



REVIEW

The role of Connected Health technologies in supporting families affected by paediatric cancer: A systematic review

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Abstract

Objectives: Families impacted by paediatric cancer are met with logistical, financial and psychological impacts, with severe acute respiratory syndrome coronavirus two creating additional barriers and stressors for these families. Connected Health (CH) may facilitate cancer care. The objective of the present study was to systematically review CH for families/informal caregivers affected by paediatric cancer.

Methods: Using search terms relating to: (1) paediatric cancer, (2) family/caregivers and (3) CH, the databases of PsycINFO, Pubmed, EMBASE and Web of Science were searched. Inclusion criteria included an evaluation of CH technologies for supportive care for families/caregivers affected by paediatric cancer at any stage of treatment or survivorship.

Results: Sixteen studies met inclusion criteria. CH was primarily web-based ($n = 6$), however smartphone applications ($n = 5$), telehealth ($n = 2$) and online groups ($n = 3$) were utilised. Intervention areas included psycho-social ($n = 6$), health and information provision ($n = 8$) and palliative care ($n = 2$).

Conclusions: While limited studies have evaluated the impact of CH on families living with paediatric cancer, emerging evidence suggests potential benefits. More evidenced-based interventions are required.

KEYWORDS

cancer, children, Connected Health, ehealth, family, oncology, paediatric cancer, parents, psychosocial support

1 | BACKGROUND

Caregivers of children with cancer can experience numerous logistic, financial¹ and psychological impacts as a result of their caring role² which may lead to decreased carer quality of life (QOL).³ Following diagnosis, the whole family system may be altered as parents assume a mediating role between their children and healthcare team,⁴ resulting in numerous negative psychosocial effects^{5,6} as well as a circularity existing between caregiver and child health,^{5,6} siblings may be affected as they are faced with new responsibilities,⁷ decreased parental attention,⁶ increased emotional burden and greater academic difficulties, particularly in the first 2 years following

diagnosis.⁷ Later, the transition from cancer treatment to normalcy can be difficult for the family.⁸

To alleviate the effects of cancer on children and their families, evidence-based interventions are needed. Previous research has examined a range of in-person interventions for families affected by paediatric cancer, including psychosocial and neurocognitive interventions for survivors,^{9,10} family-based interventions^{11–17} and sibling-specific interventions.¹⁸ While several benefits have been found from such in-person psychosocial interventions¹⁹ these may not be accessible to all. Numerous barriers, including financial or time barriers,²⁰ may prevent families accessing in-person supports. More recently, social distancing requirements introduced globally following

the severe acute respiratory syndrome coronavirus two (SARS-CoV-2), or COVID-19, pandemic, have resulted in additional barriers to services, including cancellation of in-person supports. Further, risk of exposure to SARS-CoV-2 may have increased anxiety for families,²¹ necessitating additional psychosocial supports. Even in the absence of SARS-CoV-2, staff workload has acted as a barrier to accessing psycho-oncology services,²² with a need for increased efficiencies apparent. This is echoed by European policy emphasising the need for sustainable high-quality care to support wellbeing.²³

Evidence is emerging for the potential of smart technologies within healthcare settings, or Connected Health (CH), to meet the needs of families in this context. However, limited work has reviewed its efficacy to date. CH is the development, analysis and implementation of smart technology within healthcare settings²⁴ and encompasses eHealth, mHealth, sensors and other technologies. Examples include personal health systems, intelligent information processing and active data feedback. CH differs from other technologies in that a two-way flow of information is used. Information is gathered, analysed and fed back to the user. CH may hence facilitate improved data usage within childhood cancer resulting in innovative care solutions.²⁵

CH supports exist for several chronic illnesses, such as web-based nutrition management intervention for cystic fibrosis,²⁶ psychological supports for chronic pain²⁷ and illness management for encopresis.²⁸ CH has been found to be acceptable for cancer care within the general population.²⁷ Specifically, within a Northern Irish survey, 90% of individuals found eHealth interventions a positive solution.²⁷ Caregivers of children with chronic illness also report positive perspectives on technology utility, with efficiencies, safety and decreased stress posited.²⁹ CH, however, is underutilised in practice.³⁰ While it can increase patient self-management, barriers such as regulation, cost, technical ability and cultural acceptability remain.³¹

In an increasingly burdened healthcare system, the potential utility of CH is clear, although its introduction necessitates analysis. A systematic review of telehealth interventions for family caregivers identified 32 articles focusing on caregivers of children with illness, with over 95% reporting positive effects.²⁹ Technologies employed included video, Internet and phone-based interventions for education and consultation, however other CH technologies were not evaluated. Another systematic review for families of children with chronic illness supported eHealth and mHealth in improving family functioning, however heterogeneity of findings prohibited fulsome conclusions, with limited focus on individual outcomes.³² An examination of eHealth interventions for youth living with or beyond cancer found mixed support for intervention efficacy on health behaviours, outcomes, neurocognitive functioning and emotional distress.³³ Again, limited technologies and outcomes were examined. A recent review identified 24 articles pertaining to smartphone applications to support children and families impacted by paediatric or adolescent cancer.³⁴ Interventions consisted of symptom management (90%), education/information (74%), caregiver communication (57%), social support (30%) and illness management (21%),

Key points

- Systematic review of Connected Health (CH) for families affected by paediatric cancer
- Sixteen studies met inclusion criteria
- Web-based, Smartphone, telehealth and online groups were used for CH
- Psycho-social, health and information provision and palliative care interventions
- Few studies found, though emerging evidence suggests potential benefits

with just four including parents. Again, narrow technology forms were considered. Therefore, while prior research has examined the utility of some CH, not all technologies have been examined, with limited research examining CH for family members.

