care.

The extensions we include in this scoping review are necessary to understand the broader science on digital health and telehealth practices across cancer care. Identifying whether the summarised primary literature

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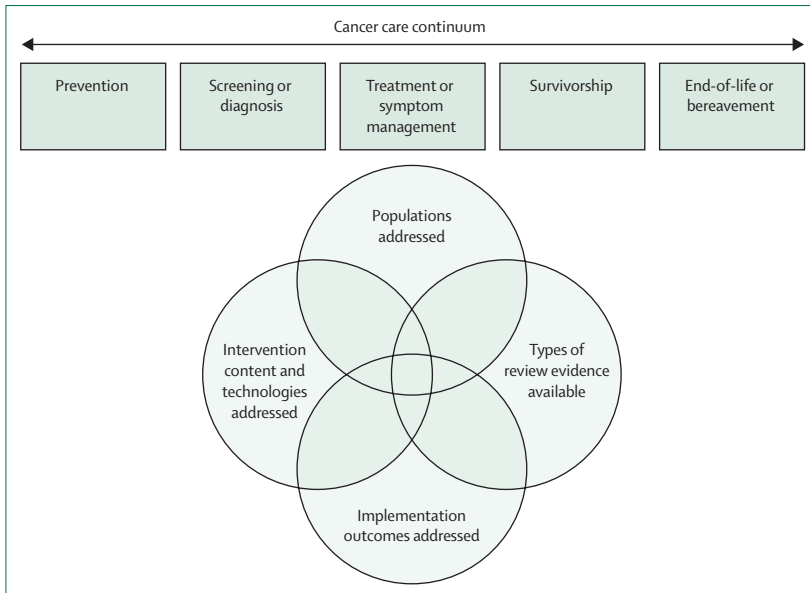


Figure 1: Framework of the scoping review

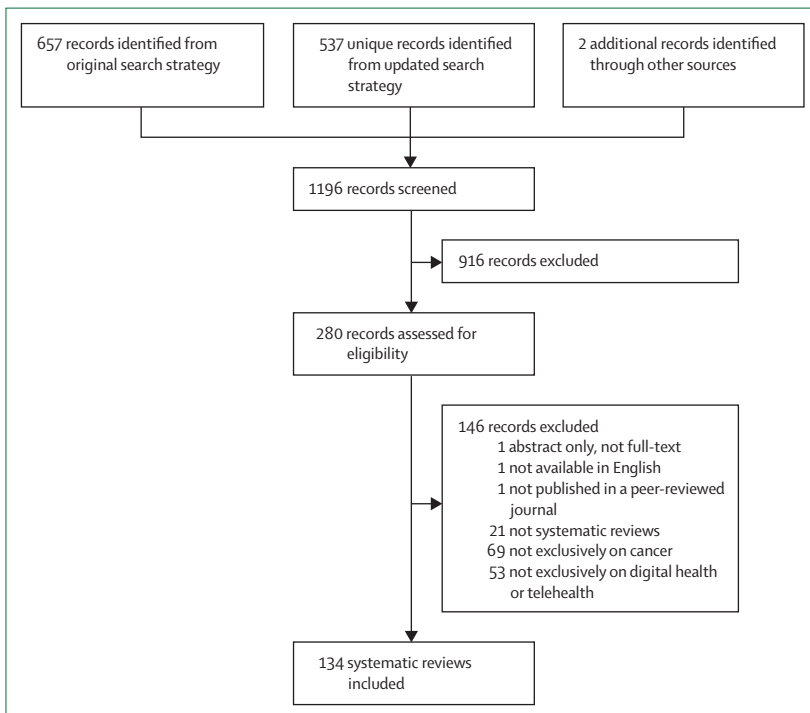


Figure 2: PRISMA flowchart

is inadequate or out of date is important to direct where research is most needed to improve cancer care delivered by digital health and telehealth. Describing trends in, and the available evidence for, digital and telehealth interventions and practices in cancer care can also help direct third-party payment for empirically supported services. Therefore, we identify and summarise

systematic reviews of digital health and telehealth across the cancer care continuum to detail the state of this science, and to identify important gaps to guide future reviews (figure 1).

