The Role of Connected Health Technologies in Supporting the Psychosocial Wellbeing of Families Impacted by Paediatric Cancer

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Abstract

Survival rates for paediatric cancers are increasing. With this comes a growing need to investigate the factors which impact the wellbeing and quality of life (QOL) of children and families affected. Across a series of eight interconnected studies, this research examined the impact of paediatric cancer on the psychosocial wellbeing of families, and the potential of Connected Health (CH) to mitigate burden and increase wellbeing. CH is defined as any technology which gathers, analyses and interprets user data in a manner intended to support health outcomes, and includes Electronic Health Records (EHRs), Mobile Health (mHealth), and sensor technologies, amongst others. Studies are presented across four sections, which outline a) the current evidence in relation to CH; b) the unmet needs of families impacted by paediatric cancer; c) the barriers and facilitators to CH use in paediatric cancer; and d) a pilot psychosocial CH intervention for families of children with cancer.

The first two studies, presented in **Section A,** explored the current role of CH for families impacted by paediatric cancer. As CH may derive from both empirical and commercial sources, both forms were analysed to determine the current availability and efficacy of such tools. **Study 1** involved a systematic review of the literature regarding CH use in supporting families with paediatric cancer, while **Study 2** consisted of a content analysis of commercially available CH mobile applications (apps). Positive effects across both commercially available and empirically driven CH were found. However, the limited number of CH interventions, alongside the high volume of feasibility and acceptability analyses, suggests that further experimental analysis is needed to determine the efficacy of CH.

Next, **Section B** explored the unmet needs of families living with paediatric cancer in Ireland, through the lens of parents and healthcare providers (HCPs). **Study 3**

involved in-depth interviews with parents and supportive personnel (specifically HCPs and hospital volunteers) to determine families' unmet needs. The results of this qualitative analysis highlighted the vast array of interconnected challenges encountered by families, across both family and individual functioning. This in turn allowed attention to be directed to several domains in which support may be meaningfully targeted.

For CH to effectively address the needs of families, technologies must be accessible to those for whom they are designed. To this end, the studies presented in **Section C** examined the factors which facilitate or inhibit CH use by families. Using secondary analysis of the Health Information National Trends dataset, **Study 4** examined the impact of the digital divide on efficacy in health information seeking for caregivers of children with illness, while **Study 5** explored its impact on CH use. Next, to determine the technological pre-requisite skills required to effectively use CH, **Study 6**, a survey of parents and HCPs, examined the role of eHealth literacy, technology use and attitude on the ability to identify higher quality CH. Following this, **Study 7** explored barriers and facilitators to CH use from the perspectives of parents and HCPs in Ireland through in-depth interviews conducted in tandem with Study 3. While positive perspectives on CH were found, the results obtained demonstrate the impact of the digital divide and technological pre-requisite skills on CH access for parents. Avenues through which CH may offer support included communication, care individualisation and information sharing, though data security and pace of change presented as hesitations to use.

Finally, drawing upon the results of Studies 1 to 7, and guided by public and patient involvement (PPI), the efficacy of an online self-paced Acceptance and Commitment Therapy (ACT) programme to support families living with paediatric

cancer is presented in **Section D.** In addition to exploring the feasibility and acceptability of this CH mediated psychosocial programme, **Study 8** sought to examine the role of psychological flexibility on parental wellbeing through this online mediated ACT programme. Specifically, a repeated measures design was used to explore the impact of the CH mediated intervention on the psychological flexibility, burden and wellbeing of parents of children with cancer. Results indicated acceptability of the programme and positive effects on wellbeing, burden and psychological flexibility, though challenges with post-intervention data collection was noted. Findings suggested a key role of cognitive defusion on the psychological flexibility of parents, suggesting a need for additional analysis in this area.

Taken as a whole, this research demonstrates the utility of CH to support families impacted by paediatric cancer and identifies key factors which should be considered to facilitate uptake in practice. Further, it presents a model through which CH may be meaningfully applied to effectively address the needs of families impacted by paediatric cancer.

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Table of Contents

Chapter 1 General Introduction 17
1.1. Paediatric Cancer and Family Wellbeing 17
1.2. Supporting Psychosocial Wellbeing in Paediatric Cancer........................ 20
1.3. Healthcare Digitalisation 23
1.4. Connected Health 26
1.5. Aims and Objectives of Thesis 27
1.6. Overview of Thesis Structure 33
Section A: Current Use of Connected Health in Paediatric Cancer 36
Section A Introduction 37
A.1. Commercially available CH 37
A.2 Section Overview 39
Chapter 2 Study 1: The role of Connected Health technologies in supporting families affected by paediatric cancer: A Systematic Review 41
2.1. Introduction 42
2.2. Method 43
2.3. Results 46
2.4. Discussion 58
Chapter 3 Study 2: Behaviour Change Techniques within Smartphone Application Connected Health Interventions for Paediatric Cancer: A Review 66
3.1. Introduction 67
3.2. Method 69
3.3. Results 71
3.4. Discussion 81
Section A Discussion 85
Section A Conclusion 88
Section B: Exploring the Needs of Families Impacted by Paediatric Cancer 89
Section B Introduction 90
B.1 Section B Overview 91
Chapter 4 Study 3: "It's a big big chunk out of life really" Perceived needs and challenges of families impacted by Paediatric Cancer: A Qualitative analysis 93
4.1. Introduction 94
4.2. Method 96
4.3. Results 100
4.4. Discussion 114
Section B Discussion 120
Section B Conclusion 120
Section C: Barriers and Facilitators to the use of CH in Practice 122
Section C Introduction 123
C.1. Digital Divide 123

C.2. Pre-requisite Skills 124
C.3. Stakeholder Perspectives 126
C.4. Overview 128
Chapter 5 Study 4: Health Information Seeking by Caregivers of Children: The use of online sources and their impact on confidence, effort, and frustration. 131
5.1. Introduction 132
5.2. Method 134
5.3. Results 136
5.4. Discussion 144
Chapter 6 Study 5: The use of Connected Health Technology by Caregivers of Children with Illness: Analysis of sociodemographic barriers and enablers 151
6.1. Introduction 152
6.2. Method 153
6.3. Results 156
6.4. Discussion 162
Chapter 7 Study 6: Technology Usage, eHealth Literacy and Attitude Towards Connected Health in Caregivers of Paediatric Cancer 167
7.1. Introduction 168
7.2. Method 169
7.3. Results 173
7.4. Discussion 177
Chapter 8 Study 7: Utility, barriers, and facilitators to the use of Connected Health to support families impacted by paediatric cancer: A Qualitative Analysis 181
8.1. Introduction 182
8.2. Method 183
8.3. Results 185
8.4. Discussion 193
Section C Discussion 199
Section D: Pilot analysis of a CH mediated Psychosocial Programme 205
Section D Introduction 206
D.1. Synthesising the Findings of Sections 1, 2 and 3 206
D.2. Recommendations for CH development 207
D.2.1. Unmet Needs 208
D.2. Designing a Psychosocial Intervention for Parents/Caregivers 215
D.3. Psychosocial Interventions in Paediatric Oncology 216
D.4. ACT Model of Psychological Flexibility/Inflexibility 219
D.5. Section Overview 226
Chapter 9 Study 8: Impact of brief online self-directed Acceptance and Commitment Therapy on psychological flexibility, parenting experience and wellbeing for parents of children with cancer. 228
9.1. Introduction 229

9.2. Method 230
9.3. Results 241
9.4. Discussion 251
Section D Discussion 257
Chapter 10 General Conclusion 258

Table of Figures

Figure A.1 Overview of Section Aims……………………………………….. 40

Figure 2.1 Prisma Diagram………………………………………………….. 47

Figure 3.1 Search Strategy and Results……………………………………… 72

Figure A.2. Summary of Section Findings……………………………………. 87

Figure 4.1 Distribution of Themes Across Participant Groups………..……. 102

Figure C.1 Graphical Depiction of Section C………………………...…… 130

Figure 6.1 Use of CH Technologies by Caregivers………………..……… 157

Figure 6.2 Caregiver Sharing of Health Data……………..………………… 160

Figure C.2 Graphical Display of Results………..………………………… 172

Figure D.1 Considerations for the Development of CH for Families of Children with Cancer……………………..…………………… 201

Figure D.2 ACT model of psychological flexibility/inflexibility with pillars of ACT overlayed………..………………………………………. 221

Figure 9.1 ACT for Parents/Caregivers Moodle Site…………………...…… 237

Figure 9.2 ACT for Parents/Caregivers Sample Exercise……………..……. 238

Figure 9.3 Research Protocol…………..…………………………………. 239

Figure 9.4 Participant Recruitment and Attrition……………………………. 242

Figure 9.5 Pre-intervention PPFQ Scores………………..…………………. 243

Figure 9.6 Pre-intervention Self-as Context scores……………………..…... 245

Figure 9.7 Pre-Intervention Parent Wellbeing……………………………….. 246

Figure 9.8 Pre-intervention Parenting Burn-out……………………...…… 247

Figure 9.9 Participant 2: Post-Intervention and Follow-up Data…………..... 248

Table of Tables

Table 2.1 Search Terms Expanded…………………………………………… 44

Table 2.2 Information from Included Manuscripts……………………………. 48

Table 3.1 App Information……………………………………………………. 74

Table 3.2 App Features by Area of Support………………………………….. 77

Table 3.3 Frequency of BCTs Across Apps………………………………….. 99

Table 4.1 Semi-Structured Interview Questions ………………………………. 98

Table 4.2 Challenges and Needs of Families………………………………... 100

Table 5.1 Caregiver Type by Child Health Condition…………………………. 138

Table 5.2 Demographic Information by Caregiver type………………………. 139

Table 5.3 Sources of Health Information by Caregiver type………………... 140

Table 5.4 Effort, Frustration and Self-efficacy in Health Information Seeking……………………………………………….………………… 142

Table 6.1 HINTS Questions Across Variables………………………………... 154

Table 6.2 Demographic Information for Caregivers of Children…………….. 156

Table 6.3 CH Use Across Caregivers………………………………………… 158

Table 7.1 Electronic Device/Internet Usage……………………………………. 170

Table 7.2 eHealth Literacy Scale……………………………………….… 171

Table 7.3 eHealth Attitude…………………………………………………….. 171

Table 7.4 CH Application Evaluation ………………………………………….. 172

Table 7.5 Demographic Information…………………………………………….. 172

Table 7.6 Mean Device, Attitude and eHealth Literacy……………………..……. 174

Table 7.7 Evaluation of CH Applications…………………………..…..……..... 175

Table 8.1 Interview Guide……………………………………………………… 184

Table 8.2 Challenges and Needs of Families…………………………………… 186

Table D.1 Recommendations Arising From Sections 1, 2 and 3……………… 211

Table 9.1 ACT Intervention Exercises per Week……………………………….. 236

Table 9.2 Means, Maximum and Minimum Scores of Pre-Intervention Survey Measures…………………………………………………….. 242

Table 9.3 Comparison of PPFQ and SACS Across Treatment Stages……….. 244

Table 9.4 Percentage Change Across Time………………………………….. 248

Table 9.5 Participant Programme Access and Use……………..……………… 249

Table 9.6 Access to Content by Topic..…………………………………….. 250

List of Abbreviations

AARP	Abbreviation Acceptability Rating Profile
ACT	Acceptance and Commitment Therapy
ALL	Acute Lymphocytic Leukaemia
Apps	Applications
AI	Artificial Intelligence
ATC/IQ	Attitudes Toward Computer/Internet Questionnaire
BAI	Beck Anxiety Inventory
BDI	Beck Depression Inventory
BCTs	Behaviour Change Techniques
BCTv1	Behaviour Change Technique Taxonomy Version 1
BMI	Body Mass Index
BPBs	Brief Parental Burnout Scale
CALPAS-G	California Psychotherapy Alliance Scale- Group Short Version
C-TIPs	Cancer-tailored intervention for pain and symptoms
CBT	Cognitive Behavioural Therapy
SDQ	Child Emotional and Behavioural Difficulties: Strengths and Difficulties Questionnaire
CSQ	Child Satisfaction Questionnaire
CH	Connected Health
DASS-21	The Depression Anxiety Stress Scale - short form
eHealth	Electronic Health
eHEALS	eHealth Literacy Scale
EHRs	Electronic Health Records
eSCIPP	Electronic Surviving Cancer Competently Intervention Program

FGT	Family Caregiver Tool
HCPs	Healthcare Providers
HEAL	Healthy Eating and Active Living
HINTS	Health Information National Trends Survey
HoMeS	Home Medication Support
HOP	Hospital Outreach Programme
IIAQ	Internet Intervention Adherence Questionnaire
MMAT	Mixed Methods Appraisal Tool
mHealth	Mobile Health
PBA	Parental Burnout Assessment
PLC-c	PTSD Checklist
PPUS	Parents' Perception of Uncertainty Scale
PPFQ	Parent Psychological Flexibility Questionnaire
PSS	The Perceived Social Support Scale
PTSS	Post-Traumatic Stress Syndrome
PPI	Public and Patient Involvement
QOL	Quality of Life
QOLLTI-F	Quality of Life in Life Threatening Illness-Family
RCT	Randomised Control Trial
SACS	The Self-as-Context Scale
SAS	Self-Rating Anxiety Scale
SDS	Self-Rating Depression Scale
SPSS	Statistical Package for Social Sciences
TAB	Take a Breath
TAM	Technology Acceptance Model

TR	Therapeutic Recreation
WHO	World Health Organisation
WHO-5	WHO Well-Being Index 5-items
YSQ	Youth Satisfaction Questionnaire
ZBI	Zarit Burden Inventory

Publications arising from the thesis

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Chapter 1 General Introduction

Each year, over 200 children in Ireland are diagnosed with cancer (National Cancer Registry Ireland, 2022). This number is growing, with rates rising by 20% between 1994 and 2019 (National Cancer Registry Ireland, 2022), and expected to double by 2040 (Department of Health Ireland, 2017). Encouragingly, survival rates are also increasing (National Cancer Registry Ireland, 2022), with five-year survival for children with cancer in Ireland at 79% (Stack, Walsh, Comber, Rylan & O'Lorcain, 2007), and 80% of children diagnosed with cancer between 1994 and 2014 alive in 2017 (National Cancer Registry Ireland, 2017). This increasing prevalence and improved survivorship has resulted in significant volumes of the population living with and beyond cancer, with four percent of the Irish population being cancer survivors (National Cancer Registry, 2018). However, many survivors face secondary impacts of cancer, impacting their access to education, social outlets and employment, overall health and quality of life (QOL). This is particularly impactful for survivors of childhood cancer, for whom secondary effects may impact key developmental and social milestones as they transition to adulthood. In response, there is a pressing need to determine how we may best support children and families living with and beyond paediatric cancer, to mitigate these secondary effects and enhance QOL.

1.1. Paediatric Cancer and Family Wellbeing

While families play an important role in supporting children with cancer (Wiener et al., 2015), the impacts on family members themselves are significant and enduring. For parents, taking on a dual role of parent and care manager may cause emotional strain (Vrijmoet-Wiersma et al., 2008; Williams et al., 2006), with fatigue, fear, and stress on marital relations common (McKiernan & Balfe, 2019; Pierzynski et al., 2020). Concerns around employment, finances and time costs are also commonly raised (Shepherd & Woodgate, 2011). Impacts often extend beyond initial diagnosis and treatment, with challenges encountered returning to employment, managing family responsibilities and maintaining parental relationships following treatment (Peikert et al., 2020). In response to these challenges, a wide range of supports are required, including decisional (Yoshida et al., 2014), informational (Longacre, 2013), psychological (Aziza et al., 2019), social (McKenzie & Curle, 2012) and care coordination (Keats et al., 2019). The wide variety of challenges and associated support needs highlights both the significance and the breadth of the challenges to QOL that may be encountered by parents of children with cancer.

Beyond this, siblings may also be negatively impacted by their brother or sister's illness (Alderfer et al., 2010; Houtzager et al., 2004), with anxiety, social isolation, guilt, anger (Houtzager et al., 2004) and educational challenges (Long et al., 2017) commonly reported. Like parents, siblings exhibit a wide variety of needs across educational, social and psychological domains. For siblings, re-establishing normalcy, maintaining familial relations (Yang et al., 2016), parental attention (O'Shea et al., 2012) and family engagement (Tasker & Stonebridge, 2016) are commonly reported areas of need. It is therefore clear that paediatric cancer significantly impacts more than just the individual child affected.

There are a range of supports that may help families cope with these challenges. For instance, family coping may be aided by information provision, psychosocial support (Aziza et al., 2019), peer support networks (McKenzie & Curle, 2012), improved communication with HCPs, and coordinated follow-up care (Keats et al., 2019). However, barriers to accessing such supports are common, fuelled by under-resourced services (Hegarty et al., 2018; Olfson, 2016), and logistical challenges (Warner et al., 2015). In Ireland, for example, while incidence rates of paediatric cancer are spread across the country (National Cancer Registry Ireland, 2017), treatment is delivered through centralised hospitals, requiring significant travel and disruption for many. In particular, for parents who reside far from their child's hospital, loss of income, travel time and cost can cause concern (Shepherd & Woodgate, 2011). These negative impacts can persist following treatment, impeding parents' return to employment, and presenting difficulties in managing family responsibilities and maintaining relationships (Peikert et al., 2018). These factors may, in turn, impact access to secondary supports (i.e. psychosocial, educational or other supports), should they too be delivered outside of local communities, presenting further challenges to families. As such, while the effects of paediatric cancer on families are significant and enduring, challenges in obtaining supports to address these needs are often faced.

Within an Irish context, increased emphasis has been placed on QOL following paediatric cancer, with the need for supports to enhance family wellbeing posited (Hegarty et al., 2018). This was echoed in the National Cancer Strategy of Ireland (Department of Health, 2017), a central goal of which is to develop QOL supports for those living with cancer. However, while this goal is positive, emphasis on understanding the needs and experiences of children with cancer in Ireland remains absent (Barrett et al., 2019). This is troublesome, as understanding unmet needs appears a prerequisite for appropriate allocation of resources, and effective service development and provision (Halpern et al., 2014; Mullen & Hanan, 2019). In addition, while previous research has explored the unmet needs of adult survivors of paediatric cancer within an Irish context (Mullen & Hanan, 2019), no research to date has examined the unmet needs of families more generally. As such, there is a need to cast light on these needs and challenges to ensure meaningful support are developed.

1.2. Supporting Psychosocial Wellbeing in Paediatric Cancer

It is clear that the impacts of a paediatric cancer diagnosis are severe and enduring, with multiple facets of individual and family functioning impacted. While the impacts across domains are significant, one domain highlighted as a priority by parents and children alike is psychological wellbeing (Aldiss et al., 2019). Children with cancer face significant psychosocial impacts including increased risk of depressive symptomology alongside increased anxiety and sadness (H. C. W. Li et al., 2010). However, parents too are significantly impacted by a diagnosis of paediatric cancer (Kearney, Salley & Muriel, 2015) with emotional strain (Vrijmoet-Wiersma et al., 2008; Williams et al., 2006), distress (Norberg et al., 2011; Wenninger et al., 2013), post-traumatic stress, depression and anxiety (L. K. Campbell et al., 2009; Cernvall et al., 2017) commonly reported, which in turn have negative impacts on daily functioning (López et al., 2021a). The impact of paediatric cancer on parental wellbeing is highly heterogenous, impacted both by their child's unique cancer journey and their own mental wellbeing prior to diagnosis. While cancer functions as an extreme stressor which causes marked but transient distress for parents who are resilient and well-functioning before the event (Alderfer et al., 2009), for parents with mental health vulnerabilities or pre-existing challenges, impacts can be overwhelming (Boman et al 2013). As such, it is clear that paediatric cancer poses significant challenges to both child and parental wellbeing. When considered in the context of the interplay between parent wellbeing and the care of the child with cancer, the need for supports to address these wellbeing concerns is highlighted. While parents are their child's strongest advocate and resource, challenges to parents' psychosocial wellbeing may pose challenges to their child's cancer treatment, impact support of the child and siblings, and threaten family functioning and stability over time (Alderfer et al., 2009). In response to these challenges there is a clear need for further exploration of how best psychological wellbeing may be supported for parents of children with cancer. While several psychological interventions have been developed to support parents of children with cancer, they often lack empirical analysis, are rarely generalised across settings (Michel et al., 2020), and lack long term effectiveness due to too limited a scope with regard the underlying therapeutic model, or with an over-focus on psychopathology (Hubert-Williams et al., 2014). One of the most common forms of psychosocial support for this group is Cognitive Behavioural Therapy (CBT), which has demonstrated positive effects when delivered both in-person and remotely (Cernvall, Carlbring, Ljungman, Ljungman, & Von Essen, 2015a). However, weaknesses in CBT have been reported. As CBT sees distress as an abnormality requiring solutions, it provides tools to minimise the impact of distressed thoughts on behaviour through avoidance or suppression. While avoidance is often effective in the moment, ongoing or high levels of avoidance is associated with negative psychological outcomes and distress (Cernvall, Carlbring, Ljungman, Ljungman, & Von Essen, 2015a). The importance of challenging cognitions, a key tool in CBT, has also been questioned, with a meta-analytic review casting doubt on its importance within intervention (Longmore & Worrell, 2007). In response to this, novel approaches which do not rely on avoidance require consideration.

1.2.1. Acceptance and Commitment Therapy

One behavioural psychosocial intervention which may be of benefit in the context of paediatric cancer is Acceptance and Commitment Therapy (ACT). ACT is a third-wave behavioural therapy (Hayes et al., 2006) which seeks to increase contact with the present moment in an effort to transition from avoidant thought patterns toward acceptance of experiences. ACT seeks to reduce avoidance and increase commitment to individual values through emphasising increased contact with the present moment in an effort to reduce avoidance and increase acceptance (Hayes et al., 2011). Through increasing contact with the present moment and disentangling the self from the difficulties faced, an individual is supported to transition from avoidant thought patterns toward acceptance. Acceptance in this context is active rather than passive, with an emphasis on continued movement in line with personal values when faced with negative thoughts or feelings. As such ACT does not seek to alter the content or form of thoughts, rather it focuses on reducing their impact on behaviour, through emphasising value-directed action (Greco et al., 2008). ACT may be well suited in the context of cancer through facilitating a more individualised approach to the analysis of individual difficulties and experiences (Arch & Mitchell, 2016). The emphasis of ACT on acceptance and committed action is also consistent with recent movement away from the ‘fighting spirit’ towards resilience, normality and acceptance (Houldin, 2007). ACT differs from past approaches such as CBT in that distress and suffering in response to cancer are viewed as normal responses (Hayes, Strosahl, et al., 2012). While ACT does not seek to alter or avoid these negative thoughts or feelings in response to cancer, it instead seeks to reduce their impact on behaviour, emphasising continued movement in line with values (Greco et al., 2008). This ability to be open, aware and engaged despite negative thoughts, feelings or emotions is termed psychological flexibility and predicts successful adjustment in response to illness for individuals (Graham et al., 2016; Hayes et al., 2006) and families alike (Van Schoors et al., 2019). Psychological flexibility is associated with better adjustment for those with cancer (Ciarrochi et al., 2011), with positive effects on QOL and distress noted (Feros et al., 2013). These positive impacts may be due to amplified distress from avoidance of negative private events and the resulting increasing salinity and narrowing of available behaviours to continue to avoid stimuli associated with negative events (Hayes et al., 2006). As such ACT may be particularly effective for cancer survivors as it promotes psychological flexibility when approached with changing circumstances and becoming ‘unstuck’ from ones thoughts. A recent systematic review of the use of ACT for psychological support of oncological patients found ACT to be effective (González-Fernández & Fernández-Rodríguez, 2019). These findings were echoed by Fashler et al., (2018) with ACT found to significantly increase QOL, psychological flexibility while reducing anxiety, distress and pain. Those patients who received interventions based on ACT showed a better emotional state and quality of life and greater psychological flexibility. While ACT has been noted as effective in increasing quality of life for those diagnosed with cancer no research to date has examined its impact on children. While ACT has demonstrated positive effects for parents of children with serious illness (Clery et al., 2021; Kallesøe et al., 2016), impact for parents of children with cancer has yet to be established.

1.3. Healthcare Digitalisation

Healthcare services worldwide are challenged by increasing patient volumes alongside staffing shortfalls (Haddad et al., 2022). This pressure on finite resources necessitates healthcare efficiencies through decreasing costs while increasing access (Wootton et al., 2004). Healthcare digitalisation has been espoused as one means through which these challenges can be addressed (Gerrits, 2019). Digitalisation of healthcare has been considered for some time, with the World Health Assembly (WHA, 2005) emphasising the need for countries to develop digital healthcare strategies. More recently, the World Health Organisation (WHO) launched its global strategy for digital health (World Health Organization, 2021), emphasising the need to develop interconnected digital health capacities both within and across countries, while seeking to minimise the privacy, security and access risks of digital health. In the context of these global efforts to increase digitalisation, analysis of how best to expand such services to enhance healthcare in an equitable, impactful manner is needed.

In recent times, healthcare digitalisation has been accelerated by the Covid-19 pandemic. In response to global social distancing requirements, limits to in-person services were introduced (Keesara et al., 2020), resulting in a greater reliance on digital technologies to support care (Badawy & Radovic, 2020). In tandem, resource constraints, waitlist volumes and staffing challenges arising from burnout post-Covid, further compounded the need to develop supports for healthcare delivery (Gavin et al., 2020). Within cancer services, rapid adoption of virtual service provision occurred in response to Covid-19 (Jiang et al., 2020). Accordingly, while the accessibility of digital service provision increased, so too did its acceptability, with reduced costs, increased convenience, flexibility and greater sense of normalcy for cancer patients, particularly for those who are frail or living in rural areas (Jiang et al., 2020). In addition, patients reported greater person-centred care arising from increased individual time with healthcare teams (Jiang et al., 2020). For providers, ease of collaboration across disciplines and access to speciality services was reported, leading to higher quality patient care (Jiang et al., 2020). Within paediatric cancer, however, concern was raised regarding a perceived lack of governance of digital healthcare by healthcare providers (Vasquez et al., 2020). Thus, while digitalisation accelerated in response to Covid-19, further efforts are required to support healthcare systems in its wake, particularly in paediatric cancer. With this comes a need to explore how digitalisation may be effectively employed to support patients and families, with learnings arising from Covid-19 likely providing beneficial insights.

However, while digital health is espoused to enhance healthcare delivery, consideration is needed to the risk of inequality in access. As highlighted by the World

Health Organisation (2021), the impact of digital determinants of health such as technological literacy and access to technology, on access requires significant consideration. This access inequality associated with healthcare digitalization is termed the ‘digital divide’, or the difference in access to digital technologies across groups (Parsons & Hick, 2008; Van Dijk & Hacker, 2003). The digital divide notes the potential negative impact of digital technologies on the health outcomes of low socio-economic groups through challenges accessing and engaging with these technologies (W. ying S. Chou et al., 2011). In contrast those from higher socio-economic groups more likely to benefit from such technologies (Parsons & Hick, 2008), and thus have greater health outcomes (W. ying S. Chou et al., 2011). This inequality in access appears to hold even for those technologies where access is mediated by a gatekeeper (Weiss et al., 2018). While the digital divide highlights the potential risks of barriers to digital healthcare for some socio-demographic groups, other digital determinants of health as noted by the WHO above may also impact. One such key pre-requisite of engaging effectively with digital healthcare are digital literacy skills. Digital literacy encompasses those skills needed to successfully navigate digital technology, including cognitive, social and motor skill domains (Cohen, 2012). Access to, and familiarity with, different forms of technology is thought to contribute to these digital literacy skills, as those who engage more often with technology are more likely fluent in its use. A *further* key aspect of digital literacy requiring consideration is eHealth literacy, or the ability to access, assess, and action health information sourced online (Norman & Skinner, 2006). Ehealth literacy is a key digital determinant of health, and vitally supports an individuals ability to process and use information sourced online (Lluch, 2011). As such, it is clear that for digital healthcare to advance in paediatric cancer, consideration is needed as to the specific digital determinants of health which may pose barriers to access for some, exacerbating the digital divide. Analysis of the impact of these domains on CH use in paediatric cancer is needed to determine areas in need of support.

1.4. Connected Health

While healthcare digitalisation takes many forms, one approach increasingly employed is Connected Health (CH). CH refers to the use of smart technology within healthcare settings (Hesse et al., 2016), and involves the two-way flow of information between technology and user. Simply put, CH technologies gather data from the user, analyse this data and feed it back to the user in a way that is intended to be meaningful. Examples of technologies considered under the CH umbrella include eHealth, mHealth, sensors and Electronic Health Records (EHRs), amongst others. CH differentiates itself from other technologies in that it seeks to connect people, processes and technology, reflecting a sociotechnical approach (Barr et al., 2014). While there are several advantages to increased connectivity within healthcare, a key benefit of CH is facilitating communication and information sharing between stakeholders, including between patients and doctors, patients and peers, and between medical professionals (Carroll, 2016). For patients, CH may be of benefit through reducing bottlenecks (Jungwirth & Haluza, 2019), facilitating communication between care providers (Hah et al., 2019), and timely sharing of clinical information (Wicks et al., 2014). For healthcare systems, CH offers scalability, customization and efficiencies (Mirza et al., 2008). While CH appears a promising means of aiding clinician workload and supporting patient care, while also addressing larger systemic healthcare challenges such as cost, access and efficiency, analysis of its use for families impacted by paediatric cancer remains outstanding.

1.5. Aims and Objectives of Thesis

This thesis seeks to explore the potential role of CH in supporting the needs of families impacted by cancer. This knowledge gap is addressed through 1) establishing what is currently known regarding the availability and efficacy of CH for families impacted by childhood cancer; 2) exploring the challenges experienced by families facing paediatric cancer and identifying unmet needs that require additional support; and 3) analysing the barriers and facilitators to CH use for this group. From this, a fulsome understanding of whether CH may offer a means to address the needs of families impacted by childhood cancer is obtained. To demonstrate these learnings in practice, a pilot study exploring the impact of an online self-directed intervention based on Acceptance and Commitment Therapy (ACT) for parents of children with cancer is presented.

1.5.1. Defining Key Terms

A brief objective definition of common terms employed across this thesis is presented below to support understanding and cohesiveness.

Connected Health (CH). CH is defined as the use of digital technologies within healthcare settings (Hesse et al., 2016) wherein there is a two-way flow of information between the technology and user. Specifically CH refers to the use of technology to gather data from the user, analyse these data and return it to the user in a way that is intended to be meaningful. CH is considered an umbrella term including technologies such as eHealth, mHealth, sensors and EHRs, amongst others. It is of note that while an umbrella term, the technologies listed above are not always considered CH. Only those which include the two-way flow of information can be considered CH. For example, a sensor which gathers health information and stores it to a cloud inaccessible to the patient, or which does not meaningfully analyse the information for those who can access it, would not be considered CH. Similarly eHealth which involves web-based provision of information with no data collection would also not be considered CH.

Digital Health. The term digital health is used across this thesis to refer to the use of technology in health care. This includes both CH and non-CH technologies, and is used where broader references to the use of technology in health care is intended.

Family. The term family is used to refer to those family members in a child's immediate environment who provide informal care (i.e. parents, or grandparents where applicable) or with whom they share a home (i.e. siblings). This terminology is consistent with behavioural analysis (see , Vaughn et al., 1997, Isaacs et al., 1982 and Neely et al., 2022) as examples.

Psychosocial Wellbeing. Psychosocial wellbeing in paediatric cancer is defined as the absence of impairment across physical, emotional, cognitive, and familial domains (Marcus, 2012). Psychosocial wellbeing includes both individual level factors such as subjective well-being, optimism, happiness, and self-determination (see Seligman & Csikszentmihalyi, 2000) alongside private events (i.e. negative thoughts or emotions, psychological distress) and the environmental context (i.e. immediate environment, and the broader cultural, socioeconomic, and historical context). Consistent with positive psychological approaches, Psychosocial wellbeing, when considered from a contextual-behavioural science lens per Coyne et al., (2020) refers to the ability to observe, assess and adapt to the demands of a situation, while continuing to engage in actions that are congruent with what matters most to that person, their values (Hayes, Strosahl, et al., 2012). As such, psychosocial wellbeing is considered as an overall cohesion between ideal and actual levels of behaviour, which facilitates movement in line with ones values (Fawcett, 1991). In line with this, the importance of cumulative effects (i.e. small changes can impact wide domains of behaviour), patterns of behaviour (i.e. the impacts of consistent actions, positive or negative) and areas of control (i.e. focus on changing what you can control) on psychological wellbeing is noted (Coyne et al., 2020).

1.5.2. Methodological Framework

A mixed methods approach underlies the present thesis, with specific methods for each study selected to best fit the specific research questions posed. As such, this thesis includes methodologies such as systematic review, content analysis, qualitative analysis, exploratory data analysis and pilot analyses. While the work contained in the thesis is exploratory in nature and not based in any specific theoretical framework, the present analysis is informed by a contextual behavioural science (CBS) perspective, with an over arching aim of exploring the broader environmental context of families of children with cancer, to identify the environmental contingencies impacting both psychosocial wellbeing and digital health adoption to allow for the development of a support which effectively addresses these factors. CBS is a pragmatic worldview of functional contextualism which derives from behaviour analysis in both methodology and underlying assumptions. As such, this approach seeks to explore the behavioural principles underlying complex behaviours so as to reduce human suffering and advance wellbeing (Hayes, Barnes-Holmes, et al., 2012). CBS posits that individual behaviour is impacted by the functionally associated circumstances and broader environment (Friman, 2021). By viewing behaviour with this wider contextual lens, the quality and social validity of interventions developed to support behaviour change can be enhanced through addressing these broader contextual factors in a systematic and considered manner (Friman, 2021). Within behavioural science, these contextual factors impacting upon a behaviour of concern are identified through functional assessment wherein the specific environmental, antecedent, behavioural, and consequent factors are explored and identified in turn. The present thesis is guided by this functional analytic approach with a comprehensive approach to exploring and identifying those factors impacting CH use for this cohort examined in turn. Those contextually related factors are then applied in practice to the development of a CH intervention to support the psychosocial wellbeing of parents of children with cancer.

In line with this, the present thesis seeks to explore 1) the current environmental and behavioural contingencies impacting the psychosocial wellbeing of families; and 2) the behavioural (i.e. prerequisite skills, psychological flexibility), environmental (i.e. access to digital technologies, access to services), and individual (i.e. learning history pertaining to digital technologies) contingencies surrounding CH for families of children with cancer. Contingency analysis in turn is supported by review of the literature to date through systematic review and content analysis to explore the efficacy of CH for this group more fully. Through this systematic approach, clearer understanding of the broader system surrounding families impacted by paediatric cancer is obtained allowing for CH responsive to these needs and challenges to be developed.

This methodological approach is also consistent with the United Kingdom Medical Research Council Framework for Complex Intervention Development (Skivington et al., 2021). Specifically, the potential application of CH to address wellbeing in paediatric cancer is explored by first considering the current evidence base (i.e. what does the literature tell us about the use of CH in paediatric cancer?), alongside the broader environmental context (inclusive of current supports, unmet needs and experiences of those living with paediatric cancer). Through this approach, greater consideration is given to the broader system in which the intervention would be placed, enhancing its impact in practice. The methodological framework of the current thesis adheres somewhat to the phases of this Framework for Complex Intervention

Development. Per the first step in this framework an intervention was identified for development, with the potential application of a CH intervention hypothesised and explored. Secondly the feasibility of the intervention is explored, in this instance with the barriers and facilitators of a CH intervention in paediatric cancer considered. Thirdly, the impact of the intervention is evaluated through pilot analysis. Through this systems-based approach to exploring the potential utility of CH for families impacted by paediatric cancer, more effective sustainable interventions reflective of real-world factors can be established.

Stakeholder Inclusion. Stakeholder engagement and collaboration played a vital role in informing the research conducted across the present thesis. Per the United Kingdom Medical Research Council Framework for Complex Intervention Development (Skivington et al., 2021), engagement with stakeholders in research is of pivotal importance to ensure that interventions developed are applicable to real-world contexts and needs, and are acceptable, accessible and effective for those for whom they are intended. Stakeholder engagement approaches were embedded across the research programme and informed the overall direction of analysis. Specific stakeholder engagement methods developed in tandem with the research programme through continuous reflection, with an overall movement from engagement to involvement as the research progressed. As such, while stakeholders at the offset of this research were engaged in consultation, the degree of collaboration with stakeholders as partners in this research increased over time as the researcher's own skills in this domain grew. The three primary forms of stakeholder engagement conducted across this research project are described in detail below.

Initial Stakeholder Engagement. Stakeholder engagement commenced at the outset of the research programme, with stakeholders from representative agencies (i.e.

Childhood Cancer Ireland, CanTeen, Barretstown, etc.) contacted to obtain their input on the overall aims and objectives of this research project. The need for analysis of the experiences of children and families was highlighted here, alongside the need to explore perspectives on, and barriers to, CH use for this group.

Research Steering Committee. Following this, and to support ongoing stakeholder engagement, a steering committee was established to guide the development of the qualitative analyses conducted within this thesis. This steering committee consisted of a healthcare provider, representatives of a charity agency (specifically Barretstown), researchers with expertise in paediatric cancer and a parent of children with cancer. Several meetings of this committee were held across the development and implementation of studies 3 and 6 to establish research aims, methods and to disseminate findings.

Patient and Public Involvement (PPI). PPI is research developed in partnership with those for whom it is intended, rather than that developed for groups without their inclusion (INVOLVE, 2012). PPI requires close collaboration and partnership between researchers and patients (or those who are the subject of the research), with both groups working together across the research lifecycle. The importance of including patient voices across all stages of research has increasingly been raised (Richards et al., 2016), and is associated with increased impact (Chalmers et al., 2014). As patients are experts in their own experiences, they may be best placed to determine where research efforts should be directed, in turn increasing integrity and social validity (Biggane et al., 2019). PPI in cancer research can help to increase the relevance of research questions, increase impact and social validity, and empower patients and caregivers (Brett et al., 2014; Froggatt et al., 2015; Thompson et al., 2014). Through inclusion of PPI in the development of supports, the lived experiences of families can be better captured and considered. In line with this a PPI panel was established to guide Section 4, from synthesis of findings across sections 1, 2 and 3 to establishing the aims and methodologies of Study 7. This panel consisted of several parents of children with cancer, who guided the direction and completion of Study 7.

1.6. Overview of Thesis Structure

Studies are presented in four sections, outlined in detail below.

1.6.1. Section A

The first two studies evaluate current CH supports for families impacted by paediatric cancer. **Study 1**, a systematic review of currently available CH, examines the research literature pertaining to the efficacy and utility of these technologies to support families of children with cancer. However, many CH supports targeted towards families of children with cancer do not derive from empirical sources, and are instead freely available on the market. To fully establish the current CH landscape for families, commercially available CH also requires consideration. To achieve this, **Study 2** examines the prevalence of Behaviour Change Techniques (BCTs) within commercial CH mobile applications (apps), and investigates their relationship with cost, download volume and rating. This is achieved through systematic searches of the Google Play and the Apple App stores and content analysis of CH arising. Through this analysis of both empirically driven and commercial CH, Section A provides an overview of the current use and efficacy of CH for families of children with cancer, as well as indicating how parents may be supported to access effective CH.

1.6.2. Section B

For any CH technology to be effective, it must address stakeholder needs. Section B, therefore, explores the needs of families impacted by paediatric cancer, and sign-posts areas requiring additional focus and support. This is achieved through the qualitative analysis of **Study 3,** in which the needs and challenges of families impacted by cancer are explored through the voices of parents themselves, and the healthcare workers who support them.

1.6.3. Section C

The third section presents a series of studies that examine the factors which may aid or inhibit CH use by families. Key barriers explored include socio-demographic factors, pre-requisite skills, technological access and comfort, amongst others. **Study 4** explores the impact of the digital divide on the use of technology in health information seeking. Using data from the Health Information National Trends Survey (HINTs), the impacts of socio-demographic factors on efficacy in health information seeking using digital tools for caregivers of children with illness is explored. **Study 5** expands on this by examining the impact of socio-demographic variables on CH use by caregivers of children with illness, also using HINTS data. While Study 4 and Study 5 focus on the digital divide, **Study 6** explores the impact of technological prerequisites on access and use of CH for caregivers of children with cancer. A survey of parents of children with cancer and their HCPs exploring the impacts of technology access, attitude and eHealth literacy on use and evaluations of CH is presented. Further, leveraging the results of Study 2, the relative impacts of eHealth literacy, technology access and attitude on evaluations of CH quality and trustworthiness are examined. From this, technological prerequisites for effective CH use are identified. To understand specific challenges within an Irish context, **Study 7** explores the perspectives of families and HCPs on CH, where it may be meaningfully employed, and the challenges to its use. Through this thorough approach, means to capture and reduce such barriers in technology development can be applied.

1.6.4. Section D

Finally, Section D integrates information gathered across Studies 1 to 7 to present a guide to inform effective CH development for families impacted by paediatric cancer. To demonstrate this in practice, a pilot CH intervention targeting the psychological wellbeing of parents, developed in line with these recommendations, is presented. Specifically, **Study 8** examines the impact of an online self-directed CH intervention on parent wellbeing. This intervention, based on ACT, seeks to support parent psychological flexibility using CH. In doing this, the research seeks to explore how aspects of treatment and survivorship impact QOL and burden experienced by the family, as well as the potential of CH to better support psychological wellbeing for this group.

Section A: Current Use of Connected Health in Paediatric Cancer

Section A Introduction

While the potential utility of CH to support families living with paediatric cancer is clear, the introduction of any novel service necessitates thorough analysis. This is particularly true in the context of paediatric cancer in which significant impacts on family functioning (Long & Marsland, 2011) and finances (Wimberly et al., 2021) are faced, with children and families often seeking informational, psychological and healthcare management support (Hendriks et al., 2020). As noted in Chapter 1, family members encounter unique psychosocial impacts, with siblings, mothers and fathers differing in the types of supports needed (Young et al., 2021). To address these multi-faceted needs effectively, evidence-based interventions are required.

Research to date has identified several such evidence-based interventions for families of children with cancer, including psychosocial interventions for children (Coughtrey et al., 2018), siblings (Guan et al., 2021), parents (Ogez et al., 2019) and families (Koumarianou et al., 2021), alongside informational supports (Slater et al., 2018a) and behaviour change interventions to reduce symptoms (Cheng et al., 2021). While promising, a need for higher quality studies has been noted, particularly with regard psychosocial interventions (Peikert et al., 2018). Furthermore, while research suggests the efficacy of psychosocial interventions in face-to-face contexts, analysis of CH-mediated supports remains outstanding. As such, complete evaluation of the impact of CH on outcomes for families of children with cancer is warranted. Through this, avenues through which CH may be meaningfully applied can be identified and further examined.

A.1. Commercially available CH

To obtain a clear sense of the efficacy and availability of CH for children with cancer and their families, all sources of CH require consideration. In addition to empirically-based sources of CH, it is important to note that many forms of CH are direct-to-market, developed by commercial entities, charity groups, insurance providers or others. Such commercially-driven CH tools are within easy reach of families, often accessible through a simple online search. Mobile health (mHealth), whereby supports are provided via smartphones or tablets, is one such easily accessible CH technology. mHealth use is growing, with over 500 million patients worldwide having used such technologies (Athilingam & Jenkins, 2018). In 2021, there were over 53 thousand commercially available healthcare apps on the Google Play store (Statista, 2021), an increase of 10 thousand over the same period in 2020, demonstrating the large growth of this area. mHealth has been buoyed by WHO digital health guidelines which encourage the use of smartphone mediated interventions for health (WHO, 2021).

While mHealth appears both acceptable and accessible for parents of children with cancer (Mueller et al., 2018), empirical analysis remains outstanding in many instances. This discrepancy in the quality of commercially-available mHealth is exemplified in a content analysis of cancer-related apps available on the Apple iTunes store (Pandey et al., 2013). Significant differences in the scientific validity of apps targeted at HCPs in comparison to the general population were found, with just over 55% of caregiver-targeted apps found to be scientifically valid. The growth of the mHealth market further complicates the search for effective CH (del Río Carral et al., 2019), with parents faced with volumes of openly available tools (Knapp et al., 2011). In this context, there is a need for analysis of the quality and scope of commercially-available CH.

However, despite uncertainties regarding the efficacy of commercial direct-to-market CH, it is clear it also offers advantages. One such advantage pertains to the research-to-practice gap. CH developed in empirical settings often does not reach the market, wasting resources in development (Chalmers et al., 2009). Real world demonstrations are needed to address this research-to-practice gap (Canter et al., 2022). Through exploring the impacts of CH in practice, alongside the evaluation of more traditional empirical approaches, a cohesive understanding of how technologies may best meet the needs of users can be attained, and impact more immediately achieved. This approach is known as hybrid effectiveness implementation and is espoused to support translation of research to practice (Curran et al., 2012).

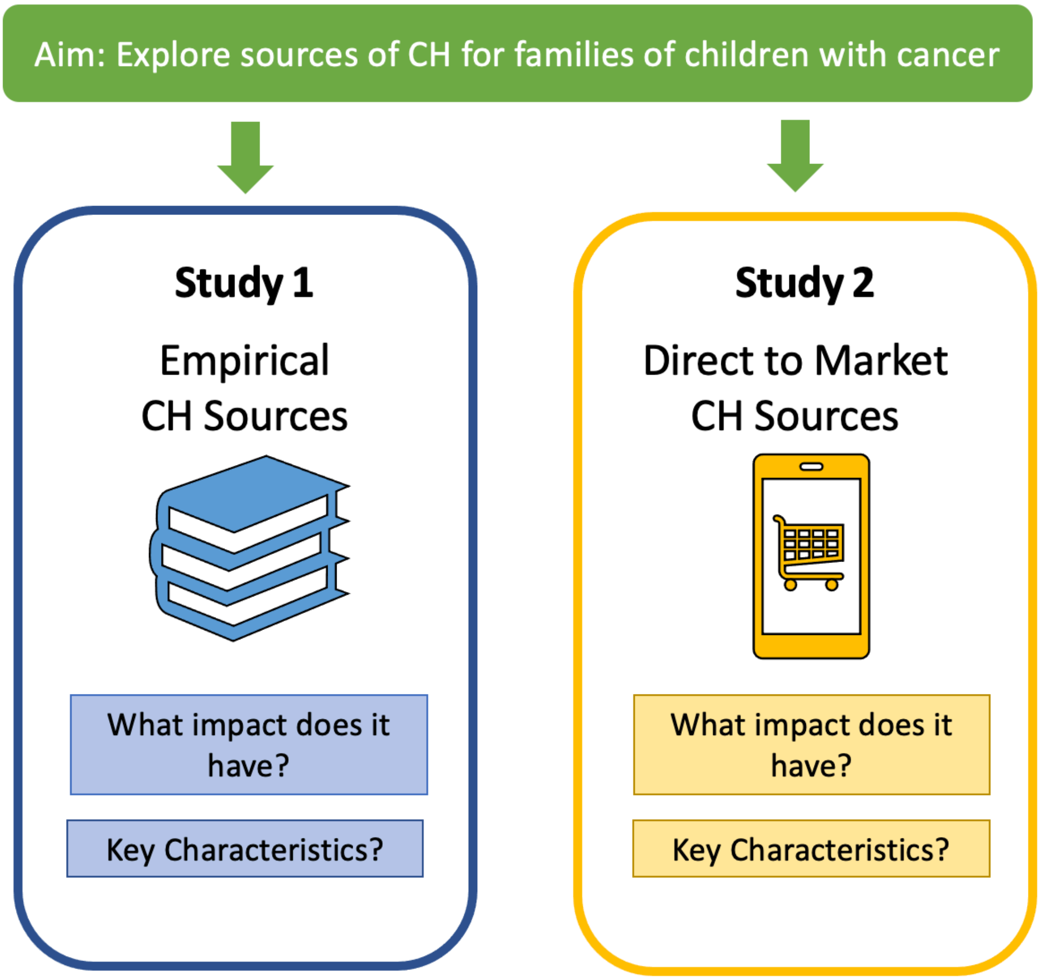
A second advantage of commercial CH is accessibility, particularly for at-risk groups. Value may emerge from testing mHealth efficacy outside of healthcare centres, facilitating access for groups removed from traditional support structures (Canter et al., 2022). This is exemplified in Schroeder et al. (2021), who demonstrated the efficacy of a freely available mHealth app in reducing care abandonment for parents of children with cancer in Tanzania. Current approaches to clinical intervention, design and evaluation often fail to consider practical factors and implementation barriers (March et al., 2005), limiting impact in practice. This suggests that, while problematic in some respects, there is an advantage to commercially- developed CH. However, for these advantages to be realised, the CH-mediated interventions themselves must be effective. Thorough analysis of currently available CH apps is required to determine the current state of play and to establish how best these technologies may be used in support of families.