For caregivers to support children effectively it is vital their needs are acknowledged and met. CH offers a way to facilitate care, however the benefits for families of paediatric cancer have not been fully explored. To the best of our knowledge, no review has focused upon CH interventions for parents, siblings and informal caregivers impacted by paediatric cancer.

1.1 | Objectives

This review aims to (1) describe the characteristics of CH interventions for parents, siblings and informal caregivers impacted by paediatric cancer and (2) summarise the efficacy of these interventions. Findings will be used to generate recommendations for future family-focused CH interventions.

2 | METHOD

This study was conducted in compliance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement guidelines. This systematic review protocol is registered with the Prospective Register of Systematic Reviews database (ID number: 159608; submitted 25 November 2019).

2.1 | Search strategy

A structured search of four databases (PsychInfo, EMBASE, PubMed and Web of Science) was completed in December 2019 and January 2020 to identify articles pertaining to CH technologies for families and informal caregivers affected by paediatric cancer (defined as a cancer diagnosis before the age of 18). Any study applying CH technologies to paediatric cancer, published in a peer reviewed

journal and in the English language was deemed eligible (see Appendix S1 for inclusionary criteria). Due to the pace of change within technology, only studies published within the past 10 years were considered. Forward citation of identified seminal articles and backward citation of studies obtained was also conducted. Reference lists of identified systematic reviews, meta-analyses and relevant studies were also examined.

The search strategy involved searching for a text word or subject heading associated with the following terms. Boolean phrases were employed to search the selected databases. MeSH, Emtree, PsychINFO thesaurus or equivalent terms were used and exploded.

- Cancer OR Neoplasm AND
- Child OR Paediatric OR Adolescent OR Youth AND
- CH OR eHealth OR mHealth OR Telehealth OR Smartphone OR Telemedicine OR Electronic Health Record OR App OR Web AND
- Family OR Caregiver OR Parent OR Sibling

2.2 | Data selection and extraction

2.2.1 | Screening

Search terms were identified by the primary author and screened by a second author prior to conducting searches. Results of database searches were exported onto Endnote and duplicates removed. Following this, remaining search results were exported to Rayyan.³⁵ Two researchers independently screened study titles and abstracts to confirm that they met the inclusionary criteria. Disagreements were discussed and consensus obtained. If agreement could not be reached a full text review was conducted to establish whether the study met eligibility criteria. Decisions were recorded using a password protected file which both researchers had access to.

2.2.2 | Eligibility

Remaining articles underwent full-text reviews by two independent researchers to confirm eligibility. Again, disagreements were discussed and consensus obtained.

2.2.3 | Data extraction

Data was systematically extracted and inputted into an Excel spreadsheet by the primary researcher and assessed for accuracy by a second researcher. Data was collected on the following criteria: author, title of study, publication year, primary participants, characteristics of participants, outcome measures, intervention utilised, study design, cancer type, results obtained and study limitations. If data was unable to be located within a study the corresponding author was contacted to obtain the unreported data or seek additional details.

2.3 | Methodological quality assessment

All articles included in the review were assessed for quality using the Mixed Methods Appraisal Tool (MMAT).³⁶ The MMAT is intended to critically assess the quality of quantitative, qualitative, randomised control trials (RCTs), non-randomised studies and mixed methods studies within systematic reviews. The MMAT consists of two screening questions followed by five questions specific to design type. No overall scores are provided by the MMAT, rather interpretation took the following form, with 4–5 criteria met deemed high quality, 2–3 criteria met indicating moderate quality and 0–1 criteria deemed low quality, as per previous analysis using this tool.^{37,38} No studies were excluded due to poor MMAT ratings. No measures of inter-rater reliability were obtained for MMAT data, however all MMAT scores were agreed upon by both coders.

2.4 | Synthesis of findings

The first author utilised Microsoft Excel to synthesise data extracted. Study characteristics, interventions and outcomes were described in table form. A thematic analysis was employed to investigate studies. Primary outcomes were divided into three categories: information sharing and illness management, palliative care and psychosocial support. Studies within each of these categories were then evaluated based on dependent variables of interest, participants employed and results obtained. No criterion for minimum number of studies needed to conduct data synthesis was set due to the newly emerging nature of knowledge in this area. Meta-analyses of findings were not conducted due to the heterogeneity of outcomes and methodologies employed.