Methods

A comprehensive electronic literature search was conducted for peer-reviewed systematic reviews published from database inception to May 1, 2022. The protocol was registered (INPLASY protocol 3635)⁷ and we adhered to PRISMA for Scoping Reviews guidelines.⁸ No funding source specifically supported this Review.

Eligibility criteria

The included reviews were required to meet a priori eligibility criteria: English-based or English-translated literature, published in a peer-reviewed journal, and met the population, intervention, comparison, outcome, and study design criteria as detailed.⁹ When possible, these criteria were built into the search strategies for each database, but all studies were reviewed manually to establish eligibility. There were no exclusion criteria based on geographical locations, participant sex or ages (ie, studies with children, adolescents, and young adults were eligible for inclusion), or reported outcomes.

For the population criteria, the exposure of interest was cancer, whether as an individual at risk for cancer, a patient undergoing cancer care, a cancer survivor, a family cancer caregiver, or a health-care provider involved in cancer care delivery. Reviews that included any studies focused on health conditions other than cancer were excluded.

For the intervention criteria, reviews were included if all studies evaluated a digital health or telehealth intervention or health-care practice, as defined by the US Health Resources and Services Administration.⁴ Reviews that focused on technologies that collect and transmit health data (ie, remote patient monitoring) without an explicit tie-in to intervention or improving health-care outcomes were excluded. For comparison and outcome criteria, there were no restrictions (eg, reviews including single-arm pilot trials were eligible for inclusion).

For the study design criteria, all included records were literature reviews that used a systematic search method. In addition to formally identified systematic reviews labelled as scoping, narrative, or integrative were systematic reviews otherwise labelled, which were eligible for inclusion if they specified a systematic literature search of electronic databases. We considered limiting our search to only systematic reviews adhering to PRISMA guidelines; however, to identify reviews summarising pertinent literature more broadly to digital health and telehealth in cancer care, we chose to include all reviews specifying a systematic search strategy.

Search strategy and selection criteria

The authors created search strategies with a medical librarian (CJ) to identify published systematic reviews on

	Reviews, n (%)
Population data*	
Targeted individuals	
Patients	128 (95.5%)
Family	18 (13.4%)
Health-care personnel	5 (3.7%)
Cancer types	
Brain	1 (0.7%)
Breast	17 (12.7%)
Colorectal	5 (3.7%)
Gynecological	7 (5.2%)
Haematological	4 (3.0%)
Lung	3 (2.2%)
Prostate	4 (3.0%)
Skin	6 (4.5%)
Multiple or not specified	95 (70.9%)
Cancer care continuum	
Prevention	5 (3.7%)
Screening or diagnosis	12 (9.0%)
Treatment or symptom management	48 (35.8%)
Survivorship	29 (21.6%)
End-of-life or bereavement	2 (1.5%)
Multiple or not specified	56 (41.8%)
Intervention data†	
Telehealth components	
Synchronous telehealth	78 (58.2%)
Text messaging or short messaging service	37 (27.6%)
Email or secure messaging	39 (29.1%)
eHealth	87 (64.9%)
Mobile application	78 (58.2%)
Types of intervention or care	
Health behaviour change	24 (17.9%)
Psychosocial support or distress management	18 (13.4%)
Disease detection or management	14 (10.4%)
Medical decision making	2 (1.5%)
Multiple or not specified	73 (54.5%)
Provider involvement	
Health-care professional	9 (6.7%)
Fully automated or self-guided	1 (0.7%)
Multiple or not specified	124 (92.5%)

(Table continues in next column)