A.2 Section Overview

The studies described in this section seek to examine the current use of CH in paediatric cancer, to determine its efficacy and impact for parents and families of children with cancer. Specifically, this section seeks to (1) describe the characteristics of current CH interventions for parents, siblings and informal caregivers impacted by paediatric cancer and, (2) evaluate the efficacy of these interventions (see Figure A.1). Findings will then be used to inform recommendations for future CH development.

Figure A.1

Overview of Section Aims



Chapter 2 Study 1: The role of Connected Health technologies in supporting families affected by paediatric cancer: A Systematic Review

Adapted from: Delemere, E., & Maguire, R. (2020). The role of Connected Health technologies in supporting families affected by paediatric cancer: A systematic review. *Psycho-Oncology,* pon.5542. https://doi.org/10.1002/pon.554

Abstract

Objectives: Families impacted by paediatric cancer are met with logistical, financial and psychological impacts, with Covid-19 creating additional barriers and stressors for these families. 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 apps (n=5), telehealth (n=2) and online groups (n=3) were utilised. Intervention areas included psychosocial (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

2.1. Introduction

In an increasingly burdened healthcare system, the potential utility of CH is clear. Past research on the use of CH in paediatric cancer is limited, hampering fulsome conclusions on the role it may play in supporting care. The impact of digital health interventions on caregivers of children with illness has been broadly explored, with positive effects identified. One such example is the systematic review of telehealth interventions for family caregivers conducted by Chouvarda et al., (2015), which identified 32 articles focusing on caregivers of children with illness, with over 95% reporting positive effects. Technologies employed included video, internet and phone-based interventions for education and consultation, however, other forms of CH, such as sensors, were not evaluated. A more recent systematic review found eHealth and mHealth effective in improving functioning of families of children with chronic illness, however, heterogeneity of findings prohibited complete conclusions (Canter, Christofferson, et al., 2019). While both studies focused on families of children with illness more broadly, this suggests promising effects for such digital interventions.

Within paediatric cancer specifically, a recent 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 (Ramsey et al., 2020). Again, limited technologies and outcomes were examined. A further review identified 24 articles pertaining to smartphone apps to support children and families impacted by paediatric or adolescent cancer (Mehdizadeh et al., 2019). Interventions consisted of symptom management, education/information, caregiver communication, social support and illness management, with just four including parents. Again, narrow technology forms were considered. In both instances, reviews focused on supports for children themselves. 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.

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 on CH interventions for parents, siblings and informal caregivers impacted by paediatric cancer. 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.

2.2. 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 (PROSPERO) database (ID number: 159608; submitted November 25th, 2019).

2.2.1. Search Strategy

A structured search of four databases (PsycInfo, 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 to paediatric cancer, published in a peer-reviewed journal, and in the English language was deemed eligible. 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, PsycINFO thesaurus or equivalent terms were used and exploded (see Table 2.1).

Table 2.1

Search Terms Expanded

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

2.2.2. Data Selection and Extraction

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 (Ouzzani et al., 2016). Two researchers independently screened study titles and abstracts to confirm that they met the inclusionary criteria. Disagreements were discussed, and consensus was 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.

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

Data extraction. Data were 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 were unable to be located within a study the corresponding author was contacted to obtain the unreported data or seek additional details.

2.2.3. Methodological Quality Assessment

All articles included in the review were assessed for quality using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018). The MMAT is intended to critically assess the quality of quantitative, qualitative, randomised control trials, non-randomised studies and mixed methods studies within systematic reviews. The MMAT consists of two screening questions followed by 5 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 (Bradford et al., 2012a; Reiners et al., 2019). 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.

2.2.4. Synthesis of Findings

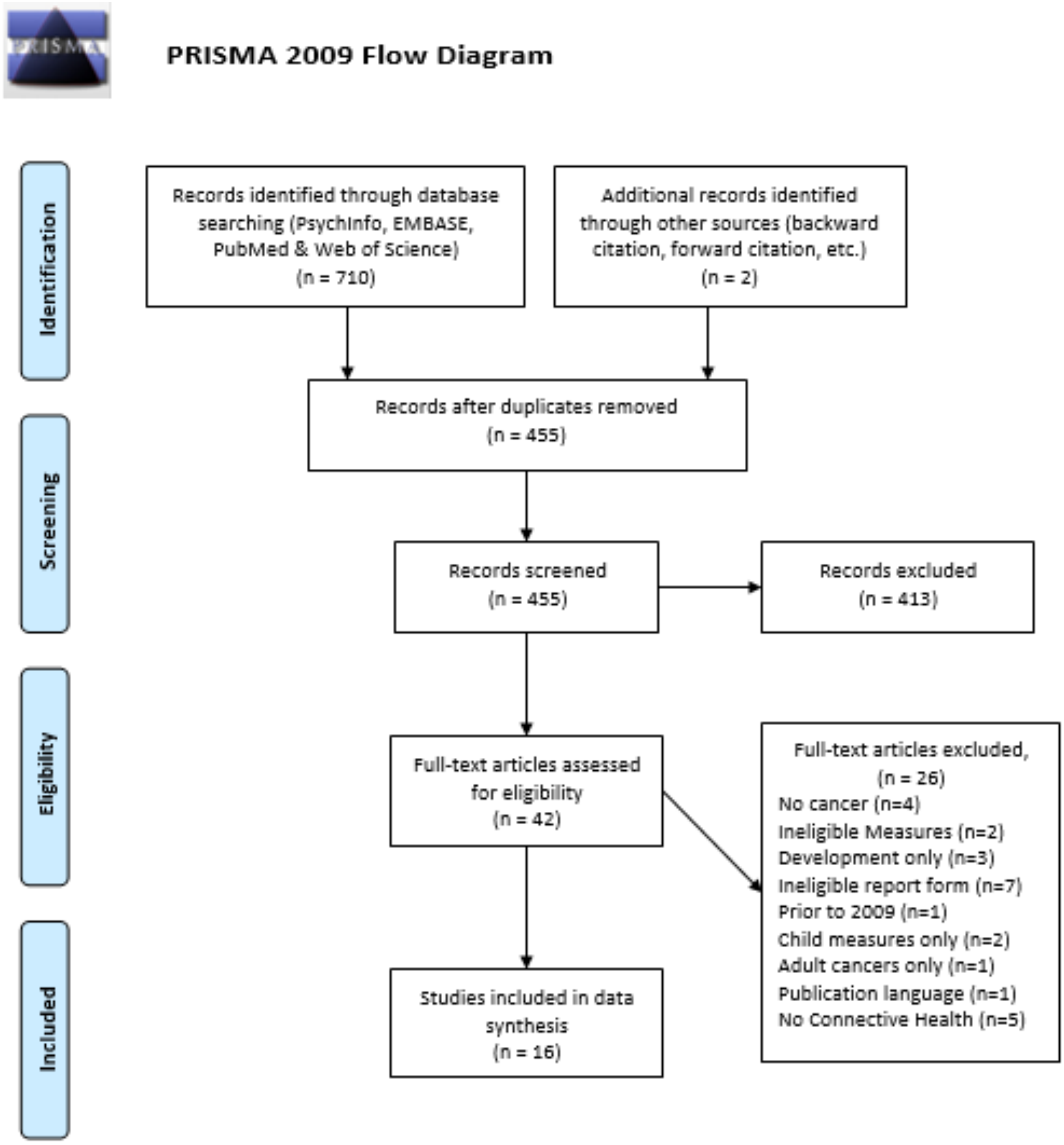
The first author utilised Microsoft Excel to synthesise data extracted. Study characteristics, interventions and outcomes were described in table form. Primary outcomes were divided into three categories: information sharing and illness management, palliative care, and psychosocial support. Studies within each of these categories were then evaluated based on dependent variables of interest, participants employed and results obtained. No criterion for the 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.

2.3. 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 2.1).

Figure 2.1

Prisma Diagram



Sixteen articles were eligible for inclusion in the systematic review. These were published between 2009 and 2020 and are based predominantly in Australia (n=6) and America (n=5). Of the sixteen 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 2.2.

Table 2.2

Information from Included Manuscripts

Reference	Participant	Sample size (Mothers, Fathers)	Age	Design Type	Intervention	Length of intervention	Measures	Results	Quality
(Akard et al., 2020)	Parents Children	98 (89, 7)	N/R †	RCT†	Web-based legacy intervention for children and their families. Usual Care control used.	2 weeks	Intervention effects. Acceptability.	28.4% expressed positive comments 23% liked design 23.5% would increase user friendliness	4
(Bensink et al., 2008)	Families (Parent, Child and Siblings)	11 (N/R)	N/R	Quantitative descriptive	24 hr '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.	4
(Bradford et al., 2012a)	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 (QOLLTI-F). The Accessibility and Remoteness Index for Australia (ARIA).	QOLLTI-F – No difference between Intervention and control groups.	2
(Burton et al., 2018)	Parents Children	30 (20, 8)	N/R	Quantitative descriptive	Brighthearts smartphone app. 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.	Good usability. 8/10 reported difficulty focusing on app. 100% parents would use again.	5

Reference	Participant	Sample size (Mothers, Fathers)	Age	Design Type	Intervention	Length of intervention	Measures	Results	Quality
(Canter, et al., 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. Self-directed content and personalized support via brief telehealth sessions with a therapist.	4 months (mean 116.4 minutes)	Demographic information. eSCCIP Evaluation Survey. Internet Intervention Adherence Questionnaire (IIAQ). Usage.	Found eSCCIP usable, feasible, and acceptable.	3
Cernvall et al., 2017)	Parents	58 (39, 19)	Mean= 38 (Range = 31-45)	RCT	Online group guided self-help program, including weekly therapist support via email, based on cognitive behaviour therapy (CBT) 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 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

Reference	Participant	Sample size (Mothers, Fathers)	Age	Design Type	Intervention	Length of intervention	Measures	Results	Quality
(Chung et al., 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 $p<0.001$. Parent reported stress significantly reduced $p=0.004$. Parent relaxation improved $p=0.05$	5
(Fuentes et al., 2014)	Mothers	6 (6)	N/R	Qualitative	EmotionMingle 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., 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
(Wakefield et al., 2016a)	Parents	47 (41, 6)	42.36 (25-55)	RCT	Cascade is an online, group-based, CBT intervention, delivered live. Waitlist control	3 weekly 120-minute sessions 6 month follow-up	Feasibility California Psychotherapy Alliance Scale-Group short version (CALPAS-G). Youth Satisfaction Questionnaire (YSQ). Family Caregiver Tool.	Described as helpful. Burden of use was low. Group cohesion scores suggest peer-to-peer benefits. No significant main effect of group or time	4

Reference	Participant	Sample size (Mothers, Fathers)	Age	Design Type	Intervention	Length of intervention	Measures	Results	Quality
							The Depression Anxiety Stress Scale short form (DASS-21). The family communication, problem-solving and general functioning subscales of the McMaster Family Assessment Device.	on QOL, psychological and family functioning. Significant main effect of time on fear of cancer recurrence (p < .01).	
(Walsh et al., 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., 2018)	Parents	101 (75, 26)	<30 = 32, 31-40 = 51, >40y = 11	Mixed methods	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 Scale (PSSS). Zarit Burden Inventory (ZBI). Parents’ Perception of Uncertainty Scale (PPUS).	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	5

Reference	Participant	Sample size (Mothers, Fathers)	Age	Design Type	Intervention	Length of intervention	Measures	Results	Quality
							Medical Outcomes Study Knowledge questionnaire.	knowledge need (P<.001).	
(Wang et al., 2016a)	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 minutes 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
(Williams et al., 2016)	Parents	12 (12)	34.99 (Range = 23.4-39.09)	RCT	Live online Triple-P delivered through GoToMeeting 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 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., 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	12 weeks	Self-Administered 24 hour (ASA24) Dietary Assessment Tool. Actigraph GT1M Monitor. Calibrated digital scale.	Parent “Pressure to eat” reduced (p= 0.03). Increased milk (p= 0.04), and protein consumption (p=0.04). No significant changes	5

Reference	Participant	Sample size (Mothers, Fathers)	Age	Design Type	Intervention	Length of intervention	Measures	Results	Quality
					educational and behavioural sessions on the “4-Health” childhood obesity prevention program		Parenting Dimensions Inventory Short Version (PDI-S)	in children’s physical activity, BMI, or waist circumference.	

2.3.1. Quality Appraisal

Variability in study quality was noted (see Table 2.2). All MMAT criteria were met by 31.3% of studies, with most others meeting at least 3 criteria. Only one study scored lower than 3 (Bradford et al., 2012a). 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 Randomised Control Trials (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; Akard et al., 2020; Cernvall et al., 2015, 2017; Wakefield et al., 2016a; Walsh et al., 2014), representative samples (n=2; Canter, Deatrick, et al., 2019; Cernvall et al., 2015), intervention adherence (n=2; Reiners et al., 2019; Williams et al., 2016) and outcome analysis (n=2; Bradford et al., 2012a; Wang et al., 2016b). All MMAT scores were agreed upon by both coders.

2.3.2. Demographic Characteristics

563 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%).

2.3.3. Characteristics of Interventions

Four primary modes of CH were reported; smartphone apps (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 included usual care. Intervention duration ranged from one hour to six months (mean=52.45 days), with two studies failing to report duration. Follow-up periods ranged from eight weeks to six months (n=2). Most did not include follow-up assessments (n=14). Six interventions included contact with HCPs. These included nurses, social workers or oncologists (n=2), and trained therapists or psychologists (n=4).

2.3.4. Adherence Measures

Adherence data were provided for 12 studies (75%). Of these, two reported duration of engagement (mean=24.4 minutes, range=8-39.2 minutes). 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%).

2.3.5. Outcomes

Due to the broad inclusion criteria and resultant heterogeneity of outcomes, studies which were primary pilot or feasibility studies are reported separately from 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.

Feasibility, acceptability, or pilot studies. Of the 16 studies included, nine examined feasibility or acceptability of a CH intervention (Akard et al., 2020; Bensink et al., 2009; Burton et al., 2018; Canter, Deatrick, et al., 2019; Fuentes et al., 2014; Slater et al., 2018a; Wakefield et al., 2016a; Walsh et al., 2014) and two were pilot studies (Cernvall et al., 2017; Chung et al., 2018). All reported positive results for feasibility and acceptability (see Table 2.2).

Psychosocial. Three studies investigated the impact of CH on psychosocial needs. Interventions varied, with one online Cognitive Behaviour Therapy (CBT) intervention (Canter et al., 2019), one online CBT-based group intervention (Wakefield et al., 2016b) and one smartphone app utilising ambient visualisation to reduce social isolation (Fuentes et al., 2014). Wakefield et. al.'s (2016b) online CBT intervention included measures of parental quality of life (QOL), parental psychological functioning and family functioning. 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 found, with decreases observed over time. One study utilised a single-group design to examine the acceptability and feasibility of the eSCCIP online CBT-based intervention (Canter et al., 2019). Previous research qualitatively analysed reported social isolation of mothers of children with cancer, however, the role of CH on social isolation was not examined (Fuentes et al., 2014).

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- based biofeedback meditation intervention for pain and anxiety during medical procedures (Burton et al., 2018), a web-based training for parents on pain and stress management (Chung et al., 2018), a web-based medication calendar with decision support and a communication tool (Walsh et al., 2014), a 24-hour videotelephone support provided by nurses for assessment, monitoring, education, and counselling (Bensink et al., 2009), an application to provide information to parents of individuals with acute lymphocytic leukaemia (ALL; Wang et al., 2016a), and "The Oncology Family App" which supports families in accessing management plans, patient-specific information and other resources (Slater et al., 2018a). Of these, one was a pilot study. All had positive outcomes. One study examined the usability of the CH only (Bensink et al., 2009). Four studies examined usage (Chung et al., 2018; Slater et al., 2018; Walsh et al., 2014; Wang et al., 2016a) with high levels reported. Two included additional measures such as medication errors, child fear, anxiety and pain. No change in medical errors was noted following the use of the HoMeS medication management intervention with decision support for families (Walsh et al., 2014). 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 (Bensink et al., 2009).

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 (Akard et al., 2020). A second was a home telehealth program for palliative care to support patient condition and subsequent management options (Bradford et al., 2012b). Both reported good acceptability and one reported good feasibility. No significant effects on familial QOL were noted (Bradford et al., 2012b).

Studies examining the impact of a CH technology. Five studies examined the impact of CH on parent or informal caregiver measure/s (see Table 2.2).

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 (Cernvall et al., 2017), a CBT-based online self-help module focusing on coping and distress (Cernvall et al., 2015), and an online group Positive Parenting Program (Triple P) to support parents with behavioural challenges (Williams et al., 2016). All were RCTs. Significant positive effects for post-traumatic stress, depression and anxiety were found following the CBT-based intervention (Cernvall et al., 2015). High acceptability and a trend for improvements in emotional and peer difficulties for both waitlist and intervention emerged following the online Triple-P Program (Williams et al., 2016), 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 (Cernvall et al., 2017). 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 (Zhang et al., 2019). No significant changes in physical activity or weight were obtained. The smartphone app 'Care Assistant' and WeChat account was used to facilitate the provision of information, illness management and to increase social contact for parents (Wang et al., 2018). 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.

2.4. 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, more evidence-based evaluations are needed. Considering the impacts of Covid-19 there is increased necessity for such remote services.

One notable observation was the low volume of CH 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 generally (Peikert et al., 2018) 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 (Cernvall et al., 2015, 2017). 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 (Mcmillan et al., 2020). 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 (Zhang et al., 2019), while significant reductions in parental anxiety and uncertainty, along with increases in social function and knowledge, were obtained following engagement with 'Care assistant' (Wang et al., 2018). 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 present 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 (Chalmers et al., 2009). However, failure to sustain or increase CH following small-scale studies may lead to frustration from HCPs (Leach, 2010). 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 (Chung et al., 2018). While the Cascade CBT-based intervention did not significantly affect QOL, psychological or family functioning, it successfully reduced fear of recurrence (Wakefield et al., 2016c). Nonsignificant effects on family QOL were noted following a telehealth palliative care program (Bradford et al., 2012a). 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 (2019) identified smartphone apps 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 (Ouzzani et al., 2016). Results differ from Canter et. al. (2019) 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 (Bensink et al., 2009; Bradford et al., 2012a). 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 (Wicks et al., 2014). The absence of measures of interest to policy makers can negatively impact translation to practice (Glasgow, 2007). However, this may change considering Covid-19, 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 (Tunis et al., 2003). CH is often developed and trialled within one setting, impacting adoption across novel settings due to lack of fit (Glasgow, 2007). 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 app, four of the five studies sought only to examine feasibility or acceptability of such apps. 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 (EHRs) or interventions delivered through sensor technology. This may be due to the focus on parent and caregiver measures (Schepers et al., 2017). Previous studies have examined sensor technology in supporting physical activity for adult cancer survivors (Beg et al., 2017) and EHRs for childhood cancer survivors (Eichenberg et al., 2013a). 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 (Bensink et al., 2009; Bradford et al., 2012a). The remaining interventions involved access to a trained therapist or psychologist, largely owing to their psychosocial focus. While not a specified outcome, parents used the HoMes intervention when communicating with their clinician, suggesting utility for HCP inclusion (Walsh et al., 2014). Similar opportunities could be noted for BrightHearts (Burton et al., 2018) and the 'Oncology Family App' (Slater et al., 2018b). While CH may reduce burden on HCPs, there is a need to examine the role of human support within eHealth (Glasgow, 2007). 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 information (Eichenberg et al., 2013b) and mediate patient attitude formation (Gun et al., 2011) Several interventions included some degree of peer communication (Cernvall et al., 2017; Fuentes et al., 2014; Wakefield et al., 2016a; Wang et al., 2018; Wang et al., 2016b; Williams et al., 2016). 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 (Peikert et al., 2018). A systematic review of smartphone apps for families of children with cancer similarly found no sibling specific interventions (Mehdizadeh et al., 2019). 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 (Williams et al., 2016) and only one balancing parenting roles (Zhang et al., 2019). While reflective of the greater caregiving role of mothers within society, this underrepresentation of fathers is in keeping with paediatric research more broadly (Panter-Brick et al., 2014). 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 found across studies, consistent with previous research (Peng et al., 2016). While concerns have been raised around ease of use (Barr et al., 2014), 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 3 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 (Glasgow, 2007). 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 (Wakefield et al., 2017). Further research is required to more fully examine the factors which may facilitate adherence.

2.4.1. Study Limitations

There are several limitations to the present study. Firstly, as CH is a developing area, its definition is broad and evolving (Wakefield et al., 2017). While every effort was made to capture all relevant studies, the lack of consistent terminology may have hampered article identification for analysis. 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 complete 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.

2.4.2. 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.

While the current study provides insight into the efficacy and availability of empirically based CH for families of children with cancer, the majority of CH examined remained in pilot stages and was not made publicly available. While this suggests a need for research of the barriers preventing CH generalisation from pilot to novel settings, it also suggests an absence of empirical analysis of commercially available CH as evidenced by its omission within the literature. This suggests a keen need to explore these commercially available CH tools to explore the areas in which they offer supports, the means through which they do this, and their overall efficacy. This challenge will be addressed within Study 2, in which a review and content analysis of such CH is presented.

Chapter 3 Study 2: Behaviour Change Techniques within Smartphone Application Connected Health Interventions for Paediatric Cancer: A Review

Adapted from: Delemere, E., & Maguire, R. (2023) ‘Behaviour Change Techniques within Smartphone Application Connected Health Interventions for Paediatric Cancer: A Review’. *IEEE International Symposium on Technology and Society.* Swansea, Wales.

Abstract

Purpose: Parents of children with cancer are increasingly turning to technology to support their needs. However, support in identifying effective technologies is needed. This study sought to examine the prevalence of Behaviour Change Techniques (BCTs) in CH smartphone apps for families of children with cancer.

Method: Systematic searches of Google Play and the Apple App Store were conducted in September 2020. To be included, apps were required to provide a CH intervention for parents or children affected by paediatric cancer. BCT Version 1 (BCTv1) was used for content analysis, with additional data on cost, downloads and ratings obtained for each app.

Results: Of the 1316 apps found, 26 met inclusion criteria. Common CH features included healthcare tracking and sharing of information with family or health care providers. Common BCTs included feedback and monitoring (n=54), social support (n=19) and goal setting/planning (n=24), with 50 unique BCTs found across apps. Good alignment between CH features and BCT use was found. Statistical analysis found no significant relation between app cost (t(17.8)=-.669, p=.512), downloads (r=-.17, n=23, p<.45) or ratings (r(21)=-.031, p=.894) and BCT volume.

Conclusion: While findings suggest a high prevalence of BCTs in CH apps for families affected by paediatric cancer, standard measures of quality, such as app rating or download volume, cannot be relied upon when evaluating apps. Analysis is needed to

determine how to support families in identifying apps that are more likely to be effective.

3.1. Introduction

As described previously, mhealth is an aspect of CH that has been gathering pace. For parents of children with cancer, several mHealth interventions exist, examples of which were highlighted in Study 1. However, while the results of Study 1 suggest mHealth positively impacts caregivers of children with cancer, interventions examined represent only a small minority of available mHealth technologies, many of which have not been the subject of experimental analysis. The use of such technologies is further complicated by the variety of intervention foci and components across areas such as information provision, psychosocial support, and medication management, amongst others. This wide variety in quality and scope, suggests a need to support access to high quality, appropriate tools.

Many patients and caregivers express challenges in accessing appropriate, high quality and relevant health content (Knapp et al., 2011). Parents of children with cancer face additional challenges due to the highly heterogeneous experiences of this group, in terms of both illness and treatment, making identifying technologies more cumbersome. This is exacerbated by caregiver digital skills, which for those lacking appropriate skills, may increase the risk of accessing inaccurate information (Neter & Brainin, 2012). This, in turn, may lead to inappropriate healthcare seeking, anxiety or uptake of inappropriate treatments (Lleras de Frutos et al., 2020). Similarly, eHealth literacy, or the ability to find, critically examine, and use health information from online sources, may impact online information processing (Lluch, 2011). Those with lesser eHealth literacy skills are at risk of accessing inappropriate or ineffective information online. As such, while many mHealth apps are available, parents are faced with several child and technology-specific barriers to their use.

To support parents in identifying relevant and appropriate mHealth supports for their child with cancer, content analysis is needed. One increasingly common means by which this can be achieved is through behaviour change taxonomy coding (Michie et al., 2013). Such a taxonomy seeks to list, according to currently available knowledge, evidence-based BCTs. BCTs are defined as the objective, replicable and directly observable aspects of behaviour interventions. The most recent and widely used is the BCT Taxonomy (BCTv1), which has previously been used to evaluate diet and physical activity mHealth interventions (Direito et al., 2014; Yang et al., 2015) and medication adherence (Morrissey et al., 2016b). While research has yet to consider BCTs in mHealth for paediatric cancer, a recent content analysis found BCTs in medical adherence interventions for adolescents and young adults with chronic illness using the BCTv1 (Carmody et al., 2019). The present analysis seeks to expand upon the methodology used within past analyses (i.e. Carmody et al., 2019; Morrisey et al., 2016), while applying this approach in a novel health and technology context. As such, exploration of the use of BCTs in paediatric cancer interventions, particularly those provided using mHealth, may provide valuable insights.

This study sought to systematically review and examine the contents of CH smartphone apps targeted towards individuals affected by paediatric cancer. Specifically, the volume and forms of BCTs within these apps and their relationship to download volume and ratings is examined. Results will shed light on the potential efficacy of CH for paediatric cancer, which may help families identify more effective supports.

3.2. Method

The overall methodology guiding the present analysis derives from similar past analyses particularly that of Carmody et al., (2019), and is described in detail below.

3.2.1. Search Strategy

Systematic searches of the Google Play and Apple App Stores were conducted on August 11th 2020, with searches repeated on September 9th 2020. Search terms were based on Boolean logic and included terms related to childhood cancer (Cancer AND Child OR Paediatric OR Adolescent OR Youth OR teen Or Kid). Preliminary searches were conducted using more specific search terms (i.e., specific cancer diagnoses or broader health search terms). However, such terms were ineffective, resulting in low volumes of search findings, leading to the adoption of the more general terms above to prevent relevant CH apps being missed. To be included, apps had to provide a CH intervention to support families (i.e. parents or siblings), or children (i.e. an individual under 18 years of age) living with paediatric cancer. As with Study 1, a CH intervention was defined as any intervention in which a two-way flow of information occurred via the app (i.e. where data inputted by the individual was utilized to inform information or intervention delivered by another person or the technology itself). Exclusionary criteria included faulty apps (frequent crashes, unable to load), irrelevance to paediatric cancer, inaccessible (e.g. required a hospital or insurance provider code to access) or which did not include CH.

3.2.2. Data Selection and Extraction

All apps which met the search criteria were downloaded and analysed.

Screening. App descriptions as per the Google Play or Apple store were screened by the primary researcher to confirm that they met the inclusionary criteria. Decisions were recorded using a password-protected file.

Eligibility. Remaining apps were downloaded onto a tablet or smartphone and underwent full review to confirm eligibility. This consisted of a fulsome examination of the app's features to ensure eligibility was met. For any apps duplicated across both sources, analysis of both iOS and Android versions occurred to confirm features across both. Where free and paid versions were available, both were analysed. For inter-observer agreement, 20% of apps (n=17) were independently reviewed by a second researcher. 100% agreement was achieved.

Data Extraction. Data were systematically extracted and inputted into an Excel spreadsheet, with the following information collected: developer, user rating, number of downloads, intended audience, past empirical analysis, CH functions and app features. Where information was not available in the app, the associated websites were checked. Each app was then thoroughly examined, screened, and coded using the BCTv1. Narrative synthesis was used to analyse app features due to the heterogeneity of apps found, with contents analysed in terms of the general features, CH features and BCTs employed. This was achieved through an initial synthesis of app features through searching each app and presenting results in tabular form. Features were then structured into themes based with a framework applied to cluster related features.

3.2.3. Measures

Content Validity. Consistent to past analyses outside of paediatric cancer (i.e. Direito et al., 2014; Yang et al., 2015; Morrisey et al., 2016b), the BCTv1 (Michie et al., 2013) was used to examine the use of evidence-based techniques within the CH apps. The BCTv1 consists of 93 individual BCTs across 16 domains (see Appendix 1 for complete depiction of structure). These include goals and planning, feedback and monitoring, social support, shaping knowledge, natural consequences, associations, repetition and substitution, comparison of outcomes, rewards and threats, regulation, antecedents, identity, scheduled consequences, self-belief, and covert learning. The presence or absence of each BCT within each smartphone app was examined (1=BCT present, 0=BCT absent), with the total volume of BCTs attained by summing each app's score.

3.2.4. Statistical Analysis

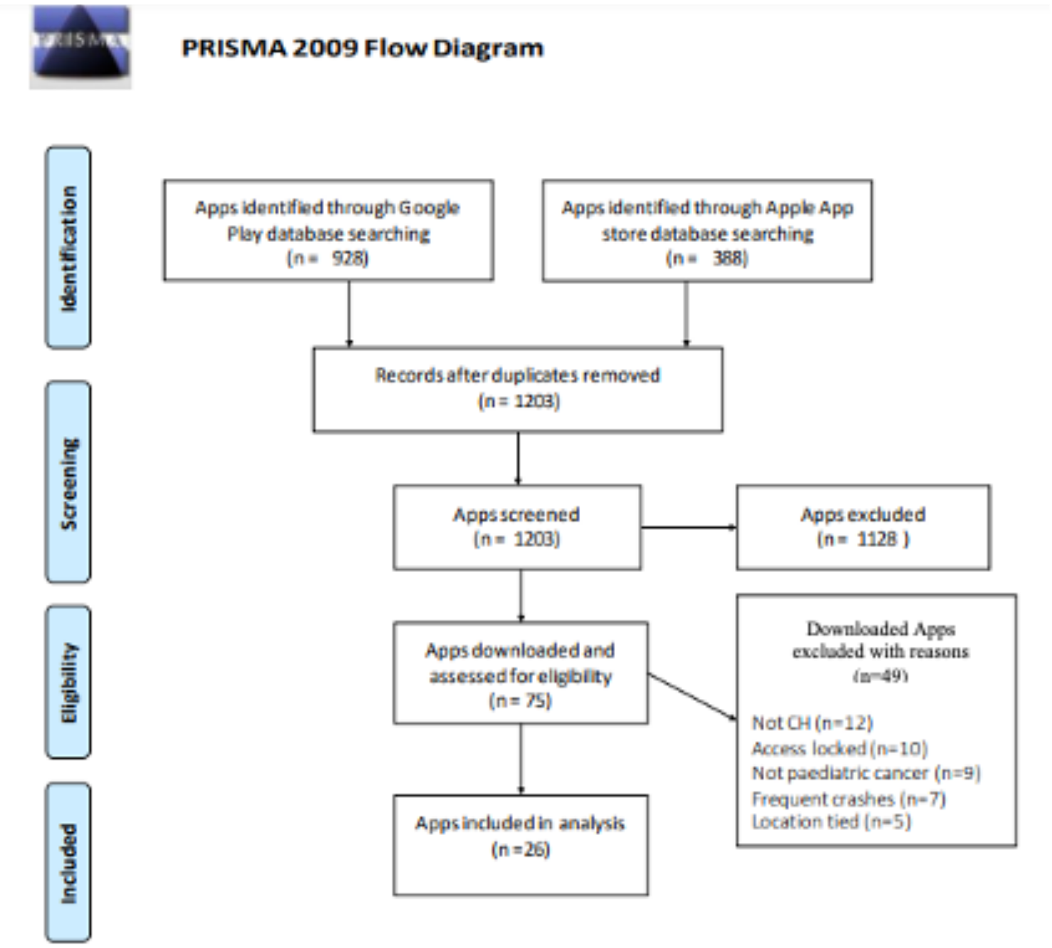
Data on cost, download volume, rating and BCTs was analysed using the Statistical Package for Social Sciences (SPSS). An independent samples t-test was used to compare the number of BCTs in paid and unpaid apps. Any app which included in-app purchases were considered paid. To explore the correlations between BCTs and download numbers, Pearson product-moment correlation coefficient tests were used. The relationship between BCTs and ratings was investigated using Spearman's rank-order correlation coefficient test due to preliminary analyses indicating some deviation from the assumptions of normality, linearity, and homoscedasticity.

3.3. Results

Searches of both the Google play (n=928) and Apple App Store (n= 388) yielded 1316 apps, of which 1203 were unique. Following screening of store descriptions, 1128 apps were removed. The remaining 75 apps were downloaded to establish eligibility. Of those downloaded, a further 49 were excluded. Common reasons for exclusion included a lack of CH (n=12), access tied to specific care provider or insurance company (n=15), not relevant for paediatric cancer (i.e. for adult cancers only, n=9) and frequent crashes (n=7). Search results are presented in Figure 3.1.

Figure 3.1

Search Strategy and Results



A total of 26 apps were coded using the BCTv1. Of these, 22 were from the Google Play store (14 free, 7 free with in-app purchases and 1 paid), three were from the Apple App store (3 free), and one was found in both (free). App information is presented in Table 3.1. Apps were developed between 2012 and 2020, with the majority developed between 2017 and 2019 (n=19). Of those for whom information on the developer background was available (n=20), five were created by an app development business, five by health care providers, three by hospitals, two by non-profits, one by a chemist chain, and one by a university. Most apps were intended to be used by parents/caregivers or patients themselves. In most instances, apps were intended for adult use. One app (Pain Squad) was intended for children only. One app had over five million downloads; though most had less than 10,000 (n=13). Three apps had been the subject of published research, with the usability of Pain Squad analysed (Stinson et al., 2013) and Bearable having been included in a past systematic review (Lu et al., 2021). Untire was the only app to have undergone empirical analysis of efficacy with a large RCT conducted by an independent research team (Spahrkäs et al., 2020).

Table 3.1

App Information

App Name	Cost/In app purchases	Year Launched	Intended Audience	Developer	Source	Rating	Downloads (As of August 2020)
Ask Apollo	Fee for Doctor	2018	Parent/caregiver or child	Hospital	Google	3.5	500,000
Bearable	Annual subscription of 2.49e per month	2020	Parent/caregiver	N/A	Google	4.1	50,000
BELONG Beating Cancer Together	None	2016	Parent/caregiver or patient	App development business	Google	4.7	100,000
Blood Cancer Storylines	None	2017	Parent/caregiver or patient	HCP	Google	N/A*	N/A
Cancer Dojo	None	2019	Parent/caregiver or patient	N/A	Google	3.4	1,000
Cancer iChart	None	2018	Parent/caregiver or patient	University	Google	N/A	1,000
Cancer.Net Mobile	None	2012	Parent/caregiver or patient	N/A	Google	4.4	10,000
CancerAid	None	2017	Parent/caregiver or patient	N/A	Google	3.7	5,000
CancerCare	None	2017	Parent/caregiver	Non-profit	Apple	3.8	100
CarcinoidNETs Cancer Storylines	None	2017	Parent/caregiver	N/A	Google	4.3	1,000
ChemoWave	None	2018	Parent/caregiver or patient	N/A	Google	4.1	1,000
German health Check-ups	None	2019	Parent/caregiver or patient	HCP	Apple	N/A	N/A
GRYT Health Cancer Community	None	2018	Parent/caregiver or patient	N/A	Google	4.1	500,000
I Online Doctor	Fee for Doctor	2017	Parent/caregiver or patient	HCP	Google	3.7	500,000
Ketogenic therapy for Cancer	€3.39	2018	Parent/caregiver or patient	App development business	Google	4.8	N/A

LCCH Oncology Family	None	2015	Parent/caregiver	Hospital	Apple	3.5	100
Pain Squad	None	2020	Child	Hospital	Both	N/A	N/A
Pancreatic Cancer Action	None	2018	Parent/caregiver or patient	Non-profit	Google	N/A	100
Paediatric Vital Parameters	None	2019	Parent/caregiver	HCP	Google	N/A	0
Pill Reminder & Medication Tracker - MyTherapy	€2.99 per month allows family access	2015	Parent/caregiver or patient	App development business	Google	4.6	1,000,000
Prato	Doctor fee	2015	Parent/caregiver, or patient	App development business	Google	4.1	5,000,000
Qare	Doctor fee	2017	Parent/caregiver or patient	App development business	Google	4.7	100,000
Symptom Tracker & Medicine, Health Symptoms Diary	€7.49 per month	2019	Parent/caregiver or patient	N/A	Google	4.3	10,000
Untire: Beating cancer fatigue	None	2018	Parent/caregiver or patient	HCP	Google	4.5	10,000
War On Cancer	None	2019	Parent/caregiver or patient	N/A	Google	4.7	5,000
Webdoctor	Doctor visits	2019	Parent/caregiver or patient	Chemist	Google	4	1,000

***Not Available**

3.3.1. App features

App contents are discussed in terms of the general features, CH features and BCTs employed. Common general features included those aimed at supporting illness management (n=40 features across 16 apps), communicating with HCPs (n=17 features across 13 apps), physical health management (n=15 features across 8 apps), emotional health (n=9 features across 8 apps), social support (n=11 features, across 10 apps) and information provision (n=10 features across 11 apps).

Of CH features, symptom tracking and graphing (n=9), medication tracking and graphing (n=9), sharing of tracked information with family members (n=8) or HCPs (n=7), appointment tracking and reminders (n=7) and vitals tracking (n=6) were prevalent. Only one app used an inbuilt sensor to track information (blood pressure), and one additional app could connect with available sensor technologies.

Table 3.2

App Features by Area of Support

		Ask Apollo	Bearable	Belong Beating Cancer Together	Blood Cancer Storylines	Cancer Dojo	Cancer Ichart	Cancer.Net Mobile	Canceraid	Cancercare By Curesearch	Carcinoidnets Cancer Storylines	Chemowave	German Health Checkups	Gryt Health Cancer Community	I Online Doctor	Ketogenic Therapy for Cancer	Lcch Oncology Family App	Pain Squad	Pancreatic Cancer Action	Paediatric Vital Parameters	Pill Reminder & Medication	Practo	Qare	Symptom Tracker	Untire	War On Cancer	Webdoctor	Total
Info.	Health Record	x								x			x						x			x		x				6
	Health Library	x						x		x					x													4
Illness management	Medication Tracking				x		x	x			x	x								x	x	x		x				9
	Medication ordering	x																										1
	Vitals tracking	x			x					x	x	x	x				x			x	x			x				1
	Diagnostics	x																						x				2
	Treatment tracking			x								x																2
	Symptom tracker				x			x	x		x	x						x						x				7
	Side-effects								x									x										2
	Appointment Tracking	x		x	x			x		x										x	x							7
Physical	Exercise tracking	x																			x			x	x			4
	Sleep tracking		x		x							x																3
	Fatigue				x							x												x	x			4
	Food tracking	x	x													x								x				4
Emoti	Mood Tracking		x			x					x							x										4
	Life factors		x															x										2

	Gratitude/selfcare		x		x	x																					x	3
Social	Support group			x					x		x			x					x							x		6
	Family sharing				x					x								x	x					x				5
HCP comm.	Doctor contact information							x									x				x							3
	Doctor tips and questions			x				x									x					x						4
	Doctor Consult	x													x							x	x				x	5
	HCP team sharing								x	x								x			x			x				5

3.3.2. BCTv1

Apps contained on average 6.9 BCTs (range=1-20, median=5.5), with a total of 50 unique BCTs across apps. The most common behaviour change technique categories were feedback and monitoring (n=40), social support (n=19), and regulation (n=13). Some BCTs pertaining to goals and planning (n=24), shaping (n=9), natural consequences (n=14), comparison of behaviour (n=4), associations (n=14), and repetition and substitution (n=9) were found. There were few BCTs on rewards and threats (n=9), antecedents (n=1) and identity (n=5) and none for scheduled consequences, self-belief, or covert learning. Detailed results of BCTs found are presented in Table 3.3 below.

Table 3.3

Frequency of BCTs Across Apps

BCT Name	Apps included
2.1. Monitoring of behaviour by others without feedback	15
2.3. Self-monitoring of behaviour	14
7.1. Prompts/cues	14
9.1. Credible source	12
3.1. Social support (unspecified)	10
11.1. Pharmacological support	10
3.2. Social support (practical)	8
1.2. Problem solving	7
5.1. Information about health consequences	7
1.1. Goal setting (behaviour)	5
5.4. Monitoring of emotional consequences	5
1.3. Goal setting (outcome)	4
4.4. Behavioural experiments	4
4.2. Information about Antecedents	3
13.1. Identification of self as role model	3
1.4. Action planning	2
1.6. Discrepancy between current behaviour and goal	2
1.9. Commitment	2
4.1. Instruction on how to perform the behaviour	2
6.3. Information about others' approval	2
8.7. Graded tasks	2
10.3. Non-specific reward	2
11.3. Conserving mental resources	2
1.5. Review behaviour goal(s)	1

BCT Name	Apps included
1.8. Behavioural contract	1
3.3. Social support (emotional)	1
5.3. Information about social and environmental consequences	1
5.6. Information about emotional consequences	1
6.1. Demonstration of the behaviour	1
6.2. Social comparison	1
8.2. Behaviour substitution	1
8.3. Habit formation	1
9.2. Pros and cons	1
9.3. Comparative imagining of future outcomes	1
10.1. Material incentive (behaviour)	1
10.2. Material reward (behaviour)	1
10.4. Social reward	1
10.5. Social incentive	1
10.6. Non-specific incentive	1
10.8. Incentive (outcome)	1
10.11. Future punishment	1
11.2. Reduce negative emotions	1
12.2. Restructuring the social environment	1
13.2. Framing/reframing	1
13.4. Valued self-identify	1

Of individual BCTs, monitoring of behaviour by others with (n=15) or without feedback (n=14), prompts/cues (n=14), credible source (n=12), unspecified social support (n=10) and pharmacological support (n=10) were the most common. Of apps, Untire (n=20 BCTs), Pain Squad (n=17), Symptom Tracker (n=16), Cancer Dojo (n=14) and Bearable (n=11) included the most BCTs. War on Cancer (n=2), Webdoc (n=2), Quare (n=2), I Online Doc (n=2) and Cancer iChart (n=1) had the lowest use of BCTs. Common combinations of BCTs across apps included problem-solving and behavioural feedback (together on 61% of occurrences), goal setting and problem-solving (57% co-occurrence), pharmacological support and prompts (57% co-occurrence), and monitoring of behaviour by others without feedback and prompts (50% co-occurrence).

3.3.3. Relationship between BCTs and App feature

An independent samples t-test indicated no significant differences between apps that were paid versus free in terms of BCT numbers (t(17.8)=-.669, p=.512), suggesting paid apps were not significantly positively related to the number of BCTs. No significant relationship between BCTs and downloads (r=-.17, n=23, p<.45) or between BCTs and ratings were noted (r(21)=-.031, p=.894). This suggests that app ratings or download volume were not related to the number of BCTs within apps.

3.4. Discussion

The present study sought to systematically review and examine the inclusion of BCTs within commercially available CH mHealth apps for families affected by paediatric cancer. CH apps primarily targeted healthcare management, information provision and social support. Notably, a high volume of BCTs were found across apps, which predominantly pertained to feedback and monitoring, social support, and regulation. Interestingly, no relationship was found between app cost, download volume or rating, and BCT volume. While results suggest a promising role for CH apps in supporting families impacted by paediatric cancer, they also highlight that commonly available metrics, such as ratings, cost and download volumes, cannot be relied on to provide an accurate picture of how effective an app may be. As such, efforts are needed to better support families in choosing apps that are most likely to meet their needs.

A high volume of BCTs were identified across included apps. This is notable as the number of unique BCTs found was greater than those identified within past reviews of apps for other health needs (Morrissey et al., 2016b). This may have been impacted by the nature of CH itself. As CH requires a two-way flow of information, the inclusion of others to share information with, be they HCPs or social supports, is more likely. This may also have increased the likelihood of BCTs pertaining to social support being included. In addition, CH requires data to be collected so it can be analysed and fed back to the individual. Again, this may have increased the likelihood of BCTs pertaining to self-monitoring, feedback on behaviour or goal setting being included within apps. This may serve as a possible advantage of CH apps, compared to non-CH apps, in that they may naturally include BCTs related to behaviour tracking or monitoring, though additional analysis is needed.

Consistent with past analyses, CH features to support tracking of medical or health information and social support were highly prevalent (Palazzo et al., 2016; Taj et al., 2019). The inclusion of tracking and social supports is promising when considered in the context of facilitating treatment adherence (Kim et al., 2015; Vermeire et al., 2001), which can often present as a challenge in care, leading to additional interventions and increased healthcare costs (Bassett, 2012). Social support is particularly encouraging due to its links to behaviour change (Abroms et al., 2011; Wang et al., 2014; West et al., 2012) and effective coping for caregivers (House et al., 1988). Interestingly good alignment between CH features and BCTs was noted across apps. For example, while tracking features for health or medical management were common, so too were BCTs that provided a means to record, monitor and cue behaviour. This suggests an alignment of BCTs within apps to support the effective use of CH features. Individualization of interventions or information was common across BCTs. Individualizing information can increase usage and behaviour change (Morrison, 2015), while the reduction in irrelevant information can allow users to focus on more salient information (Morrison, 2015). This is particularly relevant for caregivers of children who are under significant financial and time burdens (Warner et al., 2015). As such, while BCTs appear to have been successfully employed within CH apps, additional analysis is needed to enhance the impact of specific apps.

A further key finding is the lack of an association between app cost, rating or number of downloads, and volume of BCTs. This is somewhat expected, with past research suggesting cost alone as not indicative of quality in health apps (Fitzgerald & Mcclelland, 2017). This may be impacted by the potential for ratings in app stores to be inflated by software developers (Morrissey et al., 2016b) and a lack of sufficient information to permit meaningful evaluation (McKay et al., 2018). With the growing ubiquity of CH apps, HCPs and patients alike will require support to effectively assess app quality and appropriateness for their needs (Lewis & Wyatt, 2014). At present, limited guidance exists to support these decisions (Mohr et al., 2013).