3 | RESULTS

Database searches yielded 712 articles. Following extraction 257 duplicates were removed, leaving 455 articles for title and abstract screening. Following screening 42 articles remained for full-text review. Of these, 26 were excluded. Full rationale for article exclusion is presented in the PRISMA diagram (Figure 1). Sixteen articles were eligible for inclusion in the systematic review. These were published between 2009 and 2020 and based predominantly in Australia ($n = 6$) and America ($n = 5$). Of the 16 studies, five examined the impact of CH on a specified parent/caregiver measure, nine were acceptability or feasibility studies and two were pilot studies. Additional study characteristics are displayed in Table 1.

3.1 | Quality appraisal

Variability in study quality was noted (Table 1). All MMAT criteria were met by 31.3% of studies, with most others meeting at least

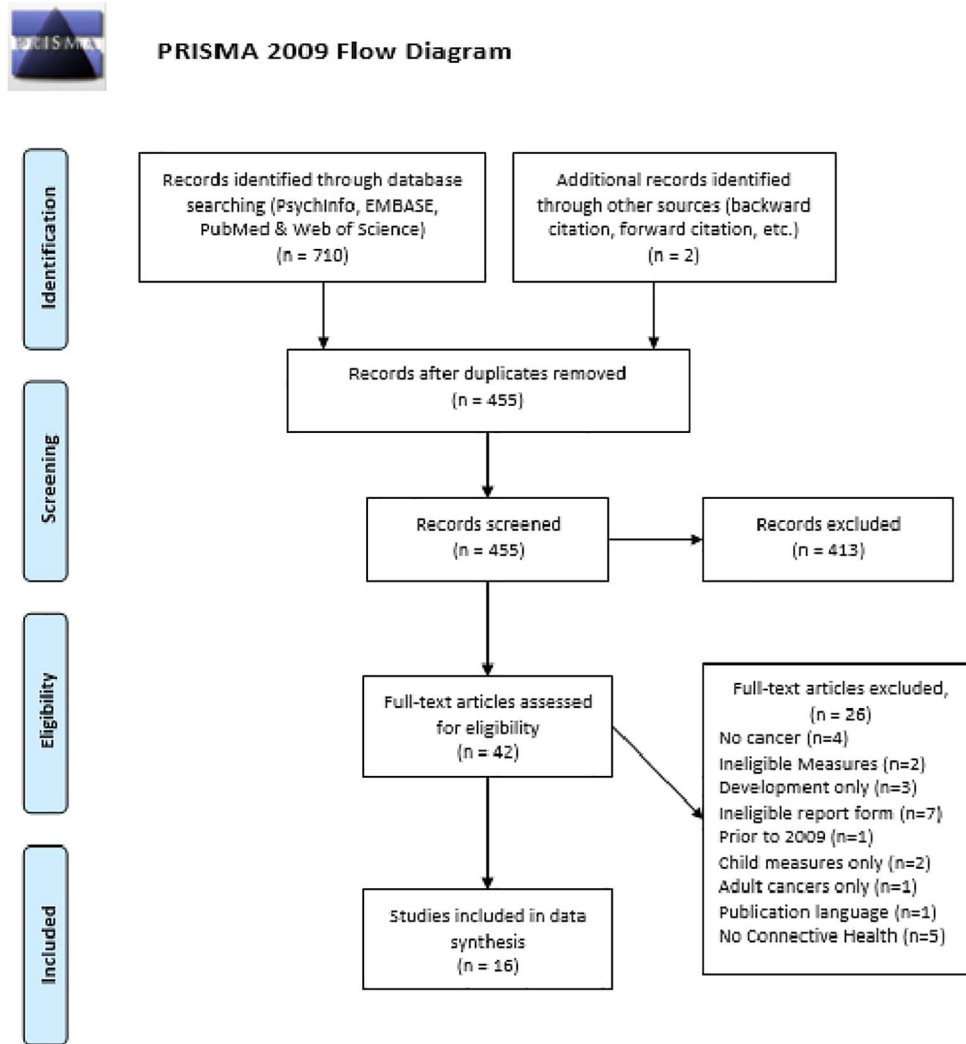


FIGURE 1 Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) diagram

three criteria. One study scored lower than 3.³⁶ Those with a mixed method design were most likely to have a higher MMAT ($n = 3$, range 4–5, mean 4.33), followed by descriptive and RCTs ($n = 6$, range 3–5, mean 4.16; $n = 5$, range 3–5, mean 3.6). The only qualitative study obtained a score of 5. Frequent limitations were blind assessors ($n = 5$),^{39,43,47,51,53} representative samples ($n = 2$),^{42,53} intervention adherence ($n = 2$)^{37,51} and outcome analysis ($n = 2$).^{36,50} All MMAT scores were agreed upon by both coders.

3.2 | Demographic characteristics

Five thirty-six participants were employed across studies (mean = 35.2, range = 6–101). All studies included parents (98.7% of participants), with three also including other caregivers and two including the child. One study examined mothers only and two included the family (not defined). No studies examined siblings or caregivers in insolation. Of studies including parents or caregivers ($n = 16$), 75.1% were mothers ($n = 386$) and 22.2% were fathers ($n = 114$). Seven

participants were informal caregivers (1.3%). Demographic characteristics are provided in the Appendix S1.