	Reviews, n (%)
(Continued from previous column)	
Review design data	
Meta-analysis	
Yes	29 (21.6%)
No	105 (78.4%)
Comparator (if required)	
Usual care	11 (8.2%)
In-person	2 (1.5%)
Any	18 (13.4%)
Other telehealth modality	0 (0%)
None required	103 (76.9%)
Quality or bias assessment	
Yes	90 (67.2%)
No	44 (32.8%)
Implementation outcome data (Proctor et al. classification)†	
None	83 (61.9%)
Acceptability	36 (26.9%)
Adoption	8 (6.0%)
Appropriateness	6 (4.5%)
Feasibility	32 (23.9%)
Fidelity	29 (21.6%)
Cost	8 (6.0%)

The median number of studies included per review was 16 with a range from 0–121. Albino de Queiroz and colleagues²¹ included two reviews within the single publication (N1=121 and N2=15). Each sample was included separately for the computation of these statistics. *Reviews might be reflected in more than one category (eg, can include interventions for both patients and family members, or report more than one kind of implementation outcome; except for multiple or not specified, or none).

Table: Descriptions of 134 included reviews from 2010 to 2022

the topic of digital health, telehealth, and cancer. By use of a combination of medical subject headings, text phrases, keywords, and other database-specific terminologies, strategies were developed to find relevant review articles. The databases searched were PubMed, Cumulative Index to Nursing and Allied Health Literature, American Psychological Association PsycINFO, Cochrane Reviews, and Web of Science. Reference lists of related literature were also reviewed for pertinent records. Review articles selected for the initial screening included a title or abstract with at least one subject heading, phrase, or keyword related to cancer and

to digital health and telehealth. Unpublished and grey literature were not pursued. Literature was initially searched on Sept 1, 2021, with an update on May 2, 2022, to include published reports before this date. As part of the peer review process, a phrase (“intervention” and “telephone”, “online”, “digital”, “mobile”, “Internet”, “technology”, “application”, or “text”) was added to the search strategy. The final search with this updated strategy was done on Sept 19, 2022, with additional search terms to identify any remaining pertinent records published up to May 1, 2022. Complete search strategies, including demarcation for the search strategy update, and database information are reported in appendix 1 (pp 1–3).

Selection and screening process

Unique records were compared with the eligibility criteria with Rayyan,¹⁰ an online review tool. Coders were not masked to journals or authors during screening. Before the first screening round, a screening guide was created to train all reviewing authors on the eligibility criteria. In the first round, study titles and abstracts were reviewed by two of three coders (KMS, RU, or JVG). Discrepancies between coders were resolved by

See Online for appendix 1

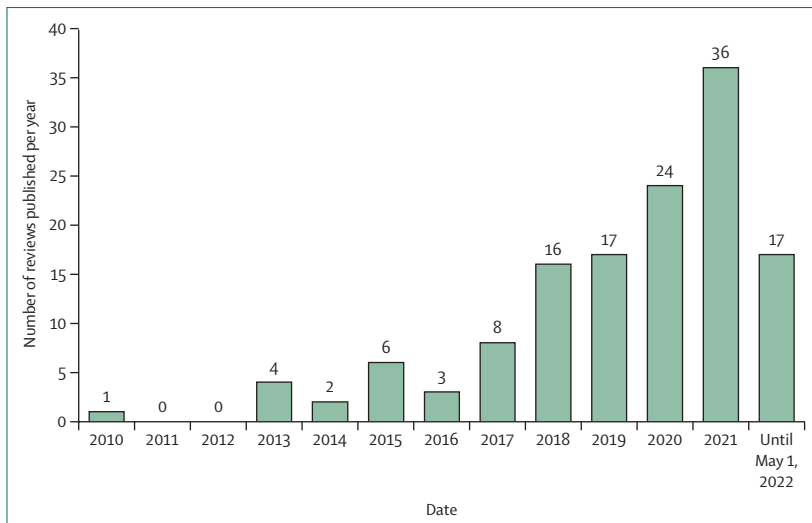


Figure 3: Number of reviews published per year on digital health and telehealth in cancer

For the data on Open Science Framework see <https://osf.io/k47hb>

consensus. All citations that initially met the criteria were included in a second round of full-text article screening. Full-text articles were reviewed by two of eight authors (KMS, KLT, CS, BDG, RU, JVG, RJF, or CAL), with discrepancies resolved by KMS or RU. Reasons for exclusion during the full-text review stage were recorded.