There were several limitations to the current study. Firstly, the search terms employed may have inadvertently led to apps being missed within the search. As broad search terms on paediatric cancer were included, apps which could be of good use to caregivers of children with cancer, but which were not specific to this population, may have been missed. Further, as only the Google Play and Apple App store were examined, apps that were not available on either platform may have been omitted. The BCT measure itself may also pose a limitation. The BCTv1 was designed to code interventions rather than apps and as such, some of the measures may not translate fully (Middelweerd et al., 2014; Morrissey et al., 2016a). Future studies should consider the development or adaptation of the BCTv1 to best examine BCTs within smartphone apps or other similar technologies.

3.4.1. Conclusion

Results suggest a strong presence of BCTs across apps for individuals and caregivers living with or beyond paediatric cancer. These findings add to the research in support of CH apps for families affected by paediatric cancer and suggest that the nature of CH may facilitate BCT inclusion in mHealth supports, with a strong alignment between BCT and CH features evident. However, further research is needed to better analyse the link between CH and BCTs more broadly, to ensure their effective inclusion. While findings suggest the high prevalence of BCTs in CH apps for families affected by paediatric cancer, standard measures of quality, such as app rating or download volume, cannot be relied upon by families when evaluating apps. Additional research is needed to determine how to support families in identifying apps that are more likely to be effective. This may be attained through cooperation between behavioural sciences and technology, to ensure alignment between technological advances and effective interventions for those seeking support (Taj et al., 2019). Through collaboration in this manner, means to ensure CH is effectively used by families to address their needs may be attained, leading to a more significant societal impact.

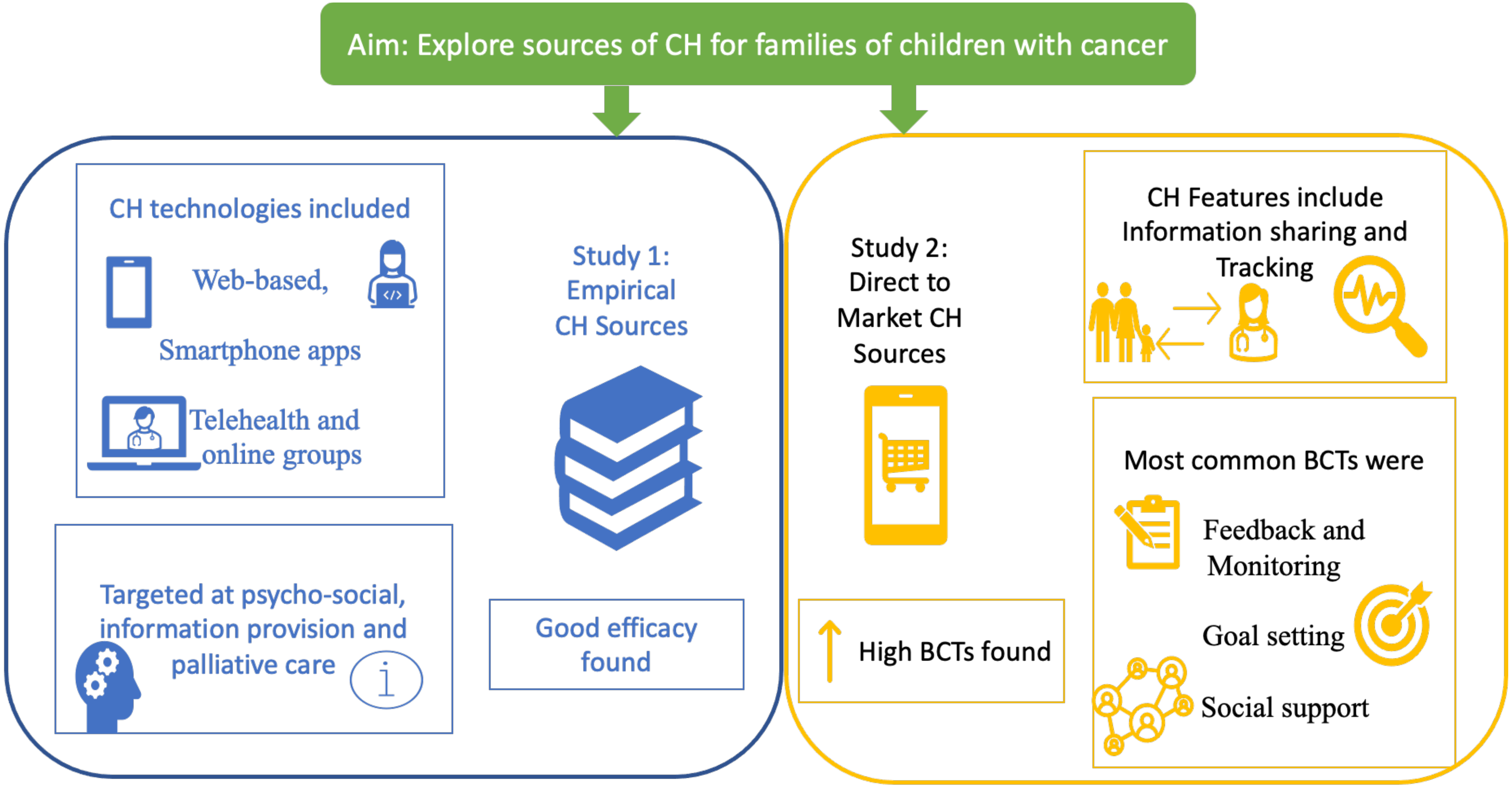
Section A Discussion

The studies presented in this section sought to explore how CH is currently used in both commercial and empirical contexts, to determine its efficacy, domains of use, and how it may be best leveraged to support families living with paediatric cancer. Encouragingly, positive effects for CH were found across both commercially available and empirically driven CH. However, the limited volume of CH and an over-reliance on feasibility and acceptability studies suggests a need for further experimental analysis to fully determine efficacy. An overview of section findings is presented in Figure A.2 below.

It is clear from review of results obtained that, while CH is acceptable, more robust analysis of effects for families of children with cancer is needed. This is highlighted in the results of Study 1, with only five included studies examining the impact of CH on a specific parent or informal caregiver outcome. Of these five studies, only three involved RCTs. Similarly, in Study 2, only three of the twenty-six included apps were the subject of published research. These findings are particularly concerning in the context of the significant and multi-faceted needs encountered by families within paediatric cancer. To address these needs effectively, evidence-based interventions are required, necessitating robust analysis of effects.

Figure A.2

Summary of Section Findings



The studies presented in this section also draw attention to the research-to-practice gap within CH for paediatric cancer. This is exemplified in the high volume of feasibility and pilot studies identified within the systematic review, with 68.7% of included manuscripts being of this nature. While there are benefits to such studies, concerns pertaining to resource wastage emerge should interventions not become available to intended users outside of pilot locations. When considered in tandem with the results of Study 2, wherein apps appear to have been used by stakeholders, with downloads ranging between 0 and 5 million, this research to practice gap appears more stark. While direct-to-market approaches are limited by the absence of empirical analysis, consideration is needed as to how the research to practice gap can be shortened for CH, while ensuring these supports are empirically sound.

Findings suggest that CH is acceptable to parents and caregivers, with generally high acceptance and adherence observed for studies within the systematic review, and ratings of 3.5-4.7 out of 5 for apps included in the content analysis. Despite this, there was only 16 CH interventions identified within the systematic review, and 26 apps found within the content analysis. This low prevalence results in gaps in areas of need supported by CH. Specifically, there is an absence of supports for siblings of children with cancer, and for commercial CH in particular, a low volume of psychosocial interventions. This highlights the need for additional CH development, particularly in response to underserved areas of need. This will be explored further in section B.

A final key finding deriving from this section is the need for decisional supports for stakeholders in paediatric cancer to aid CH seeking. There is a plethora of easily accessible CH, much of which has been developed with commercial aims in mind. This is compounded by commonly available metrics, such as ratings, cost and download numbers, being unreliable at providing an accurate picture of CH efficacy. There is a clear need for supports to be developed to aid families and other stakeholders in identifying effective CH. There is also a need to explore the factors which impact decision making in this context, including health literacy, digital skills or attitudes towards CH. Through this, protective factors which may aid families in identifying more effective supports can be targeted for intervention.

Section A Conclusion

Studies 1 and 2 highlight several factors which require attention for CH to be effectively employed for this group. The first of these is the research to practice gap for technologies developed in academic settings. Consideration as to how this gap in accessibility may be bridged is needed to reduce resource wastage, and to ensure that CH reaches those for whom it is targeted. A second factor requiring additional consideration is how families and HCPs are guided towards choosing CH which is more likely to be effective. An easily accessible metric from which CH can be evaluated is needed to prevent families choosing ineffective technologies. Finally, the limited scope of CH in paediatric cancer to date is highlighted, with most focusing on informational support, healthcare tracking or psychosocial needs. Additional consideration to the unmet needs of families is required to determine where CH may be effectively employed. This will be addressed in detail in Study 3, in which the unmet needs, challenges and barriers to accessing supports will be explored through a qualitative analysis. From this, domains in which CH may be effectively employed can be identified to guide future CH development.

Section B: Exploring the Needs of Families Impacted by Paediatric Cancer

Section B Introduction

As illustrated in Chapter 1, the effects of paediatric cancer on families are significant and broad, with wide-scale and varying impacts across social, financial and psychosocial domains. While it is acknowledged that families coping with paediatric cancer need greater support, the delivery of these supports can be complicated by the significant logistical, financial and time pressures encountered as families traverse treatment protocols and return to communities following treatment. In the context of these challenges, interventions which seek to support families must be responsive to these multiple needs, while imposing no further burden. CH, if it is to be of use in this context, must respond to family needs within the domains in which it may be most advantageous.

While the review of both commercial and empirically-based CH in Studies 1 and 2 suggest that there may be potential positive effects for CH, low volumes of CH were found. Furthermore, the range of needs addressed by CH interventions was narrow, focusing on medical management (e.g., monitoring health, managing treatment, communicating with healthcare teams), rather than family wellbeing more broadly. For example, there was a lack of CH addressing financial, educational, employment or other domains of family functioning. For the scope of CH to be widened, it is important to first consider the experiences and challenges faced by families themselves to determine avenues within which CH should be directed. Further, through adoption of a family-centric approach to CH development, limitations such as the research-to-practice gap may be mitigated.

As this thesis as a whole seeks to explore the potential role of CH for this group, applying a neutral focus to exploring whether there may be effective means of applying these technologies, rather than presupposing a role for CH and determining how best to apply it, this section takes a wide lens in exploring the needs and challenges encountered by families impacted by paediatric cancer. Rather than explore the potential avenues for CH in paediatric cancer (as is explored in Chapter 7), chapter 4 first seeks to explore more broadly the unmet needs and challenges experienced by this group in the absence of reference to any technology or specific intervention form. This approach was taken in order to explore the as-is context of families facing a paediatric cancer diagnosis, to determine the unmet needs which require additional support. Through exploring these broader needs in the absence of reference to a specific technology, it was hoped to obtain an unbiased (in as so much as this is practicable or possible) view on needs with out presupposing a role of CH or digital health interventions. This section also plays a vital role in centring the needs and challenges of families impacted by paediatric cancer, and providing a space for stakeholders to voice their experience without presupposing or imposing any criteria on intervention or solution. This approach was taken to allow for complete analysis of family needs in a neutral context without reference to technology, to allow these needs and challenges to be more fully explored.

B.1 Section B Overview

While CH appears promising for families impacted by paediatric cancer, for such technologies to be effectively employed they must meet the needs of those for whom they are intended. As such, there is a need to explore the specific challenges and barriers encountered by families to determine where CH may offer the greatest impact. This is particularly warranted within an Irish context, due to the absence of awareness of the specific needs and challenges encountered by families within the Irish healthcare system. Study 3 therefore seeks to explore, using qualitative methodologies, the needs of families of children with cancer from the perspectives of parents, and the HCPs who work with them, as well as the degree to which these needs are currently met. Through this, insight into how best CH may be employed to address challenges encountered by families will be determined.

Chapter 4 Study 3: "It's a big big chunk out of life really" Perceived needs and challenges of families impacted by Paediatric Cancer: A Qualitative analysis

Adapted from: Delemere, E, Gitonga, I., & Maguire, R (2023). "It's a really really almost impossible journey" Perceived needs and challenges of families impacted by Paediatric Cancer: A Qualitative analysis, *Comprehensive Child and Adolescent Nursing.*

Abstract

Objective: This study sought to explore the needs and challenges encountered by families impacted by paediatric cancer in Ireland from the perspectives of parents and the personnel who support them.

Method: Twenty-one participants (seven parents, nine hospital-based volunteers and five HCPs) took part in in-depth semi-structured interviews via Microsoft Teams (December 2020 to April 2021) to obtain a perspective of the needs, challenges, and currently available supports for families. Reflexive thematic analysis was employed.

Findings: The need to *navigate a new normal*, a sense of *riding the wave* and *reliance on others* were perceived to be the primary challenges encountered by families. Participants reported a need for *community service provision*, *connectivity* across the health care system and more *accessible psychological support*. High levels of overlap across themes were found for parents and supportive personnel, particularly HCPs.

Conclusions: Results highlight the significant challenges encountered by families impacted by paediatric cancer. Themes voiced by parents were frequently echoed by HCPs, suggesting this group are attuned to broader family needs. While further analysis including children's voices is needed, findings highlight key areas towards which CH may be meaningfully directed such as psychosocial support and facilitating community-based care.

4.1. Introduction

As previously highlighted, families impacted by paediatric cancer face numerous challenges to regaining family functioning. In response to this, emphasis has been placed on family-centred care within paediatric illness (Kuo et al., 2011) in an effort to decrease caregiver strain (Watt et al., 2013). While the importance of the family in care provision is acknowledged, research has typically focused on patient needs alone. Past systematic reviews of psychosocial interventions within paediatric cancer have highlighted the absence of analysis of the family unit (Enskär et al., 2015; Meyler et al., 2010; Steele et al., 2015). Furthermore, in Ireland, while there is recognition of the importance of supporting cancer survivor QOL (Hegarty et al., 2018), few studies have examined the needs of families of paediatric cancer specifically (Barrett et al., 2019).

In seeking to understand the needs of families, there may be value in exploring the perspectives of the stakeholders involved in supporting them. Through such a multi-perspective approach, a more complete exploration of the convergence and divergence of views on past experiences and perceived areas of need can be obtained (Mulligan et al., 2019). Notably, a range of HCPs are involved in paediatric cancer care, each supporting various areas of child and family health. As each of these HCPs interact in different manners with families, they may encounter a wide breath of family experiences. In addition to HCPs, in Ireland hospital-based outreach programmes (HOPs) rely on volunteers to provide services (National Cancer Control Programme, 2018). These programmes provide short-term Therapeutic Recreation activities to children with serious illness, both on-ward and in outpatient settings, with positive perceived impacts found (Delemere et al., 2022). Volunteers supporting these programmes may provide valuable insight into commonly-reported family experiences and challenges. However, while exploration of the views of supportive personnel such as these may offer valuable perspectives on the needs of families, questions remain as to whether these perspectives reflect the experiences of families themselves.

Qualitative analysis may be particularly useful in this context, as it allows for wholesome discussion of complex human experiences (Van Dongen-Melman et al., 1998). For example, a qualitative systematic review by Mu et al., (2015) explored the experiences of families impacted by paediatric cancer in the year following diagnosis, revealing needs such as family turmoil, positive future planning, the importance of family support, and HCP communication. However, as this review focused on the year following diagnosis, long-term needs were omitted. Furthermore, the perspectives of HCPs were not explored. This suggests a need for research in this area to allow for fulsome identification of the needs of families, which in turn may allow for the development of more appropriate supports.

For service provision to be effective, the context and content should reflect individual needs and resources (Halpern et al., 2014; Mullen & Hanan, 2019). However, for supports reflective of individual needs to be available, service providers must first establish a clear understanding of what those needs are, as well as the extent to which they are currently met. While CH offers a means to provide such supports, identification of service needs is required prior to determining if such needs can be effectively addressed through CH. The primary aim of this study is to explore the needs and challenges encountered by families impacted by paediatric cancer through the perspective of parents, with a secondary aim to consider the perspectives of those who work to support these families. Through exploring the perceived unmet needs experienced by families affected by childhood cancer recommendations for future support can be made.

4.2. Method

4.2.1. Public and Patient Involvement (PPI).

This study formed part of a series of studies with PPI in the design (see section 1.5.2 for definition; also Study 7). For both the current study and Study 7, a PPI panel provided insight into the methodology and research questions addressed. This panel consisted of a parent, HCP and researchers with expertise in childhood illness. Further, informal feedback on study design was obtained from several charity and non-governmental agencies in paediatric cancer via phone and email. Results of both studies was presented to this panel to gather ex-post feedback.

4.2.2. Research Design

An inductive qualitative approach was used to undertake a series of semi-structured interviews, with data analysed using a reflexive thematic approach. Three separate participant groups undertook interviews, namely parents of children with cancer, HCPs, and hospital-outreach volunteers. This multi-perspective approach is in line with past research (Mulligan et al., 2019). Ethical approval for this study was obtained through the Maynooth University social research ethics subcommittee (reference number: SRESC-2020-2414528). Full informed written consent was obtained from participants using a consent form and information sheet (see Appendix 2).

4.2.3. Participants

Participants were recruited using an exhaustive purposeful sampling strategy, with invitations to participate disseminated through social media groups, voluntary organisations, patient advocacy groups and service providers in paediatric cancer in Ireland. Eligibility criteria included being 1) the parent/caregiver of a child with cancer who was at least 3-months post-diagnosis but less than 5 years from their last active treatment session, 2) a HCP with experience in paediatric cancer, or 3) a volunteer at a hospital-based therapeutic recreation service in paediatric cancer with at least one year's experience. Supportive personnel, namely volunteers and HCPs, were included to explore their perspectives in addition to those of parents, to determine what additional insight such perspectives may offer. In line with the reflexive thematic approach to analysis (Braun et al., 2019; Braun & Clarke, 2019), richness of data, rather than data saturation was used to determine sample size. Of those approached, none declined to participate. While recruitment was conducted in tandem with study 7 to reduce burden on participants, participants for both studies differed, with not all participants in the current analysis choosing to participate in study 7 and vice versa.

4.2.4. Epistemological Approach

The current study employed a qualitative approach (Braun & Clarke, 2013), within a paradigmatic framework of constructivism and interpretivism. This research sought to reflect the needs and experiences of families in Ireland impacted by paediatric cancer from the perspectives of parents and the staff that support them, while also acknowledging the reflexive influence of the researcher on analysis. In line with this, reflexive thematic analysis (Braun & Clarke, 2006) was chosen as it allows for participant perspectives to be openly considered, while acknowledging participant subjectivity and the researchers own reflexive influence in analysis. Thematic analysis was selected as it allows for a bottom-up inductive approach to data analysis, though some deductive analysis was applied to ensure themes were applicable to research questions. The interview process was developed by the researchers with a recursive approach to research question drafting, and continuous reflection on biases through open discussion. The world view perspective of the researcher is one of a 'doctoral researcher and behaviour analyst, with no experience as a HCP, parent or with childhood illness', with an emic ontological position.

4.2.5. Interview Guide and Data Collection

In-depth semi-structured interviews with parents and supportive personnel were conducted to obtain a perspective of the needs, challenges, and currently available supports for families, in addition to some demographic information. An interview guide was developed, though specific wording and order was not firmly adhered to, to allow participants space to raise unconsidered areas. The first interview with each group (HCPs and parents) served as a pilot, with feedback gathered from participants following the interview, and applied to subsequent interviews. Additionally, three questions on needs across healthcare services, mental health and financial advice (based on Smith et al., 2013) were also asked (see Table 4.1). Interviews took place using Microsoft Teams and lasted an average of 38.16 minutes for parents (range: 23.36-56.48 minutes), 32.43 minutes for HCPs (range: 31.05-35.46 minutes), and 28.29 for volunteers (range: 19.46-44.36 minutes). Online interviews were conducted due to the Covid-19 pandemic restrictions, preventing the completion of in-person interviews.

Table 4.1

Semi-Structured Interview Questions

Interview Questions		**Participant Group**
Parental experience	Did you feel your family's needs were met across each of these domains? • Service Needs • Mental Health • Financial advice	Parents
Unmet needs of families impacted by paediatric cancer	What do you feel are the needs, challenges, and currently available supports for parents, children and families impacted by paediatric cancer? Do you feel these needs were met? If not, why? What additional services do you feel are needed?	Parents Volunteers HCPs

4.2.6. Data Analysis

Interviews were transcribed by the researcher and replayed to check for accuracy. Data analysis was completed using an inductive approach, though deductive analysis was used in part to ensure themes were relevant to the research question. Prior to analysis, all interviews were transcribed into Microsoft Word by this researcher. Firstly, familiarisation with the data occurred through re-reading transcripts. Next coding was conducted, with codes pertaining to relevant or important aspects of the data given to pieces of the transcript. QDA Miner Lite was used for coding and theme development. The researcher, a female PhD student with no past experiences in childhood cancer, completed the coding. Analysis of codes in the absence of transcripts occurred to confirm they were accurately worded. To support accurate coding and theme development, a sample of transcripts (1 per participant group) was coded by a second researcher with experience in qualitative analysis to support accuracy. Following this, the researchers openly discussed codes and themes arising. While no major disagreements occurred, minor disagreements were resolved through discussion. Themes were then determined based on the data, and codes allocated to relevant themes. A review of themes occurred to ensure data were appropriately captured. As per Tong et al., (2007) consolidated criteria for reporting qualitative research, themes were not anticipated in advance. Themes were then defined and named, and analysis written. To support analytic rigour, ongoing reflection on data during collection and credibility checks following analysis were conducted, in line with best practice (Tong et al., 2007; Wu et al., 2016).

4.3. Results

4.3.1. Demographics

A total of 21 individuals consented to participate - seven parents, five HCPs (one nurse, two doctors, one social worker and a physiotherapist) and nine volunteers. Volunteers (four male, five female) had volunteered with the HOP for an average of 3.39 years. HCPs (two male, three female) had on average 17.6 years of experience. Parents (one male, six female) had a mean age of 38.8 years. Due to the relatively small number of individuals in each participant group, demographic details of individuals are not reported to protect their anonymity. Parents were primarily married/cohabitating (n=6) and lived in small towns (n=6). Children had a mean age of 8 years (range=4-12) and most had finished active treatment (n=5). Diagnoses included Acute Lymphocytic Lymphoma (n=2), Rhabdomyosarcoma (n=2), Pilocytic Astrocytoma, Wilms tumour and Hepatoblastoma. Most had siblings (n=5; mean siblings=2.6, range 1-4). Travel to local care centres took parents an average of 22 minutes (range 10-30) and 132.5 minutes to reach primary treatment centre's (range=40-210 minutes).

4.3.2. Themes

Six key themes are presented. Of these, three pertain to challenges experienced by families, namely *navigating a new normal*, *riding the wave of change post-diagnosis* and *reliance on others*. Three further themes relate to the needs of families, namely the *need for community*, *service navigation support*, and *accessible psychological support* (see Table 4.2 for summary of themes).

Table 4.2

Challenges and Needs of Families

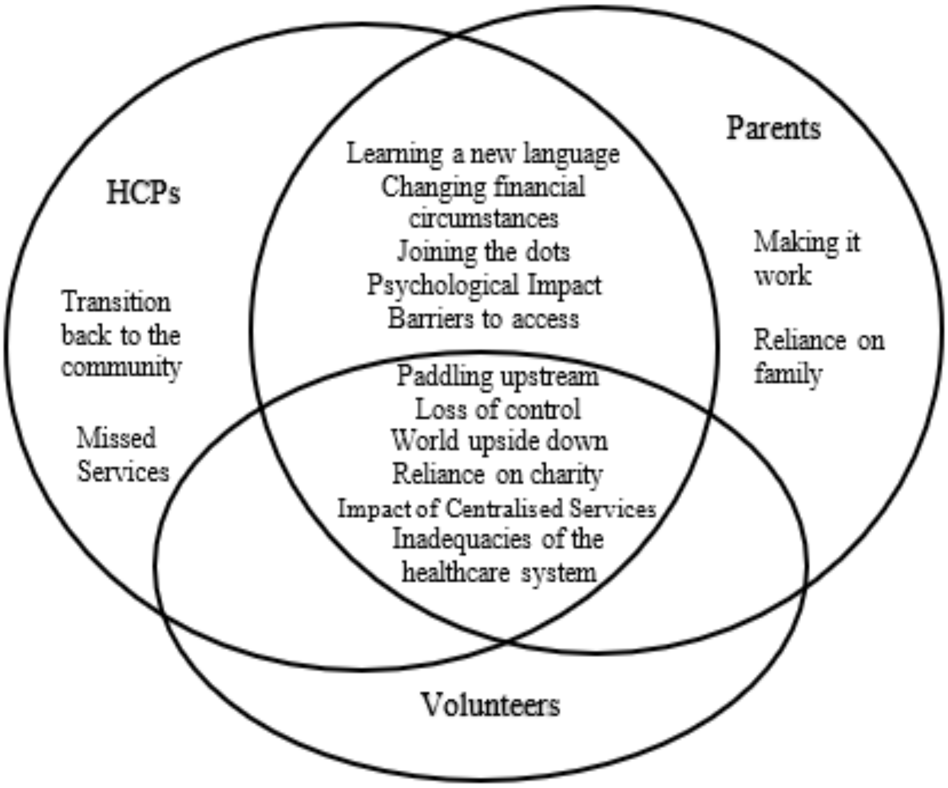
Area	**Theme**	**Sub-theme**	**Number of participants theme mentioned by**		
			Parent	**HCP**	**Volunteer**

Challenges	Navigating a new normal	Paddling upstream	7	4	**6**
		Learning a new language	7	4	**4**
		Changing financial circumstances.	7	5	**3**
	Riding the wave of change post-diagnosis	Loss of control	7	5	**6**
		World upside down	7	5	**8**
		Making it work	5	0	**2**
	Reliance on Others	Inadequacies of the healthcare system	5	5	**6**
		Reliance on charity	7	5	**6**
		Reliance on family	5	1	**3**
Needs	Service navigation support	Joining the dots	6	5	**2**
		Managing Alone	4	3	**3**
		Missed Services	2	5	**7**
	Community	Impact of Centralised Services.	7	5	**9**
		Transition back to the community	4	5	**4**
	Accessible Psychological Support	Psychological Impact	5	5	**4**
		Barriers to access	6	5	**0**

Distribution of themes across participant groups is reported in Figure 4.1. High overlap across themes was found. Some themes were not noted by volunteers, particularly those pertaining to needs for psychological supports. For HCPs specifically, an emphasis on challenges navigating the healthcare service, both during treatment and when transitioning back to their local communities, was noted. While themes pertaining to reliance on family and de-prioritisation of own needs was noted for parents, these were not reflected on by supportive personnel.

Figure 4.1

Distribution of Themes Across Participant Groups



4.3.3. Navigating a New Normal

A common theme for parents was the need to navigate a new normal for the family in response to their child's diagnosis. This was met with a swift learning curve to determine what is needed of them and to learn the language pertaining to their child's care. This theme was noted by supportive personnel also, though only HCPs noted challenges regarding medical terms or financial impacts.

Paddling upstream. Significant difficulties were perceived to be faced by families in seeking financial, informational, and other supports. At diagnosis, parents noted being overwhelmed and unable to determine what supports might be needed.

> I remember you know getting home from the hospital after being in for a week or more and sitting at my kitchen table, and I had papers and forms, and there was just stuff everywhere...I remember sitting here and crying like because I just didn't know where to start. P2

In addition, administrative burden associated with accessing support led to emotional distress in many instances. Where services were obtained, families faced continued requests to demonstrate eligibility, causing anxiety.

> We got the medical card. Six months later they were asking for more proof. They put it on hold, and we had to, it was like reapplying again. P2

Families new to the health-care system were seen to be particularly at risk.

> A lot of the other things you're kind of left to figure out for yourself … I could see families and maybe English wasn't their first language. I could see how it could be a really really really almost impossible journey for some people. P7

Learning a new Language. A further feature was the need to learn a new medical language pertaining to their child's diagnosis and treatment. As the prevalence of many paediatric cancers is low, parents reported difficulties finding peers or appropriate sources of information.

> Particularly for some of the more rarer cancers, there's often not that many other families or children going through treatment for the same diagnosis at the same time. HCP3

As parents often served as care coordinators for their child, a steep learning curve was encountered, a sentiment echoed by HCPs.

> And then there's a whole new language there yknow it's, one knowing what they're doing and then you have to, we learnt to, she was on a tube feed, like how to do that so we could come home. P3

Changing financial circumstances. Post-diagnosis, families became aware of the severe impacts of paediatric cancer on their financial circumstances.

> It has hit us financially...I reckon we were probably down about 30-40 grand. P3

This financial impact was often further exacerbated by a loss in income, with one parent taking leave from employment. Mothers appeared to be disproportionately affected by this, taking leave in most instances.

> Financially, usually from my experience one of the parents will give up work. More often than not it's the mother... And things like mortgages bills have to be paid, they don't have work and then in hospital it's very expensive. HCP4

High anxiety around the family budget was noted, with free time spent seeking financial support or identifying ways to manage finances. For single parent families increased financial burden was particularly evident.

> As a single parent I just felt that I, it's better I continue working. That was very hard on the mental health then but then at least if I'm independent I don't have the added worry of finance. P1

Riding the wave of change post-diagnosis

Another common theme for parents was the loss of control in the face of the disruptive impacts of paediatric cancer. Family routines were upended, and long-term plans removed. This upending in response to diagnosis was echoed by HCPs, and to a lesser extent by volunteers.

Loss of control. A common sentiment was parents' loss of control over their day-to-day lives and those of their children. Upon diagnosis, the child's health and wellbeing is placed in the hands of the medical team, with high uncertainty surrounding outcomes.

> You can't do anything and you're having to rely on yknow medical experts. Well basically to see if you can save your child really. P3

HCPs echoed this loss of control over medical care and outcomes, while volunteers emphasised the impacts on daily planning. Loss of control was also perceived for children themselves.

> And to cope with the eh I would guess constant source of disappointment as things continue to 'go wrong' is a description that is often used. It's not entirely true in that these are expected adverse consequences of the therapies. HCP1

Loss of control was also perceived for children themselves. Children are quickly thrown into a world in which they have little say, particularly around medical interventions. This loss of autonomy was felt to have lasting effects.

> Even though he's a child like he's still went through a trauma of yknow needles and operations and it it's something that he learned to get used to… when he was getting everything out he had a bit of like Stockholm syndrome. P5

World turned upside down. All participant groups noted disruption and shock following diagnosis, with family life thrown off course.

> A child can be playing hockey on Thursday and diagnosed on Monday with em osteosarcoma, bone cancer. So there can be quite a sudden, it usually is quite sudden. And there aren't very overt signs of something being wrong. HCP5

Parents face uncertainty in how to manage their child's health, questioning the severity of even small changes.

> It felt like bringing a new baby home from the hospital and you're like ok what do I do now. P1

Volunteers particularly voiced the tendency for families to become split as one parent cares for the ill child, causing strain. Siblings are often cared for by extended family and may go long periods removed from other family members. The parent relationship is also impacted by time at the hospital and focus on the child who is ill.

> Often families are split so you would have yknow, Dad up with the child, mom at home with the rest of the kids, or vice versa. So I suppose the strain on the families that they're quite separated. V7

Making it work. One approach to this new circumstance was a focus on supporting their child, pushing other considerations aside.

> I suppose if it's your own child you'll do whatever has to be done. V1

Parents alone noted this focus on their child often came at the expense of their own needs, with stigma attached to acknowledging these needs. This avoidance of own physical and mental wellbeing often resulted in negative effects over time.

> I think I was just on raw energy all the way through. And then after treatment, she then got sepsis and then em I just then had to take another month off work. And I just crashed basically. P3

Reliance on others

A common feature noted was an absence of adequate support from the state and healthcare system, requiring families to seek needed support from other sources including charities and extended family. While reliance on charity was echoed by supportive personnel, HCPs specifically raised the inadequacies of the healthcare system.

Inadequacies of the healthcare system. While participants reported having high quality medical care, challenges engaging with the healthcare system were reported. Under resourced services lead to high wait times, low service volume and a perceived need to fight for services.

> You know there's a whole wide range of things and chemo can leave you with a lot of side effects but I suppose then when the oncologist is referring the child

> for them it's not urgent it's not considered urgent to anybody so they can't get bumped up the list. But sometimes it could be quite debilitating to the child. P4

HCPs emphasised how this absence of services was felt particularly as families transition back into the community following treatment.

> And where we failed, and where there is a plan to do group work, is at end of treatment. Cos we know that that's another traumatic time that we didn't attend to because of capacity. HCP1

Reliance on Charity. Charity groups were relied upon to provide supports often considered within the care pathway, such as on-ward psycho-social support. An emphasis on enhancing delivery of non-medical services through alignment with charity groups was noted.

> They donated a lot of money to the service to try and help the psychosocial needs of patients and parents. And em, that is in the next year hopefully going to happen with a specific em eh project manager on the ward to help with psychosocial issues and help co-ordinate resources for them. HCP2

For HCPs however, concerns were raised regarding this reliance on external entities to provide services in hospitals due to inequalities in service provision and risk of closure.

> If they're family-initiated charities you've really concerns about their survivorship, can they keep going... We run into the problem we provide a service that people have become used to and now financially we don't have support to do that. HCP4

HCPs noted an absence of alignment across charities delivering supports, leading to service gaps and areas of overlap. For families, additional effort is required to navigate the numerous charities to determine those which may meet their needs.

> What you often find happening is different charities are doing the same thing… So em you might find that they're offering the same support but then there's gaps in the system that they're missing. HCP4

Reliance on Family. A further external source relied upon is extended family who are needed to support travel for medical treatment. While in hospital, extended family members were often relied upon to maintain things at home.

> There's one little guy he comes now a lovely little fella… and he's a tough little nut now, and his, I'd say they might be either uncles or big brothers... they left at quarter past 6 or something in the morning, to be up for a 9 o'clock appointment. V1

However, not all can rely on this support.

You're thinking god there's other people that don't have the support network that we have and there's nothing out there for them. P5

Needs of Families

Service navigation support

Parents noted a need for increased connectivity across the system and support with service navigation. Often absences of communication across care services led to burden falling on parents either to seek services or manage care. This theme was somewhat echoed by supportive personnel, though HCPs emphasised missed services, a theme not noted by parents themselves.

Joining the dots. Caring for a child with cancer requires a large multi-disciplinary team, with communication needed between and within these teams. However, an absence of communication was noted, particularly at diagnosis.

> It would have been difficult in the beginning like, cos you would've felt like there wasn't much joined up thinking as you're being told one thing and then you met the next person and then that's not the case and like what's going on here yknow. P6

This lack of connection led to a reliance on parents as a source of information, requiring them to re-tell their story across service providers.

> I was the database I felt. You restarted the story every time you met someone; you started the story from the beginning. P6

Managing Alone. This absence of connectivity led to a pressure on parents to serve as the conduit through which connection was achieved. A fear of falling through the gaps was noted by many, with pressure on parents to ensure their child obtained the services needed.

> I was responsible for making sure NAME was well cared for because you'd fall between stools…you're trying to bringing the staff in the hospitals with you, while also not being pushed over yknow. P6

For parents there was isolation in assuming sole responsibility for their child's care. For single parent families, or those with limited family support, pressure to manage care was felt more acutely.

> I mean the nurses are there the doctors are there, but with chemo every single day he has to take pills, he has to take liquids... So you feel like you are the only one responsible for that, and if it happens that you maybe you don't have that strength any more….What will happen if I just wasn't able to get out of bed one day you know? P1

Missed services. HCPs highlighted that the complexity of the system and the effort required to navigate it often led to missed services. Those who could effectively navigate the system were seen to have an advantage with inequalities in access noted.

> Some people get so much support cos they know how to access it and where it is. Others don't know that, or they don't have the energy to find out. HCP4

Community-based services

A core need reflected on by parents were the burdens imposed by centralised services, many of which could be reduced through providing community care. Removal from communities for medical care was seen to contribute greatly to family disruption and absence of supports to re-integrate. In comparison to parents, HCPs specifically emphasised the difficulties associated with transitioning back into communities.

Impact of Centralised Services. Medical services are delivered in a centre of excellence, requiring families to travel to receive treatment and out-patient care. With traveling these distances comes significant financial costs and disruption.

> Often families are split so you would have yknow dad up with the child. Mom at home with the rest of the kids or vice versa. V7

Sibling routines are impacted as they attend appointments with their ill sibling, resulting in missed education.

> There was one family who came up from Sligo … but there was three other kids came as well. So you're sort of thinking well, they've all had to come out of school, and the parents have had to give up what they're doing for the day. V1

Children too miss school and other activities to attend appointments, impacting their development and peer relationships. HCPs noted that many of these factors could be addressed through community-based service delivery.

> There's a much more normal sort of family life for the sick child and the siblings if some of the treatment could be administered locally. So, we are in a constant kind of catch up trying to deal with the consequences of that I think. HCP5

Transition back to the community. One key timepoint at which greater links to community is needed is at end of treatment. An absence of connectivity between hospital services and community-based services to support this transition was noted by HCPs particularly. Again, parents form the conduit through which communication flows in these instances.

> There is this psychologist connected to the ward who would be a specialist so we told her obviously we need to get somebody locally so we sourced our own play therapist locally and even like she said oh I'll connect with her…but even at that we weren't even able to get that that that kind of connection yknow. P4

Many communities however lacked clinicians sufficiently knowledgeable in paediatric cancer. Seeking clinicians with relevant experience may be difficult with families continuing to rely on hospital supports or their own skills.

> Depending on the public health nurses or their GPs but most of them have only seen a child once in their lifetime with cancer so their experience is limited. Not their fault, it's just the nature of the thing and therefore parents often feel quite alone dealing with this. HCP4

Accessible Psychological Support

Due to stigma and accessibility challenges, a need for access to universal-level psychological support within the care pathway for families was noted. While this theme was echoed by HCPs, it was not noted to the same extent by hospital volunteers.

Psychological Impact. All participant groups noted the significant psychological impact of a cancer diagnosis on children and their families. Parents described a need for family psychological support following their child's diagnosis.

> And the day came for his end of treatment bell, and I felt no different. I'm like, you nearly feel bad for celebrating because it's still right we got over this hurdle were in remission now, now it's to stay in remission. And it's that constant worry and it's the constant god he looks very pale today. God, he says he's not feeling well. P5

For children themselves, a need for psychological support was also noted. While treatment is key to survival, children were often unprepared for procedures leading to mistrust in medical professionals. While parents attempted to support these needs, often this was not sufficient.

> As much as I could prepare him there wasn’t enough support medically for his, for his mental health to help him prepare even more for all those situations. P5

Barriers to access. Parents noted that psychological services were often inaccessible, associated with long waitlists or difficult to find. Significant effort is needed to find supports, often at times where families may not have the capacity to seek services.

> The services weren’t there unless we actively went searching for them, and it wasn’t you would’ve had to really been looking for it like they weren’t easily in my grasp sort of thing... And sometimes you don’t know you need it so if it was hard. P2

Parents also did not recognise or prioritise their own needs. For many, psychological support was only obtained following a mental health crisis or through medical staff identifying their urgent need. Further, some parents felt stigma in seeking support when their child had survived.

> You’re kind of half afraid to go. And you get, I’ve often heard people say oh isn’t it lucky that he’s still here, and isn’t it lucky that, I can’t believe what you went through, as if it’s a past tense thing but it’s not its constantly going to be in your present. P5

4.4. Discussion

This study explored the needs and challenges of families impacted by paediatric cancer from the perspective of parents and those who support them. Results highlight the numerous impacts that living with paediatric cancer can have on the family unit, with families often facing significant disruption to routines, relationships, psychological wellbeing, finances and household management. Building on this however, results also highlight several avenues through which families may be better supported.

When considered in the context of the broader literature, commonalities between the challenges of the current sample and past research are clear. The results of Study 3 are consistent with past literature which highlights the significant impact of childhood cancer on family functioning (Gutiérrez-Colina et al., 2017) and its extension over time (Ljungman et al., 2014; Peikert et al., 2020). Consistent with past findings, needs pertaining to information seeking, psychological supports (Aziza et al., 2019) and care coordination (Keats et al., 2019) were noted. This suggests common challenges encountered by families of children with cancer across different healthcare contexts, cultures and communities. Such commonly experienced needs may be of relevance to the development of supports for this group, particularly digital supports such as CH. This high overlap of needs is also promising in the context of the high research-to-practice gap for empirically based CH (see Study 1). Through targeting shared areas of need, such as those outlined above, CH may be better able to generalise across settings, facilitating higher levels of uptake in practice and reducing resource wastage.

Difficulties navigating the system for families appear clear, with a reliance on supportive others and strong self-advocacy required to access support. This need for advocation is concerning, as it requires a level of health literacy, alongside an understanding of (and capacity to interact with) complex systems to have needs met. This poses additional disadvantage to families who are vulnerable due to a lack of supportive others, poor health literacy, unfamiliarity with healthcare services, or difficulty communicating with authority. Analysis is needed to determine if support mediated through CH may be used to mitigate risk for these families. However, as technology mediated supports, such as CH, are often subject to a digital divide, consideration is required to ensure that such supports do not exacerbate access disparities.

Results also highlight the potential of community-based service provision to reduce some of the negative impacts of paediatric cancer on families. Travelling for care was perceived to significantly impact family functioning, finances, and relationships, in addition to sibling wellbeing and parent employment. The financial impacts of a cancer diagnosis are consistent with past research (Irish Cancer Society, 2015; Kelada et al., 2020), with common areas of expenditure associated with travel and lost income. Past research echoes the need for increased community-based service delivery, since parental job-loss, reduced hours and extended leave may be required by those living further from treatment centres (Roser et al., 2019). Need for increased communication between hospitals and local HCPs, and upskilling for local doctors, may be some potential ways of improving care in local communities (Tonorezos et al., 2018), which would likely reduce negative experiences for families.

The identified need for increased psycho-oncological support for families is also consistent with past research (Aziza et al., 2019), particularly for those who are based in rural areas (Barrett et al., 2020). Poor peer support and risk of isolation for rural survivors was highlighted by Barrett et al (2020), in keeping with present findings. Results differ somewhat from those of Hegarty et al., (2018), who found higher access to psycho-oncological supports for paediatric cancer across Ireland. However, this may be attributed to the profile of the families in our study, who resided predominantly outside of urban areas. Hegarty et al., (2018) noted only 25% of non-Dublin patients had access to psycho-oncological support, which is more consistent with the present findings. Interestingly, in contrast to Christen et al., (2019) who found that needs for psychosocial support were greatest during treatment, participants in this study suggested that needs for support are greatest when transitioning back into the community following treatment. This may be facilitated through increased communication between primary and local care providers.

Comparison of themes across parents and supportive personnel suggests agreement in the perceived challenges and needs experienced by families. This was particularly clear for themes pertaining to the negative impacts of cancer on the family unit (e.g. experiencing a loss of control, paddling upstream, feeling that the world is upside down), difficulties in navigating services (e.g., impact of centralised services, inadequacies of the healthcare system), and reliance on charity for support. This suggests that supportive personnel have good general awareness of the challenges and needs experienced by families. It is of note however that while HCPs voiced all bar two of the subthemes noted by parents, volunteers differed, with only eight of the sixteen subthemes mentioned by this group. In particular, the need for 'accessible psychological support' and 'changing financial circumstances' were not emphasised by volunteers. This is somewhat to be expected as their encounters with families may be more limited than HCPs, and their focus may lie primarily with the children themselves. These results suggest that while supportive personnel may be in tune with the needs of parents and families, gaps in awareness, particularly for volunteers, may hamper their ability to fully capture family needs.

Several parent-specific themes were also noted. One such example was the need to 'make it work', or the emphasis on child wellbeing over other areas of life. This may pose a challenge when considered in the context of the HCP-parent relationship, should HCPs be unaware of parental struggles which they may be unwilling to share. This may lead to supports for parents being missed, either through them not being offered by HCPs, or being dismissed by parents due to an unwillingness to prioritise own needs.

This highlights the need for healthcare systems to reduce the ‘activation bump’ encountered by parents when seeking services by making them freely and easily available and highlighting the importance of self-care. The importance of extended family members was also highlighted by parents alone. As families may lack support systems on which they can rely, additional supports may be needed to bridge this gap. Increased awareness of this reliance on family is needed for supportive personnel to ensure those families who may lack broader family support are identified and provided appropriate support.

There are several limitations to the present study, most notably the sample size and composition, with a relatively small number of parents, particularly fathers, participating in interviews. The differing child diagnoses across parent participants may have resulted in very different treatment pathways and experiences. However, the range of perspectives obtained provides good insight into the diverse experiences that may be encountered by families. Future analysis may benefit from more in-depth review of the needs of families impacted by different forms of paediatric cancer to evaluate more specific needs for support. Furthermore, as these interviews were completed in the context of COVID-19, which had significant impacts on the healthcare system, needs and challenges experienced may have been impacted by this. As most children had finished active treatment prior to the pandemic, the impacts on results are likely limited.

To conclude, this study highlights several challenges and unmet needs experienced by families impacted by paediatric cancer. For families, key challenges include navigating the hospital landscape, managing their child’s care and accessing services within an under-resourced healthcare system. There is a clear need for increased community-based services to mitigate the negative effects associated with centralised treatment, as well as increased connectivity in terms of service navigation and communication across the healthcare system, and a need for universal psychological support. While further analysis of the experiences of families impacted by paediatric cancer is needed, these findings highlight several key areas towards which support should be directed.

Section B Discussion

While Study 3 highlights avenues through which CH may positively benefit families impacted by paediatric cancer through addressing their informational, communicative, psychosocial and household management needs, it also highlights the unique experiences of these families, and the significant and varied challenges they encounter, with impacts across varied domains of family and individual functioning. In the context of the current absence of awareness of the specific needs and challenges encountered within an Irish healthcare context for families with cancer, these findings direct attention to several domains in which support may be focused.

These findings also highlight the key role care teams may play in CH development. Consistency of observed themes across parents and HCPs indicate that professionals may be attuned to broader family needs, and may provide valuable input into CH development. The inclusion of different stakeholders in design from the outset may also reduce resource wastage, allowing for greater focus on impact, rather than acceptance, in pilot analyses. As noted in Section A, research exploring CH interventions for families of children with cancer consists primarily of pilot or feasibility analyses, with a focus on usability and acceptance rather than impact. Further exploration of stakeholder perceptions towards CH is presented in Section C.

Section B Conclusion

There is a clear need for increased community-based services to mitigate the negative effects associated with centralised treatment, as well as increased connectivity in terms of service navigation and communication across the healthcare system, and a need for universal psychological support. Taken together with Studies 1 and 2, these findings suggest the potential of CH to alleviate parent burden and support family members and activities, however analysis of the barriers and facilitators to the use of

CH is needed. While Study 3 casts light on potential areas of need which may be supported by CH, analysis of the acceptability and utility of CH in paediatric cancer remains outstanding. This will be considered across the studies described in Section C, in which the unique barriers and facilitators of CH use for this population will be explored.