3.3 | Characteristics of interventions

Four primary modes of CH were reported; smartphone applications ($n = 5$), telehealth ($n = 2$), web-based interventions ($n = 6$) and online group-based interventions ($n = 3$). Two contained a secondary intervention modality (one web-based with an additional telehealth consultation, another app-based containing a 'WeChat' messaging group). Of the five studies employing a control, four had no-treatment waitlists and one utilised usual care. Intervention duration ranged from 1 h to 6 months (mean = 52.45 days), with two studies failing to report duration. Follow-up periods ranged from 8 weeks to 6 months ($n = 2$). Most did not include follow-up assessments ($n = 14$). Six interventions included contact with Health Care Providers (HCPs). These included nurses, social worker or oncologists ($n = 2$) and trained therapists or psychologists ($n = 4$).

TABLE 1 Study Characteristics

| Reference | Participant | Sample size (Mothers, Fathers) | Age | Design Type | Intervention | Length of intervention | Measures | Results | Quality ^a (MMAT) |
|--------------------------------------|---------------------------------------|--------------------------------|---------------------------------|-----------------------------|--|----------------------------------|--|--|-----------------------------|
| Akard et al. ³⁹ (2020) | Parents children | 98 (89, 7) | N/R ^b | RCT ^b | Web-based legacy intervention for children and their families. Children build an online legacy tool, shared with the family. Usual care control used | 2 weeks | Intervention effects acceptability | 28.4% expressed positive comments 23% liked intervention design 23.5% would increase user friendliness | 4 |
| Bensink et al. ⁴⁰ (2009) | Families (parent, child and siblings) | 11 (N/R) | N/R | Quantitative descriptive | 24 h 'on-call' phone support service in addition to nurse provided telehealth support. | Mean = 73.27 days (range 10-218) | Acceptability Videotelephone call activity Audio quality Cost analysis | Calls primarily with nurses, 44% included oncologist, 8% included social workers. 60% calls from mothers. Quality of audio = 100%. | 4 |
| Bradford et al. ³⁶ (2012) | Primary caregivers | 14 (11, 3) | 25-35 = 6, 36-45 = 6, 46-55 = 2 | Quantitative non randomized | Home telehealth palliative program care. | 10 weeks | QOL in Life Threatening Illness-Family (QOLTI-F). The Accessibility and Remoteness Index for Australia (ARIA). | QOLTI-F—No difference between intervention and control groups. | 2 |
| Burton et al. ⁴¹ (2018) | Parents children | 30 (20, 8) | N/R | Quantitative descriptive | Brighthearts smartphone application. Biofeedback mediated relaxation app used with analgesic cream. | 1 session | Demographic information Parents: Feedback, pain and anxiety. Satisfaction. HCP: Satisfaction Children: Faces Pain Scale-Revised, Children's fear scale The State-Trait Anxiety Inventory for children. | All reported usability. 8/10 reported difficulty focusing on app. 100% parents would use again. | 5 |
| Canter et al. ⁴² (2019) | Parents | 9 (6, 3) | Range = 23-83 | Quantitative descriptive | Web-based electronic Surviving cancer competently intervention program (eSCCIP). A cognitive behavioural and family systems eHealth intervention utilising self-directed intervention content and personalized support via brief telehealth sessions with a therapist. | 4 months (mean 116.4 min) | Demographic information eSCCIP evaluation survey Internet Intervention Adherence Questionnaire (IIAQ)Usage | Found eSCCIP usable, feasible, and acceptable. | 3 |

(Continues)

TABLE 1 (Continued)

| Reference | Participant | Sample size (Mothers, Fathers) | Age | Design Type | Intervention | Length of intervention | Measures | Results | Quality ^a (MMAT) |
|--------------------------------------|--------------------|--------------------------------|---------------------------|--------------------------|--|------------------------|---|---|-----------------------------|
| Cernvall et al. ⁴³ (2017) | Parents | 58 (39, 19) | Mean = 38 (range = 31–45) | RCT | 10-week online group guided self-help program, including weekly therapist support via encrypted email, based on cognitive behaviour therapy (CBT) and focused on psychoeducation and coping skills. Waitlist control | 10 weeks | PTSD checklist (PLC-c) Beck Depression Inventory (BDI), Beck Anxiety Inventory (BAI), Trimbos iMTA Healthcare consumption, Sick leave | Significant positive effects of the intervention on PLC, with large between-group effect sizes at post assessment ($d = 0.89$; 95% CI 0.35–1.43) and at 12-month follow-up ($d = 0.78$; 95% CI 0.25–1.32). Significant positive effects on depression and anxiety. No effects on health care consumption or sick leave. | 3 |
| Chung et al. ⁴⁴ (2018) | Parents | 30 (24, 4) | N/R | Quantitative descriptive | Web-based cancer-tailored intervention for pain and symptoms (C-TIPs). | Not reported | Stress and Relaxation ratings. Content and usability measure. Formative evaluation interview. | High parental satisfaction with skills teaching $ps < 0.001$. Parent reported stress significantly reduced $p = 0.004$. Parent relaxation improved $p = 0.05$ | 5 |
| Fuentes et al. ⁴⁵ (2014) | Mothers | 6 (6) | N/R | Qualitative | Emotion Mingle is an application based ambient visualization, used with Facebook, to reduce caregiver social isolation. | 1 session | Demographic information social isolation, emotions, and lifestyle interview. Scenario of use. | Intervention perceived as useful. Most valued the help to interact socially. | 5 |
| Slater et al. ⁴⁶ (2018) | Parents caregivers | 38 (N/R) | N/R | Mixed methods | The oncology family application supports families in accessing information and care management plans for a deteriorating child. | Not reported | App usage Caregiver satisfaction | 68% downloaded the app. Most used were 'Blood results' 'when to call,' and 'Hospital contacts,' High satisfaction. | 4 |