Data extraction and summary

Data were extracted from the included records with a standardised, predefined form with Qualtrics, an online survey tool, which was pilot tested by coders. Articles were not blinded during data extraction. Data were extracted independently by two of eight authors (KMS, KLT, CS, BDG, RU, JVG, RJF, CAL), with discrepancies resolved by KMS, RU, or JVG. Coders extracted review metadata and data about the eligible population, intervention characteristics, and study design (appendix pp 4–7). Extraction and categorisation of implementation outcomes according to the terminology used by Proctor and colleagues¹¹ was completed post-hoc by consensus of KMS, KLT, and CS. Article selection, screening, and data extraction were completed by Oct 4, 2022. Data were tabled and summarised, and gaps in the review literature were identified.

See Online for appendix 3

Results

In total, 1196 unique records were identified, of which 280 full texts were assessed for eligibility (figure 2). Of these, 146 were excluded (see appendix 2 on screening results for a full list of excluded full text reviews with exclusion reasons). The remaining 134 reviews met eligibility criteria and were included in the synthesis.^{12–145} Study information is presented in the table and appendix (pp 8–46). Included reviews were published as early as 2010, with a notable increase beginning in 2018 (figure 3).

See Online for appendix 2

The median number of studies included in the reviews was 16 (range: 0–121). We found no evidence to indicate that any of the reviews were industry sponsored.

All extracted data are also available in sortable worksheets available at the Open Science Framework. These worksheets serve as comprehensive and complete evidence maps, which readers are encouraged to use to further examine how populations, intervention content and technologies, types of review evidence, and implementation outcomes addressed by reviews differ across the cancer-care continuum, among other questions of interest.

Populations

128 (95.5%) of 134 included reviews addressed patient-level intervention studies. 18 (13.4%) of 134 reviews included caregiver-level intervention studies and only five focused exclusively on caregivers. Five reviews (3.7%) addressed provider-level interventions that aimed to improve patient cancer care experiences through provider continued education or enhanced intra-provider collaboration.

95 reviews (70.9%) did not restrict study inclusion on the basis of cancer type. Of reviews that addressed one or more specific cancer types, 17 were on breast cancer, seven were gynaecological, six were on skin cancer, five were on colorectal cancer, four were on prostate cancer, four were haematological, three were on lung cancer, and one was on brain cancer. Ten reviews (7.5%) focused on paediatric, adolescent, or young adult patients with cancer or their caregivers. None of the reviews focused on older adult patients with cancer or caregivers.

56 (41.8%) of 134 studies did not restrict inclusion (or did not specify) on the basis of the stage of the care continuum, although they tended to focus on interventions delivered during active treatment through survivorship. Among the reviews that focused on one or more specific stages of the continuum, 48 (35.8%) addressed the active treatment phase. Two reviews addressed studies of care for patients at the end of life, but none addressed caregiver bereavement.

The frequencies of reviews targeting patients, family members, or health-care providers across the stages of the cancer care continuum are summarised in a visual evidence map in figure 4. Readers can explore additional cross-tabulations of interest with the sortable worksheets of extracted data in appendix 3 on review details.