Section C: Barriers and Facilitators to the use of CH in Practice

Section C Introduction

While CH is theorised to ease access to care for children with cancer by increasing efficiencies and reducing access barriers (Leykin et al., 2012), uptake remains low (Government Accountability Office, 2017), with poor adherence and high attrition found (Canter et al., 2020; Michie et al., 2017; Vandelanotte et al., 2016). Common factors impacting CH use include accessibility (Gell et al., 2015), perceived negative impacts on relationships with care providers (Aligning Forces for Quality, 2012), compatibility with pre-existing systems (Mohammadzadeh & Safdari, 2014), ethical and legal concerns (Anderson, 2007) and, as found in Study 1, generalisation of effects to non-pilot settings. Lack of transparency is also a challenge, with privacy, security and biases in AI decision-making systems raising concern (Hailemariam et al., 2020). For families impacted by paediatric cancer specifically, anxiety (Britto et al., 2013), understanding (Schultz & Alderfer, 2018), and feared reductions to face-to-face supports (Van Der Kleij et al., 2019) pose concerns. Further, increased risk of treatment abandonment has been found for digitally mediated interventions in paediatric cancer in Low and Middle Income Countries (LMIC; Graetz et al., 2021). This is concerning, with families at risk of missing services should they be delivered digitally. To explore the potential impact of socio-economic, technological and other factors on CH uptake, a series of studies were conducted. From this, the factors which may present barriers to CH for parents of children with cancer are identified, and can be proactively addressed in CH development.

C.1. Digital Divide

While digitalisation of CH is posited to support access to healthcare for at-risk groups, there appears a converse effect in practice, with health inequalities arising from the inaccessibility of digital services (Phelan & Link, 2013). The impact of healthcare digitalisation on access is termed the ‘digital divide’, or the discrepancy between those who have, and do not have, access to digital technologies (Parsons & Hick, 2008; Van Dijk & Hacker, 2003). This theory posits that those from higher socio-economic groups are more likely to benefit from digital technologies (Parsons & Hick, 2008), resulting in better health outcomes for those who are young, educated and urban-dwelling (Chou et al., 2011). This inequality holds for technologies where access is mediated by a gatekeeper (e.g., EHRs), for which access is obtained through a HCP (Weiss et al., 2018). The digital divide grew alongside Covid-19, with vulnerable individuals found to be at increased risk of missing care (Lee et al., 2021).

While analysis of the digital divide within paediatric cancer has been limited, research has explored inequalities in access for caregivers of children more broadly, with positive associations found between education level and use of digital health technologies (Park et al., 2016). Greater use of CH has also been found for those who are female, and have higher education and income (Hong et al., 2020). While this suggests an impact of the digital divide, analysis of specific impacts on children with cancer is needed in the context of ever-expanding digitalisation, to prevent inequalities in access.

C.2. Pre-requisite Skills

While the digital divide focuses on socio-economic factors, analysis of the impact of skill acquisition on CH use remains outstanding. Pre-requisite skills are the underlying skills necessary to effectively use health technologies. The need to consider pre-requisite skills was highlighted by WHO (2021) in their global digital health strategy, wherein digital determinants of health was identified as a key strategic pillar.

While Section C.1 highlights the impact of socio-economic factors on the successful use of digital technologies, several technology specific skills have also been identified. One such skill is digital literacy, or the array of complex cognitive, social and motor skills needed to successfully navigate technology (Cohen, 2012). Key components of digital literacy include 1) the ability to read graphical displays, 2) digital reproduction, 3) constructing knowledge from online sources, 4) assessing information quality, and 5) understanding and applying social rules online (Alkalai, 2004). Within healthcare, digital literacy is positively associated with the ability to use technology for individual benefit (Livingstone & Helsper, 2008; Neter & Brainin, 2012). Digital literacy may also impact sources of health information, with social media and online communities more accessible to caregivers with lesser health or digital literacy (Gold et al., 2012). Information from these communities may not be accurate or appropriate, this further compounding negative impacts. To support effective CH use by parents of children with cancer, analysis of the digital literacy skills needed to use such technologies with success is warranted.

The ability to seek information using online sources may also be a pre-requisite for CH use. The ability to source CH tools, and to problem solve should challenges emerge, requires the ability to use search engines or other online information sources. However, challenges such as low search tolerance (Eysenbach & Köhler, 2002) and difficulty sourcing relevant information (Taira et al., 2020), are commonly encountered. While vast swathes of information are readily available online, skills are needed on the part of the user to determine its quality (D'Alessandro et al., 2001).

Comfort and confidence using technology also appear to be prerequisite skills, both of which are associated with CH access (Hah et al., 2019). Familiarity with digital technologies may support user confidence, in turn increasing willingness to engage with novel technologies such as CH. Positive associations have been found between technological proficiency and willingness to use CH for Australian medical staff (Hofer

& Haluza, 2019). As such, efforts to support individuals to become familiar with technology is needed to facilitate comfort, in turn increasing willingness to engage with novel technologies.

A further pre-requisite skill requiring analysis is eHealth literacy, or the ability to access, assess, and action health information sourced online (Norman & Skinner, 2006). eHealth literacy is positively associated with acceptance of digital technologies (Donovan et al., 2015; Hennemann et al., 2017; Tennant et al., 2015), and impacts the processing and use of online information (Lluch, 2011). eHealth literacy also impacts HCPs attitude towards CH, with technological skills and comfort associated with greater digital usage (Konttila et al., 2019). While broad analysis of the impacts of attitude and eHealth Literacy have been conducted, no analysis of the effects of these factors within paediatric cancer has occurred to date.

As such, digital literacy, online information seeking, comfort with technology and eHealth literacy, while inter-linked and overlapping, appear key digital skills required for the successful use of CH. Analysis of the impact of these domains on CH use in paediatric cancer however remains outstanding, and is needed to determine areas in requiring support.

C.3. Stakeholder Perspectives

While both demographic and digital factors may impact CH uptake, the perspectives of those with lived experience of childhood cancer, including families and the HCPs who support them, must also be considered to allow unexplored challenges to be raised. This was highlighted within Study 3, in which significant insight into the unmet needs of families was provided by both HCPs and parents themselves. This is particularly pertinent in paediatric cancer, where barriers to CH have yet to be explored in detail. To date techno-centrist rather than system-wide CH design has been emphasised, in which CH is developed by technology experts, with the voice of users not meaningfully captured. This approach often leads to poor generalisation to real-world settings, and limited uptake in practice (Biggs et al., 2010; Frauenberger et al., 2015). In response to this, focus has shifted to a bottom-up approach in which stakeholder needs are the primary subject of analysis, and form the basis of technology development (Granja et al., 2018). The need for system-wide CH approaches is emphasised in the WHO (2021) global strategy on digital health, wherein non-systemic health care digitalisation strategies are reported to be ineffective. To ensure system-wide digitalisation can occur, all relevant stakeholders should be included. While the need for stakeholder inclusion in CH design has been espoused, limited analysis of parent preferences towards service delivery approaches in paediatric cancer has been conducted (Hashemi et al., 2018).

While parents are experts in their own experiences, in the context of the high heterogeneity of diagnoses and treatment pathways in paediatric cancer, the experience of one family may differ significantly from others. HCPs may provide unique insights in this instance, due to their exposure to many different families over time. Further, the variety of health domains encountered by HCPs, including medical care, motor skills, psychological wellbeing, and community integration, provides insight across a wide range of areas in which CH may be employed. This unique insight into patient care, and the forms of information needed to ensure wellbeing, offered by HCPs necessitates their inclusion in CH design (J. Lee et al., 2021). The inclusion of HCPs in identifying barriers to CH use is also important due to their role in supporting CH uptake (Broens et al., 2007; Eichenberg et al., 2013). However, while most HCPs view CH positively (Donovan et al., 2015), resistance to use is common (Boonstra & Broekhuis, 2010; J. Li et al., 2013), with HCPs unlikely to fully utilise digital technologies in practice (Granja et al., 2018; Hennemann et al., 2017). To support effective design and uptake for families and HCPs alike, their insights into CH design and implementation is needed.

C.4. Overview

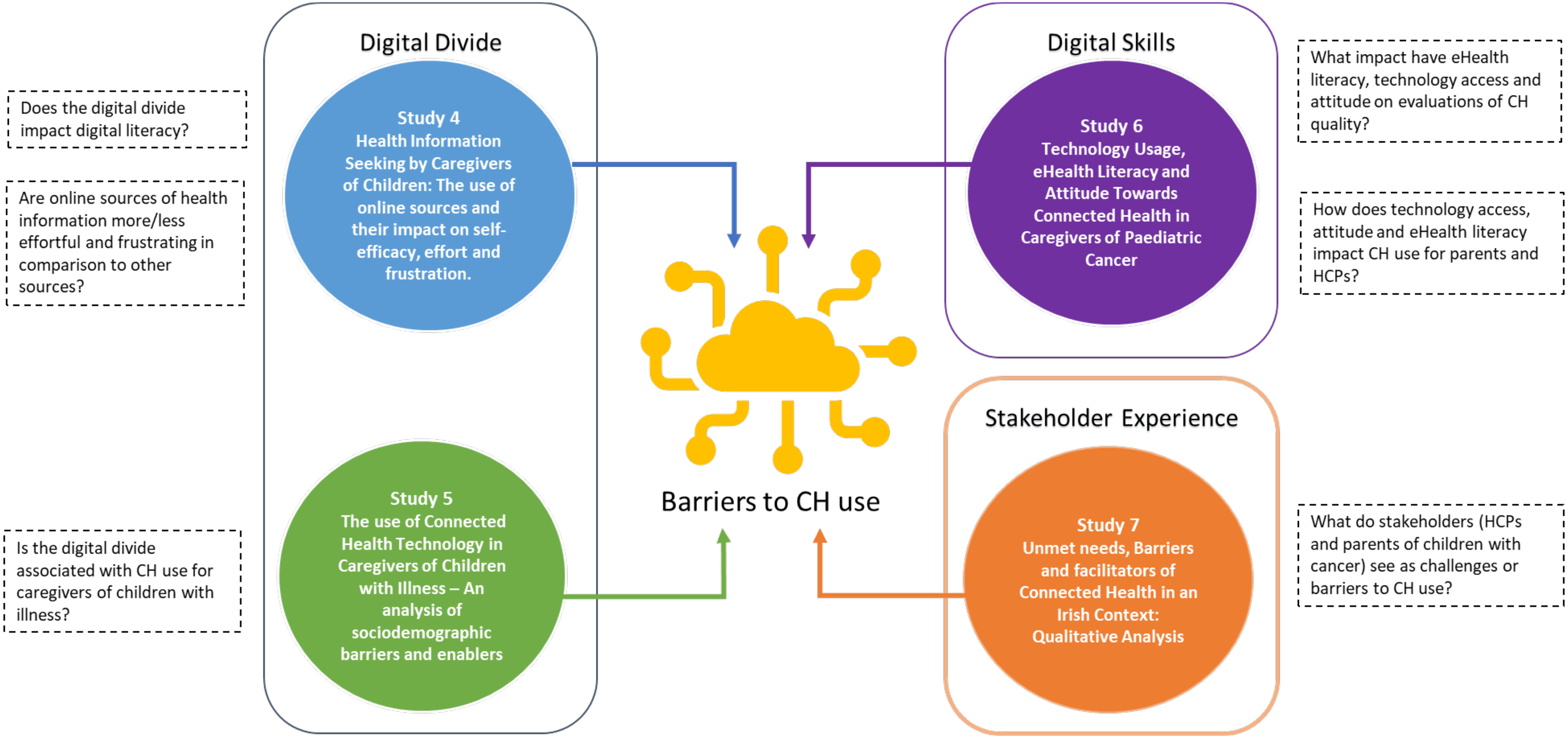
For technologies to reap the benefits espoused, they must be accessible to those for whom they are targeted. In line with this, studies 4 to 7 seek to explore the barriers and enablers which may facilitate or inhibit CH use by families. A graphical depiction of study aims is displayed in Figure C.1 below.

Firstly, demographic factors which may serve as barriers to CH access are considered in secondary data analyses of the HINTs dataset conducted within **Study 4 and 5.** While both studies 4 and 5 focus on caregivers of children with illness more broadly, rather than specifically on caregivers of children with cancer, both studies provide important information on the impact of sociodemographic factors on both CH and digital health access. One key benefit to the HINTs data is its sampling methods, and the relatedly representative sample. As the HINTs data is gathered using stratified sampling methods with minority population groups oversampled to ensure adequate representation, those from low-income or low-education areas are more likely to be represented in the data, an important factor when exploring the digital divide. Further, the use of phone, mail and online recruitment to the survey is also advantageous in that it reduces the risk of over-sampling digital nomads and excluding those with limited access to technology. As this research was conducted in the context of Covid-19, and the associated social distancing requirements, these sampling methods offered particular advantage as in-person data collection in Ireland at that time was not feasible. A second key advantage of the HINTs data is its focus on a population where CH is commonly applied and encountered by the general public, with EHRs and telehealth commonly employed. This proliferation of CH across the sample allowed for in-depth analysis of factors impacting access and use, as opportunities to use CH would be common place. This is in contrast to Ireland, wherein digital health is lagging, preventing analysis of widespread sociodemographic barriers and facilitators, as most individuals will not have had the opportunity to access such tools. As such, it was felt that the insights given through the HINTs data in studies 4 and 5 provided valuable opportunities to explore sociodemographic factors relevant to families of children with cancer, which would not be possible in an Irish context.

Following this, **Study 6** explores the role of prerequisite technological skills on CH use for parents of children with cancer and HCPs. Qualitative analysis of the specific barriers and challenges encountered by families impacted by paediatric cancer in Ireland is conducted within **Study 7.** Through this identification and analysis of the socio-demographic, technological and stakeholder-identified barriers, and facilitators, to CH use, means to capture and reduce such barriers in technology development can be applied.

Figure C.1

Graphical Depiction of Section C



Chapter 5 Study 4: Health Information Seeking by Caregivers of Children: The use of online sources and their impact on confidence, effort, and frustration.

Adapted from: Delemere, E & Maguire, R (2022). Caregivers of children feel confident about using the Internet for health information, *Health Information Libraries Journal.* DOI: 10.1111/hir.12430

Abstract

Rationale: Caregivers of children are increasingly reliant on alternative sources of health information. Little is known of the impact of online sources on effort, frustration or confidence in caregiver health information seeking.

Objective: To examine the impact of sociodemographic factors on the use of the internet for health information by caregivers of children, and the impact on confidence, effort, and frustration.

Methods: Using data from the 2019 Health Information National Trends Survey, the effects of information source on confidence, effort and frustration were examined using the complex samples module of SPSS.

Results: The internet was the most common source of health information for caregivers of children (n=247), with high confidence, low frustration and effort reported. Younger, higher educated and higher income caregivers were significantly more likely to use the internet for health information. Information from HCPs was associated with greater confidence, and information from peers associated with lesser effort and frustration. No significant effects on confidence, effort or frustration for online health information was noted compared to other sources.

Conclusion: Effort to reduce caregiver barriers to online health information is needed. Results suggest a role for HCPs in supporting online health information.

5.1. Introduction

The internet is the most common source of health information (Bujnowska-Fedak et al., 2019; Finney Rutten et al., 2019), often supplementing that obtained from HCPs on medical conditions, treatments, or prescriptions, and informing health and lifestyle changes (Beckjord et al., 2007), facilitated by its ubiquitous, low-cost, and interactive nature (Camden & Silva, 2021; Ziebland & Wyke, 2012). One group for whom the internet is an important source of health information is caregivers of children with illness. Caregivers of children, typically their parents, play an important role in optimising child health (Guerra et al., 2011; Sultan et al., 2016), mediating HCP communication, disease management, and decision making (Hill et al., 2014; Koch & Jones, 2018). As quick deteriorations in health status can occur in many chronic childhood illnesses (Gentles et al., 2010), caregivers must continually monitor child health, relying on observation and intuition to determine when HCP support is needed. As caregivers of children encounter numerous logistic, financial and time barriers (Gutiérrez-Colina et al., 2017), the speed and accessibility of online health information is of particular value to this group.

It is clear however that limitations exist when seeking information online, including difficulties accessing appropriate, high quality and relevant health content (Knapp et al., 2011), and the risk of obtaining inaccurate information (Daraz et al., 2019), leading to inappropriate healthcare seeking, and increased anxiety (Lleras de Frutos et al., 2020). Search engines, while proficient at identifying large volumes of information, do not provide simple access to relevant health information (Eysenbach & Köhler, 2002; Taira et al., 2020). Furthermore, the quality of online health information may be questionable, with the scientific basis of findings often not readily accessible (Daraz et al., 2019; Son et al., 2018; Sun et al., 2019). This necessitates sufficient health literacy in users to determine whether to act or accept findings (D'Alessandro et al., 2001), a feat impeded by technical terms or jargon (Benigeri & Pluye, 2003).

While access to timely, relevant information can empower caregivers of children, the absence of sufficient information can increase parental stress (Jackson et al., 2007). Caregivers are also often hesitant to discuss health information uncovered online with HCPs (Kim et al., 2017; Kubb & Foran, 2020). This is of concern as inaccuracies may not be corrected, posing risk. Further, concerns regarding equality of healthcare access across population sub-groups have been raised. As noted in the Section C introduction above, those with higher socio-economic status appear more likely to benefit from digital technologies, an effect termed the "digital divide" (Parsons & Hick, 2008). While the internet may decrease anxiety through timely access to information, prerequisite digital and health literacy skills, in addition to confidence and effort, are needed to obtain information in this manner.

A systematic review of health-related internet use among informal caregivers of children and adolescents examined prevalence, predictors, and perceived barriers of internet use for health information (Park et al., 2016). Prevalence of internet use varied considerably between 11-90%, depending upon definition and measurement used. Primary uses included decision making, and social support via online peer groups. Education was positively correlated with use of the internet for health information, suggesting an impact of the digital divide. However, participants were not representative of the diverse population of caregivers, particularly regarding gender, race, employment, and education. As such, there is a need for research using more representative samples to examine the impact of socio-economic factors on the use of the internet to seek health information for caregivers of children.

This study seeks to examine the experiences and sources of health information seeking for caregivers of children, as compared to other caregivers and non-caregivers. Firstly, the impact of socio-demographic factors on the use of the internet to obtain health information is explored. Secondly, the relationship between the use of internet for health information and perceptions of having health information needs met is examined. Specifically, this research seeks to establish whether the source of health information is associated with perceived efficacy, confidence, and frustration in seeking health information for caregivers.

5.2. Method

5.2.1. Study Design

This study is based on data obtained from the 2019 Health Information National Trends Survey (HINTS), a nationally representative survey of United States civilian non-institutionalized adults. This survey, administered by the National Institute of Health and conducted bi-annually, examines health-related topics, behaviours, attitudes, and awareness. Since 2017, the HINTS has sought to examine health information seeking behaviours and the use of technology in health. The current study examines responses to sections on ‘Health Information’, along with demographic information for caregivers. Ethical approval for this analysis was obtained from Maynooth University Social Ethics Sub Committee on June 3rd, 2020 (Reference: SRESC-2020-2408297).

5.2.2. Participants

A total of 5,438 individuals participated in the 2019 HINTS survey, of which 4.8% (n=247) were caregivers of children. This compares to 8% (n=410) who were caregivers of adults, 1.6% (n=85) who provided care for multiple groups and 85.6% (n=4413) who were non-caregivers. Caregivers of children were identified if they responded ‘yes’ to the question: “Are you currently caring for or making health care decisions for someone with a medical, behavioural, disability, or other condition?" and selected "caring for a child".

5.2.3. Measures

Demographic Information. Data was gathered on participants' marital status, gender, banded combined annual pre-tax income, race/ethnicity, age, and highest level of education (less than high school, high school, some college, bachelor's degree, or post-baccalaureate degree). Data was also gathered on participants' caregiving responsibilities, including the type of individual they cared for (i.e. child, adult etc.) and their condition.

Source of Health Information. Two aspects of health information source were examined: actual and hypothetical use of internet for health information. Actual use was defined as the primary source used most recently to seek health information. Hypothetical source of health information was determined based on what respondents said they would use should they need to seek health information. Health information sources included one of four categories 1) books/literature, 2) friends and family, 3) HCPs and 4) online sources.

Confidence in health information seeking. This was measured using a single item asking respondents to self-report how confident they were that they could get information about health or medical topics if needed, on a 5-point Likert scale (1 = not confident at all; 5 = completely confident).

Effort in health information seeking. This was measured using a single item asking respondents to self-report how effortful they felt it was to seek health or medical information, on a 4-point Likert scale (1 = strongly agree; 4 = strongly disagree).

Frustration in health information seeking. This was measured using a single item asking respondents to self-report how frustrating they felt it was to seek health or medical information, on a 4-point Likert scale (1 = strongly agree; 4 = strongly disagree).

5.2.4. Data Analysis

The complex samples application of SPSS was used due to stratification within sampling. Specifically, to ensure representation of minority sub-populations, two explicit sampling strata were used for this HINTs cycle, one consisted of addresses from areas with high minority populations and the second had low volumes of individuals from minority groups. The high minority sample was oversampled to increase the representation of minority sub-population groups. Full sample weights were used due to complexity of sampling methods to ensure accurate calculations of national population estimates and to compute standard errors. Descriptive analysis was used to examine the source of health information and confidence, effort and frustration in health information seeking. Multiple logistic regression analyses were used to examine whether the actual or hypothetical source of health information could be explained by demographic variables, with sequential Bonferroni scores used. General linear model analysis was conducted to examine the relationships between frustration, effort and confidence and source of health information for caregivers of children and to examine whether the trends observed held for other caregivers.

5.3. Results

5.3.1. Demographic Information

For caregivers of children, 19.4% (n=48) cared for children with mental health, behavioural or substance abuse issues, 14.2% (n=35) cared for children with neurological/developmental concerns, while 7.6% (n=19) did not know how to categorise their child’s condition. The remainder (n=145, 68.8%) cared for children with a range of other health conditions, inclusive of 11.3% who cared for children with cancer. See Table 5.1 for additional detail, which also includes comparisons with caregivers of adults (n=410).

Table 5.1

Caregiver Type by Child Health Condition

Caregiver type	**Percentage of HINTS sample**	**Cancer**	**Alzheimer's, dementia, forgetfulness**	**Orthopaedic/ Musculoskeletal**	**Mental health Behavioural Issues**	**Other Chronic Conditions**	**Neurological/ Developmental Issues**	**Acute Conditions**	**Aging/Aging related health issues**	**Not sure/ Don't know**	**Multiple caregiving conditions selected**	**Other**
Caregivers of children	4,8% (n=247)	11.3% (n=28)	0%	1.2% (n=2)	19.4% (n=48)	2.4% (n=6)	14.2% (n=35)	0%	0%	7.6% (n=19)	19.4% (n=49)	21.8% (n=54)
Caregivers of adults	8% (n=410)	3.1% (n=17)	8.3% (n=42)	4.3% (n=23)	2.9% (n=21)	6.7% (n=33)	3.4% (n=25)	0.2% (n=1)	5.2% (n=25)	1.6% (n=7)	60.8% (n=309)	3.6% (n=23)
Multiple caregivers	1.6% (n=85)	2.6 (n=2)	2.5% (n=2)	1.4% (n=1)	1.2% (n=4)	7.7% (n=6)	2.6% (n=2)	0	2.6% (n=2)	6.5% (n=5)	66.3% (n=51)	6.5% (n=5)
Non-caregivers	85.6% (n=4413)											

Caregivers of children were predominantly aged between 35-49 (41.8%), female (57.8%), married (64.3%) and white (61.8%). Caregivers of children were slightly more likely to have completed at least some college education (54.9%) in comparison to caregivers of adults (41.6%), and non-caregivers (43.4%). Household income did not vary largely across caregiver groups. Additional demographic information is displayed in Table 5.2.

Table 5.2

Demographic Information by Caregiver type

Demographic information by Caregiver type			
Demographic factors	Caregivers of children	Caregivers of adults	Non- caregivers
Age			
18-34	20.0%	10.8%	26.7%
35-49	41.8%	13.5%	24.8%
50-64	32.1%	55.5%	29.7%
64-74	5.2%	11.7%	11.6%
75+	0.9%	8.4%	7.2%
Gender			
Male	42.2%	46.3%	48.7%
Female	57.8%	53.7%	51.3%
Education			
< High School	0.7%	1.3%	4.8%
High School	9.5%	19.9%	16.7%
Some College	54.9%	41.6%	43.3%
Bachelor's Degree	18.8%	19.3%	21.2%
Post-Baccalaureate Degree	16.1%	18.0%	13.9%
Household Income			
< $20,000	10.5%	13.4%	13.7%
$20,000 -$35,000	7.7%	5.7%	10.2%
$35,000 - $50,000	11.7%	9.8%	13.7%
$50,000 - $75,000	13.9%	19.0%	17.5%
$75,000 or More	56.2%	52.1%	44.8%
Marital Status			
Married	64.3%	68.0%	50.1%
Co-habiting	6.2%	2.3%	5.5%
Divorced/Separated	9.7%	5.5%	7.5%
Widowed	1.2%	1.0%	3.1%
Single	18.5%	23.1%	33.8%
Ethnicity/Race			
White	61.8%	68.1%	69.5%

Black	13.7%	6.5%	9.4%
Hispanic	13.7%	14.9%	13.7%
Asian	1.3%	7.6%	4.8%
Other	9.5%	2.9%	2.7%

Information on actual caregiver sources of health information is presented in Table 5.3. Caregivers primarily sought health information from internet sources. For caregivers of children, 79.4% used the internet to seek health information, while 45% used HCPs as an information source. This trend held too for caregivers of children with cancer, with 78.6% using the internet to seek health information. Few caregivers had used literature, family, or helplines as sources of health information. Of interest, all caregivers were much more likely to have used the internet as their last source of health information (75.6%) in comparison to a hypothetical source (50.2%). This suggests that, while non-internet sources are thought to be commonly consulted for health information, in practice the internet is used more frequently.

Table 5.3

Sources of Health Information by Caregiver type

	Actual Use of Internet for Health Information		Hypothetical Use of Internet for Health Information		Source of health information						
	Internet	Non-internet	Internet	Non-Internet	Books / Brochure	Family	Friend	HCP	Internet	Helpline / Cancer org	Other
Caregivers of children	75.6 %	24.4 %	53.5%	46.5%	3.1%	1.3%		45.0%	50.2%	0.2%	0.3%
Caregivers of adults	79.4 %	20.6 %	50.2%	49.8%	1.3%	3.9%	0.2%	39.6%	53.5%	0.0%	1.5%
Multiple caregivers	87%	13%	53.3%	46.7%	0/7	1.7%	0.1%	35.1%	53.7%		9.1%
Non caregivers	71.9 %	28.1 %	54.3%	45.7%	2.3%	4.8%	0.5%	44.3%	45.7%	0.5%	1.4%

5.3.2. Actual use of Internet for Health Information

Logistic regression was performed to determine how well actual use of the internet to obtain health information could be explained by seven variables: gender, age, education, household income, marital status, race, and caregiver type. The use of internet to seek health information was treated as the reference category for all analyses. There was a statistically significant effect for the model as a whole (χ^2 (21, N = 3048) = 151.055, p = <.001) which explained between 9.9% (Cox and Snell) and 14.5% (Nagelkerke) of the variance. A statistically significant effect for age (χ^2 (4, N = 3048) = 71.93, p < .001) and education (χ^2 (4, N = 3048) = 13.91, p = 0.008) were noted. Through further examination of individual factors, significant positive effects for being aged 18-34 (Odds Ratio [*OR*] = 7.47, 95% Confidence Interval [CI; 4.20 ,13.29].), 35-49 (*OR*=8.78, 95% CI [5.08, 15.19]), 50-64 (*OR*=5.5, 95% CI [3.06, 9.89]) and 64-74 (*OR* = 3.86, 95% CI [2.35, 6.32]) were observed. Strongest effects were observed for being aged 35-49 and 18-34, suggesting younger age groups were most likely to use the internet for health information. As illustrated by the OR of less than 1, those who had attended high school (*OR* =.28, 95% CI [0.13, 0.62]), completed high school (*OR*=.57, 95% CI [0.33, 0.98]) or completed some college education (*OR* = .57, 95% CI [0.35, 0.93]) were less likely to have used the internet for health information than those with higher educational attainment. A significant positive effect was noted for those earning $50,000 to < $75,000 (*OR*=1.64, 95% CI [0.97, 2.75]). No significant effects for caregiver type were noted.

5.3.3. Hypothetical use of internet for Health Information

Logistic regression analyses were performed to determine how hypothetical use of internet to obtain health information could be explained by demographic variables or caregiver type. There was a statistically significant effect for the model as a whole (χ^2

(21, N = 3965) = 153.937, $p < 0.001$) which explained between 6.8% (Cox and Snell) and 9.1% (Nagelkerke) of the variance. A statistically significant effect for age (χ^2 (4, N = 3965) = 55.80, $p < .001$) and education χ^2 (4, N = 3965) = 27.792, $p < .001$) again were noted. Through further examination of individual factors, those aged 18-34 (*OR* = .21, 95% CI [0.14, 0.34]), 35-49 (*OR*=.23, 95% CI [0.15, 0.36]), 50-64 (*OR*=.28, 95% CI [0.18, 0.43]) and 64-74 (*OR* = .43, 95% CI [0.28, 0.66]) were less likely to see the internet as their hypothetical information source in comparison to other age groups. As indicated by the OR greater than 1, those who had completed less than high school (*OR*=3.9, 95% CI [2.14, 7.10]), were a high school graduate (*OR* = 1.98, 95% CI [1.32, 2.97]) or had completed some college education (*OR* =1.85, 95% CI [1.31, 2.63]) were more likely to choose the internet as a hypothetical source of information. This suggests that those with less education see the internet as a viable source of health information.

5.3.4. Sources of health information and health information needs

For caregivers of children, seeking health information was associated with low frustration (*M*= 2.95, *SE*=.09) and effort (*M*= 2.95, *SE* =.25). Generally high levels of confidence in seeking information were also observed (*M*= 2.26, *SE* =.21). This held also for parents of children with cancer, for whom seeking health information was associated with low frustration (*M*= 2.25, *SE*=.19) and effort (*M*= 2.14, *SE* =.05). and high levels of confidence (*M*= 3.89, *SE* =.18). Mean scores were in line with those observed for other caregivers (see Table 5.4).

Table 5.4

Effort, Frustration and Confidence in Health Information Seeking

	Caregivers of Children	**Caregivers of Adults**	**Multiple Caregivers**	**Non-caregivers**
Source of health info (%)				
Books/literature	4.7%	5.4%	4.9%	7.6%
Friends/Family	2.8%	3.8%	4.9%	3.8%
HCPs	16.9%	13.0%	13.1%	17.6%
Int	75.6%	77.8%	77.0%	71.0%
Frustration* (M)	2.95 (SE=.09)	2.99 (SE=.11)	2.6 (SE=.26)	2.95 (SE=.33)
Effort* (M)	2.75 (SE=.25)	2.99 (SE=.11)	2.65 (SE=.24)	2.84 (SE=.03)
Confidence*(M)	2.26 (SE=.21)	2.04 (SE=.76)	2.48 (SE=.29)	2.21 (SE=.167)

*Range 1-5

General linear model analysis was conducted to examine the relationships between frustration, effort, and confidence with source of health information for caregivers of children. A statistically significant effect for source of health information on confidence was found (Wald *F* (3, N = 3644) = 19.753, *p* <.001), with approximately 10.4% of variance explained according to the R^2 value. Analysis of parameter estimates suggested a significant negative effect for use of both friends and family (*t*=-3.17, *p*=.002) and HCP (*t*=-3.57, *p*<.001) suggesting caregivers of children who sourced information in this manner were more confident in this information.

Similarly, a statistically significant effect for source of health information on effort (Wald *F* (3, N = 3616) = 14.38, *p* =.002) and frustration (Wald *F* (3, N = 3531) = 21.03, *p* <.001) were noted for caregivers of children. However, only a very small percentage of variance was explained by either according to the R^2 value (effort = 2.8%, frustration = 3.6%). Analysis of parameter estimates suggested a significant positive effect for use of friends and family for both effort (*t*=3.67, *p*<.001) and frustration (*t*=4.41, *p*<.001) suggesting caregivers of children who sourced information in this manner found it less effortful and less frustrating.

To examine whether the trends observed held for other caregivers, general linear analyses were repeated for this group. For confidence, there was no significant effect for the model as a whole (Wald F (6, N = 3644) = 9.99, $p = 0.125$). No significant effects for individual parameters were noted, however caregivers of children had greater negative associations with confidence, suggesting somewhat greater confidence in health information seeking for this population, though not significant. For frustration, there was no significant effect for the model as a whole (Wald F (6, N = 3531) = 4.22 $p = 0.646$), or for individual parameters. For effort, there was a statistically significant effect for the model as a whole (Wald F (6, N = 3616) = 13.02, $p = 0.03$). However, only 1.5% of the variance in the model was explained as per R^2 values. There was no significant effect for caregivers (Wald F (3, N = 3616) = 3.78, $p = 0.29$), though a significant effect for health information source (Wald F (3, N = 3616) = 9.92, $p<.001$) was noted with significant negative effects for books/literature (t=-2.77, p=.006). This suggests increased effort across caregivers who use this source of health information.

5.4. Discussion

This study sought to examine the sources of health information used by caregivers of children, and the impact of these sources on confidence, effort and frustration in health information seeking. Across subgroups, the internet was the most common source of health information, with several demographic factors impacting ability to access information online. Specifically, those who were younger and higher educated were more likely to use the internet for health information. Caregivers of children were generally confident in their ability to find needed health information online and reported low frustration and effort overall. Analyses showed that those who obtained health information from HCPs were more confident in their ability to source information, while those who obtained health information from friends and family found the process less effortful and frustrating. However, only a small proportion of respondents sought health information in this way. Online health information seeking did not impact perceptions of confidence, effort, or frustration. This suggests that while the internet is the most used source of health information, it is not necessarily the least effortful or frustrating. Opposingly, results highlighted that while peers and HCPs were less commonly relied on as sources of health information, seeking information from these groups resulted in less effort and frustration. In the context of increased service digitalisation. this suggests an ongoing need for consideration of how peers and HCPs can be incorporated into digital services to support caregiver needs.

Demographic data of the present sample was broadly in line with US population norms (U.S. Census Bureau, 2018). In comparison with caregiver demographics more specifically, the current population is in line with expected variations. Previous research suggests that 5.7% of the US population (Public Policy Institute, 2019), and 4% of the European population (Eurostat, 2018) are caregivers of children with illness, compared with 4.7% of the current sample, suggesting proportionate representation. Race, average age, and gender are also in line with population norms for caregivers (Eurostat, 2018; Public Policy Institute, 2019). This suggests that the demographics of the current sample may be reflective of caregivers and the population more generally. The more representative sample employed in the present study addresses the sample limitations of Park et al., (2016) and may allow for increased generalisation of findings.

Results highlight the dominance of the internet as a source of health information across respondents. Caregivers and non-caregivers predominantly used internet sources when last seeking health information in comparison to other sources, consistent with past research (Jaks et al., 2019; Kim et al., 2017; Park et al., 2016). Usage has grown considerably when compared even to the 2017 HINTs dataset (Bangerter et al., 2019).

Of note is the discrepancy between reported hypothetical and actual health information sources. Rates of non-internet hypothetical sources were two times higher than actual non-internet health information source use. This suggest that while caregivers may plan to seek information from HCPs, peers, or other sources, in practice the internet is used. Analysis of the factors which may pose barriers to the use of planned non-internet sources requires additional consideration to facilitate their use for those who require them. As past research has highlighted, the ubiquitous, low-cost, convenient, and efficient nature of the internet (Camden & Silva, 2021; Kubb & Foran, 2020) may influence this. However, the factors impacting the discrepancy between intended and actual health information sources should be examined further.

A significant positive association for age on hypothetical use of the internet to seek health information was noted, with those aged 64-74 most likely to select this source. This suggests an interest in sourcing online health information by this age group not actioned in practice. This is echoed by van Deursen, (2020) who found age to be positively associated with the use of the internet for health information, but negatively associated with information attainment. Ybarra & Suman, (2008) found that adults over 60 were as likely to use the internet as adolescents, but frustration and inability to source needed information online significantly increased with age. Consideration of barriers encountered by this group when seeking to use online sources is needed to facilitate use in practice.

Decreased likelihood of both actual and hypothetical internet use was found for caregivers with lesser education, consistent with past research (Park et al., 2016; van Deursen, 2020). Educational attainment has been found to be the greatest predictor of internet use for strategic benefit (Van Deursen et al., 2011). The impact of education on internet use for health may also derive from limitations in health and fundamental literacy for this group (Chu et al., 2021; Hutchinson et al., 2016). Those with lesser education may have limited skills in understanding and seeking health information, thus impacting ability to successfully use online sources of health information. Further analysis of the barriers which may be limiting use for this group is needed.

Of note within present findings is the absence of associations between household income, gender or race, and online sources of health information for caregivers of children, suggesting these factors did not contribute significantly to likelihood of use. Weiss et al., (2018) note that while inequalities in access to technology exist, technology itself can reduce these inequalities over time. As the internet is somewhat pervasive in comparison to other technologies, this may have reduced the impact of the digital divide in this instance. As such, research should continue to examine the impact of technological development on health for socio-economic strata over time.

A key finding of the present study pertains to the importance of HCPs in the provision of health information for caregivers of children. HCPs were the second highest source of information across groups at 35-45%. Notably, caregivers of children who sought information from HCPs were significantly more likely to express confidence in the ability to source information in this manner. Past research echoes this caregiver preference for information from HCPs (Corcoran et al., 2010; Jackson et al., 2007; Khoo et al., 2008; Kubb & Foran, 2020; H. S. Lee, 2018). However, limitations to seeking health information in this manner have been highlighted. Information provided by HCPs is often forgotten or misunderstood, particularly when shared in large volumes or at emotional times (Friis et al., 2003; Nwaneri et al., 2014). Further, lack of HCP continuity across the illness trajectory may lead to information omission or contradiction (McPherson et al., 2001). Time limitations may also impact HCPs ability provide complete information and respond to all queries (Campbell et al., 2018; Worth et al., 2000). Additionally, caregiver reluctance to discuss information retrieved from online sources with HCPs can pose problems (Kubb & Foran, 2020). While HCPs are a preferred source, it may be difficult to obtain timely, understandable information in this manner, requiring supplementation from other sources. An increasing need for the provision of health information by HCPs through online means has been noted (Plantin & Daneback, 2009; Slomian et al., 2017). Present findings highlight the need for HCP inclusion in online information sharing. CH may be an effective means to provide this HCP contact in a manner that is not cost or time intensive (Study 1; Delemere & Maguire, 2020). Future online information sources for caregivers of children should consider the inclusion of HCPs where possible.

5.4.1. Limitations

Several limitations to the current study exist. While significant effects were found, effect sizes were generally low, suggesting that effects in practice may be small. Secondly, the heterogeneity of the sample may serve as a limitation. As participants caring for children were considered as a single group, the needs of specific subgroups may have been missed. For example, the needs of those caring for a child with mental health needs will likely differ from those caring for a child with a physical illness. Due to this broader lens, the specific needs of those caring for children with cancer are not addressed. Future research should seek to examine caregiver groups more specifically to better capture information sources. Additionally, as this study examined a US population, analysis in other settings is needed, particularly in non-western countries which face substantial increases in technology use and where such analyses are lacking (Poushter, 2016). Analysis within an Irish context is also needed to more fully explore and identify any unique aspects impacting health information seeking for caregivers of children. A further limitation was possible selection bias, due to the HINTs participant recruitment methods. As respondents were recruited online in addition to phone and post, this may have impacted respondent's likelihood of using the internet. Sample weights were applied to minimise potential impacts of sampling methods and increase generalisability of findings. A further limitation was the broad nature of questions pertaining to uses of the internet for health. In depth analysis of the specific information sought and its use would be beneficial. Additionally, the source of online information, its quality and associations with demographic factors should be examined. Research suggests low-income parents caring for children tend to seek information through social media (Swindle et al., 2014) or online communities (Gold et al., 2012), which may have varying quality. Future research should examine different online health information sources and their quality of information to examine the impact on use of these sources by sub-populations.

5.4.2. Conclusion

The present analysis highlights the important role played by the internet as a source of health information for caregivers of children. Notably, results suggest the impact of a digital divide on use of the internet for health, with those who are younger or who have completed higher levels of education more likely to have used it. This requires further analysis and action to prevent deepening inequality. Deviation between hypothetical and actual sources of health information were noted for caregivers of children, suggesting a need for analysis of factors which may be preventing use in practice. Encouragingly, caregivers of children were confident in their ability to seek health information, and felt it required low effort and frustration. However, while online sources of health information were common, they did not significantly impact perceptions of confidence, effort, or frustration. Instead, results highlighted the positive impacts of both the healthcare team and peers on health information seeking, suggesting a need for future interventions to consider how access to these supports may be facilitated. As digitalisation of health continues, efforts are needed to ensure caregivers of children are supported to obtain health information in a manner which best meets their needs while minimising the impact of the digital divide.

While the results of this study suggest an impact of the digital divide on health information seeking for caregivers of children, analysis of factors impeding use of other digital technologies is outstanding. As CH is novel and less pervasive than health information seeking, access to such technologies may be more limited than online sources of health information. As such analysis of the relationship between socio-demographic factors and use of more novel digital technologies remains outstanding. This will be addressed in Study 5 which focuses on factors impacting CH use by caregivers of children.

Chapter 6 Study 5: The use of Connected Health Technology by Caregivers of Children with Illness: Analysis of sociodemographic barriers and enablers

Abstract

Objective: As healthcare digitalisation grows, CH is increasingly advocated to support caregivers of children. However, access disparities amongst population groups may inhibit uptake in practice. This study sought to examine the association between socio-economic factors and different forms of CH use, and comfort in electronically sharing data, for caregivers of children.

Method: Using data from the 2019 HINTS, associations between technology use, demographic factors and CH use for caregivers of children with illness (n= 247) was examined.

Results: While high e- and mHealth use (67.1%), and EHR use (61.2%) was found, caregivers with lower household income and education were significantly less likely to have accessed CH.

Conclusion: While some use of CH by caregivers of children was noted, results suggest evidence of a digital divide. As such, there is a need for HCPs to be aware of the digital divide when considering digital tools in care provision. As remote service delivery becomes increasingly relied upon, further analysis is needed.

6.1. Introduction

Technological fluency is increasingly required to fully participate in modern life. This applies also within healthcare, which is becoming increasing digitalised (Casper & Morrison, 2010; Cockerham, 2005; Swan, 2009), a trend exacerbated by the Covid-19 pandemic. While digitalisation may facilitate healthcare provision, the impact of increased reliance on digital technologies for health requires examination (Baum et al., 2014; Warschauer & Matuchniak, 2010), particularly for vulnerable groups. This includes caregivers of children with illness, who play an important role in the management of their child's care (Bevan & Pecchioni, 2008; Karmiloff-Smith, 1998). To date, there has been little analysis of the impact of digital technologies on this group.

As noted in previous chapters, CH is one such technology espoused to support caregivers of children, the positive effects of which have been well documented (Newman et al., 2019; Signorelli et al., 2019). While CH use increased during the Covid-19 pandemic, many at risk groups, such as those with lower income and education, did not increase their adoption of these technologies (Luo et al., 2021). This impact of digitalisation on inequity in access to services is termed the 'digital divide' (Parsons & Hick, 2008), as described previously. While the results of Study 4 above highlight the impact of the digital divide on health information seeking using technology, its impact on CH use remains outstanding. Understanding how the digital divide is impacted by CH for caregivers of children is required to reduce inequalities in access. This study aims to identify those at risk of low CH adoption by examining associations between technology access, demographic factors, and CH for caregivers of children, in comparison with caregivers of adults and non-caregivers. Further, through exploring different forms of CH in turn to determine inequalities in access, unique impacts of different technology types can be determined.

6.2. Method

6.2.1. Study context

As in Study 4, data derived from the 2019 HINTS. This study focuses on responses to questions on ‘Health Information’, ‘Internet Use’, ‘Medical Record Use’, and demographic information. Ethical approval for this study was obtained from the Maynooth University Social Science Ethics Committee on June 3rd, 2020 (Reference number = 2408297).

6.2.2. Participants

Detail on participants is outlined within Study 4. Of participants (n=5438), 4.8% were caregivers of children (n=247), 8% were caregivers of adults (n=410), 1.6% cared for multiple groups (n=85) and 85.6% were non-caregivers (n=4413).

6.2.3. Measures

CH. Eleven variables pertaining to CH were included, namely: the use of the internet to seek health information, eHealth sum scores, frequency of sensor use, EHR access, use and reasons for non-use, mHealth access and use for a health goal, willingness, and actual sharing of health data, and communicating with a HCP using CH (see Table 6.1). These variables were selected from the HINTs data set for analysis as they represented all data pertaining to CH use. For five variables (use of internet to seek health information, EHR access and non-use, mHealth use, willingness and actual sharing of health data), a score of 1 was given if participants reported having used that technology. For other variables, a scale was created across multiple questions pertaining to the use of that technology, with higher scores demonstrating greater use (namely, a seven-point scale for EHR use, and five-point scales for the use of mHealth for a health goal and technology to communicate with a HCP). For eHealth sum scores, an eight-point scale was developed based on responses to seven questions pertaining to the use of eHealth (Sherman et al., 2020). Frequency of sensor use was determined using a five-point Likert scale, with lower scores indicating greater use.

Demographic Information. Variables included age, marital status, race/ethnicity, gender, education, and household income. Responses were divided into quintiles for education, age, and household income.

Frequency of Internet Use. Frequency of internet use was measured by four questions, each containing four-point scales, examining how frequently the internet was accessed across settings. Responses ranged from 1 (no use) to 4 (frequent use) and summed to obtain a score between 4 and 16. Higher scores indicated more frequent use.