TABLE 1 (Continued)

| Reference | Participant | Sample size (Mothers, Fathers) | Age | Design Type | Intervention | Length of intervention | Measures | Results | Quality ^a (MMAT) |
|---------------------------------------|--------------------|--------------------------------|---------------------------------|--------------------------|---|---|--|--|-----------------------------|
| Wakefield et al. ⁴⁷ (2016) | Parents | 47 (41, 6) | 42.36 (25–55) | RCT | Cascade is an online, group-based, CBT intervention, delivered live. Waitlist control | 3 weekly 120-min sessions 6 month follow-up | Feasibility California Psychotherapy Alliance scale-group short version (CALPAS-G). Youth Satisfaction Questionnaire (YSQ). Family Caregiver tool. The Depression Anxiety Stress Scale short form (DASS-21). The family communication, problem-solving and general functioning subscales of the McMaster family assessment Device. | Described as helpful. Burden of use was low. Group cohesion scores suggest peer-to-peer benefits. No significant main effect of group or time (i.e., baseline vs. post-intervention vs. follow-up) on QOL, psychological and family functioning. A significant main effect of time on fear of cancer recurrence ($p < .01$). | 4 |
| Walsh et al. ⁴⁸ (2014) | Parents | 23 (N/R) | N/R | Quantitative descriptive | Home medication support (HoMeS) is a web-based family intervention including a medication calendar with decision support, a communication tool, adverse effect information and a metric conversion chart. | 2 months | Feasibility/acceptability 21-item survey. Medical records Phone based interviews | 92% would recommend All accessed the site, 68% multiple times. Half used recorded information to inform caregivers, 34% used it to communicate with clinicians. No change in medication errors. | 3 |
| Wang et al. ⁴⁹ (2018) | Parents | 101 (75, 26) | <30 = 32, 31-40 = 51, >40y = 11 | Mixed methods | mHealth intervention consisting of an Android smartphone application 'care assistant (CA)' which provided information and a WeChat account. | 3 months | Zung's Self-Rating Anxiety Scale (SAS) Zung's Self-Rating Depression Scale (SDS) The Perceived Social Support Inventory (ZBI) Parents' Perception of uncertainty scale (PPUS) Medical outcomes study knowledge questionnaire. | Reductions in parental anxiety ($p = .03$), uncertainty ($p = .01$), improved social function ($p = .01$), increased parental knowledge of ALL and care ($p < .001$), and decreased unmet knowledge need ($p < .001$). Qualitative results suggest satisfaction. | 5 |
| Wang et al. ⁵⁰ (2016) | Parents caregivers | 15 (9, 6) | 23-42 | Mixed methods | Smartphone application to provide information and support to parents of individuals with ALL. | 2 weeks (average 8 min daily) 8-week follow-up | Audit Log Administration Portal Semi-structured interviews | Parents reported greater knowledge, confidence, social support, and information on stress reduction. Usability rated as stable. | 4 |

(Continues)

TABLE 1 (Continued)

| Reference | Participant | Sample size (Mothers, Fathers) | Age | Design Type | Intervention | Length of intervention | Measures | Results | Quality ^a (MMAT) |
|--------------------------------------|---------------------------------------|--------------------------------|----------------------------|--------------------------|---|------------------------|--|--|-----------------------------|
| Williams et al. ⁵¹ (2016) | Parents | 12 (12) | 34.99 (range = 23.4–39.09) | RCT | Live online Triple-P delivered through GoTo Meeting in a group setting. Waitlist control | 8 weeks | Child Satisfaction Questionnaire (CSQ)Abbreviation Acceptability Rating Profile (AARP) Child emotional and behavioural difficulties: Strengths and Difficulties Questionnaire form (SDQ) Post-intervention interview | High satisfaction and acceptability. Improvements in emotional and peer problems in both groups. Reduction in child conduct difficulties observed following intervention. Decreased hyperactivity for control. No improvements in child prosocial behaviour. No interaction between group and time. | 3 |
| Zhang et al. ⁵² (2019) | Families (parent, child and siblings) | 13 (13, 13) | N/R | Quantitative descriptive | Healthy Eating and Active Living (HEAL) program consisting of 12 weekly web-based self-guided educational and behavioural sessions on the '4-health' childhood obesity prevention program | 12 weeks | Self-administered 24 h (ASA24) Dietary assessment tool. Actigraph GT1M monitor. Calibrated digital scale. Parenting Dimensions Inventory Short version (PDI-S) | Parent 'pressure to eat' reduced ($p = 0.03$). Increased milk ($p = 0.04$), and protein consumption ($p = 0.04$). Decreased potato consumption ($p = 0.02$). No significant changes in children's physical activity, BMI, or waist circumference. | 5 |
| Cernvall et al. ⁴³ (2015) | Parents | 58 (39, 19) | 38 (range = 31–45) | RCT | CBT-based guided self-help delivered online. Waitlist control | 10 weeks | PCL-C, BDIBAI | Significant effect on PCL-C, ($p < 0.05$) and BDI-II with a large between-group effects size at post-assessment. Significant effects on BAI with reduction in symptoms in the intervention group. However, due to baseline differences, the between-group effect size at post-assessment was small. | 4 |

Abbreviations: BDI, beck depression inventory; PLC-C, post-traumatic stress disorder checkList – civilian version; RCT, randomised control trial.