Interventions

Rather than focus on a single intervention delivery method, reviews tended to include studies of interventions across digital health and telehealth delivery methods. 87 (64.9%) included studies of interventions delivered entirely or in part by eHealth interventions, 78 (58.2%) of synchronous telehealth, and 78 (58.2%) of mobile applications. Reviews less commonly included studies of interventions that used email or secure asynchronous messaging platforms (n=39; 29.1%) or

text or short messaging services (n=37; 27.6%). Other delivery components included use of wearable devices (n=12; 9.0%), social media (n=8; 6.0%), virtual reality (n=8; 6.0%), automated phone calls or interactive voice response calls (n=7; 5.2%), store-and-forward image transfer (n=6; 4.5%), electronic health records or patient portals (n=5; 3.7%), active or video games (n=4; 3.0%), and interactive robot-assisted therapy (3; 2.2%).

73 (54.5%) reviews did not restrict inclusion (or did not specify) on the basis of intervention type. Among reviews that addressed one or more specific types of interventions, 24 (17.9%) addressed health behaviour change, followed by 18 (13.4%) of psychosocial support or distress management, and 14 (10.4%) of disease detection or management. In addition, 124 reviews (92.5%) did not restrict (or did not specify) inclusion on the basis of the type of provider involvement in delivery. Only one review clearly specified inclusion of only fully automated programmes (ie, no human involvement), regarding the use of artificial intelligence (AI) for diagnosing skin cancer or melanoma from skin lesion pictures.²²

Review design

29 reviews (21.6%) included a meta-analysis of all or a subset of their included studies. Among these 29 meta-analyses, digital health and telehealth interventions were compared with any comparator in 14 meta-analyses (48.3%) or to usual care in nine meta-analyses (31.0%). One meta-analysis compared genetic counselling delivered by telehealth versus in-person, determining that telehealth was not inferior to in-person counselling on the two evaluated outcomes of cancer-specific distress and knowledge. Across meta-analyses, the most examined outcome was quality of life: 11 meta-analyses reported positive effects of interventions relative to control and six reported null findings. Meta-analyses also frequently reported positive findings for interventions for outcomes including depression (nine positive effects, four null effects), anxiety (eight positive, three null), self-efficacy (five positive, no null), physical activity (four positive, one null), and cancer screenings (four positive, no null). The evidence was mixed for other outcomes like fatigue (five positive effects, five null effects), pain (three positive, four null), and distress (two positive, two null). Many reviews indicated that a meta-analysis was not done due to heterogeneity of methods and outcomes.^{13,15,18,21,23,29,40,45,46,49,60,65,69,74,75,86,88–90,97,100,104,110,116,118,131,134}

113 reviews (84.3%) were termed systematic review; seven (5.2%) included the term scoping, and five (3.7%) included the term integrative. Methodological quality or risk of bias assessment is considered an essential reporting element for systematic reviews¹⁴⁶ and 81 of the 113 systematic reviews (71.7%) reported such an assessment.

Implementation outcomes

83 (61.9%) of 134 reviews did not report implementation-related outcomes. This finding could either be because



Figure 4: Evidence map illustrating frequencies of reviews by individual targeted by intervention across the cancer care continuum

studies included in reviews did not report these outcomes or because reviews did not extract this information from studies. Among reviews that extracted implementation-related outcomes, 36 (26.9%) fell into the categories of acceptability, 32 (23.9%) of feasibility, and 29 (21.6%) of fidelity. None of the reviews extracted mid-stage to late-stage implementation outcomes like penetration or sustainability.

Discussion

To our knowledge, we conducted the first scoping review of literature reviews on the use of digital health and telehealth interventions across the cancer continuum for

patients, caregivers, and health-care providers. The spread of digital health and telehealth in cancer care during the COVID-19 pandemic necessitated an overview of the state of this science, to identify gaps in what is known about remote cancer care delivery. Our scoping review revealed an extensive and recent body of review literature on digital health and telehealth interventions in cancer care. Overall, most reviews focused on interventions delivered to patients with cancer in the active treatment and survivorship phases using eHealth programs, synchronous calls by telephone or video-conferencing, and mobile applications. Common conclusions drawn by reviews were that digital health and telehealth interventions were feasible and effective, but the need for larger-scale and robust efficacy testing remains.