Table 6.1

HINTS Questions Across Variables

Variable	Question	Scoring Range
Use of Internet to seek health information	The most recent time you looked for information about health or medical topics, where did you go first?	N/A
eHealth Sum Score	In the past 12 months, have you used a computer, smartphone, or other electronic device as a means to: Bought medicine or vitamins online Used email or the internet to communicate with a doctor or doctor's office Looked for medical health information for self Looked for medical health information for others Looked for assistance for the person cared for Track medical costs Looked up medical tests	1-8
Sensor use	In the last 12 months, have you used an electronic medical device to monitor or track your health? In the past 12 months, have you used an electronic wearable device to monitor or track your health or activity?	Yes/No
Frequency of sensor use	In the past month, how often did you use a wearable device to track your health?	1-5
EHR Access	Have you ever been offered online access to your medical records by your health care provider? Have you ever been offered online access to your medical records by your health insurer?	Yes/No

Use of EHR	In the past 12 months, have you used your online medical record to Request refill of medications? Request correction of inaccurate information? Securely message health care provider and staff (e.g., e-mail)? Look up test results? Download your health information to your computer or mobile device, such as a cell phone or tablet? Add health information to share with your health care provider, such as health concerns, symptoms, and side-effects? Help you make a decision about how to treat an illness or condition?	1-7
Non-use of EHR	Why have you not accessed your medical records online? Is it because you prefer to speak to your health care provider directly? Is it because you do not have a way to access the website? Is it because you did not have a need to use your online medical record? Is it because you were concerned about the privacy or security of the website that had your medical records? Is it because you don't have an online medical record? Is it because you found it difficult to login (for example, you had trouble remembering your password)? Is it because you are not comfortable or experienced with computers? Is it because you have more than one online medical record?	Yes/No
mhealth use	On your tablet or smartphone, do you have any software applications or apps related to health?	Yes/No
mHealth for health goal	Has your tablet or smartphone helped you achieve a health-related goal such as quitting smoking, losing weight, or increasing physical activity? Has your tablet or smartphone helped you make a decision about how to treat an illness or condition? Has your tablet or smartphone helped you in discussion with your healthcare provider? Have you shared health information from either an electronic monitoring device or smartphone with a health professional within the last 12 months?	1-5
Willingness to share health data	Would you be willing to share health data from your wearable device with your health care provider?	Yes/No
Actual sharing of Health data	Have you electronically sent your medical information to another health care provider?	Yes/No
	Exchanging medical information with health care professionals	0-4

Use of IT to communicate with HCP	via email via text message via app on a smartphone or mobile device via video conference

Data Analysis. Data was analysed using the approach described in Study 4 (see Section 5.2.4). Descriptive analyses were conducted to examine the use of CH amongst caregivers of children. Logistic regression analyses were used to examine whether a) use of technology to communicate with HCPs and b) electronic sharing of health data could be explained by demographic variables and frequency of internet use. General linear analysis was performed to determine how well a) eHealth use b) EHR use and c) sensor frequency of use, could be explained by independent variables. Chi-square and t-tests were used to determine if there were significant differences between caregivers of children and non-caregivers or caregivers of adults. An alpha level of 0.05 was used, with sequential Bonferroni used in all analyses due to the number of variables examined.

6.3. Results

6.3.1. Demographic information

Of children being cared for, 31.5% (n=78) had mental health, behavioural or substance abuse issues, 19.2% cared for a child with cancer, 15% (n=37) had neurological or developmental issues, while 15.3% (n=38) were unsure of the condition. Caregivers of children were predominantly female (61.3%), aged 35-49 (47.8%), had completed some college (53.3%), earned over $75,0000 (56.2%) and were married (62%). Demographic information is presented in Table 6.2.

Table 6.2

Demographic Information for Caregivers of Children

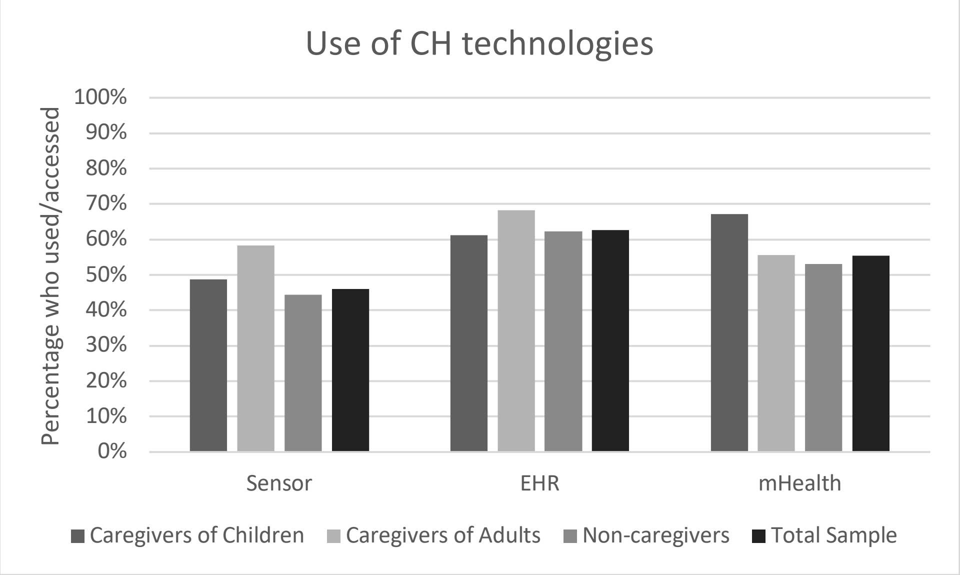
Variable		Caregivers of Children	Total HINTS Sample
Household income	Less than $20,000	10.5%	18.8%
	$20,000 to < $35,000	7.7%	12.8%
	$35,000 to < $50,000	11.7%	13.1%
	$50,000 to < $75,000	13.9%	17.7%
	$75,000 or More	56.2%	37.6%
Gender	Male	38.7%	42.7%
	Female	61.3%	57.3%
Education	Less than High School	2.6%	6.3%
	High School Graduate	10.1%	17.9%
	Some College	53.3%	30.1%
	Bachelor's Degree	15.6%	26.5%
	Post-Baccalaureate Degree	18.4%	19.1%
Marital Status	Married	62.0%	49.1%
	Living as married	7.4%	4.9%
	Divorced/Separated	10.9%	17.9%
	Widowed	2.9%	11.3%
	Single/Never married	16.9%	16.7%
Age	18-34	17.8%	13.0%
	35-49	47.8%	18.3%
	50-64	28.7%	31.6%
	64-74	5.0%	22.2%
	75+	0.8%	15%
Race	White	61.8%	63%
	Black	13.7%	14%
	Hispanic	13.7%	15.1%
	Asian	1.3%	4.6%
	Other	9.5%	3.4%

6.3.2. Descriptive Analysis

CH Technology Usage. Descriptive analyses examined CH use across caregivers (Figure 6.1). Mean internet (12.2, *SE*=.20) and eHealth (3.51, *SE*=.20) use was high among caregivers of children. Less than half reported using a sensor for health purposes (48.7%), with those who did primarily using them daily (49.8%).

Figure 6.1

Use of CH Technologies by Caregivers



For EHRs, 61.2% of caregivers of children reported access, lower than caregivers of adults (68.3%), though in line with non-caregivers (62.3%). Mean EHR use for caregivers of children (2.86, *SE*=.24), suggested some, though not frequent use, in line with other groups. Reasons for non-use included a preference to speaking directly with HCPs (66.5%), no perceived need (63.8%), and privacy concerns (21%). While broadly consistent with other groups, caregivers of adults (28%) and non-caregivers (28.2%) noted not having access as an additional reason for non-use. Caregivers of children were more likely to see no need for an EHR (63.8%) but less likely to feel uncomfortable with technology (12.6%) than other caregiver groups. Caregivers of children had higher use of mHealth (67.1%), than caregivers of adults (55.6%) and non-caregivers (53%). Mean use of mHealth to meet a health goal was 1.73, suggesting mHealth was used to meet at least one goal for caregivers of children, slightly higher than other caregiver types (*M*= 1.4). While similar CH use was observed across groups, caregivers of children were less likely to use sensors in comparison to caregivers of adults, but more likely to have used mHealth. Additional detail is presented in Table 6.3 below.

Table 6.3

CH Use Across Caregivers

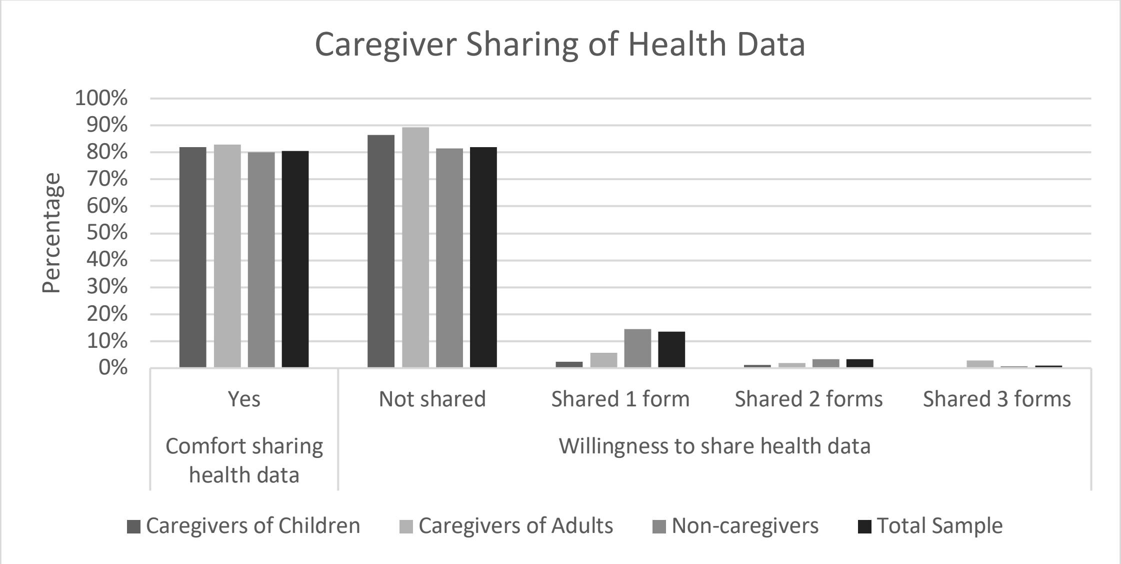
Factors			**Caregivers of Children**	**Caregivers of Adults**	**Non-caregivers**	**Total Sample**
Where seek health info		Non-internet	21.2%	24.4%	28.1%	27.0%
		Internet	78.8%	75.6%	71.9%	73.0%
Internet Frequency		M	12.19	11.77	11.71	11.42
		SE	.20	.21	.06	.19
eHealth Sum Score		M	3.51	3.07	3.26	3.29
		SE	.20	.14	.06	.05
Sensor	Use	Yes	48.7%	58.4%	44.4%	46.1%
		No	51.3%	41.6%	55.6%	53.9%
	Frequency of Use	Everyday	49.8%	47.3%	45.8%	48.9%
		Almost everyday	17.3%	15.8%	26.5%	20.2%
		1-2 per week	12.2%	17.1%	8.1%	9.5%
		<1 per week	6.8%	13.4%	6.4%	7.4%
		Did not use	13.9%		13.3%	13.9%
EHR	Access	Yes	61.2%	68.3%	62.3%	62.7%
		No	38.8%	31.7%	37.7%	37.3%
	Use	Mean	2.86	2.70	2.73	3.24
		SE	.24	.25	.08	.13
Non-use of an EHR	Prefer to speak directly	Yes	66.5%	69.9%	71.1%	72.6%
		No	33.5%	30.1%	28.9%	27.4%
	No Internet	Yes	18.7%	15.3%	22.5%	23.4%
		No	81.3%	84.7%	77.5%	76.6%
	See no need for it	Yes	63.8%	52.6%	59.7%	54.6%
		No	38.2%	47.4%	40.3%	45.4%
	Privacy	Yes	21%	20.6%	21.7%	24.2%
		No	79%	79.4%	78.3%	75.8%
	No EHR	Yes	21.3%	28.0%	28.2%	25.9%
		No	78.7%	72.0%	71.8%	74.1%
	No login details	Yes	17%	21.4%	18.2%	21.4%
		No	83%	78.6%	81.8%	78.6%
	Have multiple records	Yes	10.8%	10.7%	8.4%	10.1%
		No	89.2%	89.3%	91.6%	89.9%
	Uncomfortable	Yes	12.6%	20.1%	22.8%	26.6%
		No	87.4%	79.9%	77.2%	73.4%
mHealth	Use	Yes	67.1%	55.6%	53.0%	55.4%
		No	32.9%	44.4%	41.9%	44.6%

	To achieve a health goal	M SE	1.73 .05	1.44 .05	1.44 .02	1.18 .01
Health Data sharing	Comfort sharing health data	Yes No	81.9% 18.1%	83.0% 17.0%	80.0% 20.0%	80.6% 19.4%
	Willingness to share health data	Not shared	86.4%	89.4%	81.5%	82.0%
		Shared 1 form	2.4%	5.7%	14.6%	13.6%
		Shared 2 forms	1.1%	2.0%	3.4%	3.3%
		Shared 3 forms	0%	2.9%	0.6%	1.0%
	Tech. to communicate with HCP	Mean SE	2.26 .11	2.15 .12	2.01 .04	2.06 SD=.96

Health Data. Caregivers of children were broadly willing to share health data with HCPs (81.9%, n=201), though few (13.6%, n=34) had actually done so (see Figure 6.2). Mean use of technology to communicate with HCPs was 2.26 (*SE*=.11), suggesting participants shared health information using two forms of technology.

Figure 6.2

Caregiver Sharing of Health Data



Regression Analysis. Five regression analyses were conducted to further explore the factors which may have impacted technology usage. General linear analyses were performed to determine how well use of eHealth, sensors, and technology to communicate with HCPs could be explained by internet use, gender, education, household income and ethnicity for caregivers of children. Gender was omitted for use of technology to communicate with HCPs due to insufficient responses.

For eHealth use, there was a statistically significant effect for the model as a whole (Wald F (14, N=3215)=58.41, p =0.01) with an R^2 of 19.5. Results show a significant effect for household income (Wald F (4, N=3215)=11.674, p=0.004) with negative effects of earning between \$20-35,000 (t=-3.29, p=0.02), suggesting lesser eHealth use for lower household incomes.

For sensor use, again a significant effect for the model was found (Wald F (12, N=1039)=144.27 p=.01) with an R^2 of 38.9. Significant effects for ethnicity (Wald F (4, N=1039)=12.32, p=.003), household income (Wald F (3,N=1039)=25.345, p=.02) and education χ^2(3,N=1039)=11.03, p=.045) were noted. Less frequent usage was associated with leaving education following high school graduation (t=-2.80, p=0.01), with more frequent usage associated with being white (t=3.34, p<0.001), Asian (t=1.96, p=0.05), earning between \$20-35,000 (t=3.03, p<.001) and being male (t=2.01, p=0.05).

For use of technology to communicate with HCPs, a statistically significant effect for the model was again found (Wald F (14,N =2477)=172.87 p<.001) with an R^2 of 25.4. Significant effects for ethnicity (Wald F (4,N=2477)=44.87, p<.001) were noted, with positive effects found for being white (t=6.42, p<0.001), black (t=3.09, p=0.004) or Hispanic (t= 4.36, p<0.001) suggesting increased use for these groups.

Logistic regression analyses were performed to determine whether actual electronic sharing of health data and EHR access could be explained by internet use, education, ethnicity, and household income for caregivers of children. For sharing of health data, a significant effect for the model as a whole was found

(χ^2(8,N=1580)=25.51 *p*=.04) with between 15.5% (Cox and Snell) and 27.6% (Nagelkerke) of variance explained. A statistically significant effect for education (χ^2(2,N=1580)=5.256, *p*=.01) was noted, with positive effects for completing some college (*OR*=17.69, *p*=.01, CI[2.31,135.60]). Significant negative effects of having a total household income of $20,000 or less (*OR*=.68, *p*=.002, CI[0.01,0.50]) were found, suggesting less sharing for those with lower household incomes.

For access to an EHR, there was a significant effect for the model (χ^2(10,N=2287)=26.18 *p*=.001) with between 32.7% (Cox and Snell) and 44.3% (Nagelkerke) of variance explained. Significant negative effects for household incomes less than $20,000 (*OR*=.14, *p*=.05, CI [0.02, 1.00]), having completed some college (*OR*=.13, *p*=.04 CI[0.02,0.86]), or being male (*OR*=.07, *p*<.001, CI[0.02,0.26]) were found, suggesting access was less likely for these groups.

6.4. Discussion

This study examined the impact of sociodemographic factors on use of CH by caregivers of children. Findings uncovered variability in the use of CH, and inequalities in access and use, particularly for those of lesser education and lower household income. Results obtained suggest an association between household income and some CH technologies, with those with lower household incomes less likely to have used eHealth and sensor technologies, and to have access to an EHR, or shared health data. Education too was associated with CH use, with those with lower education levels less likely to have EHR access, shared health data, or used a sensor. An impact of gender on sensor use was also noted, with male respondents more likely to have used this technology. This suggests that while CH appears used by many caregivers of children, access appears linked to household income, education and gender, suggesting the impact of a digital divide. In response to these access disparities, additional analysis of how best to close these gaps is needed.

Good uptake of CH technologies across caregivers generally was found, particularly for e- and mHealth. This is in line with past research showing high mHealth use for caregivers in paediatric cancer (Mueller et al., 2018). This high uptake may derive from efforts to move a number of evidence-based in-person interventions online for this group (Cernvall et al., 2015; Williams et al., 2016). Differences may also be attributed to the age demographics of carers of children, as opposed to general family caregivers. These results suggest that caregivers of children may interact differently with CH, and may have different opportunities to use CH, in comparison to other caregiver groups, necessitating a unique approach to facilitating access.

Over half of caregivers had used EHRs, a rate that has grown in comparison to previous HINTs cycles (Anthony et al., 2018; Hong et al., 2020). However, caregivers of children were more likely than other caregivers to report no need for their use. Primary reasons for non-use included a preference to speak directly with HCPs, no perceived need, and privacy concerns. This adds to past findings which highlighted increased worry (Britto et al., 2013), and the complexity and comprehension of information (Schultz & Alderfer, 2018) as key concerns regarding EHR use by caregivers of children. These reasons for reluctance to engage with EHRs may serve as barriers to uptake in practice. Reasons for non-use emphasise the need for careful communication with caregivers of children when introducing EHRs, to address and dispel concerns regarding privacy and potential benefits of use. Again, results highlight the distinctiveness of caregivers of children in comparison to other caregivers.

A further notable finding was the relationship between household income and CH use. Caregivers with a total household income of $20,000 per annum were less likely to have used eHealth, accessed an EHR, or shared health data using technology. This is concerning in the context of the long-standing positive association between health and income (Adler et al., 1994), particularly for caregivers of children, for whom poorer health outcomes are associated with lower income (Case et al., 2002). It is interesting to note that EHR access was also impacted by income, as it is often provided through a gatekeeper. This is consistent with past research which highlighted the impact of socioeconomic status on access to health technology, including those accessed through a gatekeeper (Weiss et al., 2018). This suggests a need for those who act as gatekeepers, commonly HCPs, to be supported to ensure access across socioeconomic strata. Additionally, as gatekeepers, HCPs should ensure CH is employed in a manner that supports access for caregivers of children with differing digital literacy skills and technological comfort.

An impact of education on CH use was also noted. Education levels were associated with use of sensors, EHR access and the sharing of health data using technology. This is consistent with past research suggesting caregivers of children with lesser education were less likely to use digital technologies for health (Park et al., 2016). Similarly, educational attainment was the greatest predictor of use of the internet for strategic benefit in a Dutch sample (Van Deursen & Van Dijk, 2011). Findings suggest that increasing health literacy among lower educated groups may enhance CH uptake, though additional analysis is needed on how this may be achieved. Again, this highlights the need for CH tools to be sensitive to differing health and digital literacy levels, and for those who use CH in practice consider how best to support caregivers in these skills to facilitate more equal access.

There are several limitations to the current study. As with Study 4 the heterogeneity of the sample poses a limitation. As sample sizes were too small to examine each illness in turn, caregivers of children included those caring for children with various diagnoses. As such, variation in needs and attitudes towards CH may have occurred. Again, in line with Study 4 the inclusion of online sampling methods, in addition to phone and mail, may have resulted in higher technological literacy and can be considered a limitation. Sample weights were applied to minimise impact on results. This risk may have been mitigated by the sample being consistent with both broader population norms (US census, 2018) and norms for US (Public Policy Institute, 2019) and European (Eurostat, 2018) caregivers, suggesting the demographics of the current sample reflect caregivers more generally. A further limitation was the absence of specific questions on the use of each technology to support caregiving. Additional information on the specific utility of CH would help identify gaps or areas of common use. Further, questions on CH use to specifically support child health would be beneficial to examine.

Several recommendations for practice can be derived from the current study. Firstly, when seeking to introduce CH technologies within healthcare settings, HCPs should actively consider the impact of access disparities across patient and caregiver groups. Efforts to address these disparities when digitalising aspects of the care pathway should be considered. Inclusion of at-risk groups in the design and implementation of digital services may support increased awareness of the needs of differing stakeholder groups. The present study also points to the important role of HCPs, both as gatekeepers of CH and in determining how technologies are introduced in care, and in mitigating against inequalities in access. Careful consideration is needed as to how those with differing health and digital literacy levels, and differing technological comfort, can be supported to access and engage with CH. Additionally, efforts to identify and address caregiver perceived barriers to use are needed to increase uptake.

6.4.1. Conclusion

While CH use appears relatively high for caregivers of children, use varied across technology types, and disparities across social strata were found. Caregivers of children with lesser education or household income were less likely to have accessed CH, suggesting an impact of the digital divide and, through it, health inequality. As remote service delivery becomes increasingly relied upon, analysis of these effects is needed. In response to these access disparities, analysis of how best to support CH use for caregivers of children is also needed. Access to digital technologies is a social determinant of health (Baum et al., 2014). As such, it is of utmost importance that those developing, designing, and implementing CH understand the relation between socioeconomic status and effective use of such technologies.

While the results of studies 4 and 5 suggest an impact of CH on the digital divide, highlighting the need for accessible design of supports delivered in this manner, analysis of pre-requisite skills which may also impact effective use of CH remains outstanding. This will be addressed in Study 6.

Chapter 7 Study 6: Technology Usage, eHealth Literacy and Attitude Towards Connected Health in Caregivers of Paediatric Cancer

Adapted from: Delemere, E & Maguire, R. (2021). Technology usage, eHealth literacy and attitude towards connected health in caregivers of paediatric cancer. 2021 IEEE International Symposium on Technology and Society (ISTAS), DOI: 10.1109/istas52410.2021.9629210

Abstract

Rationale: While CH presents an attractive solution to supporting children with paediatric cancer within a burdened healthcare system, uptake is limited in practice. This study explored the extent to which attitudes towards CH, and the ability to identify evidence-based CH interventions, could be predicted by technology usage and eHealth literacy for parents of children with cancer and their HCPs.

Method: A survey of 57 parents of children with cancer and 28 HCPs was conducted. Measures included eHealth literacy, attitude towards online sources, electronic device/internet usage and evaluations of existing CH technologies.

Results: While respondents frequently interacted with online supports, CH use was limited (30.8%). While positive attitudes towards CH and strong eHealth literacy skills were found, those who had not used CH had significantly lower eHealth literacy than those who had ($t(74)=2.08$, $p=.04$ (two-tailed). Further, eHealth Literacy and device use significantly impacted attitude ($F(3,75)=12.01$, $p<.001$) and trust in higher quality CH applications ($F(2,58)=3.87$, $p=.03$).

Conclusion: eHealth literacy and device access play a crucial role in facilitating CH use for stakeholders in paediatric cancer. Consideration of how best to support those with differing eHealth literacy when developing CH technologies is needed to support effective employment in practice.

7.1. Introduction

While CH may benefit families impacted by paediatric cancer (see Study 1), there is a need to increase engagement with these technologies (Perski et al., 2017). Limited research has examined the reasons for the reluctance of families to engage with CH. While acceptance of CH has been linked with experience and proficiency (Hofer & Haluza, 2019), and is a predictor of use (Hennemann et al., 2017), there is a need to examine further its role in facilitating CH uptake. One factor which may impact CH acceptance is eHealth literacy, which, as noted previously (see Section C.2), is the ability to locate, evaluate and apply health-based information pertaining to a specific concern from internet-based sources (Norman & Skinner, 2006). Positive associations between eHealth literacy and acceptance have been found (Donovan et al., 2015; Hennemann et al., 2017; Tennant et al., 2015), with expectations of CH positively associated with intention to use (Liu et al., 2015). eHealth literacy also impacts attitude towards CH for HCPs, with technological skills and comfort associated with greater use of digital technologies (Konttila et al., 2019). However, while broad analysis of the impacts of attitude and eHealth Literacy have been conducted, no analysis of their effects within paediatric cancer has occurred to date.

As healthcare systems are increasingly burdened, CH's efficiencies and cost savings present an attractive solution. While positive impacts of CH have been noted, barriers such as attitude, eHealth literacy and comfort with technology may impact uptake. Further, stakeholders demonstrate skills deficits in identifying effective, relevant, and evidence-based CH technologies, presenting risks to impact and uptake. This study seeks to 1) analyse the relationship between technology usage, eHealth literacy and attitude towards CH for parents of children with cancer and their HCPs; and

2) examine the relationship between eHealth literacy, technology use and the ability to identify evidence-based CH for parents and healthcare providers.

7.2. Method

7.2.1. Participants

Parents/caregivers (n=57) and HCPs (n=28) were recruited between October 2020 and March 2021. Online recruitment was conducted due to social distancing in response to Covid-19. For HCPs, eligibility criteria included being qualified with at least one year's experience working with children with cancer. For parents/caregivers, eligibility criteria consisted of having a child (aged 0-18) with cancer who was at least six months post-diagnosis but less than five years from active treatment. Invitations to participate were circulated on social media, and among support services and non-governmental organisations in the paediatric cancer space. Full ethical approval for this study was obtained through the Maynooth University ethics board on June 17th, 2020 (reference number: 2408299). Full informed consent was obtained from all participants.

7.2.2. Measures

The following information was collected from participants using an online survey. As this research was conducted during the Covid-19 pandemic, in person data collection was prevented due to social distancing requirements implemented by the Government of Ireland.

Demographic Information. Brief demographic information was obtained, including age, gender, marital status, and ethnicity. For parents, child age, diagnosis, and stage in the treatment/survivorship trajectory was collected. Specifically, parents were asked how long it had been since their child was in active treatment, with an option to select still receiving treatment.

Electronic Device/Internet Usage. Electronic device and internet usage for health was measured using an adapted version of the Internet Use section of the HINTS (Nelson et al., 2004). Three questions were asked pertaining to internet use through different technologies, devices used, and online health behaviours completed in the past year. See Table 7.1. Responses were then summed to result in an overall electronic device/internet usage total score.

Table 7.1

Electronic Device/Internet Usage

Question	Response options
How often do you access the Internet through each of the following?	Daily Weekly Never
a) Computer	
b) On a mobile device (phone/smart phone/tablet)	
c) On a connected health device (i.e. smart watch, smart speaker, etc.)	
Please indicate if you have any of the following:	(Tick to indicate having the technology)
a) Tablet computer (for example, an iPad, Samsung Galaxy)	
b) Smartphone (for example, an iPhone, Android)	
c) Basic phone only (no internet/Wi-Fi)	
d) A smart device (i.e. Alexa, google home etc.)	
e) A body sensor/application (i.e. heart monitor with app, Fitbit etc)	
f) Apps related to health or wellness	
g) I do not have any of the above	
In the past 12 months, have you used a computer, smartphone, or other electronic means to do any of the following?	(Tick to indicate having used the technology)
a) Looked for health or medical information for yourself	
b) Bought medicine or vitamins online	
c) Used e-mail or the Internet to communicate with a doctor or a doctor's office	
d) Tracked health care charges and costs	
e) Looked up medical test results online	
f) Made appointments with a health care Provider online	
g) Shared health information on social networking sites, such as Facebook or Twitter	
h) Wrote in an online diary or blog	
i) Participated in an online forum or support group for people with a similar health or medical issue	
j) Watched a health-related video on YouTube	
k) Visited a social networking site, such as Facebook or LinkedIn	
l) Shared health information from either an electronic monitoring device or smartphone with a health professional	

eHealth Literacy: The eHealth literacy eScale (eHEALS; (Norman & Skinner, 2006), was used to measure participants eHealth Literacy. The eHEALS is an 8-item measure of knowledge, skills, and comfort at finding, evaluating, and applying eHealth information to health concerns. Cronbach's alpha was .92 suggesting strong reliability. See Table 7.2 for complete description.

Table 7.2

eHealth Literacy eScale

Question	Response Options
I know how to find helpful health resources on the Internet I know how to use the Internet to answer my health questions I know what health resources are available on the Internet. I know where to find helpful health resources on the Internet. I know how to use the health information I find on the Internet to help me. I have the skills I need to evaluate the health resources I find on the Internet. I can tell high quality from low quality health resources on the Internet. I feel confident in using information from the Internet to make health decisions	1= Completely Disagree; 5 = Completely Agree

eHealth Attitude: The 5-item computer interest subscale of the adapted Attitudes Toward Computer/Internet Questionnaire (ATC/IQ) (Bear et al., 1987; Choi & Dinitto, 2013) was utilised to measure attitudes towards eHealth. Cronbach's alpha was 0.65 suggesting an acceptable level of reliability within the scale. See Table 7.3 for detail.

Table 7.3

eHealth Attitude

Question	Response Options
Learning about health online is worthwhile and necessary Reading or hearing about health online is boring I don't care to know more about health online Online health is fun Learning about health online is a waste of time	1= Completely Disagree; 5 = Completely Agree

App evaluation: Four simple Likert scale questions with responses ranging from 1 (strongly disagree) to 5 (strongly agree) was developed to measure participants' self-reported trust in a selection of six CH smartphone apps (see Table 7.4). These apps were selected based on systematic searches of the Google Play and the Apple App Store in September 2020. Full detail on the search process and apps found is presented in Study 2. The three identified apps with the greatest and the three apps with the least number of BCTs were selected for use in this study. Complete detail on BCTs and the content analysis methodology is presented in Study 2. To recap, the BCTv1 (Michie et al., 2013) consists of 93 individual BCTs across 16 domains. The presence or absence of each of the individual BCTs for each app was examined, and a one scored if the BCT was present. Scores were then summed to determine an apps total volume of BCTs. The three applications from Study 2 with the greatest and least number of BCTs were selected for inclusion. Included apps targeted symptom tracking and management (n=4) and communication with HCPs (n=2). Low BCT apps included on 1.7 BCTs on average, compared to 16.7 within high BCT apps. Screenshots of each App were taken from the Google play or Apple app store, with all information available at point of download for each app made available to participants through these screenshots. Images were then presented to participants within the online survey.

Table 7.4

CH Application Evaluation

Question	Response Options
This application seems to be based in scientific evidence	1= Completely Disagree;
I trust this application will do as it says	5 = Completely Agree
I would download this application	
I would use this application	

7.2.3. Data Analysis

Data were analysed using SPSS. Multiple regression analyses were conducted to assess the influence of eHealth literacy and Internet/Device usage on ATC/IQ. To determine the relationship between technology usage, eHealth literacy and attitude toward CH. and participants self-reported trust, likelihood to use and perceived quality of CH apps, multiple regression analyses were conducted. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. Two blocks of predictor variables were employed for each multiple regression model, internet/device usage and eHealth Literacy. The Pearson product-moment correlation coefficient was used to examine the relationship between eHealth literacy and scientific evidence and trust in high and low BCT apps. To determine the impact of eHealth Literacy on past use of CH for HCPs and parents, an independent samples t-test was conducted.

7.3. Results

7.3.1. Participant Characteristics

Participants were primarily aged 35-44 years (44.6%, n=25), resided in Ireland (64.6%, n=53), were female (89.4%, n=76), married (70.6%, n=60) and lived in a large town or city (44.7%, n=38). For parents of children with cancer, diagnoses included ALL (40.8%), brain or spinal cord cancer (10.2%) or another cancer (12.2%). Children were primarily aged under five (36.4%) or between six and ten (34.5%) and had finished active treatment for over one year (27.1%), though a variety of treatment/survivorship stages were noted (see Table 7.5).

Table 7.5

Demographic Information

		Participant Type					
		Parents (n=57)		*HCPs (n=28)*		*Total (n=85)*	
		n	%	n	%	n	%
Age	18-24	2	4.9	0	0	2	3.6
	25-34	6	14.6	7	46.7	13	23.2
	35-44	22	53.7	3	20.0	25	44.6
	45-54	9	22.0	3	20.0	12	21.4
	55-64	1	2.4	2	13.3	3	5.4
	65+	1	2.4	0	0.0	1	1.8
Gender	Male	3	5.3	6	21.4	9	10.6
	Female	54	94.7	22	78.6	76	89.4
Habituation	Rural (<5,000 inhabitants)	19	33.3	5	17.9	24	28.2
	Small Town (<10,000 inhabitants)	21	36.8	2	7.1	23	27.1
	Large town/City (>10,000 inhabitants)	17	29.8	21	75.0	38	44.7
Marital status	Married	41	71.9	19	67.9	60	70.6
	Widowed	1	1.8	1	3.6	2	2.4
	Divorced/ Separated	2	3.5	1	3.6	3	3.5
	Cohabitating	9	15.8	5	17.9	14	16.5
	Never married	4	7.0	2	7.1	6	7.1

7.3.2. Electronic Device/Internet Usage

Most respondents accessed the internet daily using computers (61.5%), a mobile device (92.3%) or CH (30.8%). However, 5.6% of parents only accessed the internet weekly. Smartphones were the most common device used within the past year by both groups (91.8%), with tablet computers (63.5%), wellness apps (48.2%) and smart devices also common (47.1%). Participants engaged with an average of three different technologies within the past year, with both group means relatively equal. Mean online health behaviours for HCPs were slightly higher (*M*= 6.12) than parents (*M*= 5.55). HCPs also completed more CH activities across the past year (*M*= 2.32) in comparison to parents (*M*= 1.92).

To determine the impact of eHealth Literacy on past use of CH for HCPs and parents, an independent samples t-test was conducted. Past CH use was determined based on answers to the technology/device use questions pertaining specifically to CH use. There was a significant difference in scores for those who had used CH (*M*= 32.6, *SD*=6.9) and those who had not (*M*= 29.1, *SD*=7.4; *t*(74)=2.08, *p*=.04, two-tailed). The magnitude in differences in the means (mean difference=3.47, 95% Cl:.145-6.81) was moderate (eta squared =.06). An independent samples t-test was also conducted to compare eHealth Literacy scores across the two participant groups. No significant difference was found in scores between parents (*M*= 29.98, *SD*=6.37) and HCPs (*M*= 32.6, *SD*=8.7); *t*(74)=-1.4, *p*=.16 (two-tailed).

7.3.3. eHealth Literacy & Attitudes

Participants reported positive attitudes towards online sources with mean scores of 20.67. Parents (*M*= 21.05) were slightly more positive than HCPs (*M*= 19.92). The reverse was the case for eHealth Literacy, with HCPs (*M*= 32.48) scoring higher than parents (*M*=29.98), though both groups had good eHealth Literacy skills (see Table 7.6).

Table 7.6

Mean Device, Attitude and eHealth Literacy

			Participant Type		
			Parent (n=51)	*HCP (n=25)*	*All (n=76)*
Electronic Device/ Internet Usage	Mean actions in past year	*M*	5.55	6.12	5.73
		SD	2.11	2.72	3.32
	Mean CH actions in the past year	*M*	1.98	2.32	2.10
		SD	0.77	0.98	0.86
Attitude	ATC/IQ	*M*	21.05	19.92	20.67
		SD	3.22	3.30	3.27
eHealth Literacy	eHEALS	*M*	29.98	32.48	30.80
		SD	6.37	8.68	7.25

Standard multiple regression was used to assess the impact of eHealth Literacy, device use and group on CH attitude as measured by the ACT/IQ. The total variance explained by the model as a whole was 30.6%, *F* (3,75)=12.01, *p*<.001. Significant unique contributions for both eHealth Literacy (beta=-.377; *p*<.001) and device use (beta=.356; *p*<.001) were found, with the largest single contribution to attitude from eLiteracy which explained 13% of the variance in the ACT/IQ scores, followed closely by device use at 11.3%.

7.3.4. Evaluation of CH applications with high and low BCTs

Participants responded similarly to both high and low BCT CH apps regarding their scientific evidence and trust. Participant mean responses suggest both groups did not highly trust the quality of the apps for those with high or low BCTs.

Table 7.7

Evaluation of CH Applications

		BCT Measure			
		Scientific Evidence		Trust	
Participant group	BCTs	High	Low	High	Low
Parent (n=43)	*M*	8.16	8.05	8.79	8.47
	SD	3.12	2.81	2.86	2.86
HCP (n=16)	*M*	9.00	8.63	9.94	9.25
	SD	3.246	2.029	3.043	1.81
Total (n=59)	*M*	8.39	8.20	9.10	8.68
	SD	3.146	2.618	2.928	2.622

The relationship between eHealth literacy and scientific evidence, and trust in high and low BCT apps was examined using the Pearson product-moment correlation coefficient. There was a medium positive correlation between trust in high BCT apps and eHealth literacy (*r*=.41, n=59, *p*=.001) with high eHealth literacy associated with greater trust in high BCT apps. There was a small negative correlation between trust in low BCT apps and device use (*r*=.27, n=59, *p*=.04), with technology use associated with less trust in low BCT apps.

Several standard multiple regression analyses were conducted to assess the ability of eHealth Literacy and device use to predict trust and perceived degree of scientific evidence for CH applications with low or high volumes of BCTs. No significant effects for scientific evidence for low (*F* (2,58)=2.81, *p*=.07) or high BCTs (*F* (2,58)=1.17, *p*=.321), or trust for apps with low BCTs (*F* (2,58)=1.9, *p*=.15) were found. For trust in high BCT applications, the total variance explained by the model as a whole was 9% (*F* (2,58)=3.87, *p*=.03). Significant unique contributions for eHealth Literacy (beta=-.348; *p*=.008) were found, explaining 11.8% of the variance in trust scores.

7.4. Discussion

The current study sought to examine the impact of eHealth literacy, technology use, and attitude towards CH, on CH use. Results suggest that, while HCPs and parents frequently interacted with technology and online supports for health, CH use was limited. Encouragingly, positive attitudes and strong eHealth Literacy skills were found in both groups, with HCPs demonstrating slightly higher eHealth literacy and past CH use, while parents expressed more positive attitudes. Results suggest both eHealth literacy and past device usage play important roles in CH evaluation and use, with both contributing significantly to respondents' attitudes towards online sources and trust in high BCT apps. This suggests a key role of eHealth literacy and device access in supporting accurate evaluations of CH technologies, and may facilitate effective use for stakeholders in paediatric cancer.

The important role of technology familiarity on CH use is consistent with past findings suggesting technological comfort, self-efficacy and habit predict CH use (Hah et al., 2019). Perhaps surprisingly, and in contrast to studies 4 and 5, no associations between demographic factors were found in relation to CH use, attitudes, or eHealth literacy. This is somewhat contradictory to past findings (Tennant et al., 2015) and may have been impacted by the smaller sample size and relative heterogeneity. Present results support past analyses that suggest a need to encourage patient and HCP comfort with technology to reduce negative CH attitudes (Haluza et al., 2016).

A lack of trust and perceived quality of CH apps was found for this group, suggesting a need for increased efforts to support the dissemination of such tools. Results highlight the important role of eHealth literacy in supporting effective CH evaluation and use. While the present analysis highlights eHealth literacy and encouraging device use as possible avenues to support CH uptake, additional efforts are required. Specifically, there is a need for expert analysis and dissemination of paediatric health apps through reputable and accessible sources (Psihogios et al., 2020), alongside a need to incorporate CH technologies into HCP training to support integration within clinical pathways (Lavigne et al., 2016; Psihogios et al., 2020).

The present results highlight a need for decisional supports for parents and HCPs to support them in determining which CH tools may be of benefit. Many CH tools with empirical support are not publicly available (Psihogios et al., 2020) creating difficulties in accessing higher quality supports (Knapp et al., 2011; Rathnayake & Senevirathna, 2019). This absence of high-quality CH is particularly concerning when considered in the context of the high volume of freely available non-evidence-based CH on the market, as evidenced by the findings of Study 2. This environment presents significant challenges to stakeholders in determining whether a CH app may be effective for their family. While the present analysis lends support to the importance of eHealth literacy in determining CH quality, analysis of factors which may support stakeholder decision making in this context is required. Future research should consider how best to engage with parents, HCPs, and other key stakeholders to support CH decision making.

There are several limitations to the present study. Notably there were considerable difficulties with participant recruitment and retention, with some respondents electing not to complete the BCT section of the survey, meaning that the present analysis was somewhat underpowered. Due to the constraints of the Covid-19 pandemic, participant recruitment occurred online. As a result, device use and internet access may be higher in this sample due to the sampling methods employed. Additional efforts to examine eHealth literacy for hard-to-reach populations is needed. A further limitation is the timing of the present study. As recruitment occurred during Covid-19, the associated increased use of remote service delivery methods may have impacted attitudes and device use.

7.4.1. Conclusion

In conclusion, this study highlights the importance of eHealth Literacy and technology use on CH uptake for HCPs and parents of children with cancer. While high device use and online health behaviours were suggested, low CH use was found. Further, respondents did not rate the CH apps shown as highly trustworthy or evidence-based, indicating a scepticism towards such tools. As such, there is a clear need for efforts to support eHealth Literacy and comfort in device use to aid CH adoption within paediatric cancer. The present analysis also suggests a need for technology developers to consider the eHealth Literacy or device familiarity required by users to successfully engage with CH tools. By considering those with lesser eHealth Literacy or device use in the development of CH through user co-design, increased accessibility and engagement may be attained. Increased cooperation between psychological sciences, technology developers and end-users is needed to ensure alignment between technological advances and effective interventions for those seeking support (Taj et al., 2019). Through this, greater societal impact may be attained through more effective CH use.

The relatively low levels of trust in CH and past use by both HCPs and parents alike suggests a reluctance to engage with CH. Additional analysis of stakeholder perceptions towards CH is needed to determine how best to increase its acceptability and use in practice. This will be achieved within Study 7, which explores the stakeholder perceived barriers and facilitators to CH use in paediatric cancer.

Chapter 8 Study 7: Utility, barriers, and facilitators to the use of Connected Health to support families impacted by paediatric cancer: A Qualitative Analysis

Adapted from: Delemere, E., Gitonga, I. & Maguire, R. Utility, barriers and facilitators to the use of connected health to support families impacted by paediatric cancer: a qualitative analysis. *Supportive Care in Cancer* (2022). https://doi.org/10.1007/s00520-022-07077-4

Abstract

Aim: As healthcare systems are increasingly burdened, the efficiencies and cost savings offered by CH present an attractive solution for supporting families impacted by cancer. This study seeks to examine the utility, barriers, and facilitators of CH use for families affected by paediatric cancer living in Ireland.

Methods: Healthcare professionals (n=5) and parents of children with cancer (n=7) completed semi-structured interviews on their experiences of and attitudes to CH via Microsoft Teams. A reflexive thematic approach to analysis was employed.

Results: CH was perceived to provide support for several current needs with themes of *'shifting responsibilities'*, '*individualisation of care'* and *'knowledge as power'*. Through facilitating communication, information sharing and monitoring of child health, CH was perceived to support decreased parental burden and increased parental control, with positive child outcomes thought likely. Perceived barriers and facilitators to the use of CH included the *'importance of trust'*, *'pace of change'* and *'access'*.

Conclusion: Results suggest an acceptance of CH across key stakeholders, however barriers and facilitators should be considered to support effective implementation. While further analysis of the efficacy of CH to support families impacted by paediatric cancer is needed, these findings highlight key areas where CH may be effectively employed.

8.1. Introduction

A key factor inhibiting CH adoption is patient and provider acceptability. While mixed acceptability has been found for adult cancer patients (Hennemann et al., 2017), limited analysis has been conducted in paediatric cancer. The systematic review conducted within Study 1 of CH for families living with or beyond childhood cancer, found good acceptability and usability. However, attrition from paediatric cancer CH interventions remains high, with difficulties recruiting and retaining users (Canter et al., 2020), and, as seen in Study 6, low trust in this technology prevails. This holds for medical staff also, as while positive HCP attitudes towards CH been found (Donovan et al., 2015), so too has resistance to use (J. Li et al., 2013). Concerns regarding limitations on communication, data security, privacy and impacts on the therapeutic relationship have been raised (Sinclair et al., 2013). While HCPs report positive impacts of CH on patient knowledge, quality of life and living standards, few wished to use these tools themselves (Jungwirth & Haluza, 2019).

One theoretical approach which may provide insight into CH uptake is the Technology Acceptance Model (TAM; Davis, 1989). The TAM posits that behavioural intention, or willingness to use a technology, is impacted by the degree to which the technology is perceived as useful and easy to use (Mohr et al., 2013). This TAM has received significant attention, with a meta-analysis highlighting its efficacy as a model of technology acceptance (King & He, 2006). The impact of perceived usefulness and usability on uptake has also been demonstrated for health technology (Dehghani et al., 2018; Kalantari & Rauschnabel, 2018). Analysis of the TAM within healthcare found it to effectively explain user acceptance, however additional analysis within individual healthcare contexts are needed (Holden & Karsh, 2010). More recent research has expanded this model, with social influence (Venkatesh & Davis, 2000), economic burden and data privacy also found to impact acceptance (Huarng et al., 2022). As such, for CH to be acceptable to stakeholders in paediatric cancer, exploration of how these technologies may be applied in a manner which is useful is needed, while also considering economic and privacy impacts.

This study seeks to examine the utility, barriers, and facilitators of CH within an Irish context for families affected by paediatric cancer and their HCPs. Within the Irish healthcare system there is an absence of digitalisation. Paediatric cancer care in Ireland tends to rely on physical patient records, with little or no use of EHRs or other digital communicative supports. A commitment to digitalisation has, however, been espoused (HSE, 2013). Qualitative analysis was employed as it allowed for an in-depth exploration of stakeholder perspectives towards CH (Gray, 2013)

8.2. Method

8.2.1. Recruitment of Study Participants

Recruitment was conducted in tandem with Study 3, with the same eligibility criteria and recruitment strategy applied across both studies. As a reflexive thematic approach to analysis was applied, and consistent with best practice (Braun et al., 2019; Braun & Clarke, 2019), data saturation was not used to determine sample size, with focus instead on rich data acquisition. Of individuals approached, only one HCP declined to participate. Full ethical approval for this study was obtained through the Maynooth University ethics board on the 16th of October, 2020 (reference number: SRESC-2020-2414528).

8.2.2. Epistemological Approach

This study employed a paradigmatic framework of interpretivism and constructivism within a qualitative approach (Braun & Clarke, 2013). The focus of this research was to understand participants' view of CH as it pertains to their role.

Specifically, this study sought to reflect parent and HCP accounts of their needs and hesitations pertaining to CH, while also accounting for the reflexive influence of the researcher on analysis. Detail on the epistemological approach can be found in Study 3.

8.2.3. Interview Guide and Data Collection:

A semi-structured interview format was used to facilitate open discussion and allow exploration of topics raised by participants (see Table 8.1). As such, while a set interview guide was developed, the specific wording and order was not rigidly adhered to. The interview with the first participant from each group (HCPs and parents) acted as a pilot, with these participants asked to share feedback and suggestions. Feedback was then used to refine the questions and probes in subsequent interviews.

Table 8.1

Interview Guide

Connected health is defined as the use of smart technologies, like sensors, telehealth or electronic health records, within healthcare. It differs from other technologies in that a two-way flow of information is used. Information is gathered, analysed and then fed back to the individual. With that in mind what potential use would CH offer parents, children and families impacted by paediatric cancer? Specifically, what unmet needs could it aid?
What currently unmet needs of parents, children and families affected by paediatric cancer could CH support?
What barriers or limitations would there be to the use of CH?