^aNot reported.

^bRandomised control trial.

3.4 | Adherence measures

Adherence data was provided for 12 studies (75%). Of these, two reported duration of engagement (mean = 24.4 min, range = 8–39.2 min). The remaining 10 examined the percentage of participants who adhered to the intervention. On average, 65.7% of participants completed the full CH intervention (range = 16.2%–96%).

3.5 | Outcomes

Due to the broad inclusion criteria and resultant heterogeneity of outcomes, studies which were primary pilot or feasibility studies are reported separately to those which sought to examine the impact of CH on specific measures. Both were analysed across three primary thematic intervention areas: (1) psychosocial support, (2) information provision and illness management and (3) palliative support.

3.5.1 | Feasibility, acceptability or pilot studies

Of the 16 studies included nine examined feasibility or acceptability of a CH intervention^{39–42,44–48} and two were pilot studies.^{43,46} All reported positive results for feasibility and acceptability (see Table 1).

Psychosocial

Three studies investigated the impact of CH on psychosocial needs. Interventions varied, with one online Cognitive Behaviour Therapy (CBT)-based intervention,⁴² one online CBT-based group intervention⁴⁷ and one smartphone application utilising ambient visualisation to reduce social isolation.⁴⁵ Wakefield et al.'s analysis of an online CBT intervention included measures of parental QOL, parental psychological functioning and family functioning.⁴⁷ No significant effects of group or time of analysis (i.e., pre, post or follow-up) on QOL or functioning measures were noted. A main effect of time on fear of recurrence was noted, with fear of recurrence decreasing over time. One study utilised a single-group design to examine the acceptability and feasibility of the eSCCIP online CBT-based intervention.⁴² Previous research qualitatively analysed reported social isolation of mothers of children with cancer, however the role of CH on social isolation was not examined.⁴⁵

Information provision or illness management

Six studies examined the acceptability and feasibility of CH to support information provision and illness management. Interventions included a smartphone application-based biofeedback meditation intervention for pain and anxiety during medical procedures,⁴¹ a web-based training for parents on pain and stress management,⁴⁴ a web-based medication calendar with decision support and communication tool,⁴⁸ a 24-h video telephone support provided by nurses for assessment, monitoring, education and counselling,⁴⁰ an application to provide information to parents of individuals with

acute lymphocytic leukaemia,⁵⁰ and 'The Oncology Family App' which supports families in accessing management plans, patient specific information and other resources.⁴⁶ Of these, one was a pilot study. All had positive outcomes. One study examined the usability of the CH only.⁴⁰ Four studies examined usage^{44,46,48,50} with high levels reported. Two included additional measures including medication errors, child fear, anxiety and pain. No change in medical errors was noted following use of the HoMeS medication management intervention with decision support for families.⁴⁸ Positive effects of the Brighthearts biofeedback app on pain (Faces Pain Scale-Revised), fear (the Children's Fear Scale) and anxiety (the State-Trait Anxiety Inventory for Children) were reported, although no statistical analysis was employed.⁴⁰

Palliative support

Two studies examined the use of CH in palliative care. One intervention sought to provide a web-based legacy intervention for children and their families.³⁹ A second was a home telehealth program for palliative care to support patient condition and subsequent management options.³⁶ Both reported good acceptability and one reported good feasibility. No significant effects on familial QOL were noted.³⁶

3.5.2 | Studies examining the impact of a CH technology

Five studies examined the impact of CH on a parent or informal caregiver measure/s (see Table 1).

Psychosocial support

Three studies examined the use of CH to provide psychosocial supports. This included a CBT-based online group to increase coping skills with one-to-one therapist support,⁴³ a CBT-based online self-help module focusing on coping and distress,⁵³ and an online group Positive Parenting Program (Triple-P) to support parents with behavioural challenges.⁵¹ All were RCTs. Significant positive effects for post-traumatic stress, depression and anxiety were found following the CBT-based intervention.⁵³ High acceptability and a trend for improvements in emotional and peer difficulties for both waitlist and intervention emerged following the online Triple-P program,⁵¹ along with a reduction in conduct problems for the intervention group. Significant effects of online guided CBT on post-traumatic stress syndrome (PTSS) and depressive symptomology were found.⁴³ While changes in anxiety were noted, small effect sizes were observed due to pre-intervention differences between groups.