This scoping review identified several major gaps in the review literature in digital health and telehealth in cancer care. Specifically, there are opportunities to improve the knowledge base related to populations, interventions, review designs, and implementation outcomes. Systematic reviews addressing these gaps can help improve digital health and telehealth cancer care for all individuals by establishing the extent of the primary research and potential efficacy of interventions across the broad scope of remote cancer care.

Opportunities in populations

Most of the included reviews addressed digital health and telehealth interventions for individuals at risk for cancer (ie, cancer prevention), those receiving treatment (ie, patients), or those recovered from cancer (ie, survivors); however, several subpopulations were missing. For example, none of the reviews focused on older patients with cancer, which is a considerable gap given that more than half of individuals diagnosed with cancer are aged 65 years or older.¹⁴⁷ Although often assumed that digital health or telehealth interventions are a poor fit for older adults, there is substantial promise for this type of care to support independent ageing.¹⁴⁸ The adoption of digital technologies among older adults continues to rise,¹⁴⁹ and digital health and telehealth interventions can help alleviate common health-care barriers faced by older adults, such as rurality¹⁵⁰ and poverty.¹⁵¹ Moreover, one study of patients with uro-oncological cancer suggests similar interest in remote patient monitoring with digital technologies between older and younger patients, with older patients even reporting to be willing to engage with digital technologies as part of trials more frequently than younger patients.¹⁵²

Three reviews addressed telehealth interventions for individuals facing advanced cancer, including those at the end of life.^{17,23,73} Characterising the use and benefits of digital health and telehealth interventions for these populations is important as many patients with terminal cancer and their families prefer palliative care delivered at home versus a health-care facility.¹⁵³ Although

bereavement care for families is traditionally a component of comprehensive palliative care and was included in several of the digital health and telehealth palliative care programs covered in reviews (eg, Dionne-Odom and colleagues and Pearce and colleagues),^{154,155} none of the reviews specifically addressed family caregiver bereavement. This finding reflects the restricted focus on family cancer caregivers across reviews overall. Reviews have been conducted on digital health and telehealth bereavement care outside of oncology.^{156,157} As caregivers' health-related needs and grief reactions differ by disease context,^{158,159} it is necessary to explore the availability, efficacy, and acceptability of digital health and telehealth interventions for cancer-related bereavement.

Opportunities in interventions

Digital health and telehealth interventions can range in their purpose to support "long-distance clinical health care, patient and professional health-related education, public health, and health administration".⁴ Most identified reviews focused on long-distance cancer care, patient education, and public health (ie, cancer prevention interventions), with less focus on professional health-related education and administration. Synchronous telehealth services for long-distance cancer care were perhaps most commonly reviewed, in part due to a record of reimbursement before (and expanded upon during) the COVID-19 pandemic. In the example of US states and territories, telehealth services before the pandemic were reimbursed by government and private health insurance payers, although typically with requirements such as patients must have had previously received services in a licensed health-care facility. These requirements were largely dropped during the COVID-19 pandemic, and reimbursement policies continue to evolve. Monitoring professional reimbursement policy changes will be crucial to optimise the use and dissemination of telehealth services moving forward.

Five reviews did specifically address digital health and telehealth practices to support interdisciplinary collaboration and continuing education for oncology providers, with the end goal of improving cancer care for patients.^{25,49,82,109,127} However, no reviews addressed tools for oncology health-care provider wellbeing. Given the serious toll of the COVID-19 pandemic on health-care workers,¹⁶⁰ there is an opportunity to establish viable digital health and telehealth interventions to mitigate occupational-health effects under the ongoing pandemic conditions.

Relatively few reviews included interventions with emerging technologies (eg, serious games and virtual reality) or integration with the internet of things (eg, wearable devices and smart speakers). One notable exception was a review by Albino de Queiroz and colleagues,⁵⁵ which comprehensively described the utility and results of applying the internet of things to cancer care. Given the rapid evolution of the technical capacity

of digital health, continually updating summaries of this literature will be crucial for the field to stay current and identify emerging opportunities to improve digital health interventions in cancer care.