Interviews were conducted via Microsoft Teams between December 2020 and April 2021. Online interviews were conducted due to the covid-19 pandemic, impeding in-person interviews. Both audio and video were recorded for most interviewees (2 HCPs used audio only due to connectivity challenges in the hospital). Average interview duration for HCPs was 32.43 minutes (range: 31.05-35.46 minutes) and 38.16 for parents (range: 23.36 to 56.48 minutes).

8.2.4. Data Analysis

A reflexive thematic content analysis approach was chosen due to its flexibility and accessibility (Braun & Clarke, 2006, 2013). Complete detail on the approach to data analysis is presented in Study 3. While uncommon in thematic analysis (Vaismoradi et al., 2013), theme frequencies across participant groups were reported in an effort to reflect the unique experiences and contexts of participant groups, and to allow for differences between them to be considered. However, these frequencies are intended to highlight shared experiences across groups only, with no additional strength in themes reflected by frequencies.

8.3. Results

Participants consisted of parents of children with paediatric cancer (n=7) and HCPs (n=5; one nurse, two doctors, one social worker and a physiotherapist). HCPs were primarily female (n=4) and had an average of 17.6 years' experience. Parents were 38.8 years old on average, were primarily female (n=6), married (n=3) or cohabitating (n=3) and lived in small towns (n=6). The mean age of children was 8 (range=4-12), and most had siblings (n=5; mean siblings=2.6, range 1-4). Children were primarily diagnosed with Acute Lymphocytic Lymphoma (n=2) and Rhabdomyosarcoma (n=2), and most had finished active treatment (n=5).

8.3.1. Themes

Six themes were noted, of which three pertained to potential areas of need which CH may support, and three which described facilitators or barriers that may impact CH use. 'Shifting Responsibilities', 'Individualisation of Care' and 'Knowledge as Power' were perceived as needs which could be addressed by CH, while 'Importance of Trust', 'Pace of Change' and 'Access' were noted as barriers and facilitators of CH. Table 8.2 includes additional detail and illustrative quotes.

Table 8.2

Challenges and Needs of Families

Area	Themes and Sub-themes	Number of participants who mentioned the theme		Illustrative Quotes
		Parent	HCP	
Needs	1) Shifting Responsibilities	7	5	"I suppose from the starting out again when you're on your journey, and fair enough when you being and they're assessing everything, but like yknow meeting the intern, consultant at the start and starting the story again and yknow it's the middle of the night you haven't slept in a day or two and you've been at work and to start from the start is very upsetting" P6 "Every time you go into hospital it's almost like you're doing mastermind on the treatment like literally printed sheet you could just hand over so when you go, cos you could be in and out of hospital constantly" P3 "A lot of the time HOSPITAL are saying oh yeah we'll have to ring Dublin for that or we'll have to, yknow. There's definitely a space for sharing that information in a far more efficient way" P7 "You're ringing and ringing and ringing for results …. Like when a report is ready it should be ready when it's ready for the oncologist it should be ready for the parent I don't see why not." P4 "I mean it's really important that technology would help us be very accurate yknow the parents would get rather than have to write things down on paper, that they'd get a printout of the child's blood results…. Like that kind of thing should be done to make information available to parents" HCP5
	2) Individualisation of Care	6	3	"There's work with a Swiss group that have used sort of high-tech Fitbit like things to look at heart rate blood pressure temperature, changes from baseline rather than absolute temperatures and so on to see if that would give us an early warning of of adverse consequences coming on and potentially really serious adverse consequences coming on… and the idea being that that might lead on to us being able to intervene em before the infection took hold for example and give some sort of treatment that would be less and lower level and keeping the patient well-er without being in hospital for so long." HCP1

				“If we knew what their ideal target amount of chemo was, and we know of the variation between people maybe we could get the blood monitored in a really regular and straight forward way and alter the dosing for that person and maybe that would then get us the most anti-canceriness without getting the most, without getting the side effects that go with it” HCP1 “I know our physiotherapists who deal with our patients are very keen to try and promote physical activity. And maybe that is someway tangently to start is to monitor physical activity in the community and when they come and see us in the clinic just look at their electronic footprint of activity and see can we improve it” HCP2 “I remember thinking oh god wouldn’t it be great to have an app to be record these things so we could build a picture cos there was a cycle of sick, yknow like she would be ok for a while and then there was a dip and that would be when she would be in her neutropenic phase, and you had to be so careful” P4
	3) Knowledge as Power	7	3	“Where to get information from I think that’s kind of half the battle” P2 “We’d have conversations with the consultant but like my mind was just I still have memory loss from it I swear somethings gone in my brain. … And even, me and FATHER used to remember different bits of conversations, so maybe like a summary you could see electronically of the conversation you had” P3 “I would often ask the doctors can I see, can I see his ultrasounds can I see his MRIs, and I’d ask to compare to the last one. I think I think it’s needed, cos I think when you can’t see something that’s going on you can’t fully understand it” P5 “Tracking eh symptoms definitely that would be useful especially from the beginning when you are not used to everything. When if he has a temperature between this range then you should bring him in and that was a big struggle because now, I know from the top of my head when I should bring him in or not, but back then it was all new” P1
Facilitators and Barriers	1) Importance of Trust 1a) Privacy	3	4	“I can’t see anyone being held to ransom over the fact their blood count was a haemoglobin of 73 or whatever. But I I understand the the fear of other people being able to see other things about me that I don’t want them to know” HCP1 “If there is a GDPR breach there is a GDPR breach, so who wants to know NAME’s neutrophils like.” P6
	1b) Monitoring and Accuracy	4	4	“I wouldn’t have concerns just yknow just I suppose that its validated so like yknow… that records are kept accurately. So, somebody isn’t acting, that there is a bit of triangulation.” P6

			“We’d need to make sure what information we’re expecting of them, how we’re measuring it and how accurate it is and then what we’re going to do with it.” HCP4 “There’s no point like getting emails that come in and we don’t look at them for 24 hours and somebody’s email is saying they’re unwell. Those things would concern me.” HCP4
1c) Recommendations for use	3	0	“I remember they tell you not to go on, only look at these sites, you need information if you can’t quite find the information on that one, then you end up googling it and you end up on the bad sites that you’re not supposed to read. And it’s this whole misinformation really,” P3 “I would always look to the to the hospital, it’s like right if they recommend then I would be happy enough to do it but if something popped up on my whatever social media to say awh you can use this app or use this for id still be fairly wary of it” P2
2) Pace of Change	6	5	“We are not em user friendly with modern IT patient interactive bits, em I I think we could be a little bit better in that, but we are putting our trust in the electronic patient record going forward” HCP2 “No. never heard of it. I was only saying to NAME she is going to talk to me about Connected Health and I’ve no idea what that is, should I have an idea of what that is?” P5 “We’re collaborating with NAME with the redcap database, and it’s taken 2, 3 years to get to this point where we are now, ready to go.” HCP2 “I do wonder a bit whether it’s partly it worked much better than people expected. It’s probably better to do lots of things in person but everything’s got a price and the price of getting your kid to a group for them to be part of it if your geographically disparate, versus being able to do it over a zoomy thing, so yknow I can see how things will maybe shake out a little differently than before” HCP1
3) Access 3a) Facilitate Access	5	3	“Some of our patients can travel 4-5 hours to get to us. And we may not need to see each patient in the clinic every time. We may be able to do it virtually and therefore maybe every second visit then can come to Dublin for their interaction.” HCP2 “There is something floating around that’s been talked about a lot. And that’s having the ability to almost do your own blood tests at home so you wouldn’t even need to have the blood sent somewhere to be counted.” HCP1 “You are conscious of, you know, infection if your child has an infection, everyone is immunocompromised so if there was like a parents support online at a suitable time that we don’t have the added stress of struggling somewhere to meet physically” P1

			“They had mentioned something about being able to do the neutrophils at home, and it’s like electronic like what you’d have I suppose for like for blood sugars, you know you take with the prick. And I was like that to me would’ve been amazing when we were doing it, so you’d just be aware of how her immune system, how her neutrophils, how things are yknow whether shed be able to go maybe try going somewhere” P4 “Having the ability for kids even in isolation or even young people in isolation to get together and go around things and that in itself with the online gaming communities is certainly a way that many teens, maybe more boys than girls, but many teens stay connected to their peer group” HCP1
3b) Reduce Access	4	5	“From a financial point of view some bits of equipment can be quite expensive and childhood cancer, having a diagnosis of childhood cancer can have quite financial burden on families… And so some families may not be in a position to purchase equipment” HCP3 “Not all parents are able to read or write. Em and so I know some platforms obviously can have built in things I suppose to dictate and read out what’s on screens but that could be another potential barrier” HCP3 “Well if you think of family who weren’t in a good broadband area or some people don’t have technology em they might not have a phone even you know” P4

8.3.2. Needs CH may Support

Shifting Responsibilities. The potential for CH to shift communicative responsibilities was noted, particularly by parents. When meeting with HCPs, parents were often required to recall information on child health. This requirement to re-tell your child's story was seen as a source of stress, with concerns over the impact an error or omission may have on their child's care. Parents felt CH may alleviate this by providing a single source of information which could be updated and accessed by multiple professionals.

Potential for CH to aid communication between HCPs was also posited. Often children have large medical teams, requiring frequent transfer of information between disciplines or healthcare settings. While information was shared using paper files, parents were frequently relied upon to share this information across HCPs. Rather than parents having to directly seek or share information, seen as an "activation bump" (HCP1), CH could allow for more free and timely transfer of information.

While CH may facilitate communication, the importance of supplementing, rather than replacing, face to face communication was noted. This was emphasised for disciplines relying on interpersonal connection, particularly psychology and social work services.

Individualisation of Care. The potential benefits of individualising healthcare were expressed, particularly by HCPs. Through more systematic and comprehensive tracking of child health, CH could allow for more timely responses to infections or adverse consequences. HCPs queried whether ongoing monitoring and analysis of blood or other measures using CH could facilitate more individualised protocols, while reducing side-effects. For out-patient care, support to monitor treatment adherence and progress was highlighted, facilitating individualised future recommendations.

Knowledge as power. Parents expressed the importance of a single source of trusted information to facilitate ongoing knowledge exchange. Parents frequently sought additional information on their child's health to increase their understanding and to aid in care provision. Difficulties identifying trusted sources of information was noted. While parents were provided with information by HCPs verbally, they felt this was often insufficient. Difficulties remembering information shared during conversations with HCPs were reported, often due to the high stress and volumes of information shared. As a result, questions would often arise following the appointment. Additionally, terms used by HCPs were sometimes difficult to follow. Support to visualise their child's diagnosis and progress in treatment was sought, with access to x-rays or scans felt to be a more accessible means for parents. In addition to understanding, information to support decision making by parents was also needed, particularly in determining when actions should be taken regarding their child's health.

8.3.3. Factors impacting CH uptake: Facilitators and Barriers

Importance of Trust. The importance of trust when considering the use of CH was noted. This included trust in data privacy, in the quality of the system, and that data were being appropriately monitored.

Privacy. For HCPs, ensuring that any system was secure was a key consideration for use. HCPs concerns pertained more to alleviating parental concerns, rather than fear of harm. For parents, security of data was a key consideration. Again, the risk of harm should privacy be breached was perceived to be low.

Monitoring/accuracy. For systems such as EHRs where multiple HCPs may be accessing information, ensuring data remained up to date was a key priority. Additionally, HCPs noted a need to ensure accuracy, particularly where parents were inputting or monitoring data. HCPs also raised concerns regarding the monitoring of data inputted into CH. As data inputted may require action on the part of healthcare teams, effective monitoring and response protocols are needed.

Recommendations for use. The need for trusted professionals or HCPs to act as gatekeepers to CH was felt to aid trust in the technology. Parents reported cynicism towards online sources of health information, with inappropriate or inaccurate content common. To mitigate this risk, and to facilitate use and trust of a CH system, a referral from a trusted source, such as an HCP, is needed.

Pace of change. At present, there appears an absence of technology within service provision, with a conservative approach taken to technology introduction. HCPs noted a reliance on paper to manage information, though this was an area of upcoming change. While HCPs were highly aware of the many CH tools which could support service delivery, a disbelief in their introduction in the short term was noted, alongside an acceptance of the slow pace of change. For those HCPs who had participated in digitalisation efforts, the pace of introduction was felt to be slow and hard fought. Covid-19 was thought to have had a positive impact on the use of technology in health, with many previously in-person services forced online, often successfully.

Access. Access to services was felt to be both positively and negatively impacted by CH. CH was seen as an avenue to reduce the response effort to access services, increase access to one's own community and provide social support for children. However, cost, access to WI-FI and literacy were seen as means through which CH may limit service access.

Increase access. Both groups noted the potential for CH to increase access to services through reducing the response effort required. As healthcare services for children with cancer in Ireland are delivered through a central children's hospital in a large urban area, families travel long distances to access treatment. CH may reduce some of this travel through allowing for monitoring of health at home. Time pressures placed on parents due to caregiving responsibilities often led to needed, but not urgent, services being missed. CH may aid access in this regard through reducing the impacts of logistics such as time and travel.

CH may also reduce illness-related barriers to accessing services. Treatment regimens may impact the immune system, requiring isolation to reduce risk of infection. While in-person services may be unavailable, CH was felt to facilitate continued access to services while in isolation. The ability to monitor health outcomes from home was seen to offer families the opportunity to engage more within their communities. Due to the impacts of some paediatric cancer treatments on the immune system, parents were often hesitant to attend events. Through real-time monitoring of child health, parents could be more aware of their child's immune system and thus more confident to engage in activities. CH was also noted as a potential avenue through which children could access peers with children noted to be eager to engage socially online.

Decrease access. Both groups noted the significant financial pressure imposed by a paediatric cancer diagnosis. Additional cost for CH may further fuel this. Parent literacy may also prevent access to CH, with poor literacy felt to be common, particularly for at-risk groups. The absence of strong WI-FI connectivity across Ireland and within hospitals may limit CH use. Further pressure to access high quality WI-FI signals to manage their child's care was thought to present additional burden for parents.

8.4. Discussion

This study sought to explore HCP and parents' perspectives on the potential use, barriers, and facilitators of CH, to better understand how its uptake may be facilitated in practice. Areas of need which may be supported by CH included communication, individualisation of care and access to information. Consideration to the importance of trust, pace of change, and impact of digitalisation on access to services was also highlighted. Results suggest several roles for CH in paediatric cancer, including supporting access to services, individualised treatment, illness monitoring, aiding communication between stakeholders, reducing parental administrative and decision burden, and meeting informational needs. However, the pace of digitalisation appears slow and hard fought, with concerns regarding privacy and digital skills raised. It is of note that the present analysis was conducted in the context of a healthcare system within which digitalisation efforts have been slow and limited in scope. As such, while the utility of CH broadly was explored, many of the needs raised could likely be addressed with simpler technological solutions such as EHRs. While results suggest acceptance and enthusiasm by key stakeholders towards the use of CH, barriers should be considered to ensure effective implementation.

Parent and HCP willingness to use CH is consistent with Sin et al. (2018), who found good acceptance of eHealth psychosocial interventions for family caregivers. As acceptance appears a predictor of use (Hennemann et al., 2017), these results are positive and suggest a willingness to engage with CH. The positive attitudes noted by HCPs too is promising and may support CH use due to the known impact of HCPs on patient attitudes (Gun et al., 2011).

However, several concerns were raised regarding data privacy which may inhibit CH use. This is of note as within the TAM data privacy may impact acceptance (Huarng et al., 2022). The broader study context however may have impacted these results. As data breaches have occurred within the Irish health service in recent years (Gallagher, 2021), privacy concerns and distrust are somewhat expected. The importance of ensuring data security in CH has been noted across health sectors (Karampela et al., 2019), with a clear need for robust regulatory and privacy frameworks (Signorelli et al., 2019). As personal data protection is a right within Europe (The European Parliament, 1995), ensuring privacy within CH is of utmost importance.

The present analysis highlights several avenues through which CH may support families impacted by paediatric cancer. One means of which is through the sharing of information, both across healthcare teams, and between HCPs and parents. Shared access to information across HCPs and parents may decrease parental responsibility, while simplifying information sharing may enable enhanced communication between parents and HCPs. This mirrors previous research suggesting the potential for CH to support communication in paediatric cancer (Chi & Demiris, 2015; Hah et al., 2019), as well as communication between primary and secondary care (Hah et al., 2019) and sharing of clinical information (Wicks et al., 2014). However, this need for increased access to health information may be facilitated by more simple CH approaches, such as the use of EHRs, which are unavailable in Ireland. While communication was felt to be an area positively impacted by CH, concerns were raised regarding reductions in face-to-face supports, consistent with previous research (Kailas, 2011). As such, while CH may be beneficial in supporting communication between key stakeholders, efforts to ensure it does not replace in-person communication are needed, along with additional analysis of the most optimal frequency and form of communication between parents and HCPs to ensure effective distribution across communicative modalities. Further, in the context of the low digitalisation encountered by this population, analysis of the impacts of more basic CH on communication and information needs is needed to determine if these may sufficiently meet needs.

Another finding from this study pertained to parental informational needs. Seeking, sharing and managing information were all felt to be areas in which CH may provide aid, consistent with past research (Newman et al., 2019). Reliable health information is particularly necessary in the context of the negative impacts of misinformation on treatment adherence, inappropriate treatment seeking (Lleras de Frutos et al., 2020) and patient-HCP relationships, alongside the difficulties in falsifying misinformed beliefs (Caruso Brown, 2021; Chou et al., 2020). CH however may mitigate these impacts through the use of machine learning to remove such health misinformation (Firouzi et al., 2021). As such, CH may be beneficial in establishing trustworthy and accurate sources of health information, mitigating these concerns. In the context of the TAM, CH may be perceived as useful through easing access to health information. This in turn may positively impact acceptability. For HCPs too, CH had perceived benefits in increasing access to information on child treatment responses. More specifically, means to monitor health through digital technologies were felt to impact positively on responses to infection, health outcomes, and time in clinical settings. For parents, the importance of a reliable source of information was noted, with a need for technology to be sourced from a trusted health professional. The key role of HCPs in the dissemination of digital technologies has been found previously with CH needing to be integrated within care pathways (Psihogios et al., 2020). As such, while results suggest information provision as an area in which CH may provide support, efforts are needed to aid HCPs in the dissemination of technologies to parents to support uptake.

The absence of digitalisation and pace of change within the healthcare service in Ireland were described as key barriers to the use of CH within paediatric cancer. Organisational reluctance to change and ineffective change management are key impediments to CH use (Wicks et al., 2014). This lack of digitalisation is an area of focus within healthcare in Ireland, with the national eHealth strategy advocating for digitalisation as a national infrastructural investment (HSE, 2013). Specifically, there is a need for a properly executed national eHealth strategy, with an emphasis on delivery of key areas of digitalisation such as ePrescription and EHRs, amongst others. Reluctance to digitalise care in Ireland may have arisen from past unsuccessful efforts, such as electronic voting and PPARS (Personnel, Payroll And Related Systems) resulting in reluctance to trust technology-based interventions (Lang et al., 2009). It is also of note that this study was completed prior to the ransomware attack of Irish hospitals in June of 2021, which resulted in the loss of IT systems and breaches of personal healthcare data (Gallagher, 2021). This event may have impacted trust in CH and willingness of the healthcare system to further invest in digital technologies. Organisational factors play a significant role in the use of CH with additional efforts needed to examine how best to support effective and timely change to ensure technologies are effectively employed.

Several limitations to the present study are noted. Firstly, the timing of the study may serve as a limitation, with interviews conducted during the Covid-19 pandemic with restrictions on non-essential movements across the country. Due to social distancing requirements, many previously in-person services were moved online. This increased access to digital health services may have impacted the perceived acceptability of CH through demonstrating its use in practice. Many respondents noted the impact of Covid-19 on their use of technology and the opportunity it presented to trial digital service delivery. The absence of digitalisation within the Irish healthcare system also poses a limitation, as some needs identified may be addressed through the adoption of technologies such as EHRs, which are highly prevalent across healthcare services globally (World Health Organization, 2016), but not available in Ireland. This in turn limits our ability to explore more complex CH technologies, as basic digitalisation remains outstanding. A further limitation is the small sample size and constituents. However, as good variety in experiences for both parents and HCPs were obtained, this may have allowed for a broader range of views to be captured. As few fathers participated further analysis of this group is needed. Additionally, the voice of children themselves was omitted from the present study. As many CH tools in the space are targeted towards parents rather than children, their participation was not sought. To determine perspectives on the utility of CH for children themselves, particularly teenagers or older children who may derive increased agency over own health information through such tools, additional analysis is needed.

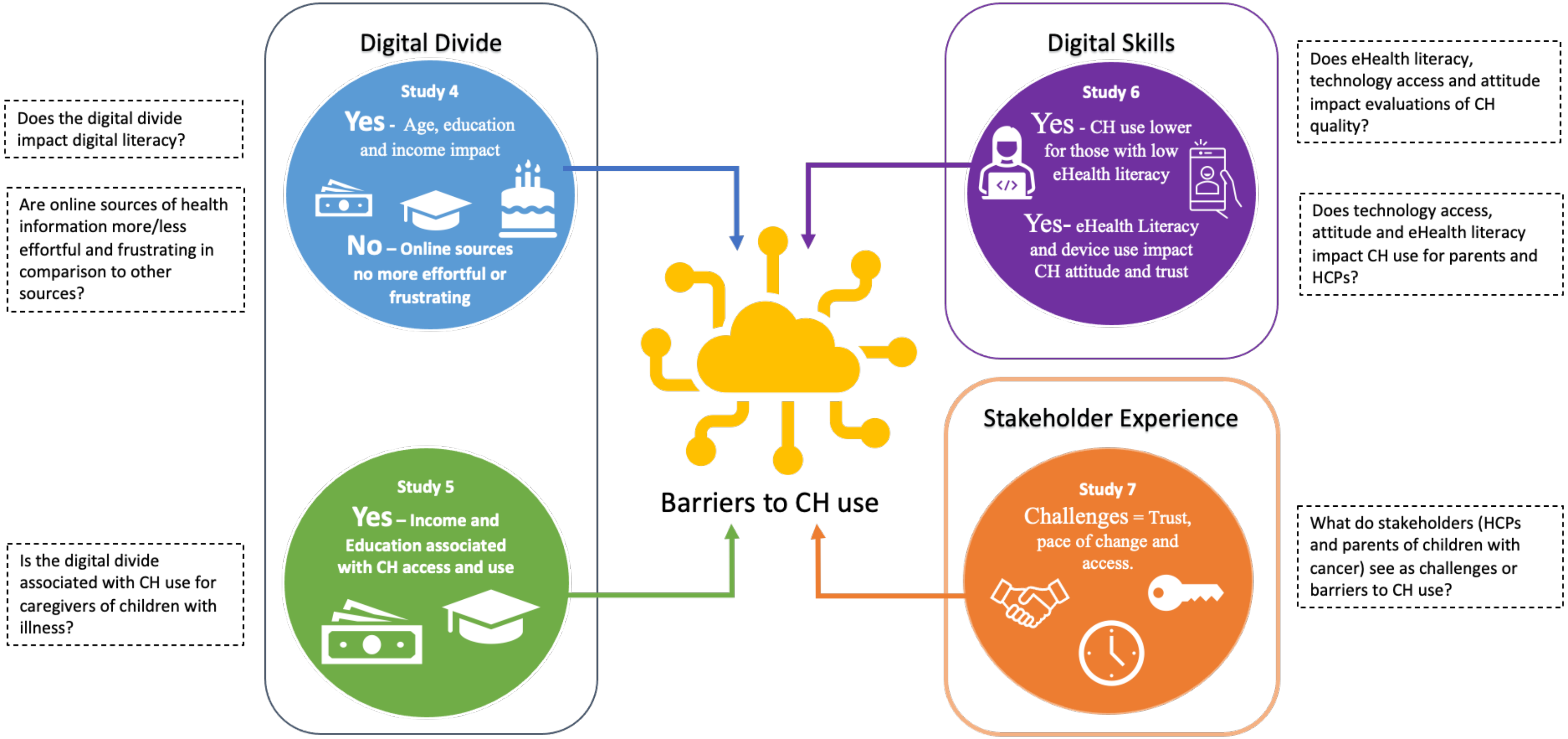
The results of the present study cast positive light on the potential for CH to be effectively employed to support families impacted by paediatric cancer. The need for inclusion of parents, HCPs, and the broader healthcare systems within the design of CH in user centred design is clear to ensure alignment between technological advances and service delivery. While further analysis is need on the efficacy of CH to support families impacted by paediatric cancer, the present findings highlight key areas where CH may be effectively employed.

Section C Discussion

For CH to positively impact children and families living with paediatric cancer, it must be accessible and meet the needs of those for whom it is intended. To this end, the studies described in this section explored the multi-faceted barriers to CH faced by families of children with cancer, through exploring three distinct domains: 1) the digital divide; 2) technological pre-requisite skills; and 3) stakeholder perceived challenges. A graphical summary of findings are displayed in Figure C.2 below. Findings highlight the role of education and income level on CH access and use. Technological barriers to CH were also found, with eHealth literacy and technological comfort impacting use. Privacy, security, and systemic reluctance to change were identified as key factors limiting CH uptake in practice by parents and HCPs. Overall positive perspectives on CH were obtained across studies, with online sources of health information commonly used, and some use by caregivers of children with cancer in Ireland. Both parents and HCPs felt that CH may positively impact communication, individualisation of care and access to information within the healthcare service for children with cancer. This suggests that, while CH is welcomed by key stakeholders, efforts to address socio-economic, technological, and systemic factors are needed to ensure effective uptake in practice.

Figure C.2

Graphical Display of Results



Inequalities in access to CH technologies are reflected in Study 4. Results of Study 4 suggest a digital divide in the use of internet for health, with those who are younger, with higher incomes or higher levels of education more likely to have accessed health information online. Study 5 explored the digital divide further by examining CH use for caregivers of children more specifically. While good uptake of CH was found, particularly for eHealth, mHealth and EHRs, again caregivers with lower household incomes and education were significantly less likely to have accessed CH. When considered in tandem, these results highlight inequalities in CH access for families of children with illness. However, it is of note that no associations between demographic factors and CH use was found in the analysis of survey data from a predominately Irish sample (Study 6), though this may have been impacted by the small sample size and online recruitment. Some suggestion of socio-demographic barriers to access were found in the qualitative analysis (Study 7), with both cost of technologies and access to strong Wi-Fi connections perceived as barriers to CH uptake by parents and HCPs. Additional effort is needed to reduce the impacts of these inequalities through reducing access barriers and ensuring technology is developed in a more accessible manner.

The impact of technological pre-requisite skills on CH use and attitude is highlighted in Study 6. Positive attitudes and strong eHealth Literacy skills for both HCPs and parents of children with cancer were found, though CH use by both groups was limited. This may be somewhat expected in the context of the relative absence of digital technologies within the healthcare service in Ireland. As basic digital technologies such as EHRs have yet to be introduced, it is understandable that HCPs and parents may not have had opportunities to engage with them. Results however suggest that both eHealth literacy and device access play a crucial role in facilitating CH use, attitudes, and trust towards higher quality CH applications. Scepticism towards commercially available CH was found for parents and HCPs alike, with CH apps not deemed trustworthy or evidence-based, suggesting a hesitancy towards freely available

CH apps. This is somewhat echoed in Study 7 in which concerns regarding the quality of CH were noted. This suggests a need to ensure those with differing eHealth literacy and technological comfort are considered when developing CH technologies to support effective use in practice.

Fulsome analysis of the perspectives of families and HCPs on use of CH in paediatric cancer in an Irish context was conducted in Study 7. Several areas were highlighted in which CH could be meaningfully applied, including signposting services, individualisation of treatment, monitoring of health, information sharing, reducing parental administrative burden, and supporting access to information. HCPs also posited a role of CH in monitoring child health and responses to treatment, which may positively impact health outcomes. While parents and HCPs were broadly positive towards the use of CH, barriers included systemic issues, such as the slow pace and general reluctance towards digitalisation within the health service in Ireland. As such, should CH be employed within paediatric cancer care in Ireland, efforts to ensure it is secure, derived from a trustworthy source, and accessible to those with low income and based in remote locations, are needed.

Positive perspectives on CH for parents and HCPs were obtained across analyses. This is exemplified in the strong use of CH by caregivers of children (Study 5), and the perceptions of parents and HCPs (Study 7). However, use of CH in the Irish sample appeared low (Study 6), particularly in comparison to the HINTs data. While this may have been due to the poor digitalisation of healthcare service in Ireland, limiting access to such technologies, when considered in tandem with the low trust and perceived quality of publicly available CH apps (Study 6: Technology Usage, eHealth Literacy and Attitude Towards Connected Health in Caregivers of Paediatric Cancer), hesitancy towards CH use appears clear. To address this, careful communication with caregivers of children when introducing CH is needed, to address and dispel concerns regarding privacy and potential benefits of use.

A further finding arising from this section is the importance of disseminating CH in a manner which facilitates stakeholder trust. Low trustworthiness and perceived quality of freely available CH apps was identified in Study 6. Further, as noted within Study 7, a reliable and trustworthy source of CH is of utmost importance to parents, and a factor which impacts willingness to use. One means through which this dissemination challenge may be addressed is through trusted professionals, such as HCPs. The importance of HCPs as sources of information was demonstrated in the analysis of HINTs data (Study 4), with caregivers of children who obtained health information from HCPs more confident in what they found. As HCPs positively impact health information seeking, there is a need to consider how HCPs are best supported to provide information on CH. This is particularly relevant in an Irish context in which fewer HCPs had experienced using CH (Study 6) and where HCPs identified privacy, quality, and access barriers to CH use for families (Study 7). Decision support tools for HCPs are needed to facilitate determinations of CH quality and efficacy based on empirical analysis. In addition, inclusion of effective CH within care pathways is needed to aid decision making and to support HCP referrals.

Section C Conclusion

Positive attitudes and strong willingness to use CH were found across the included studies for both parents and HCPs. This finding, in tandem with the identified areas in which stakeholders felt CH may be most of benefit, is positive and suggests such tools may provide helpful benefits for families in practice. However, the present analysis identified several barriers which may impact CH use for families, including inequalities in access, pre-requisite technological skills, privacy, and systemic pace of change. While these barriers span multiple domains, recommendations on how they may be addressed can be made. Firstly, for those designing CH efforts are needed to ensure that technologies are accessible to families with lower education and income, and those with lesser eHealth literacy and access to technology. This may be best achieved through user inclusion in design. Through ensuring CH tools are designed with those at risk of exclusion in mind, reductions in the digital divide for CH may result. Secondly, effective dissemination of CH is required, to support stakeholder trust in the quality, accuracy and privacy of CH. Dissemination may be enhanced through linking directly with healthcare services and HCPs to ensure they are informed about CH, and where technologies would effectively sit within care pathways. Finally, while parents and HCPs appear willing to embrace CH, systemic reluctance to change and poor use of digital technologies within the Irish healthcare service pose barriers. Efforts to encourage digitalisation within the broader healthcare system is needed should such technologies be effectively employed. As such, while there is a need for steps to be taken to address the barriers identified, the strong willingness to use and positive attitudes suggests value to the addition of CH in practice for both families of children with cancer and HCPs alike.

When considered within the broader context of the current research, it appears that while some CH is available for families, research-led supports struggle to extend past pilot stages (Study 1), and commercial CH often is not the subject of empirical analysis, necessitating additional research (Study 2). Currently, families impacted by paediatric cancer in Ireland require accessible psychological, informational and healthcare management supports, amongst others (Study 3). However, as noted in Study 1 and 2, there is an absence of available, evidence-based psychosocial CH supports for parents. As such, there is a need for accessible CH to be developed to support these currently unmet psychosocial needs. This will be addressed in Section D, in which the design and evaluation of an online psychosocial CH programme for parents of children (Study 8) will be presented.

Section D: Pilot analysis of a CH mediated Psychosocial Programme

Section D Introduction

The results of studies 1-7 suggest that while CH holds promise as a means of addressing the unmet needs of families impacted by paediatric cancer, efforts are needed to 1) ensure socio-economic, technological, and systemic factors do not pose barriers to CH use; and 2) explore the impact of CH on parent and family member outcomes in real world settings. Leveraging learnings derived from sections A, B and C, this section presents the final study of the thesis, a CH mediated psychosocial programme for parents of children with cancer (Study 8). Prior to this, building on the findings presented thus far, a set of recommendations guiding the development of CH interventions is presented.

D.1. Synthesising the Findings of Sections 1, 2 and 3

D.1.1. Approach to Synthesis. An informal narrative synthesis approach was applied to synthesising the findings of sections 1, 2 and 3, with an overarching aim of summarising key learnings obtained across each section to identify overarching themes or insights. Firstly all studies across the three sections were reviewed by the researcher to increase familiarity and to identify the findings resulting from each. Findings across all studies were then amalgamated in a document and reviewed to identify areas of overlap and disagreement. Key themes were then identified and summarised. Following this each section was re-read to ensure themes accurately reflected what was found across the three sections.

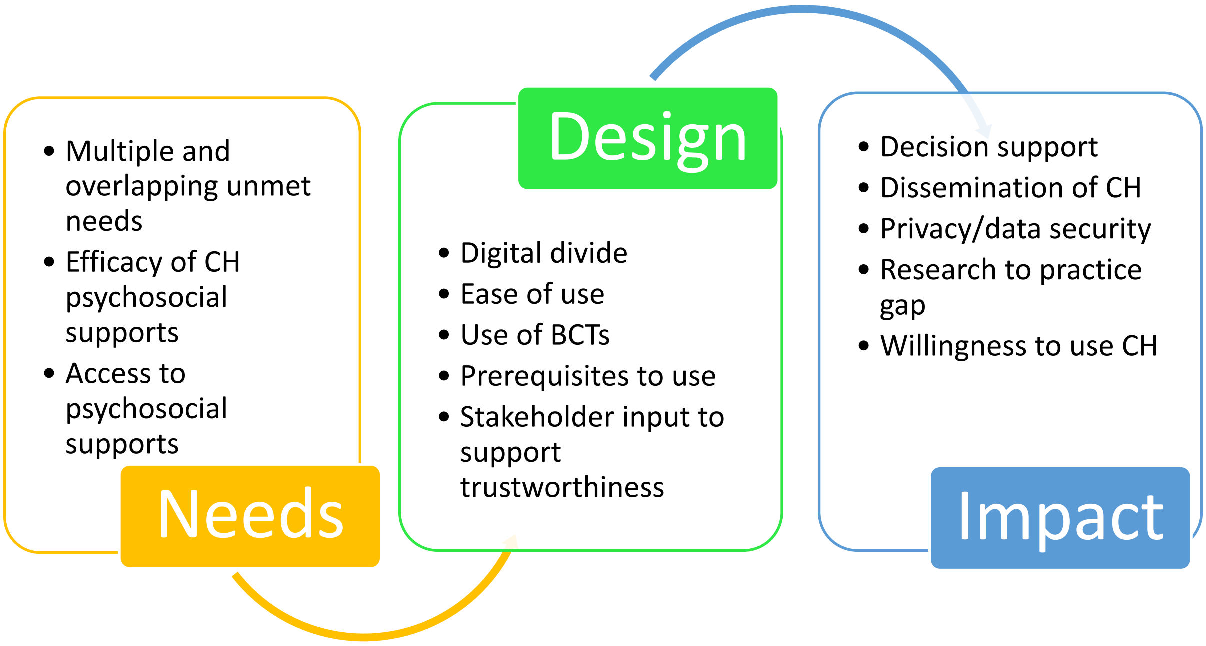
D.1.2. Stakeholder Input. Following the synthesis of information gathered across sections 1, 2 and 3, as described above, the information was shared with key stakeholders to gather their insight on what was found and to provide insight the validity of findings from their perspectives. Through this input, further insight into the key learnings deriving from the findings of the research conducted across sections 1, 2 and 3 were hoped to be obtained, alongside direction for further research. To this end presentations of the synthesised findings of sections 1, 2 and 3 were presented to two stakeholder groups, parents and HCPs. Firstly, the synthesised findings were presented to the PPI panel (see section 9.2.1 below for detail on constituents and approach) in a Microsoft Teams meeting using Microsoft PowerPoint. Key findings from sections 1, 2 and 3 were presented to the PPI panel, and an open discussion on these findings and proposed next steps was discussed. PPI panel members responded positively to the findings of sections 1, 2 and 3 and felt that they were broadly representative of their experiences. PPI panel members particularly echoed the need for psychosocial and service navigation supports, and suggested a need for further research in these areas. In addition to the PPI panel input, a workshop with HCPs working within an Irish Children's Hospital was also conducted again to gather their perspectives on the results to date and to direct future aspects of the research project. HCP input was gathered as it was felt that they would offer a unique perspective due to the breadth of families and treatment pathways they would encounter, allowing for a broader range of family experiences to be considered. This workshop took place in person and was attended by nurses, physiotherapists, occupational therapists, speech language therapists, social workers and doctors. Again a PowerPoint presentation was shared followed by an open discussion. Positive feedback on findings was obtained, with HCPs emphasising the highly heterogenous nature of paediatric cancer treatment and survivorship.

D.2. Recommendations for CH development

Analysis of results obtained across studies 1-7 highlight several key factors which should be embedded into the design of any novel CH. These key contributions of this research to CH development are discussed across three areas, which relate to considerations of 1) the unmet needs of families; 2) CH design; and 3) CH impact. An overview of these recommendations is presented in Figure D.1, with a detailed description presented in Table D.1.

Figure D.1

Considerations for the Development of CH for Families of Children with Cancer



D.2.1. Unmet Needs

Previous sections note several areas of need for families of children with cancer which may be addressed through CH. Three key themes arising include 1) multiple, overlapping unmet needs; 2) the efficacy of CH psychosocial supports; and 3) access to psychosocial supports. Many overlapping needs are encountered by families across informational, healthcare, communication, psychosocial, household management, financial and service navigation domains. Study 3 outlined how these needs are felt more sharply by rural families for whom the time, financial, familial and employment concerns are amplified as they travel to access healthcare services. In this context, supports developed should not impose further burden, with those accessible within communities (i.e. locally based or online) offering particular benefits.

While findings of studies 1-7 suggest the potential of CH to support the psychosocial needs of families impacted by paediatric cancer, results also highlight the absence of analysis of CH's impact in practice. Specifically, only limited types of psychosocial supports have demonstrated effects to date, with most that do utilising CBT techniques or being non-theoretically based (see section D.5 below for further description). As such, it is vital that future CH which seeks to support the psychosocial needs of families should explore impact in practice.

D.2.2. Design

Sections A, B and C suggest several factors that should be considered when designing CH for families of children with cancer. These are 1) ease of use, 2) the digital divide, 4) prerequisites to use, 5) stakeholder input to support trustworthiness, and 5) use of BCTs. By considering each of these within the design process, more accessible and acceptable CH may be developed.

The importance of accessible CH is articulated in Section C. While CH appears to have good utility, acceptability, and feasibility (Study 1), those who have higher levels of education, household incomes, eHealth literacy and comfort with technology are more likely to have accessed it (Study 4 and 5). Technological comfort is of particular relevance within an Irish context, with the slow pace of digitalisation likely resulting in less familiarity with CH (Study 6 and 7). In response, CH design should minimise the impact of these factors. Short, simple phraseology and simple instructions (using audio, visual and written mediums) should be used to support those with differing education and literacy levels to use CH. Hosting technologies (i.e. computer, phone, sensor etc. through which the CH intervention is accessed) which are more common and less costly should be chosen to reduce barriers to entry. Technological prerequisites for use should be minimised, for example the strength of internet connection, or technical skills (i.e. syncing sensors, downloading programmes, remembering multiple passwords etc.). Consideration should be given to the use of BCTs within CH to support meaningful behaviour change, and to address the functional relations underlying the behaviours of concern. Again, stakeholder co-design through

PPI may be of benefit here, to ensure the voice of parents and children are captured in the development of CH, particularly as it pertains to barriers to use.

D.2.3. Increasing Impact

Results obtained from studies 1-7 also provide guidance on how the impact of CH may be increased. Key findings arising here relate to (1) willingness to use CH, (2) decision support, (3) privacy and data security, (4) the research to practice gap, and (5) dissemination strategies.

Positively, results of studies 2-7 suggest a general willingness to use CH. This can be seen, for example, in the volume of downloads of commercially available CH (Study 2), and the strong use of CH for caregivers of children (Study 5). This willingness is echoed within an Irish context (Study 7), even if past use is low (Study 6). However, empirically driven CH is often not openly available on the market, with a strong research-to-practice gap. Efforts to bridge this gap are needed to support any conclusions drawn about its impact in practice. This may be achieved through piloting and evaluating CH in commercial settings or using PPI to act as a mechanism through which usability analyses can be conducted, in turn allowing impact to be determined more quickly.

Results highlight several factors which may limit CH impact in practice, requiring proactive consideration in design. Firstly, concerns pertaining to overall trustworthiness of CH were raised, including data security and privacy (Study 7) and concerns pertaining to legitimacy of commercial CH (Study 6). It is therefore recommended that trustworthy sources of information on CH are established to increase legitimacy. Consideration is also needed as to how parents, caregivers and HCPs may be supported to identify CH which is evidence-based and effective. While the inclusion of CH within care pathways may be one means to achieve this, decision supports and guides are needed. Through these efforts, the impact of CH in practice may be increased.

Table D.1

Key contributions of Sections 1, 2 and 3 to CH development and Recommendations Arising

Domain	Input	Study	Finding	Recommendations
Needs	Multiple and overlapping unmet needs	Study 3	Families report overlapping needs, including information, service navigation, psychosocial, healthcare management and community support needs, amongst others.	Supports should minimise further burden. Accessible supports which do not require travel away from communities are needed. PPI should be used to ensure needs are effectively addressed and burden not added.
	Efficacy of CH psychosocial supports	Study 1	Some existing psychosocial support delivered through CH identified. Only 50% (n=3) of these were the subject of empirical analysis. Of these two used CBT, and one behavioural support strategies.	Additional analysis of CH impact is needed. Analysis of additional psycho-oncology supports is needed.
		Study 2	A number of commercially available CH providing psychosocial supports identified, none the subject of empirical analysis.	
	Access to psychosocial supports	Study 7	Challenges accessing psychological supports were noted, particularly for individuals from rural locations. Time limitations further impact accessibility, particularly the impact of travel on time. A need for accessible psychological supports was found, particularly at the post-treatment transition. However, this is complicated by parents' reluctance to consider own needs.	CH should be applied to reduce parental administrative burden, and support access to services.
Design	Digital divide	Study 4/5	Income and education associated with access to CH.	CH should be designed in a manner that minimises impact of the digital divide. Simple language should be used to

Domain	Input	Study	Finding	Recommendations
		Study 6	No associations between demographic factors and CH use were found in the analysis of survey data from a predominately Irish sample, though there was a small sample and online recruitment.	support those with differing education and literacy levels. Hosting technologies (i.e. computer, phone, sensor etc.) which are more accessible and less costly should be used where possible. Analysis of accessibility of CH should occur, and challenges to access addressed.
		Study 7	Cost of technologies, literacy, and access to strong Wi-Fi connections barriers to CH uptake.	
	Ease of use	Study 4	Caregivers of children reported high confidence in their ability to seek health information online, and felt it required low effort and frustration. Online sources were not associated with differences in confidence, effort, or frustration.	In the context of low CH use in Ireland, additional supports to facilitate uptake are needed. All CH should minimise the volume of technological prerequisites to use, such as strength of internet connection and hosting technology (i.e. tablet, smartphone, sensor etc.).
		Study 6	Low use of CH was found for the Irish sample. As technological comfort was found to be linked to CH attitude, some support to increase familiarity may be needed.	
		Study 7	While CH was viewed positively, the need for access to pre-requisites such as WI-FI and the technologies themselves was noted.	
	Use of Behaviour Change Techniques in CH	Study 2	Generally good use of BCTs within commercially available CH.	Need to consider how BCTs will be included within future CH to increase impact.
	Prerequisites to use	Study 6	eHealth literacy and technological comfort linked to attitude toward CH.	Technology which is easily accessible, in comparison to more novel or expensive options should be considered.
		Study 7	CH access may be impacted by Wi-Fi, cost, and literacy	

Domain	Input	Study	Finding	Recommendations
	Stakeholder input to support trustworthiness	Study 4	Peers/HCPs as important sources of health information. As such their input into the development of CH may support uptake.	To mitigate the impacts of the digital divide, stakeholder inclusion across design and development of CH is needed to facilitate uptake. CH should be disseminated in a manner which facilitates stakeholder trust.
		Study 6	Low trustworthiness and perceived quality of freely available CH apps was identified.	
		Study 7	Reliable and trustworthy source of CH is of utmost importance to parents, and a factor which impacts willingness to use. Value of HCP input shown, with good consistency between parent and HCP perceived needs.	
Impact	Decision support	Study 6	Scepticism towards publicly available CH was found for parents and HCPs alike, with CH apps not deemed trustworthy or evidence-based.	PPI needed in development (those with differing eHealth literacy and technological comfort are considered when developing CH). HCPs should be supported to disseminate CH.
		Study 7	Concerns regarding the quality of CH was noted.	
	Dissemination	Study 4	Information from HCPs and peers associated with lower effort and frustration in health information seeking. May be useful means of disseminating information on CH.	While HCPs and peers may be good means of disseminating CH, awareness of potential impacts of the digital divide require consideration.
		Study 5	A digital divide was found even for HCP mediated technologies, suggesting that even HCP disseminated technologies are not immune from inequities in access.	
		Study 6	Low levels of trust in, and perceived quality of, commercial CH for parents and HCPs in Ireland, suggesting some hesitation.	
		Study 7	Reliability and trust in CH sources of utmost importance to parents, and a factor which impacts willingness to use.	

Domain	Input	Study	Finding	Recommendations
	Privacy/data security	Study 7	Efforts are needed to ensure secure storage of data within CH. Further, assurances on the privacy of data gathered should be shared with HCPs and families.	Consider 1) how security will be ensured; 2) how users will be informed of how data privacy/security is ensured.
	Research to practice gap	Study 1	Of included studies, 68.7% explored acceptability/feasibility. Generalization to non-pilot settings needed.	Need for practical clinical trials including representative participants, settings, controls etc. in real world settings. An emphasis on impact as well as acceptability/usability is needed in analysis
		Study 2	Not enough available CH empirically analysed.	
	Willingness to use CH	Study 2	High volume of commercially available CH available, and generally high downloads. However, no data on actual or ongoing use.	The general willingness to use CH in an Irish context should be used to facilitate uptake.
		Study 5	For US caregivers of children there is high use of CH.	
		Study 6	Somewhat low current use of CH by an Irish sample.	
		Study 7	Parent and HCP express willingness to use CH to support care. CH may reduce the impact of illness related barriers to in-person services such as immune system risks, travel, etc.	

D.2. Designing a Psychosocial Intervention for Parents/Caregivers

While the current thesis outlines how CH may be designed and disseminated effectively in the context of paediatric cancer, analysis of the impact of such recommendations in practice remains outstanding. As such, the final study consists of a brief online psychosocial intervention, developed in line with the recommendations above.