Information provision or illness management

Two studies examined the utility of CH to support information provision or illness management. Quantitative descriptive and mixed methods approaches were used respectively. Reductions in 'pressure to eat' feeding practices by parents and increased milk and protein consumption for the child followed an online guided Healthy Eating and Active Living (HEAL) program.⁵² No significant changes in physical

activity or weight were obtained. The smartphone application 'Care Assistant' and WeChat account was used to facilitate the provision of information, illness management and to increase social contact for parents.⁴⁹ Reductions in parental anxiety ($p = .03$), uncertainty ($p = .01$), improved social function ($p = .01$), increased knowledge ($p < .001$) and decreased need for knowledge ($p < .001$) were observed.

4 | DISCUSSION

Two primary questions were examined within this review. Firstly, how does CH impact families affected by paediatric cancer? Secondly, what recommendations can be made for CH based upon current literature? This review suggests that, while there is considerable potential for CH to support families affected by paediatric cancer, there is a need for more evidence-based evaluations. Considering the impacts of Sars-CoV-2, there is an increased necessity for such remote services.

One notable observation was the low volume of CH studies identified. Only five studies examined the impact of CH on specific parent or informal caregiver measures. This is consistent with previous work examining psychosocial interventions for parents of children with cancer more generally¹⁹ and suggests a need for additional work in this area. Of the three studies examining psychosocial CH interventions, significant effects for CBT-based interventions on parental depressive symptomology and PTSS were suggested, albeit using the same participant groups for both studies.^{43,53} Positive effects of online Triple-P on child conduct were also observed, however reductions in child emotional and behavioural difficulties were not maintained over time.⁵¹ Positive results were obtained for interventions focusing on the provision of information or illness management. Specifically, reductions in parental 'pressure to eat' behaviours were noted for the HEAL web-based program,⁵² while significant reductions in parental anxiety and uncertainty, along with increases in social function and knowledge, were obtained following engagement with 'Care assistant'.⁴⁹ While these results suggest the efficacy of CH in supporting parents affected by childhood cancer, the limited volume of studies and narrow range of CH employed suggests a need for further empirical analysis.

The review included a high volume of pilot and feasibility studies (68.7% of reported studies). There are several benefits to such studies, including reduced research wastage.⁵⁴ However, failure to sustain or increase CH following small-scale studies may lead to frustration from HCPs.⁵⁵ While all these studies reported positive feasibility and acceptability, they only entailed minimal analysis of the impact of interventions on parent or family outcomes. Those which did reported mixed results. Significant reductions in parental stress followed the C-Tips pain management intervention.⁴⁴ While the Cascade CBT-based intervention did not significantly affect QOL, psychological or family functioning, it successfully reduced fear of recurrence.⁴⁷ Non-significant effects on family QOL were noted following a telehealth palliative care program.³⁶ Taken together, these findings suggest that CH may play a role in reducing fears and decreasing parental stress but may not increase QOL.

While this review is the first of its kind, comparisons can be drawn with past reviews examining the use of technology in supporting childhood cancer and other chronic illnesses. For example, Mehdizadeh et al. identified smartphone applications primarily targeting education, information, and illness management for children and adolescents with cancer and their families, echoing our finding that illness management is an important goal of CH.³⁵ Results differ from Canter et al.³² who evaluated RCTs of technology interventions for families of children with chronic illness. Common intervention domains included conflict and communication, protective parenting behaviours and self-efficacy. The results of our review differ in the greater emphasis placed on psychosocial and informational supports across interventions. Differences may result from the focus on family outcomes and paediatric chronic illness. All palliative care interventions within the present study examined feasibility and acceptability only, with both reporting difficulties in participant recruitment and retention.^{36,40} While high acceptability and feasibility of palliative interventions was reported, recruitment difficulties may have contributed to the lack of more substantial CH evaluation.

Demonstration of efficacy across multiple measures, settings and subgroups is required for healthcare adaptation, which may explain the slow adoption of CH to date.⁵⁶ The absence of measures of interest to policy makers can negatively impact translation to practice.⁵⁷ However, this may change considering Sars-CoV-2, where circumstances have necessitated uptake, and reliance on, technology in healthcare. There is now a pressing need for practical clinical trials of digital interventions, inclusive of representative participants, settings, alternative interventions as controls, and measures of stakeholder interest.⁵⁸ CH is often developed and trialled within one setting, impacting adoption across novel settings due to lack of fit.⁵⁷ A need for additional research focus, to examine the potential utility and role of CH in paediatric cancer and the healthcare system more broadly is required.

While a high volume of studies reviewed utilised a smartphone application, four of the five studies sought only to examine feasibility or acceptability of such applications. Similarly, all telehealth studies examined feasibility or acceptability alone. In contrast, two of the three studies which employed an online group intervention sought to examine the impact on parent outcomes. This may suggest an ease to transition typical face-to-face interventions online rather than other intervention modalities. Significant effects for CBT-based interventions and online Triple-P were observed. It is of note that both interventions have proven efficacy in face-to-face contexts, providing a strong rationale for further analysis of the efficacy of such interventions via CH.