There was also only one review focusing on digital health programs delivered without the input of any support personnel: a study of mobile applications that use AI to diagnose skin cancer or melanoma from skin lesion pictures, which concluded that evidence was insufficient (by the time of the review) to rely on AI to identify all diagnoses.²² No reviews specifically focused on entirely self-guided psychological, behavioural, or educational interventions delivered without the support of any personnel. Although there were reviews of interventions that could plausibly be fully automated,^{12–14,18,21,36,38,52,66} eligibility criteria did not require full automation, and incorporation of clinical support was unclear. Kiss and colleagues⁸⁹ focused on self-guided interventions but included those with minimal facilitation. The public health effects of including professional guidance should be carefully weighed. Digital health interventions that include some guidance tend to result in greater improvements than stand-alone interventions.^{161,162} Conversely, fully automated interventions provide greater scalability, accessibility, and cost-effectiveness.¹⁶³ Rigorous reviews regarding this topic could help ascertain the benefits and costs of including professional guidance to better decide when more or less clinician support is warranted.

Opportunities in review designs

Approximately one-fifth of the reviews included a meta-analysis, and of those, most compared digital health and telehealth interventions with usual care or any kind of comparator. Only one meta-analysis compared telehealth with in-person care delivery. This unique review by Bracke and colleagues³⁴ concluded that telehealth genetic counselling did not differ from in-person counselling regarding patients' cancer-related distress or knowledge. Further reviews establishing how digital health and telehealth interventions intended for remote care delivery compare with in-person interventions on clinically salient outcomes might be important in ensuring that digital health and telehealth care becomes reimbursable,¹⁶⁴ or remains reimbursable following expiration of COVID-19 public health emergency policies. Comparison with in-person care, however, is not pertinent for every research question. For example, payers might want to know whether it is equally beneficial to see a provider in-office versus by videoconference call, whereas consumers might be more interested in information to better choose between two or more digital health and telehealth programs. Importantly, none of the reviews attempted to compare different digital health and telehealth interventions to one another.

Another gap in the meta-analysis literature is that there were no meta-analyses identified that tested the effects of

digital health or telehealth on real-world health-care utilisation data. Meta-analyses tended to focus on self-reported symptom questionnaires, which might reflect the primary literature tending to have self-reported endpoints. There were three meta-analyses that addressed objective clinical outcomes like range-of-motion and lymphoedema,^{14,50,52} with all three focusing on patients and survivors of breast cancer. Future meta-analyses regarding the effects of digital health and telehealth intervention on patient morbidity, mortality, and health-care utilisation factors (eg, office visits, use of emergency services, and hospitalisations) would provide crucial information to inform reimbursement and coverage decisions. Such reviews would also reveal the extent to which primary literature in digital health and telehealth has examined these outcomes, potentially revealing where gaps in the primary literature exist.

Regardless of the research question addressed by a systematic review, about 30% of the identified systematic reviews identified in our search did not conduct a methodological quality rating of the included studies, which is essential for interpreting findings. This outcome is consistent with an earlier meta-review of telehealth in cancer care⁵ that also identified a need to ensure consistent adherence to PRISMA guidelines, another opportunity for future improvement of this literature base.

Opportunities in implementation outcomes

About two in five reviews reported implementation-related outcomes. Of particular interest, because reimbursement and coverage of digital health and telehealth services remains in flux, only eight reviews directly addressed economic outcomes, with three specifically discussing these findings in a dedicated section.^{61,68,90} Across all eight reviews, the proportion of primary studies including health economic outcomes ranged from 0% (0/8)²⁰ to 31% (6/19)⁹⁰ of included studies, with outcomes including direct costs, cost minimisation, and cost-effectiveness (eg, on quality-adjusted life-years). As with mortality and health-care utilisation outcomes, more synthesised data on the various economic effects of digital health and telehealth interventions will be helpful to decision makers when considering coverage and implementation of such interventions.