While parents and children impacted by paediatric cancer have highlighted psychological wellbeing as a top research priority (Aldiss et al., 2019), limited brief, cost-effective psychological interventions for parents of children with serious illness have been developed. As noted, families often face significant travel burden to access care (Cernvall et al., 2015; Pöder et al., 2008). While tolerated for treatment, this may pose a barrier to accessing psychological support, particularly for parents who are often reluctant to obtain supports for themselves (Pöder et al., 2009). As such, there is a need for accessible psychological support embedded within communities. One means of facilitating access is through remote service delivery. An important advantage of online psychosocial supports is that they can be delivered at a convenient time and place, and reach people in remote locations (Proudfoot et al., 2011), increasing access to evidence-based care. Additionally, in the context of restrictions imposed in response to COVID-19, and the geographical organisation of paediatric oncology services primarily within urban centres, remote service delivery is likely a more effective and accessible medium (Malins et al., 2021).

While several psychological interventions have been developed to support parents of children with cancer, they often lack empirical analysis and are rarely generalised to practical settings (Michel et al., 2020). A systematic review of psychological interventions for family members of children with cancer found mild to moderate effects, with results of behavioural interventions most promising, particularly those of low intensity (Sánchez-Egea et al., 2019). To ensure optimal and efficient resource allotment into psychosocial supports, analysis of the underlying mechanisms of change is needed.

D.3. Psychosocial Interventions in Paediatric Oncology

While psychosocial support is necessitated, there are limitations to current approaches in paediatric cancer. Past psychological interventions in paediatric oncology lack long term effectiveness due to too limited a scope with regard the underlying therapeutic model, or with an over-focus on psychopathology (Hubert-Williams et al., 2014). Past online psychosocial supports for parents of children with cancer have successfully employed CBT (Cernvall et al., 2015). However, weaknesses in such an approach have been reported. For example, CBT sees distress as an abnormality requiring solutions, and provides tools to minimise the impact of distressed thoughts on behaviour through avoidance or suppression. While avoidance is often effective in the moment, ongoing or high levels of avoidance is associated with negative psychological outcomes and distress (Cernvall et al., 2015). The importance of challenging cognitions, a key tool in CBT, has also been questioned, with a meta-analytic review casting doubt on its importance within intervention (Longmore & Worrell, 2007). In response to this, novel approaches may be needed.

One behavioural psychosocial intervention which may be of benefit in the context of paediatric cancer is Acceptance and Commitment Therapy (ACT). ACT, described in detail in section D.6, is a third-wave behavioural therapy (Hayes, Strosahl, et al., 2012) which seeks to increase contact with the present moment in an effort to transition from avoidant thought patterns toward acceptance of experiences. ACT seeks to help individuals to accept challenging experiences, identify personal values, and engage in activities in line with these values (Hayes, Strosahl, et al., 2012). ACT may be uniquely positioned to support those impacted by cancer due to its focus on adjustment and coping, in line with the individualistic nature of coping with cancer (Hubert-Williams et al., 2014).

Third-wave approaches such as ACT differ from approaches such as CBT in that distress and suffering are viewed as an expected part of existence, with distress in response to cancer seen as normal (Hayes, Strosahl, et al., 2012). ACT does not seek to alter the content or form of thoughts, rather it focuses on reducing their impact on behaviour, through emphasising value-directed action (Greco et al., 2008). Through this, ACT seeks to build psychological flexibility, in turn reducing distress. By increasing contact with the present moment, individuals can move from avoidant to accepting behaviours. When thoughts and emotions are not changed, fled, or avoided, their control over behaviour is reduced. By allowing thoughts and emotions to occur without the intent to fix them, individuals can avoid being drawn into their immediate psychological struggle (Kohlenberg et al., 1993).

Results obtained within the context of the current research lend support to the use of ACT as a potential intervention for parents of children with cancer. For example, results of the qualitative analyses, particularly Study 3, highlight challenges that parents can face in present moment living. While not identified as a specific theme, results suggested some fusion for parent participants to the role of self as a caregiver, and a negative impact of this on valued action, consistent with the ACT model of psychological inflexibility (see section D.6 for more detail). This is exemplified in the challenges encountered by parents and children re-integrating into their lives following active treatment and getting back to the things they enjoyed or valued, as evident in the themes ‘making it work’ and ‘managing alone’. Challenges dealing with ongoing pervasive negative thoughts relating to their child's illness, and fear of its return, were also voiced in Study 3. This implies a need to effectively manage these negative thoughts and emotions as they arise, in a manner which enables valued living. ACT, through its focus on psychological flexibility, may offer useful avenues to address these needs (Hayes, Strosahl, et al., 2012).

The need for support in being present, and obtaining a sense of self larger than an identity of being 'ill' (in the case of the child) or a 'caregiver' (in the case of the parent), was also emphasised in a qualitative analysis of perceived outcomes of an Irish Therapeutic Recreation (TR) Hospital Outreach Programme (HOP) (Delemere et al., 2022), a study completed in tandem with the current project. The HOP provides short-term TR activities to children with serious or chronic illness on-ward and in waiting rooms across hospitals in Ireland and the United Kingdom. Activities typically include arts and crafts, card games or boardgames with an overarching goal of providing fun within a challenge by choice model. Key perceived benefits of the HOP programme included the opportunity to be present and to engage in valued activities. The positive perceived impacts of these factors again lend support to ACT as a promising intervention for those impacted by paediatric cancer, as valued living and present moment awareness are more specifically targeted (Hayes, Strosahl, et al., 2012).

Aside from the findings of the research described in this thesis thus far, several other studies have demonstrated the utility of online ACT to support children with cancer, from aiding pain management (Cederberg et al., 2017), reducing anxiety and depression (Ander et al., 2017), to supporting older children and young adults (11-24 years of age) recovering from brain tumours (Malins et al., 2021). ACT has also been found to be effective in supporting parents of children with medical conditions (Han et al., 2020; Parmar et al., 2019), though limited research has examined impact for parents of children with cancer specifically. A recent systematic review by Parmar et al., (2019) found that of the nine ACT interventions for parents of children with medical conditions, only one included cancer. This study examined the impact of an online group-based ACT and problem-solving skills training programme Take a Breath (TAB), on parental distress for those with a child with a life threatening illness (Burke et al., 2014). While the results of this intervention were promising with medium to large effects at 6-month follow-up, it focused on parents of children with life threatening illness rather than cancer specifically. More recently, Muscara et al (2020) conducted a trial of TAB using video-conferencing with parents of children with illness, of whom 39.5% (n=32) were parents of children with cancer. Positive effects on post-traumatic stress were noted. Meanwhile, positive effects of in-person group ACT on self-efficacy among mothers of children with cancer has been found (Akbari et al., 2020). While these results suggest likely positive effects of ACT for parents of children with cancer, the absence of analysis of the specific ACT components which mediated any effects observed is lacking. In addition, the use of self-directed online intervention in the absence of group or individual support from a practitioner is yet to be examined for this group.

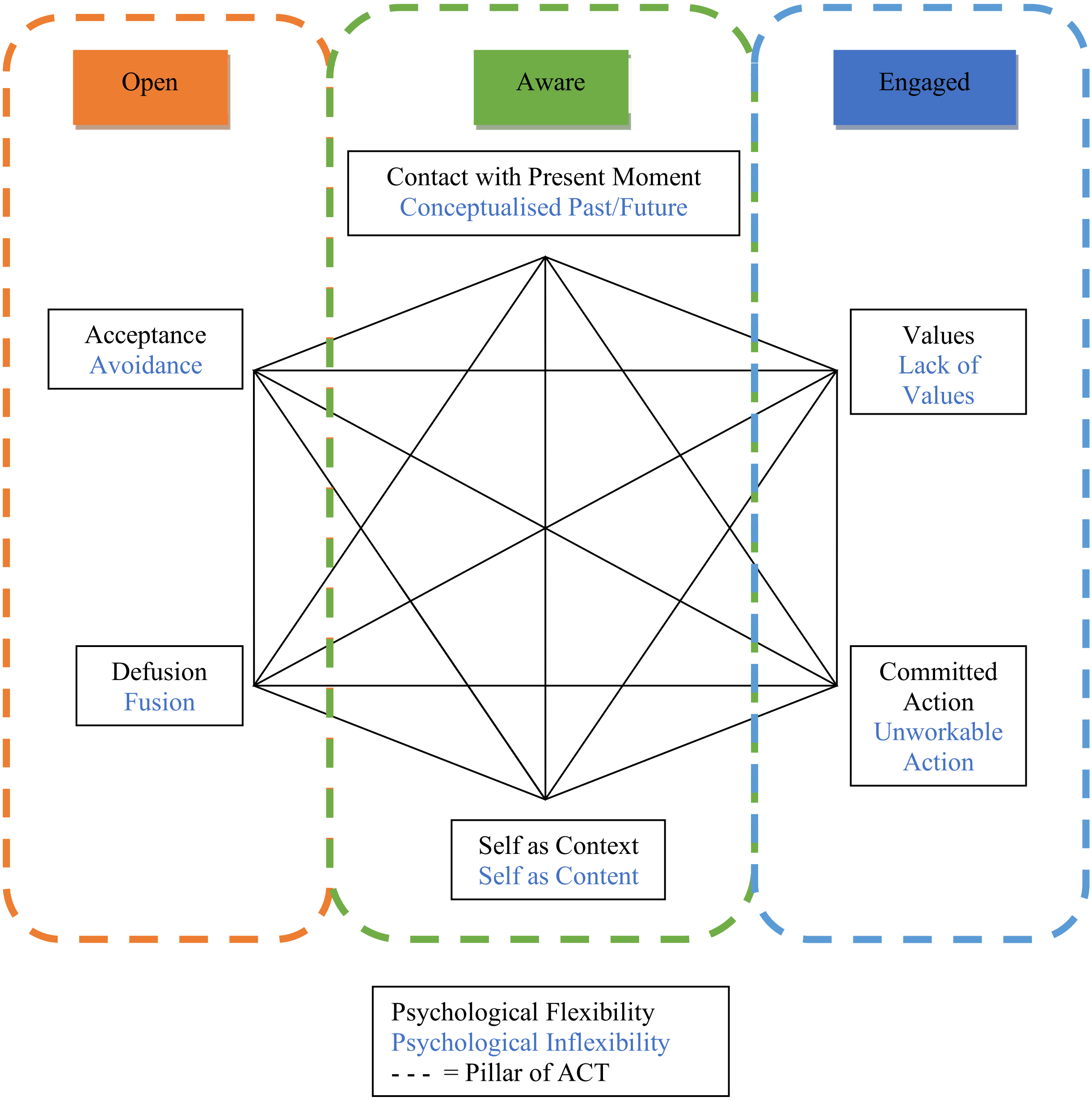
D.4. ACT Model of Psychological Flexibility/Inflexibility

ACT consists of a six component Hexaflex model of psychological inflexibility/flexibility (Wilson & DuFrene, 2008), with emotional distress thought to result from psychological inflexibility (Hayes, Strosahl, et al., 2012). Psychological flexibility has been found to be a protective factor for family coping following diagnosis of leukaemia or non-Hodgkin lymphoma, with psychological flexibility, dyadic coping and network support positively related to parents' perception of family adjustment post-diagnosis, and predictive of family adjustment over time (Van Schoors et al., 2019). Through examining the role of psychological (in)flexibility in contributing to the distress of individuals affected by paediatric cancer, therapeutic interventions can be developed to best meet the needs of those impacted.

ACT includes three overarching pillars of psychological flexibility that contribute to healthy adjustment when faced with challenges such as cancer diagnosis, treatment, survivorship, or advanced disease. These are 1) being present or aware, 2) opening up, and 3) being engaged and doing what matters (Harris, 2019; Hayes et al., 2011). Figure D.2 below outlines the ACT models of psychological (in)flexibility, and the overarching role of each aspect of the Hexaflex within the pillars of ACT. This figure presents the individual aspects of the Hexaflex as they pertain to the three pillars of ACT (Hayes et al., 2011), namely: 1) being open to what occurs within the present moment; 2) being aware of one's ability to contact the present moment, and 3) being engaged in valued actions.

Figure D.2

ACT model of psychological flexibility/inflexibility with pillars of ACT overlayed



As noted above, there are six core processes included within the ACT model of psychological (in)flexibility, or the ACT Hexaflex. The first of these is experiential avoidance, or the effort to supress or resist unwanted thoughts (Petkus & Wetherell, 2013). For example, a caregiver may avoid discussing end of life plans with their partner to avoid upsetting them, however this avoidance may result in the build-up of increased distress surrounding this topic. A psychologically flexible alternative to this would be acceptance, wherein challenging thoughts are acknowledged, rather than avoided.

Secondly, self-as-content refers to an overemphasis on the contents of thoughts in the stories individuals create about themselves. For example, rather than noticing the thought of having not done enough for their child, this thought of ‘not being enough’ may become part of a parent’s sense of self. The psychologically flexible alternative to this is considered “self as context” or seeing oneself as the arena in which thoughts occur, rather than the contents of their thoughts.

Thirdly, cognitive fusion is an attachment to thoughts or emotions as absolute truth (Petkus & Wetherell, 2013). For example, if a parent cannot meet a child’s needs on a day, they may feel they are a ‘bad parent’. A psychologically flexible alternative response would be defusion from one’s thoughts, or the ability to not become ‘stuck’ to what their thoughts tell them.

Fourthly, lack of contact with the present moment can be exemplified in a caregiver who focuses on what may happen to their child in the future, and resultingly missing what is happening in the present. Psychological flexibility would be shown through being present in each moment, irrespective of how uncomfortable a moment may be.

Fifthly, lack of values is the absence of awareness of the things most meaningful to individuals, or engaging in actions incongruent with the larger overarching aspects of life they deem important. This is demonstrated wherein demands of caregiving result in a disconnection from important values. Psychological flexibility instead is demonstrated through awareness of values, and a connection to them.

Finally, unworkable action is demonstrated in a caregiver engaging in actions which move them away from living in line with values, through inaction or avoidance. Again, psychological flexibility would be demonstrated through committed action, or taking steps to move closer to values.

By focusing on these six tenets, ACT seeks to increase a willingness for individuals to contact private events, decrease fusion with negative experiences, increase present moment contact, and facilitate them in becoming aware of private events without becoming attached. Further, the importance of identifying and moving towards values and engaging in committed action toward life goals is emphasised (Hayes, Strosahl, et al., 2012). The overarching aim of ACT is psychological flexibility, which predicts successful adjustment to life and physical health conditions (Graham et al., 2016; Hayes et al., 2006).

D.4.1. ACT and Paediatric Cancer

Digitally mediated ACT for families of children with cancer is underexplored to date. This is further evidenced in the results of studies 1 and 2, with no ACT-based psychosocial CH found in the CH reviewed. Separately, none of the commercially available CH (Study 2) specified an underlying theoretical framework. Of the studies identified in Study 1, most used CBT to address psychosocial needs (Canter et al., 2019; Cernvall et al., 2015; Cernvall et al., 2017; Wakefield et al., 2016), with all but two remaining in pilot stages (Cernvall et al., 2015; Cernvall et al., 2017).

As noted above, CBT views challenging thoughts or emotions as abnormal, and focuses on avoidance or suppression of such thoughts. While research for parents of children with cancer remains outstanding, thought suppression is a key predictor of psychological distress (Wenninger et al., 2013), and PTSD (L. K. Campbell et al., 2009), for survivors of childhood cancer. Further, while positive effects for avoidance strategies are found in the short term, over time attention and willingness to engage with negative events has been found to be more adaptive (Aaron et al., 1999). For parents themselves, associations between thought suppression and negative long-term impacts on attention and memory were identified (Vander Haegen & Luminet, 2015). As such, consideration is needed as to whether similar affects for acceptance, rather than thought suppression-based approaches may be found. However, in the absence of analysis for this population, impact of acceptance-based strategies remains outstanding.

One aspect of the ACT Hexaflex which may be particularly relevant to paediatric cancer is experiential avoidance. Research suggests that avoidance of disease and treatment related stimuli associated with distress is associated with PTSS in parents of children with cancer (Norberg et al., 2011), and negatively impacts daily functioning and psychosocial outcomes (López et al., 2021b). Experiential avoidance is an unwillingness to remain in contact with private events or experiences, resulting in efforts to amend the form or frequency of these private events and the environments which may give rise to them (Hayes, Strosahl, et al., 2012). Through seeking to avoid an experience however, individuals may become trapped by the conditions they are seeking to avoid, resulting in distress (Hayes, Strosahl, et al., 2012), with supressed thoughts likely to return at increased intensity and frequency (Hayes et al., 2011; Wenzlaff & Wegner, 2000). Avoidance may also result in actions at odds with one's values further increasing the intensity of negative experiences (Hayes et al., 2006). While experientially avoidant strategies may allow parents a mental escape from the negative private events associated with their child's illness (Sairanen et al., 2018) those who avoid cancer-related cognitions and behaviours are at a greater risk of psychological distress (Costanzo et al., 2006; Donovan-Kicken & Caughlin, 2011), decreased QOL (Watson et al., 2005) and emotional distress (Chawla & Ostafin, 2007). For parents, avoidance of oneself (i.e. forgetting personal needs), their child (i.e. difficulties setting limits) and others (i.e. avoiding other to avoid discussions) negatively impacts emotional adjustment (López et al., 2021b). However, through increasing contact with experiences, and the resulting positive consequences, experiential avoidance can be reduced (Jacobson & Hooke, 2016).

Increasing contact, rather than avoidance, is termed acceptance. Acceptance is defined as adopting a non-judgemental view of moment-to-moment experiences (Hayes et al., 2011), supported by an openness to experiencing distressing situations or environments rather than avoiding them (Hayes et al., 2011). Acceptance-based strategies may aid the adjustment of parents at highly distressing times such as diagnosis due to increased willingness to be present for their child (Cederberg et al., 2018; Cernvall et al., 2015), positively affecting their child´s adjustment (Murrell & Scherbarth, 2006). In addition, as the treatment of paediatric cancer extends over long periods of time, avoidance of disease related cognitions, environments or activities may be particularly restricting (Cernvall et al., 2015). While the impact of acceptance on outcomes for parents of children with cancer has been posited, no analysis of its impact within larger ACT interventions has occurred, suggesting a need for further exploration.

Two further aspects of ACT which may be of importance within paediatric cancer are valued living and self-as-context. The importance of living in line with ones values is emphasised in ACT, with values defined as individually determined, verbally constructed, patterns of activity against which experiences can be evaluated (Hayes, Strosahl, et al., 2012). Within ACT, individuals are asked to identify what they value and are tasked with committing to behaviours that allow them to move closer to these values. Value-directed behaviour is particularly important for those with cancer, predicting psychosocial outcomes such as anxiety, depression and QOL (Hubert-

Williams et al., 2014). For individuals with cancer, valued living is negatively correlated with emotional avoidance and cancer-related distress (Ciarrochi et al., 2011), and positively correlated with psychological well-being. However, no analysis of its role for parents of children with paediatric cancer has been found to date.

Secondly, the impact of self-as-context, or the ability to separate self from the content of ones thoughts, may be of importance. Often parents may struggle to regain a sense of their child that is more than just 'illness' or 'sick' as they transition back into their community. Parental subjective appraisals of child health have been found to influence psychological wellbeing (Stoppelbein et al., 2006). As such, should these subjective appraisals become fused with parents' perception of their child, wellbeing may be negatively impacted. ACT seeks to target these appraisals through 'unsticking' parents from these thoughts to support present moment living. While negative and distressing cognitive appraisals of child illness are common for parents, the role of ACT to support this population not yet been evaluated.

D.5. Section Overview

Results obtained across the studies in sections A, B and C highlight the potential of CH to support families impacted by paediatric cancer, and address the challenges presented by traditional, face-to-face mediums. This informed the development of recommendations for a means through which more accessible CH may be designed. Through a stakeholder led approach, CH may be developed in a manner more likely to be impactful for those for whom it is intended.

One area of need for which CH has demonstrated positive effects is psychosocial support, for which challenges with access to more traditional supports have been found. One promising approach to supporting psychological wellbeing for parents of children with cancer is ACT. However, while parents of children with cancer have been included in ACT interventions for caregivers of children more broadly (i.e. Burke et al., 2014), there is a need for an intervention which directly targets the specific needs of this group. In addition, the impact of the ACT Hexaflex on psychosocial wellbeing has yet to be established. While ACT has been mediated digitally in the past, an analysis of online self-directed programmes has yet to occur for this group.

As such, **Study 8** seeks to explore the impact of an online self-directed ACT programme on the psychological flexibility, wellbeing and burden of parents (or primary caregivers) of children with cancer. In addition, the impact of specific aspects of psychological flexibility, namely self-as-context, acceptance, cognitive defusion and committed action, on outcomes will be explored. Through this, specific aspects of psychological flexibility which may be most impactful for parents of children with cancer may be identified. Study 8 also describes in detail the PPI approach taken across the development of the ‘ACT for parents/caregivers’ programme, with the input of parents and caregivers sought across the development of the programme, from conception to testing.

Chapter 9 Study 8: Impact of brief online self-directed Acceptance and Commitment Therapy on psychological flexibility, parenting experience and wellbeing for parents of children with cancer.

Abstract

Aim: While research suggests the utility of ACT to support caregivers of children with illness, its use for parents of children impacted by paediatric cancer has yet to be fully examined. This study seeks to explore the impact of an online self-paced ACT intervention on the psychological flexibility, burden and mental wellbeing of parents of children with cancer.

Method: Four parents of children with cancer (male=1; female=3) completed a six-week online self-directed ACT programme. Pre-, post- and 30-day follow-up measures of parental psychological flexibility, wellbeing and burden were obtained through parent self-report. Feasibility was determined through analysis of recruitment, retention and duration of programme use.

Results: The programme was found to be acceptable, with 80% completion rates obtained. Challenges were encountered in gathering follow-up data, with only one participant providing this information. For this participant, positive impacts on psychological flexibility, wellbeing and parenting burden were obtained, which were maintained at 30-day follow-up**.**

Conclusions: While results shed positive light on the potential of online-mediated ACT for parents of children with cancer, additional analysis with larger sample sizes is warranted.

9.1. Introduction

While parents of children with cancer may seek to improve their psychosocial wellbeing, current interventions are limited by scope, poor maintenance of effects, overemphasis on psychopathology (Hubert-Williams et al., 2014), and challenges accessing in-person services, as highlighted in Study 3. CH offers one means to minimise some of these barriers, while maintaining positive effects. However, for CH-mediated interventions to be effective, they must provide supports which effectively address the challenges families face.

One promising approach to support the psychological wellbeing for parents of children with cancer is ACT (Malins et al., 2021). While ACT has demonstrated positive effects for parents of children with serious illness (Clery et al., 2021; Kallesøe et al., 2016; Swain et al., 2015), its impact for parents of children with cancer has yet to be established. Evaluation is particularly important for online treatments which omit some of the effective components of in-person treatments such as a therapeutic alliance (Martin et al., 2000), and for which limited formal mediational analyses of change processes have been conducted (Byrne et al., 2021; Pots et al., 2016; Sairanen et al., 2020; Trompetter et al., 2015). As such, an understanding of the specific processes by which an intervention has its effects is particularly needed for digital interventions (Sairanen et al., 2020).

In the context of the significant travel and time burdens experienced by parents caring for a child with cancer (Borrescio-Higa & Valdés, 2022; Iragorri et al., 2021; Nipp et al., 2017), the potential for CH mediated psychosocial supports appears clear, though unestablished. This study seeks to examine the effects of an online self-directed ACT intervention for parents of children with cancer on psychological flexibility, parental burden and mental wellbeing. Burden was selected in the context of both the high burden experienced by caregivers of children with cancer (see Study 3; Junkins et al., 2020), and past research in support of ACT as a means to address this. While the impact of ACT on burden of caregivers in paediatric cancer is yet to be established, efficacy in addressing burden of caregivers of adults with cancer (Treanor, 2020), amongst other illnesses such as dementia (George et al., 2021) and paediatric asthma (Silva et al., 2015) has been shown. The focus on committed action and valued living within ACT appear well suited to address parental burden, through supporting parents to identify their own overarching values, and committing to act in a manner consistent with these. As such, it was hypothesised that ACT may be of benefit in addressing this challenge encountered by parents.

To explore the specific aspects of ACT, the impact of the intervention on self-as-context, cognitive defusion, committed action, and acceptance will be examined. Through this, it is hoped to identify the impacts of individual components of psychological flexibility on parent wellbeing. This study will also seek to examine the usability and acceptability of the intervention for parents of children with cancer. As online supports are purported to meet the challenges of families who experience burden accessing traditional supports (i.e. those based in rural locations and those from low socio-economic status), analysis of attrition and acceptance for these groups will be conducted.

9.2. Method

9.2.1. PPI

This study was developed in collaboration with a PPI panel consisting of parents of children with cancer, who provided insight across the development and design of the present protocol. The panel consisted of several parents of children with cancer, with six parents providing insight across the differing stages of the intervention development.

Due to the unique time, household and illness management challenges imposed by paediatric cancer, membership of the PPI panel varied across the project, with parents providing input in group discussions, email and by phone depending on their preference. All were mothers of children who had completed treatment between 2-5 years prior. Members of this PPI panel met at the outset of the project (May 2021) to determine priorities for research, questions to be examined and mode of intervention delivery. These recommendations were then used as the basis for the current research study, in conjunction with the recommendations of previous studies outlined in Section D.1. above. Feedback on the intervention was gathered across its development, and final design determined through discussion.

9.2.2. Participants

To participate in the ACT for Parents/Caregivers programme individuals were required to be the parent or caregiver of a child who had received a diagnosis of cancer at least 6 months before, and no more than 10 years since. Individuals were required to live in Ireland or the United Kingdom, be proficient in English, and have access to a smartphone, tablet or computer with which they could access the internet. As the programme was intended as a universal level intervention, those with mental health concerns which required immediate support or which placed them at immediate risk to self or others were excluded and directed towards more appropriate supports based upon self-declaration (for example, those with current psychosis, suicidality, or PTSD). Participants were also excluded if they had received a structured psychosocial intervention within the past 6 months or were due to commence a psychosocial intervention during the 6 weeks of the ACT intervention. Ethical approval was obtained from the Maynooth University Social Research Ethics Sub-committee (SRESC-2021-2452856) and the children's hospital ethical committee (REC-096-22). A Data

Protection Impact Assessment (DPIA) was also completed through Maynooth University, the data controller of the current research.

Recruitment was conducted between July and September 2022, in collaboration with a member of the psycho-oncology team at a paediatric cancer centre of excellence within a children's hospital in Ireland. Invitations to participate were circulated by the multi-disciplinary paediatric oncology team at the hospital to those who met inclusionary criteria. Invitations were also circulated to non-profit groups and key stakeholders in the paediatric cancer space, and on social media, using a snowballing strategy. In all instances, individuals interested in participating were directed to contact the researcher by email or phone to receive additional information on the study. A screening phone call was then completed with interested participants to ensure eligibility.

9.2.3. Research Design

This study employed a pre-post (AB) design to pilot the effectiveness of the intervention. Baseline measures of psychological flexibility and parental wellbeing were taken prior to commencing the intervention, and were repeated following completion, and at a four-week follow up, to determine if any change had occurred. Additional detail on both dependent and independent variables are outlined below.

9.2.4. Measures

Individual measures employed are discussed below and presented in detail in Appendix 3.

Demographic Information. Participant age, gender, relationship status and urban/rural habituation was sought at baseline. The age, gender, diagnosis, and time since active treatment of their child with cancer was also gathered, alongside their number of siblings.

Psychological Flexibility. To determine participant psychological flexibility, several measures were used.

Parent Psychological Flexibility Questionnaire (PPFQ; Burke & Moore, 2015). This 19-item parent-report measure determines the psychological flexibility of parents using a Likert scale from 0 (never true) to 6 (always true). Parental committed action (questions 9-13; i.e. "I don't let my child do things that I'll worry about"), cognitive defusion (questions 1-8; i.e. "my emotions get in the way of the being the type of parent I would ideally like to be") and acceptance (questions 14-19; "the unpredictability of being a parent is one of the things that makes parenting fun and rewarding") are examined in turn to determine the degree to which parents accept negative thoughts and feelings, and act in a manner consistent with their parenting values. Total scores are obtained by adding acceptance scores to reversed committed action and cognitive defusion scores. Good reliability (Burke & Moore, 2015) and validity (Timmers et al., 2019) have been found.

The Self-as-Context Scale (SACS; Zettle et al., 2018). The SACS is a 10-item self-report measure which consists of two subscales namely centering (reacting neutrally to unwanted psychological experiences; i.e. "when I am upset, I am able to find a place of calm within myself") and transcending (fixed perspective taking; i.e. "despite the many changes in my life, there is a basic part of who I am that remains unchanged"). Each question is responded to using a Likert scale from 1 (strongly disagree) to 7 (strongly agree*)*. Total scores are computed by summing individual scores. Good internal validity has been noted (Zettle et al., 2018).

Parent wellbeing. To establish parental wellbeing, measures of wellbeing and parental burnout were included.

WHO Well-Being Index 5-items (WHO-5; WHO, 1998). The WHO-5 is a self-report measure of mental wellbeing responded to using a 6-point Likert scale from 0 (at no time) to 5 (all of the time). A total score is obtained by summing responses to individual items. Good reliability has been found (Topp et al., 2015)

Brief Parental Burnout Scale (BPBs; Aunola et al., 2021). The BPB is a validated brief scale, based upon the Parental Burnout Assessment (PBA; Roskam et al., 2018), which seeks to measure risk of parenting burnout. This measure consists of five items (i.e. "I sometimes have the impression that I'm looking after my child(ren) on autopilot") scored using a three-point scale from 2 (daily) to 0 (seldom/never). Total scores are obtained through summing individual question responses. Strong psychometric properties and good sensitivity in comparison to PBA total score has been found (Roskam et al., 2018).

Feasibility. Feasibility was determined through recruitment and retention rates, and rates of intervention completion.

Acceptability. At the end of the intervention participants were asked a series of questions on the acceptability of the ACT intervention, inclusive of both open and closed questions. See Appendix 3 for full details of questions posed.

9.2.5. ACT for Parents/Caregivers Programme

The 'ACT for Parents/Caregivers' programme consisted of six weekly sessions each themed around an individual aspect of the ACT Hexaflex (see section D.6. for additional detail). These were 1) acceptance, 2) attention to the present moment, 3) defusion, 4) self-as-context, 5) values and 6) committed action. Within each topic, specific exercises were derived based on past research analysis and best practice (Cameron et al., 2020; Gordon et al., 2019; Hahs et al., 2019; Hayes, Strosahl, et al., 2012; Jenkins & Ahles, 2021; Polk, 2021; RMIT University, 2016; Whittingham &

Coyne, 2019), and guided by the researchers clinical experience as a Board Certified Behaviour Analyst with over 10 years experience in the area. Each session consisted of an introduction to the topic, metaphors, experiential exercises and suggested tasks to practice (in line with Sairanen et al., 2020). Information was presented in a variety of formats including audio files, interactive worksheets through H5P, videos and text files. To facilitate the CH aspect of the intervention, several of the exercises were developed in a manner which allowed participants to input responses within the exercises which informed the activities suggested to them. One such example are the self-practice exercises in which participants inputted their desired goals and based on these self-practice recommendations were provided. A second example of CH inclusion is within specific exercises, such as the defusion exercises, in which participant responses guided the suggested activities provided. Sessions were made available on a weekly basis to facilitate pacing and reduce risk of overload, with participants able to complete each session at a time that works best for them. Participants were provided with an email prompt once per week to inform them when each session was available, and to encourage them to access it. This is in line with Potts et al., (2020) who found that prompts by email for self-directed ACT were more effective than self-directed ACT with no prompts. Specific exercises used within each session are presented in Table 9.1.

Table 9.1

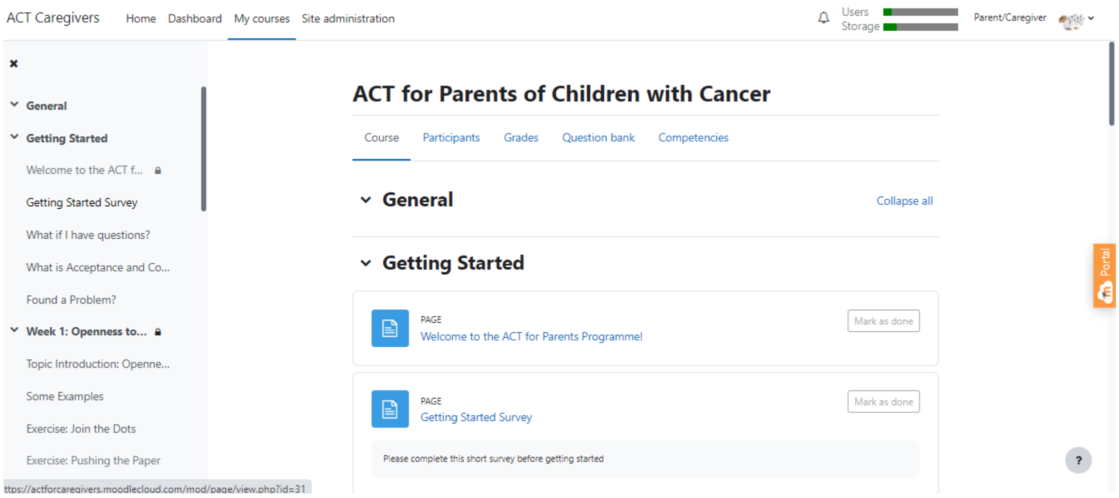
ACT Intervention Exercises per Week

Topic	Introduction	Metaphors	Experiential Exercises	Self-practice
Getting Started	Welcome Getting started survey What if I have questions? What if I have a problem? ACT: An overview	N/A	The three Happiness Myths The Struggle Switch	N/A
Openness to Experience	What is acceptance? Finger trap metaphor	Tug-of-war The unwelcome party guest	Join the dots Accepting emotions	SOAL: Stop, Observe, Accept, Let Go
Attention to present moment	What is Mindfulness? Changing perspectives	Notice your hand	Engaging savouring noticing worksheet	Mindful in everyday tasks
Untangling from thoughts	What is Defusion? Mailbox Metaphor	Playing the game	How's your mind hooking you?	Practice options for defusion: Drop anchor Thank your mind Happy Birthday Milk, Milk Milk Sing it out
Flexible perspective taking	What is self-as-context?	Chessboard Metaphor	Observer Self Exercise	Practice noticing
Values	The Values-Focused vs The Goals-Focused Life	80-year-old birthday party	The life compass worksheet	Act! Think about what action you can perform today
Committed Action	What is Committed Action? The choice point	The gardening metaphor	Setting SMART goals and practice opportunities (implementation intention and behaviour cue)	Purposeful steps

The intervention was provided using Moodle, an online learning platform available as an app and website. Moodle was selected both due to its ease of use and accessibility, and as it allows for the recording of participant access data across the programme (see Figure 9.1). Past research has demonstrated the efficacy of Moodle as a means to deliver psychosocial interventions for adults (Ochoa-Arnedo et al., 2021) and young adults (Salsman et al., 2020) with cancer. Further, it has been identified as a cost effective means to deliver widespread psychosocial and behavioural interventions (Zhang & Ho, 2017). Seven session folders were provided through Moodle, one for each weekly session and one introductory folder which gives some context on ACT and the programme itself (see Figure 9.1).

Figure 9.1

ACT for Parents/Caregivers Moodle Site



ACT for Parents of Children with Cancer

General

Getting Started

Welcome to the ACT for Parents Programme!

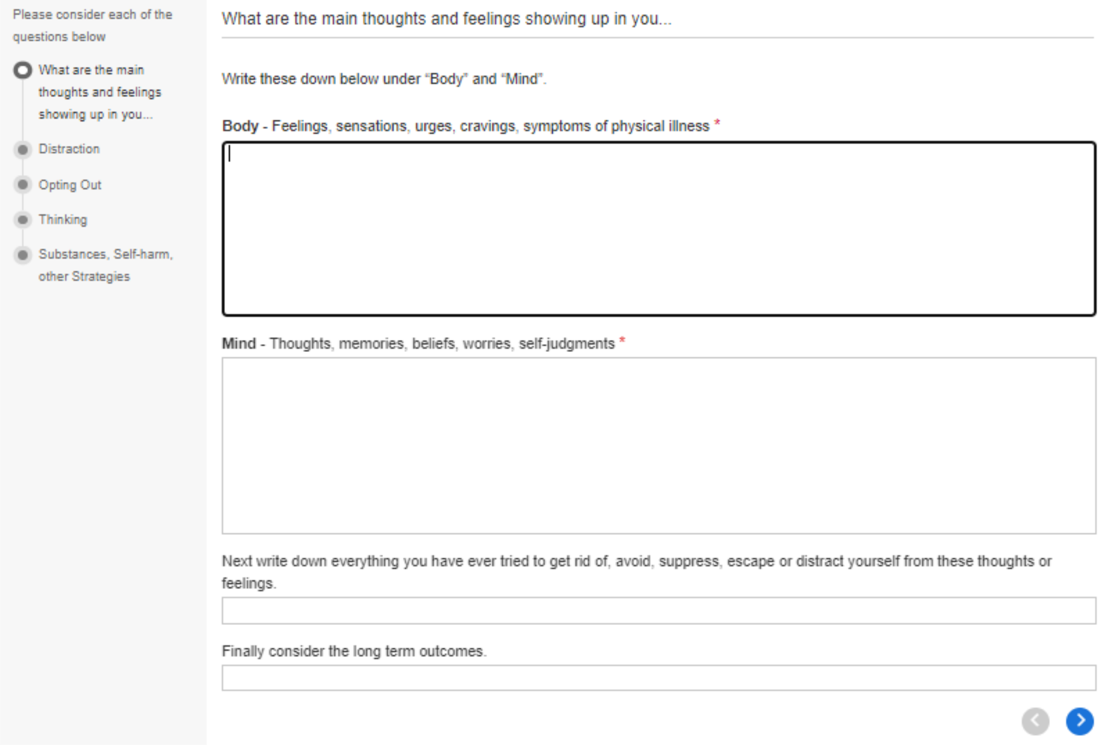
Getting Started Survey

Please complete this short survey before getting started

Each folder contained individual pages hosting an introduction, metaphors, exercises, and suggested homework (see Figure 9.2).

Figure 9.2

ACT for Parents/Caregivers Sample Exercise



What are the main thoughts and feelings showing up in you…

Write these down below under "Body" and "Mind".

Body - Feelings, sensations, urges, cravings, symptoms of physical illness *

Mind - Thoughts, memories, beliefs, worries, self-judgments *

Next write down everything you have ever tried to get rid of, avoid, suppress, escape or distract yourself from these thoughts or feelings.

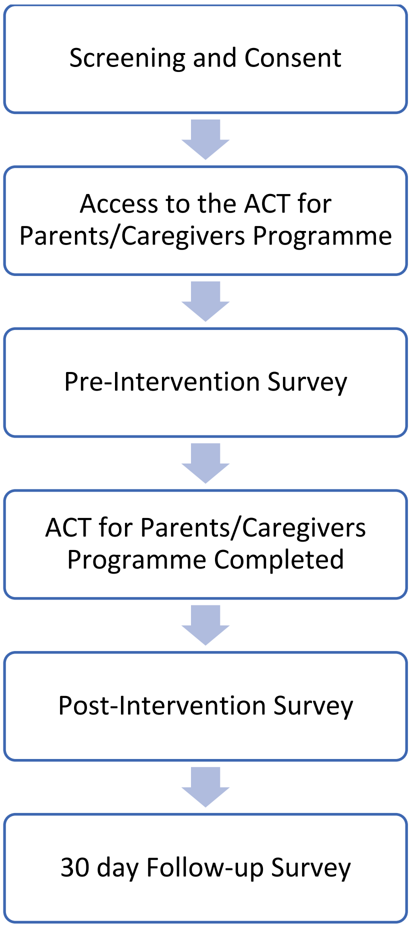
Finally consider the long term outcomes.

9.2.6. Procedure

The procedure employed is outlined in Figure 9.3 and in detail below.

Figure 9.3

Research Protocol



1) **Screening and Consent.** All participants were contacted by the researcher by phone or video chat (Microsoft Teams) to complete a brief screening call prior to the intervention. During this call eligibility and interest was determined. Participants were given information on what the intervention entailed and provided an opportunity to ask questions. For those ineligible, direction to more suitable services was provided (n=1). If individuals remained willing to participate following the screening call, informed consent was obtained using an online form (hosted on Qualtrics).

2) **Access to the ACT for Parents/Caregivers Programme**. Once the consent form was completed participants were emailed 1) a how-to document outlining how to access the intervention; 2) their start date; and 3) a link to access the programme from Moodle, including a password and username.
3) **Pre-Intervention Survey.** Upon opening the ACT for Parents/Caregivers programme, all participants were given access to a 'Getting Started' folder, consisting of some general information on the programme and ACT, and a link to the pre-intervention survey.
4) **Intervention.** Participants then commenced the ACT intervention across a period of 6 weeks with one topic covered per week. Each week participants were provided an overview of a topic and given some metaphors, experiential exercises and self-practice to work through to support the development of this domain. Self-practice exercises were emphasised, though not mandatory, across the intervention.
5) **Post-Intervention Survey.** Following completion of the intervention, participants were asked to re-complete the survey to determine if there have been any changes and to determine intervention acceptability. Participants retained access to the intervention following completion for a period of 1 month to allow for continued use of any tools they found helpful.
6) **Follow-up Survey.** One-month following the completion of the interview participants were sent the survey again to determine if changes observed were maintained and if ongoing practice of interventions has occurred.

9.2.7. Data Analysis

Data were analysed using SPSS. Descriptive analyses were conducted to explore parent baseline psychological flexibility, burden and parental wellbeing, in addition to post-intervention measures of each. Acceptability and feasibility data obtained through the follow-up survey was also analysed using descriptive methods.

9.3. Results

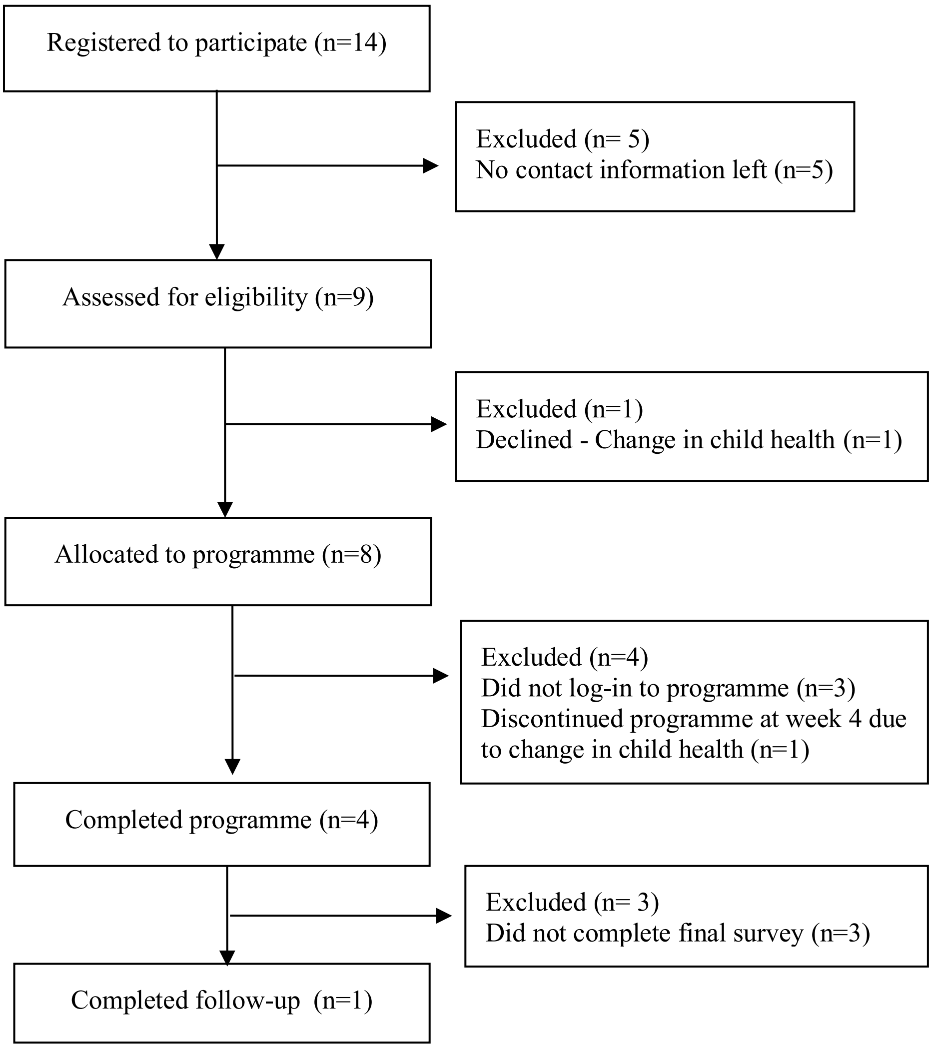
9.3.1. Participant Demographics

Additional detail on participant recruitment and retention is outlined in Figure 9.4. A total of fourteen parents registered interest in the programme, of whom five did not leave contact information to facilitate a screening call. The remaining nine completed screening calls, with eight eligible to register. Following consent gathering, all eight participants were provided access to the online programme. However, three participants did not access the online programme at any time, and one elected to stop participating at week four due to a change in their child's health. This resulted in four participants who completed the online programme. Of these, only one completed the post-intervention and follow-up survey.

Parents who completed the pre-intervention survey (n=5; 1 male, 4 females), had an average age of 39.5 years (range=35-44), lived in rural areas (<500 inhabitants; n=4), and all were married/cohabitating. Most lived 20-50km from their primary treatment centre (n=3), with two living over 200km away. Children (female=3; male =2) had an average age at diagnosis of 6.2 years (range= 1-16), though most (n=3) were aged under 3. Diagnoses included Acute Lymphoblastic Leukaemia (ALL; n=3) and Central Nervous System tumours (n=2). Children remained in treatment (n=2), were 2-5 years (n=2), or 0-1 years (n=1) post-treatment. Most had one (n=2) or two (n=2) siblings.

Figure 9.4

Participant Recruitment and Attrition



9.3.2. Pre-Intervention Survey

A total of five parents completed the pre-intervention survey. Mean results across each individual measure are presented in Table 9.2 below. For clarity, minimum and maximum possible scores for each measure are also included.