No studies examined electronic health records or interventions delivered through sensor technology. This may be due to the focus on parent and caregiver measures.⁵⁹ Previous studies have examined sensor technology in supporting physical activity for adult cancer survivors⁶⁰ and electronic health records for childhood cancer survivors.⁶¹ However, no examination of use for families of paediatric cancer has occurred. If such technologies are to become embedded within healthcare systems, additional analysis is required.

Despite their importance in care provision, a limited role for HCPs was observed in interventions reviewed. Six included contact with a HCP, with two including healthcare team members.^{36,40} The remaining interventions involved access to a trained therapist or psychologist, largely owing to their psycho-social focus. While not a specified outcome, parents used the HoMes intervention when communicating with their clinician, suggesting utility for HCP inclusion.⁴⁸ Similar opportunities could be noted for BrightHearts⁴¹ and the 'Oncology Family App'.⁴⁶ While CH may reduce burden on HCPs, there is a need to examine the role of human support within eHealth.⁵⁷ Specifically, consideration to who provides support, how and to what extent is needed. The inclusion of HCPs within CH may enhance efficacy as they act as sources of healthcare information⁶² and mediate patient attitude formation.⁶³ Several interventions included some degree of peer communication.^{43,44,45,48,49,55} The extent to which peer support contributed to intervention success requires additional analysis as it may offer a relatively low cost, but highly beneficial form of support.

No sibling-focused interventions were found within our review. This finding echoes that of a recent systematic review of psychosocial interventions for families affected by paediatric cancer, with only two interventions targeting siblings identified.¹⁹ A systematic review of smartphone applications for families of children with cancer similarly found no sibling specific interventions.³⁴ This is consistent with the present study wherein two studies specified families as participants, but no sibling outcomes were reported. Further, few informal caregivers (1.3%) served as participants across studies. This may be due to the role of parents typically as primary caregivers. An imbalance in parenting genders was also observed. Of studies including parents, 75% were mothers and 22% were fathers, with two studies employing mothers alone^{45,51} and only one balancing parenting roles.⁵² While reflective of the greater caregiving role of mothers within society, this underrepresentation of fathers is in keeping with paediatric research more broadly.⁶⁴ Future recruitment efforts should seek to gather samples reflective of the experiences of parents and caregivers affected.

On a positive note, high acceptability rates were noted across studies, which is consistent with previous research.^{65,66} While concerns have been raised around ease of use,²⁷ this was not reflected in our study. High levels of adherence to interventions was noted across the 12 studies which reported it, with adherence of less than 60% for only three studies. Of these however, two were from the same research group and used the same participants, and one employed make-up sessions to increase completion to over 80%. Two of these three studies provided intervention via online group, suggesting a limitation to the provision of supports in this manner. Retaining interest in internet-based programmes over time appears a common challenge across sub-groups.⁵⁷ The time limitations faced by children with cancer may have impacted their ability to complete scheduled interventions. These results are broadly consistent with prior analysis. A systematic review of psychosocial and QOL interventions in paediatric oncology suggested a 72% participation rate.⁶⁷ Further research is required to more fully examine the factors which may facilitate adherence.

4.1 | Study limitations

There are several limitations to the present study. Firstly, as CH is a developing area, the definition of CH is somewhat broad and evolving.⁶⁷ While every effort was made to capture all relevant studies, the lack of consistent terminology may have hampered article identification for analysis. Additionally, a focus on novel technology, rather than interventions may have been beneficial. A second limitation was the volume of pilot or feasibility studies included. The lack of research examining outcomes of CH limits the generalisability of findings to healthcare practice. Thirdly, heterogeneity of findings serves as a limitation. As a small number of interventions were observed across a variety of outcome measures and CH, limited conclusions can be drawn. Additionally, the lack of dosage information in several studies impedes a fulsome analysis. A final limitation is variability in study quality, with only 31.3% of studies meeting all MMAT criteria. To further establish the utility and efficacy of CH higher quality analysis is needed.

4.2 | Clinical implications

Several implications for practice can be derived. Research suggests the potential utility of CH to support the psychosocial, informational and illness management needs of parents and caregivers affected by cancer, suggesting possible benefits of introducing such interventions in practice. Due to the Sars-CoV-2 pandemic, and the reduction in the ability of patients, caregivers and HCPs to interact face-to-face, CH has become more pressing. The adoption of technological solutions may enable access to support in circumstances. While the research examining CH for parents, caregivers and families affected by paediatric cancer is emerging, the potential utility of CH within healthcare settings is clear.

5 | CONCLUSION

The role of CH in supporting families impacted by paediatric cancer is an emerging area of research. While this review demonstrates the acceptability and feasibility of CH for families, future work should examine CH impact on specific family and caregiver outcomes using more robust experimental designs. An emphasis on representative samples, specifically with respect to balancing caregiver genders, should be ensured. For CH interventions which have been the subject of outcomes analysis, replications or follow-up studies should be conducted to further examine effects. Additionally, research examining the generalisability of CH should be conducted to establish the scalability of such technologies, as well as additional research to examine the utility of CH to support sibling and informal caregiver needs. As considerable heterogeneity in CH was observed, future research should examine research by outcome to more clearly reflect the efficacy of such interventions. Due to the limited volume of studies this may not be presently possible.

Considerable research growth over the coming years however is anticipated.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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