Most of the implementation outcomes data were extracted from early-stage research studies, with few reviews focusing on the implementation of digital health and telehealth interventions into routine care. With a shift toward remotely delivered care precipitated by the COVID-19 pandemic, there might be opportunities to review studies focused on the use of digital health and telehealth practices within standard care, and eventual opportunities to describe mid-range to long-range implementation outcomes related to reach and sustainability of these practices. One of the earliest identified reviews,

Sanchez and colleagues' 2013 review, stands out in its application of implementation frameworks to their review of internet-based cancer prevention and control interventions.¹²⁴ This review highlighted the need for more pragmatic trial designs to accelerate the implementation of effective digital health and telehealth interventions into routine care. Unfortunately, it seems that the field of cancer-related digital health and telehealth interventions is still struggling to implement this finding almost a decade later, given that reviews since that time frequently concluded that findings were preliminary and more robust, larger-scale studies were needed.

Limitations

Given that we conducted a scoping review of reviews, the identified gaps in the literature only establish that a review was not identified in a given area of remote cancer care, which might not generalise to the primary literature. Because we restricted the scope of our review to cancer, there could be reviews pertinent to identified gaps that are disease-agnostic. In addition, we did not extract review information pertinent to health equity, such as the racial or ethnic composition of samples or rurality. Several reviews indicated the generalisability of the included literature was restricted due to study samples comprising largely non-Hispanic White, highly educated, or breast cancer participants;^{44,78,111} however, there were reviews specifically focused on underserved populations and studies in low-income and middle-income countries.^{57,109,120,131,142}

Conclusions

In this first-of-its-kind comprehensive scoping review of reviews on digital health and telehealth interventions across the cancer continuum, we summarised the existing review literature and identified several gaps. We identified an absence of review literature for older adults in cancer care, cancer-related bereavement, oncology provider wellness, and mid-range to long-range implementation outcomes. Additionally, there were few meta-analytic comparisons to traditional in-person care or between multiple digital health and telehealth programmes. Establishing the state of the science in these areas with high-quality reviews might help guide continued innovation in remote care delivery, particularly for older adults and bereaved families, and support the integration and sustainability of these interventions within standard oncology practice. This work will support continued growth in the reach and effects of digital health and telehealth interventions to reduce cancer risk and improve cancer care for all individuals.

Contributors

KMS led all aspects of the Review: conceptualisation, data curation (title and abstract screening, full-text screening, and data extraction), formal analysis, project administration, supervision, validation, and writing (original draft, review, and editing); KLT, CS, and BDG were involved in data curation (full-text screening and data extraction), validation, and writing (review and editing); RU and JVG were involved in data curation (title and abstract screening, full-text screening, and data extraction),

validation, writing, and review; RJF was involved in conceptualisation, data curation (full text screening and data extraction), and writing (review and editing); CJ is the medical librarian and was responsible for devising (in collaboration with KMS) and executing the search strategy for this scoping review, and was involved in writing (original draft and writing, review, and editing); CAL was involved in conceptualisation, data curation (full text screening and data extraction), validation, writing (original draft), and writing (review and editing). All authors have had full access to the data and accept responsibility to submit for publication.

Declaration of interests

BDG reports fees unrelated to this work from Sure Med Compliance and Elly Health, and was supported in part by a National Cancer Institute Cancer Center Support Grant supporting the Population Research, Interventions, and Measurements Core at Moffitt Cancer Center (P30 CA076292). CS was supported by a National Center for Complementary and Integrative Health T32 Fellowship (5T32AT003997-13). RJF and CAL were supported by the National Cancer Institute Cancer Center Support Grant (P30CA047904). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. All other authors declare no competing interests.

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