Table 9.2

Means, Maximum and Minimum Scores of Pre-Intervention Survey Measures

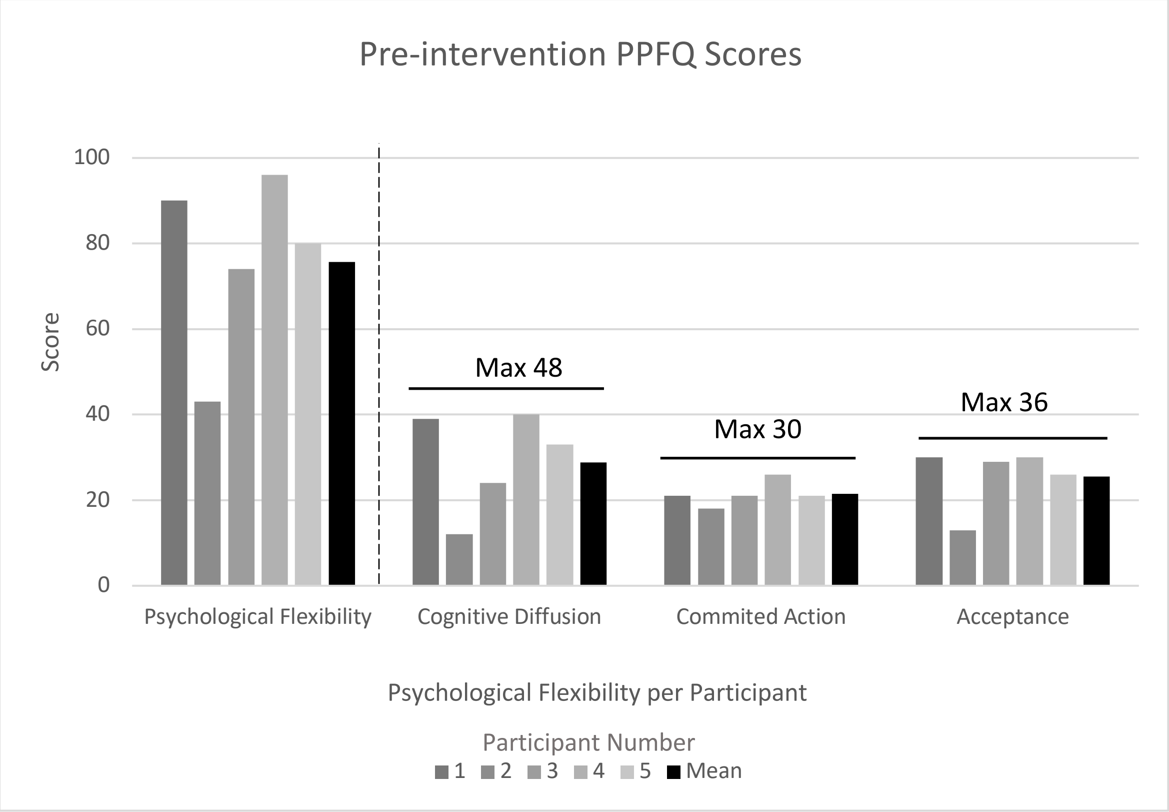
		Mean	SD	Maximum	Minimum
Psychological Flexibility	Total	75.75	20.6	114	0
	Cognitive Defusion	28.75	11.7	48	0
	Committed Action	21.5	2.8	30	0

		Mean	SD	Maximum	Minimum
	Acceptance	25.5	7.2	36	0
Self as Context	Total	50.25	1.6	70	10
	Centering	19	12.1	28	4
	Transcending	31.25	6.14	42	6
Wellbeing	Total	9.75	6.7	25	0
Parenting Burden	Total	3.75	2.1	10	0

Parent Psychological Flexibility. Results of the PPFQ showed a mean overall psychological flexibility score of 77.75 (range = 43-96). Middling levels of acceptance (*M*= 25.5; range=13-30) and committed action (*M*= 21.5; range = 18-26) were noted, with low cognitive defusion (*M*= 28.75; range = 12-40). As such, while parents' psychological flexibility appeared low at baseline, this was primarily driven by challenges with cognitive defusion. See Figure 9.5Figure 9.5 below.

Figure 9.5

Pre-intervention PPFQ Scores



Differences were found between those whose children were currently receiving treatment (participants 2 and 4), and those who had finished treatment (participants 1, 3 and 5), with those finished active treatment having higher psychological flexibility (mean difference = 12.2; Table 9.3). Higher cognitive defusion and acceptance were seen for parents whose child was currently finished treatment, with greater committed action for those still in treatment. This suggests overall greater challenges accepting difficult thoughts and emotions, and greater fusion with negative thoughts and emotions for those in active treatment.

Table 9.3

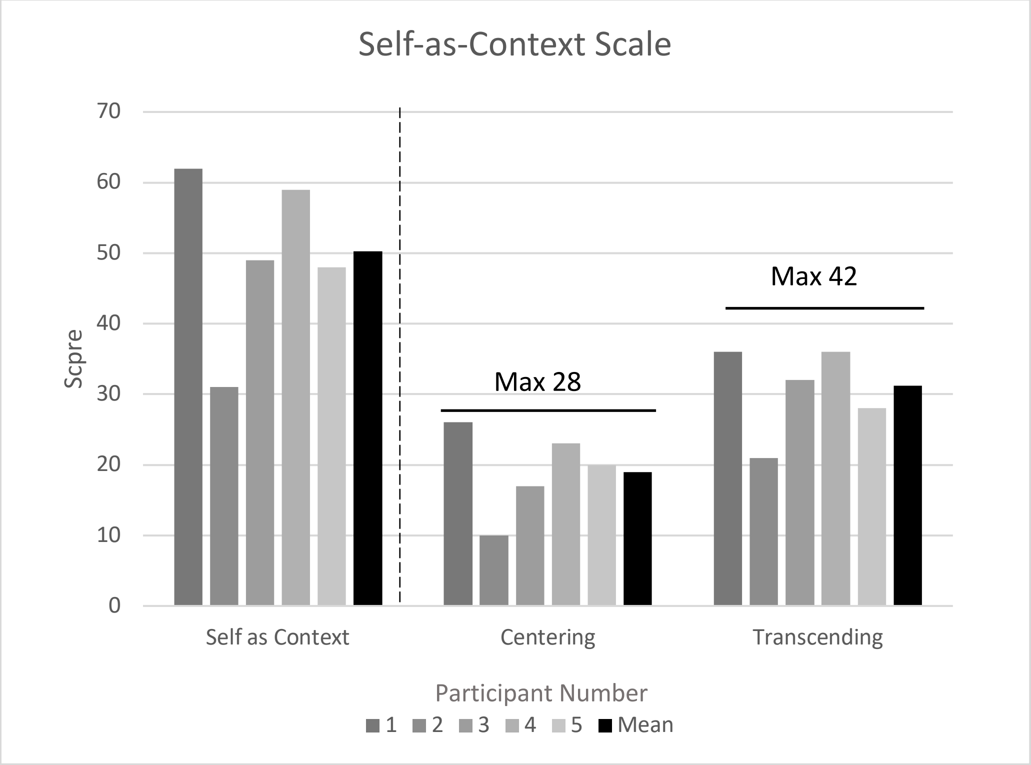
Comparison of PPFQ and SACS Across Treatment Stages

	Currently receiving treatment (n=2)	**Finished active treatment (n=3)**
Psychological Flexibility	**69.5**	**81.3**
Cognitive Defusion	26	32
Committed Action	22	21
Acceptance	21.5	28.3
Self as Context	**45**	**53**
Centering	16.5	21
Transcending	28.5	32

Parenting Self-as-Context. A mean SACS score of 50.25 was obtained, though this was likely somewhat skewed by participant 2, who had much lower SACS scores than other participants (see Figure 9.6). Broadly similar scores were identified across both the transcending (*M*= 31.5; range 21-36) and centering (*M*= 19; range = 10-26) subscales. This suggests that participants were somewhat able to react calmly to unwanted experiences (centering) and demonstrate invariant perspective taking in these contexts (transcending). Of individual items, low agreement was obtained for the item "When I am upset, I am able to find a place of calm within myself" suggesting a need for additional supports to respond to negative stimuli, thoughts or emotions in the moment.

Figure 9.6

Pre-intervention Self-as Context scores

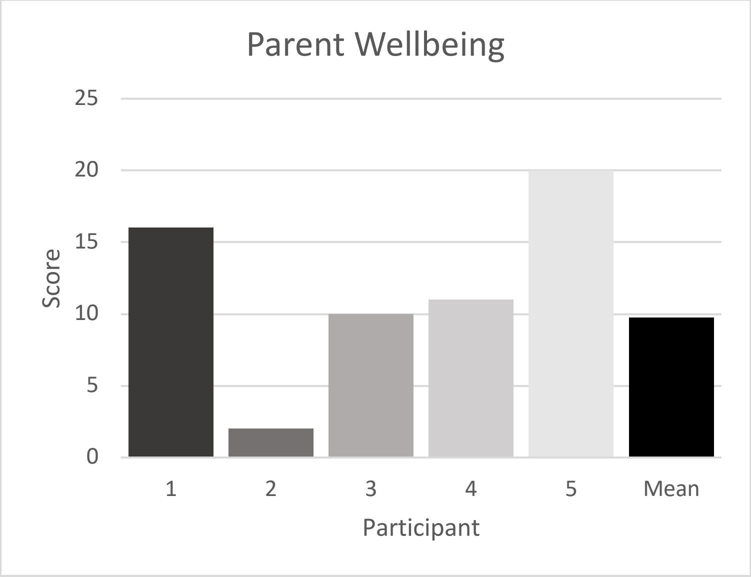


Comparison of SACS between participants currently in active treatment and those who have finished (see Table 9.3) highlight much higher mean scores for those finished treatment. These differences appear to hold evenly across both subscales, suggesting greater challenges with self-as-context for those in active treatment.

Parenting Wellbeing. WHO-5 data prior to intervention suggests low wellbeing for parents (*M*= 10; range = 2-20). Again, results for participant 2 appear much lower than that of other participants which may have skewed this result. Of individual measures, lowest scores were obtained for the items "I woke up feeling fresh and rested" and "My life has been filled with things that interest me".

Figure 9.7

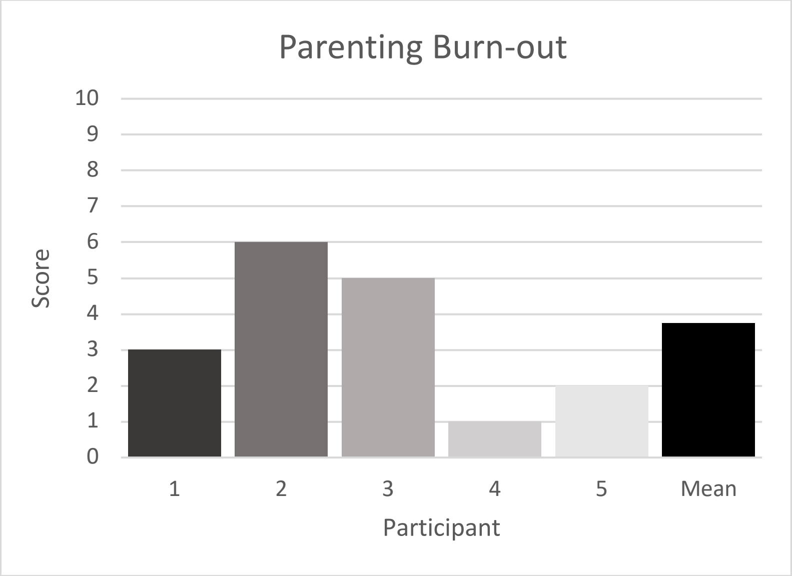
Pre-Intervention Parent Wellbeing



Parenting Burn-out. BPBs data indicated mixed levels of burnout across parent participants (*M*= 4; range = 1-6; see Figure 9.8). Highest agreement across participants was obtained for the item “I have the sense that I’m really worn out as a parent” and “I’m so tired by my role as a parent that sleeping doesn’t seem like enough”, with all participants having experienced these thoughts. No respondents reported having the thought that “I struggle to show my child(ren) how much I love them”.

Figure 9.8

Pre-intervention Parenting Burn-out



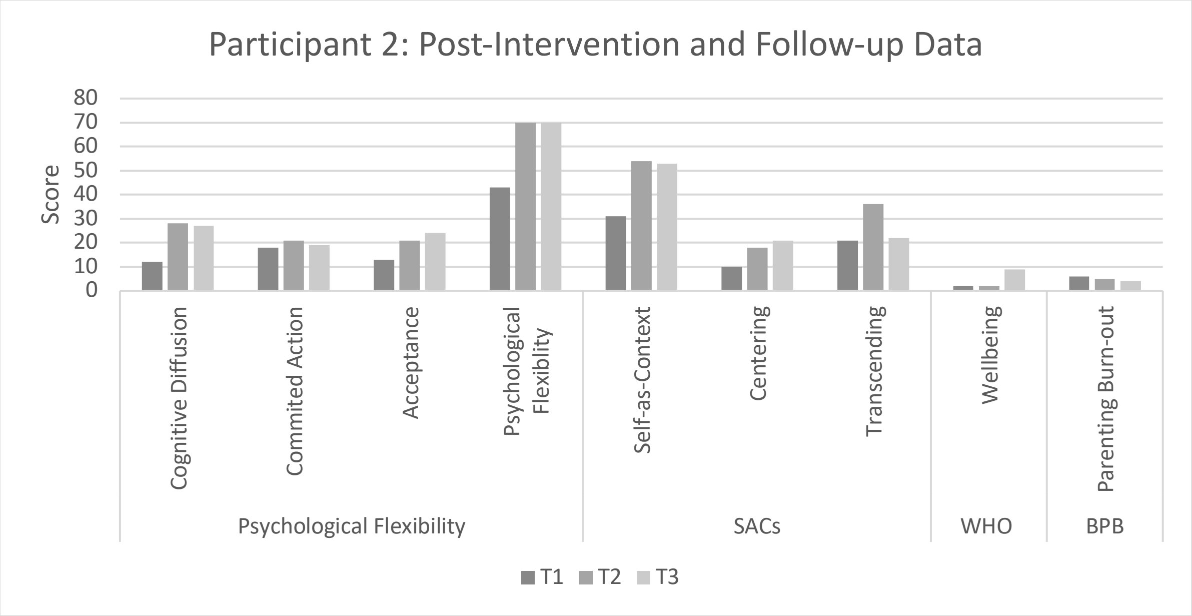
9.3.3. Post-Intervention and Follow-up Survey

One participant completed the post-intervention survey, a mother of a child currently undergoing treatment. Comparison of scores across pre- (time 1), post- (time 2), and follow-up surveys is included in Figure 9.9 below. Large increases in psychological flexibility (43 vs 70) were observed following completion of the programme. Increases across all three sub-scales of psychological flexibility were noted, with highest increases for cognitive defusion. Increases in psychological flexibility were observed to hold at follow-up, though slight decreases in committed action and cognitive defusion were found, alongside slight increases in acceptance. A similar pattern of results was observed for self-as-context, with increases noted following the intervention (31 vs 54). Slight decreases in self-as-context however were observed at follow-up, with the transcending sub-scale returning to near pre-intervention levels. Reductions in parenting burn-out were also noted, with decreases in the BPB across the three timepoints. In contrast to the above, WHO-5 responses held steady across pre- and post-intervention surveys, suggesting no impact of the intervention on wellbeing.

Increases in wellbeing however were observed at follow-up, suggesting some impact over-time.

Figure 9.9

Participant 2: Post-Intervention and Follow-up Data



To explore the degree of change in dependent variables over time, percentage change in scores was explored. Data is outlined in detail in Figure 9.9Table 9.4 below. Largest changes post-intervention were noted for transcending (35.7%), cognitive defusion (33.3%), and centering (28.6%) subscales. However, as noted above, the changes in the transcending subscale were not maintained at follow-up, with a 33.3% reduction noted. Challenges with maintenance of change was also noted for committed action, with a 10.7% reduction between time 2 and 3.

Table 9.4

Percentage Change Across Time

Measure	**Sub-scale**	**Percentage Change**	
		Time 1- Time 2	**Time 2 - Time 3**
PPFQ	Cognitive Defusion	33.3	-2.1
	Committed Action	10	-6.7
	Acceptance	22.2	8.3

Measure	Sub-scale	Percentage Change	
	Total	23.7	0
SACs	Centering	28.6	10.7
	Transcending	35.7	-33.3
	Total	32.9	-1.4
WHO		0	28
BPB		10	10

9.3.4. Programme Feasibility

Of the eight parent participants who were granted access to the programme, four completed all six weeks of the programme. Of those who did not complete the programme, one withdrew at week four due to a change in their child's health, and three did not access the programme at any stage. On average, participants visited the programme 4 times (range 2-7) and spent 32 minutes and 54 seconds per visit. Participants' total average duration spent on the programme was 2 hours 28 minutes and 24 seconds (10 minutes 25 seconds - 4 hours 23 minutes and 6 seconds). Complete detail on participant access to the programme is presented in Table 9.5 below, with each row presenting an individual participants access to aspects of the programme. Participants primarily accessed the programme between 9pm-4am (35%), or 8am-12pm (30%), and 5-8pm (25%), with some accessing the programme between 2-5pm (10%) and between 4-8am (10%).

Table 9.5

Participant Programme Access and Use

Number of weeks completed	Total # visits	Average duration of visit	Total duration	Activities completed by each participant		
				Exercise	Introduction	Practice
6	3	58:37:00	02:55:52	4	6	1
6	6	29:35:00	02:57:31	5	7	3
6	4	57:32:00	01.55.04	3	5	3
6	7	37:35:00	04.23.06	9	6	6
4	2	00:05:13	00:10:25	1	2	1

Of those who completed all six weeks of the programme, only one individual accessed all content (a participant who did not complete the post-intervention survey). The three additional participants instead selected different content from each week to complete, commonly accessing the introduction and exercises only. Of weekly topics, acceptance content was most frequently accessed, and values least frequently accessed across participants. Specific content completed per topic is presented in Table 9.6.

Table 9.6

Access to Content by Topic

Topic	Content	Number of times accessed
Introduction	Getting Started Survey	12
	Welcome to the ACT for Parents Programme!	11
	Found a Problem?	10
	What is Acceptance and Commitment Therapy	8
	What if I have questions?	4
Acceptance	Topic Introduction: Openness to Experience	34
	Some Examples	24
	Self-Practice: Observe, Breathe, Allow, Expand	16
	Exercise: Join the Dots	15
	Let’s Practice: Accepting Emotions	7
Mindfulness	Let's Practice: Engaging, Savouring, Focusing	5
	Topic Introduction: Attention to the present moment	5
	Self-Practice: Attention to the present moment	4
	Exercise: Notice Your Hand	3
Fusion	Exercise: How's your mind hooking you?	4
	Exercise: Playing the game	2
	Topic Introduction: Untangling from thoughts	1
	Self-practice: Strategies to try	4
Self-as-Context	Self-practice: Practice Noticing	4
	Exercise - The Observer Exercise	3
	Topic Introduction - Flexible Perspective Taking	1
Values	Exercise: The life compass worksheet	2
	Self-practice: ACT!	2
	Exercise: The 80th Birthday Party	1
	Topic Introduction - Values	1
Committed Action	Exercise - Setting goals	4
	Topic Introduction - Committed Action	3
	Self-practice: Set a Goal	2
	Exercise: The Gardening Metaphor	2

9.3.5. Acceptability

Acceptability was determined through self-reported challenges accessing or using the programme, and through the post-intervention survey. Across the duration of the programme two participants reported challenges with access, one required a new password, and one had a query with having an activity marked as complete. Acceptability survey responses were collected from one participant. For this participant, results indicated strong agreement that the programme was helpful, that they would recommend it to other parents, that the strategies were useful, that the programme was easy to use, and that the online and self-directed format was helpful.

9.4. Discussion

This study sought to examine the impact of an online self-directed ACT programme on the psychological flexibility, parental burden and wellbeing of parents of children with cancer. Results obtained from the one participant completing this programme suggest positive effects on parental psychological flexibility and wellbeing, though, unfortunately, significant challenges in obtaining post-intervention measures from participants were encountered. For the participant from whom follow-up data was obtained, increased psychological flexibility and self-as-context was observed following the ACT for parents/caregivers programme. Positive effects were observed across all psychological flexibility subscales, with highest increases observed for cognitive defusion. These effects were largely maintained at four-week follow-up, though transcending scores returned to pre-intervention levels. Parental burn-out was also observed to decrease across the three time-points. Interestingly, while wellbeing appeared unchanged directly following the intervention, increases were observed at follow-up suggesting perhaps some impact over time. While these results are promising, additional analysis with larger sample sizes is needed.

In the context of the significant time, travel and household management burdens imposed by paediatric cancer, and their impact on ease of access to services (see Study 3), findings from the current study suggest some potential of CH to minimise these challenges. While traditional in-person psychosocial interventions require travel to access, and many online interventions require parents to be available at scheduled times, the present programme offers advantages as it was both self-directed and online, meaning parents could access the intervention in a manner and at a time most appropriate for them. Results also suggest that the current approach was acceptable for parents, with 80% of those who accessed the programme completing all six weeks. When compared with previous online ACT interventions for parents of children with serious illness, such as Burke et al., (2014) for whom 72% completed the intervention (8 of 11 participants), and Muscara et al., (2020), for whom 24% completed the intervention (37 of 152 participants), the current completion rate appears positive. However, the ACT programmes in both instances were delivered via videoconferencing, and as such do not serve as direct comparisons. While the Moodle platform does not appear to have been used previously to deliver psychosocial support in paediatric cancer, it has been effectively employed to support HCP training (Sharma & Arora, 2020). While the absence of past use prevents complete comparison, the familiarity of the healthcare system with Moodle may impact willingness to use such a tool in practice.

The strong completion rate is particularly positive in the context of the rural habituation of most participants, with 40% living more than 200km from their primary treatment site. As those who live rurally face greater challenges accessing services than those in urban areas (Proudfoot et al., 2011), this is particularly promising. A further finding of note was the time that participants accessed the programme, with a large portion of parents accessing it outside of traditional service hours. Of visits to the programme, 60% occurred between 6pm and 8am. This shows how CH can offer unique benefits through facilitating access to supports at any time, in contrast to traditional supports.

A further aim of the present analysis was to explore the impact of the intervention on specific aspects of psychological flexibility, namely self-as-context, cognitive defusion, committed action and acceptance. Baseline parental psychological flexibility scores for this sample (77.75) were somewhat low in comparison to parents of children more generally (88.66 in LI et al., 2018; and 96.80 in Yu & Xiao, 2021), suggesting challenges for this cohort. These lower psychological flexibility scores appeared to derive from cognitive defusion, with lowest scores obtained here. This suggests that parents of children with cancer may find it challenging to allow negative thoughts or feelings to pass without engaging with them, instead becoming ‘stuck’ to these negative cognitions. This is consistent with Sairanen et al., (2020), who found cognitive defusion to mediate the impact of psychological support on distress, burnout and anxiety for parents of children with illness. This suggests a unique impact of paediatric cancer on cognitive defusion for parents of children with cancer, necessitating additional analysis and support.

In contrast to cognitive defusion, neither acceptance nor committed action scores were low at baseline. While encouraging, analysis of whether committed action scores reflect action in line with individual values, rather than child or parenting specific values, is needed. As the PPF is a measure of parent psychological flexibility, many of the committed action questions pertain to acting in line with parenting values (“I don’t let my child do many things with their friends because I don't think I could cope if something bad happened to him/her") rather than parent specific values (e.g., parents own value of leisure activities or employment progression etc.). As such, analysis of the impact of paediatric cancer on parent individual values is needed.

In line with broader psychological flexibility scores, self-as-content scores (50.25) were slightly lower than population means (52.5; Zettle et al., 2018), though only minimally so. Analysis of subset scores were again slightly below population levels, with parents reporting generally being able to react calmly to unwanted experiences (centering) and being able to demonstrate invariant perspective taking in these contexts (transcending). These results suggest that while psychological flexibility is low for parents of children with cancer, this may be impacted primarily by challenges defusing from negative thoughts, rather than self-as-context related challenges.

A further key finding arising from the current analysis is the differences in psychological flexibility across the treatment and survivorship journey (Wilford et al., 2019). In our sample, parents whose child had finished active treatment had higher psychological flexibility levels than those still in treatment. This difference was particularly visible for cognitive defusion, acceptance and self-as-context subscales, with greater scores obtained for those whose child had finished active treatment. Opposingly, greater levels of committed action were observed for those still in treatment. As such, while those in active treatment appeared to have greater challenges accepting and defusing from difficult thoughts and emotions and seeing themselves as more than their current context (for example "parent of sick child", rather than a person who is also caring for their child), they appeared more committed to acting in line with their values as a parent. These findings are important and suggest a need for more focused interventions depending on child stage. Further analysis is required to explore whether more tailored interventions depending on child stage may be more impactful.

9.4.1. Limitations

Several limitations to the present analysis should be noted. Firstly, significant challenges were encountered in having participants complete post-intervention and follow-up surveys. This significantly impacted the ability to explore the effects of the intervention on parent outcomes, and their maintenance over time. While positive effects were obtained for the participant who completed all three surveys, analysis of effects across multiple participants may have provided additional valuable information. Additionally, as the participant who completed the follow-up measures had particularly low psychological flexibility in comparison to other participants at baseline, they may not have been representative of this cohort in general. A second challenge encountered pertained to participant recruitment. Though recruitment was supported by a member of the psycho-oncology team at the primary children's cancer treatment hospital in Ireland, and by many charity and non-governmental groups in paediatric cancer, ultimately a low number of individuals were recruited to participate. This low volume of participants may have been impacted by the timing of recruitment (summer 2022), but could also be attributed to a number of other factors which may be unique to this cohort such as lack of time, high caregiver burden and reluctance to prioritise own wellbeing (see Study 3 for additional discussion and detail). Analysis as to whether low recruitment may have derived from parent interest in digital, rather than physical, supports is needed. While PPI group members and past analysis (Study 7) suggest willingness to engage with CH, the low recruitment may suggest unwillingness or disinterest in CH mediated psychosocial supports in practice. Further, an activation bump associated with CH may have hampered access for some parents, with three of the eight registrants never accessing the online programme. This is somewhat concerning, particularly in the context of general parental reluctance to obtain psychological supports to address their own needs (Pöder et al., 2009; Study 3). While no data is available on the specific reasons as to why the programme was not accessed, consideration is needed to ensure that CH supports for this group are easy to access for parents to minimise pre-programme attrition. Future analyses should consider direct comparison of the acceptability, attrition and impact of in-person, online scheduled and self-directed ACT programmes to explore which may be best suited for differing parent needs. A further limitation is the use of a parent-specific measure of psychological flexibility within the present analysis. While the PPF is an effective measure of parental psychological flexibility, it may be beneficial in future to explore participant psychological flexibility more broadly. In line with this, future studies should consider the use of generic psychological flexibility measures to determine outcomes for participants as individuals, not specific to their role as parents.

In conclusion, the present analysis demonstrates the acceptability of an online self-directed ACT programme for parents of children with cancer. While positive effects of the intervention on parent psychological flexibility, burden and wellbeing were obtained for one participant, additional analysis with larger sample sizes is needed. In addition, while this analysis highlights the specific impact of cognitive defusion on psychological flexibility for parents, more complete analysis of the mediational effects is needed to develop more tailored interventions in future for this cohort.

Section D Discussion

While the utility of CH to support the psychosocial needs of parents of children with cancer appears promising, limited psychosocial interventions have been the subject of analysis to date. Of psychosocial interventions which have demonstrated effects, most are based in CBT, an approach which may not be best suited to paediatric cancer due to its emphasis on avoidance of negative thoughts and feelings, which is negatively associated with wellbeing and psychological outcomes for this cohort (Cernvall et al., 2015). ACT appears a promising approach to support psychological wellbeing for parents of children with cancer, while addressing the limitations of CBT approaches. Results of Study 8 suggest that a CH-mediated self-directed ACT programme is acceptable for parents of children with cancer, and has promising effects on wellbeing, psychological flexibility and burden. Importantly, results suggest that cognitive defusion may play a role in supporting the psychological flexibility of parents, necessitating additional focus in future interventions.

The present section casts positive light on the utility of CH to address common challenges encountered by parents of children with cancer when seeking to access supports. As CH allows parents to access interventions from the comfort of their home, or any chosen location, at a time that best suits them, additional travel, financial and household management burdens are not added. This is echoed in the results of Study 8, wherein participants were primarily based in rural locations, and commonly accessed the programme outside of traditional business hours. This suggests CH may be an effective means of providing supports in a manner which minimises the barriers identified in Studies 3 and 7.

Chapter 10 General Conclusion

In the context of a growing prevalence of paediatric cancer, and associated increased survival rates, the numbers of families affected is ever growing. The impact of paediatric cancer on families is significant and enduring, impacting numerous facets of family functioning and hampering psychological wellbeing. Identifying ways to minimise these impacts in order to facilitate greater psychosocial wellbeing is merited. To decrease burden and increase the QOL of these families as they transition through treatment, survivorship and beyond, numerous multifaceted supports are needed. To ensure supports are developed which effectively address the needs of families, analysis of the specific challenges encountered and the degree to which they are currently met is warranted. In the context of increased healthcare digitalisation, consideration is required as to how digital technologies such as CH may be leveraged to support these unmet needs.

The research presented in this thesis has addressed this knowledge gap through exploring both the unmet needs of families, and the potential role of CH to support parent and sibling wellbeing. This was achieved through eight interconnected studies, which explored the current impact of CH, and the barriers and facilitators to its use in paediatric cancer, alongside a comprehensive exploration of the unmet needs of families in an Irish context. From this, recommendations as to how CH may be best designed to support the needs of families in an accessible and impactful manner were presented. Arising from this, and co-designed with parents themselves, a pilot CH intervention applying these recommendations was developed. This online self-directed ACT programme was highly acceptable for parents and had promising impacts on parent psychosocial outcomes such as psychological flexibility and wellbeing. Taken as a whole, this research suggests the utility of CH to support the psychosocial wellbeing of families impacted by paediatric cancer and outlines key recommendations to be considered in its development.

Several major contributions to knowledge are offered by the present research. Firstly, this research programme presents a comprehensive analysis of the barriers and facilitators to CH use in paediatric cancer, which inform clear recommendations as to how CH may be best developed and deployed in an accessible, and effective manner. In addition, this research demonstrates the impact of these recommendations in practice through the CH-mediated ACT intervention for parents and caregivers. This research offers a further key contribution to knowledge through presenting an in-depth evaluation of the challenges encountered by families impacted by paediatric cancer in Ireland, with particular emphasis on their unmet needs. This insight is particularly important as the experiences of families impacted by paediatric cancer in an Irish context has not previously been explored. As such, this research provides important insight into avenues requiring additional support and service development. Finally, this research also demonstrates in practice the utility of ACT to support the psychosocial wellbeing of parents of children with cancer, and suggests an important role of psychological flexibility for this group. Considered together, the key learnings offered by this research provide valuable knowledge on the needs of families impacted by paediatric cancer, and how CH may best support these needs.

A key finding arising from the present thesis is the potential offered by CH to mitigate some of the key challenges encountered by families living with childhood cancer. As identified in Study 3, and echoed in past research (i.e. Shepherd & Woodgate, 2011; Warner et al., 2015), the financial and travel costs of accessing necessary non-medical supports outside of communities poses additional burden for parents, and adds household and family management challenges, including, for example, leave from employment, care of siblings, time with family members, and financial cost of travel, among others. CH offers a solution to these challenges by making supports available remotely, and thereby reducing the need to travel outside of communities to access support (as noted in Study 7). In the context of the positive effects of CH and the multiple domains across which supports are currently offered (see Study 1), this suggests CH may offer a means to meaningfully support families.

While promising, for CH to be impactful for families living with paediatric cancer, it is necessary for to ensure it is be accessible. Inequality and a widening of the digital divide and associated health disparities is a potential side-effect of CH if developed and applied inappropriately. To minimise this risk, the recommendations presented in Section D should be considered. Particular attention should be paid to financial, educational or technological barriers to entry, alongside how such CH supports are disseminated (see Section C). In an Irish context particularly, work is needed to support the trustworthiness of CH and parental buy-in to digitally mediated healthcare supports, as exemplified in the findings of Study 7 in which the pace of digitalisation was deemed slow, in Study 6, in which low trust towards some CH was observed. To ensure any inequities in access to CH are minimised, and effectively acted on, ongoing evaluation and monitoring of supports is required.

While this dissertation demonstrated how a CH-mediated psychosocial intervention can be developed to support the wellbeing of parents of children with cancer, it also highlights the challenges in engaging parents in psychosocial interventions to address their own needs. As noted, challenges were encountered in recruiting participants to the programme, despite significant efforts to disseminate invitations to participate through relevant stakeholder groups. Further, several individuals who registered for the programme did not access it. Several factors may have impacted uptake, including parental reluctance, or lack of time, to prioritise their own wellbeing (Study 3), barriers to CH use such as technological comfort or skills (Study 4), or a preference for in-person supports. While efforts were made to remove or reduce barriers to access through PPI input into the design of the programme, and the actioning of results of Studies 1 to 7, uptake of the intervention remained low. Additional analysis is needed to determine the specific factors impacting uptake, to fully determine the feasibility of CH-mediated supports, and for whom they may be most effective.

The findings of the present research highlight several avenues for future research. Firstly, as emphasised in Studies 1 and 2, there is a need for further analysis as to how parents and HCPs may be best guided towards effective, evidence-based CH, rather than non-empirical commercial CH. Analysis as to how the quality of CH may be best communicated to key stakeholders, while acknowledging the multifaceted needs of families and the vast array of CH is needed. A further avenue of future research pertains to expanding the use of CH to children impacted by paediatric cancer themselves. While many CH interventions for children themselves exist (Ramsey et al., 2020; Shaffer et al., 2020), analysis of how CH may be best developed to support positive impact for those with paediatric cancer may be beneficial, in the same way that this research project focused on the development of CH for families (see Section D).

Finally, there are several areas warranting future research arising from the pilot ACT programme (see Study 8). The role of cognitive fusion on parent psychosocial outcomes warrants further analysis and may necessitate more focus within intervention. Exploration of the degree to which cognitive fusion may explain the psychosocial outcomes of parents would be valuable and may provide useful information from which further programmes could be developed. In addition, further expansion and complete evaluation of the ACT programme piloted is also warranted considering the positive results obtained. Large-scale experimental analysis to further explore effects is needed, though efforts to address participant recruitment challenges will be needed firstly to allow this to occur.

To conclude, this research demonstrates the utility of CH to support families impacted by paediatric cancer and identifies key factors which must be considered to facilitate uptake in practice. Further, it presents a model through which CH may be meaningfully applied to address the needs of families impacted by paediatric cancer.

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Appendix 1: BCTv1

BCT	
1. Goals and planning	1.1. Goal setting (behaviour)
	1.2. Problem solving
	1.3. Goal setting (outcome)
	1.4. Action planning
	1.5. Review behaviour goal(s)
	1.6. Discrepancy between current behaviour and goal
	1.7. Review outcome goal(s)
	1.8. Behavioural contract
	1.9. Commitment
2. Feedback and monitoring	2.1. Monitoring of behaviour by others without feedback
	2.2. Feedback on behaviour
	2.3. Self-monitoring of behaviour
	2.4. Self-monitoring of outcome(s) of behaviour
	2.5. Monitoring of outcome(s) of behaviour without feedback
	2.6. Biofeedback
	2.7. Feedback on outcome(s) of behaviour
3. Social support	3.1. Social support (unspecified)
	3.2. Social support (practical)
	3.3. Social support (emotional)
Shaping knowledge	4.1. Instruction on how to perform the behaviour
	4.2. Information about Antecedents
	4.3. Re-attribution
	4.4. Behavioural experiments
5. Natural consequences	5.1. Information about health consequences
	5.2. Salience of consequences
	5.3. Information about social and environmental consequences
	5.4. Monitoring of emotional consequences

	5.5. Anticipated regret
	5.6. Information about emotional consequences
6. Comparison of behaviour	6.1. Demonstration of the behaviour
	6.2. Social comparison
	6.3. Information about others' approval
7. Associations	7.1. Prompts/cues
	7.2. Cue signalling reward
	7.3. Reduce prompts/cues
	7.4. Remove access to the reward
	7.5. Remove aversive stimulus
	7.6. Satiation
	7.7. Exposure
	7.8. Associative learning
8. Repetition and substitution	8.1. Behavioural practice/rehearsal
	8.2. Behaviour substitution
	8.3. Habit formation
	8.4. Habit reversal
	8.5. Overcorrection
	8.6. Generalisation of target behaviour
	8.7. Graded tasks
9. Comparison of outcomes	9.1. Credible source
	9.2. Pros and cons
	9.3. Comparative imagining of future outcomes
10. Reward and threat	10.1. Material incentive (behaviour)
	10.2. Material reward (behaviour)
	10.3. Non-specific reward
	10.4. Social reward
	10.5. Social incentive
	10.6. Non-specific incentive
	10.7. Self-incentive

	10.8. Incentive (outcome)
	10.9. Self-reward
	10.10. Reward (outcome)
	10.11. Future punishment
11. Regulation	11.1. Pharmacological support
	11.2. Reduce negative emotions
	11.3. Conserving mental resources
	11.4. Paradoxical instructions
12. Antecedents	12.1. Restructuring the physical environment
	12.2. Restructuring the social environment
	12.3. Avoidance/reducing exposure to cues for the behaviour
	12.4. Distraction
	12.5. Adding objects to the environment
	12.6. Body changes
13. Identity	13.1. Identification of self as role model
	13.2. Framing/reframing
	13.3. Incompatible beliefs
	13.4. Valued self-identify
	13.5. Identity associated with changed behaviour
14. Scheduled consequences	14.1. Behaviour cost
	14.2. Punishment
	14.3. Remove reward
	14.4. Reward approximation
	14.5. Rewarding completion
	14.6. Situation-specific reward
	14.7. Reward incompatible behaviour
	14.8. Reward alternative behaviour
	14.9. Reduce reward frequency
	14.10. Remove punishment
15. Self-belief	15.1. Verbal persuasion about capability

	15.2. Mental rehearsal of successful performance
	15.3. Focus on past success
	15.4. Self-talk
16. Covert learning	16.1. Imaginary punishment
	16.2. Imaginary reward
	16.3. Vicarious consequences

Appendix 2: Information and Consent Form Sample

Maynooth University
National University of Ireland Maynooth

Information Sheet

Purpose of the Study. I am Emma Delemere a doctoral student in the Department of Psychology, Maynooth University.

As part of the requirements for a Doctor of Psychology degree, I am undertaking a research study under the supervision of Dr. Rebecca Maguire. This research is funded by the Science Foundation Ireland, under the Advance Centre for Research Training.

The study is concerned with three interrelated topics. Firstly it is concerned with the needs and challenges experienced by parents and families impacted by paediatric cancer. Secondly, it looks to examine perspectives on the potential utility of Connected Health within paediatric cancer. Connected Health is the use of smart technologies, like sensors, telehealth or electronic health records, within healthcare. Finally, this research seeks to examine parent, volunteer and healthcare providers perceptions of the impact of a Therapeutic Recreation-based hospital outreach program (HOP) on children with paediatric cancer. This final piece of the research is being conducted in collaboration with Barretstown, in order to evaluate their Hospital Outreach Program (HOP).

What will the study involve? The study will involve a 45-minute interview to discuss your perspectives on these topics. Three or four questions on each of the three topics will be presented allowing you to provide your perspective. If you do not wish to respond to any question or area of questioning you can choose not to answer those questions. You may also terminate the interview at any time. Your interview will be recorded to allow for transcription to occur. Once the interview has been transcribed, the recording will be deleted. Prior to the interview some short demographic information will be gathered. All information will be anonymous, with pseudonyms used.

Who has approved this study? This study has been reviewed and received ethical approval from Maynooth University Research Ethics committee and the Barretstown Child Advisory Committee (Date). You may have a copy of this approval if you request it.

Why have you been asked to take part? You have been asked because you are the parent or caregiver of a child who has received treatment for paediatric cancer within the past five years. You have also attended the Barretstown Hospital Outreach Program between October 2019 - March 2020, and are fluent in English.

Do you have to take part?
No, you are under no obligation whatsoever to take part in this research. However, we hope that you will agree to take part and give us some of your time to complete the short interview. It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, you will be asked to sign a consent form and given a copy and the information sheet for your own records. If you decide to take part, you are still free to withdraw at any time without giving a reason and/or to withdraw your information up until such time as the research

findings are analysed. You may also choose not to answer specific questions if you so choose. A decision to withdraw at any time, or a decision not to take part, will not affect your relationships with the Hospital Outreach Program or Barretstown.

What information will be collected? Two primary types of data will be collected. Firstly, some demographic data will be gathered. This will include parent/caregiver age, gender, marital status and ethnicity, child age, gender and diagnosis, time since active treatment, family size, distance from treatment centre and unmet needs. Interview questions will then be asked on your experiences with the therapeutic recreation-based Hospital Outreach Program, the utility of connected health and the needs of families impacted by paediatric cancer

Will your participation in the study be kept confidential? Yes, all information that is collected about you during the course of the research will be kept confidential. No names will be identifiable at any time. All hard copy information will be held in a locked cabinet at the researchers' place of work, electronic information will be encrypted and held securely on MU PC or servers and will be accessed only by Emma Delemere and Dr Rebecca Maguire.

No information will be distributed to any other unauthorised individual or third party. If you so wish, the data that you provide can also be made available to you at your own discretion.

It must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.

What will happen to the information which you give? All the information you provide will be kept at Maynooth University in such a way that it will not be possible to identify you. On completion of the research, the data will be retained on the MU server. After ten years, all data will be destroyed (by Emma Delemere). Manual data will be shredded confidentially, and electronic data will be reformatted or overwritten by the Principal Investigator in Maynooth University.

What will happen to the results? The research will be written up and presented as a doctoral dissertation. It is hoped for the information to be presented at National or International conferences and may be published in a scientific journal. A copy of the research findings will be made available to you upon request.

What are the possible disadvantages of taking part? I don't envisage any negative consequences for you in taking part. It is possible that talking about your experience may cause some distress. If distress is experienced, you will be provided with contact details for publicly available supports.

What if there is a problem? At the end of the interview, I will discuss with you how you found the experience and how you are feeling. If you experience any distress following the interview you may contact Arch Cancer support centre (http://arccancersupport.ie/). You may contact my supervisor, Dr. Rebecca Maguire (Rebecca.maguire@mu.ie) if you feel the research has not been carried out as described above.

Any further queries? If you need any further information, you can contact me: Emma Delemere (emma.delemere.2020@mumail.ie). If you agree to take part in the study, please complete and sign the consent form overleaf.

Thank you for taking the time to read this

Consent Form

I……………………………………agree to participate in Emma Delemere's research study titled 'The role of Connected Technologies on Quality of Life of those impacted by Paediatric Cancer'.

Please tick each statement below:

The purpose and nature of the study has been explained to me verbally & in writing. I've been able to ask questions, which were answered satisfactorily. ☐
I am participating voluntarily. ☐
I give permission for my interview with Emma to be audio-recorded ☐
I understand that I can withdraw from the study, without repercussions, at any time, whether that is before it starts or while I am participating. ☐
I understand that I can withdraw permission to use the data right up to analysis. ☐
It has been explained to me how my data will be managed and that I may access it on request.☐
I understand the limits of confidentiality as described in the information sheet ☐
I agree to quotation/publication of extracts from my interview ☐
I agree to quotation/publication of extracts from my interview ☐
I agree for my data, once anonymised, to be retained indefinitely in the IQDA archive ☐

Signed…………………………………. Date………………

Participant Name in block capitals ……………………………………………..

I the undersigned have taken the time to fully explain to the above participant the nature and purpose of this study in a manner that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

Signed…………………………………. Date………………

Researcher Name in block capitals Emma Delemere

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@mu.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

For your information the Data Controller for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at ann.mckeon@mu.ie. Maynooth University Data Privacy policies can be found at https://www.maynoothuniversity.ie/data-protection.

Appendix 3: Study 7 Measures

Study 7 Survey Questions	
Demographic Questions	
Some questions on you	
Question	**Response**
What is your age?	(Free text)
In what country do you reside?	Ireland United Kingdom
Do you live in an urban or rural area?	Rural area (<5000 inhabitants) Small town (<10,000 inhabitants) Large town (<50,000 inhabitants) Urban area (<50,000 inhabitants)
What is your gender?	(Free text)
What is your marital status?	Single Married/cohabitating Divorced/separated Widowed
How many children are in your family?	(Free text)
Some questions on your child	
What is your child's age?	(Free text)
What gender is your child?	(Free text)
What diagnosis does your child have?	(Free text)
At what stage of the cancer journey is your child?	Treatment 1 year Post-treatment 2-5 years Pot-treatment 5 years + Post-treatment My child has died from cancer.
How far away are you from your child's primary treatment centre (the place they received the majority of their care)? An estimation is fine here.	____Km
Parent Psychological Flexibility Questionnaire (PPFQ-17)	
Question	**Response**
My emotions get in the way of the being the type of parent I would ideally like to be	1 (never true) – 7 (always true)
My worries get in the way of me being successful as a parent	
My emotions cause problems in my relationship with my child	
It seems to me that most people are better parents than I am	

My painful memories prevent me from parenting the way that I would like	
My feelings stop me from doing what I know is best for my children	
I worry about not being able to control the feelings I have about my children	
I have to feel in the mood before I can give my child affection or attention	
I could not cope with the guilt if my child did something wrong .	
I don’t let my child do many things with their friends because I don’t think I could cope if something bad happened to him/her	
I have refused to let my child do things that were important to them because I would worry too much (e.g., spend time with friends, walk to school by themselves)	
I don’t let my child do things that I’ll worry about	
I am responsible for my child’s behaviour	
I can still take care of my parenting responsibilities even when I feel tired, stressed, sad or angry	
I can get angry with my children and still be a good parent	
I can have a good relationship with my children no matter what I am thinking and feeling	
Watching my child deal with new experiences as he/she grows up (e.g., starting high school, first kiss, puberty) is interesting and exciting	
I am able to separate how I respond to my children from how I am feeling	
The unpredictability of being a parent is one of the things that makes parenting fun and rewarding	

The Self-as-Context Scale

Question	**Response**
When I am upset, I am able to find a place of calm within myself.	1 (Strongly disagree) to 7 (Strongly agree)
I have a perspective on life that allows me to deal with life’s disappointments without getting overwhelmed with them	
Despite the many changes in my life, there is a basic part of who I am that remains unchanged.	

As I look back upon my life so far, I have a sense that part of me has been there for all of it.	
I allow my emotions to come and go without struggling with them.	
I am able to notice my changing thoughts without getting caught up in them.	
There is a basic sense I have of myself that doesn't change even though my thoughts and feelings do	
Even though there have been many changes in my life, I'm aware of a part of me that has witnessed it all.	
I am able to access a perspective from which I can notice my thoughts, feelings, and emotions.	
When I think back to when I was younger, I recognize that a part of me that was there then is still here now.	
WHO-5, WHO Well-Being Index 5-items	
Question	**Response**
Please respond to each item by marking one box per row, regarding how you felt in the last two weeks: I have felt cheerful in good spirits.	5 All of the time 4 Most of the time 3 More than half the time 2 Less than half the time 1 Some of the time 0 At no time
I have felt calm and relaxed	
I have felt active and vigorous.	
I woke up feeling fresh and rested.	
My daily life has been filled with things that interest me	
Brief Parenting Burnout Survey	
Question	**Response**
I sometimes have the impression that I'm looking after my child(ren) on autopilot (the lowest item difficulty	2 (daily) 1 (once or twice a week) 0 (more seldom/never)
I'm no longer able to show my child(ren) how much I love them	
I have the sense that I'm really worn out as a parent	
I'm so tired out by my role as a parent that sleeping doesn't seem like enough	
I feel like I can't take any more as a parent	
Intervention Acceptance	
Question	**Response**
This programme was helpful	1 (Strongly disagree) 2 (Disagree) 3 (Neither agree nor disagree) 4 (Agree)
I would recommend this programme to other parents	
I found the strategies included in the programme to be useful	

I found the programme easy to use	5 (Strongly agree)
I liked that this programme was online	
I liked that I could complete this programme at a time that suited me across the week	
What suggestions do you have on how this programme could be better?	(Open ended)