Life After Childhood Leukaemia: Exploring the Relationship Between Social Support, Resilience and Quality of Life Amongst Children and their Parents.

Study submitted in partial fulfilment for the requirement for the award of Doctor of Philosophy (PhD)

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January 2026

Declaration

hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctor of Philosophy (PhD) is entirely my own work, and that I have exercised reasonable care to ensure that the work is original and have conformed to the regulations on the use and declaration of Generative AI, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work. I hereby certify that no Generative Artificial Intelligence (Gen AI) tools have been used in the creation of the thesis.

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Acknowledgements

First and foremost, I would like to express my deepest gratitude to my supervisors, Dr. Simon Dunne, Prof. Pamela Gallagher and Prof. Veronica Lambert. This PhD would not have been possible without your guidance, thoughtful feedback and continuous support. I am immensely grateful for the support and encouragement you have offered at every stage of this research.

I would also like to extend my sincere thanks to Dr. Chiara Besani and Prof. Owen Smith for their invaluable contributions and expertise, which greatly enriched this work. I feel extremely fortunate to have had the opportunity to collaborate with you both.

My sincere thanks go to Research Ireland and Breakthrough Cancer Research for funding this research. I am also grateful to Orla Dolan, Dr. Frances Drummond, and Linda O'Connell for the support and opportunities you provided throughout this research. I hope this work contributes to improving the care of childhood leukaemia survivors and their parents in Ireland and beyond.

My thanks also go to the staff at Children's Health Ireland at Crumlin, particularly Prof. Aengus O'Marcaigh, Dr. Andrea Malone, Dr. Charlotte O'Sullivan, Dr. Peter McCarthy, Dr. Neil Barrett, Lorna Storey and Elizabeth Power, all of whom assisted with recruitment. Special thanks also to Childhood Cancer Ireland, CanTeen Ireland, the Young Persons Advisory Group and the many other wonderful organisations who supported the study.

I would also like to thank everyone within the School of Psychology for the support, guidance and education needed to complete this project. Thanks also to my independent panel member Dr Catherine Fassbender for her involvement in the annual review process and to Dr Darragh McCashin for chairing my Viva examination.

Finally, to the most important people in my life, my parents and family, thank you for absolutely everything. I am also profoundly grateful to the children and parents who participated in this research, thank you for generously sharing your experiences, your time and your stories, without which this work would not have been possible.

Table of Contents

Declaration ..... **i**

Acknowledgements ..... **ii**

List of Figures ..... **xiii**

List of Tables ..... **xiv**

List of Appendices ..... **xvi**

List of Abbreviations ..... **xviii**

Abstract ..... **xx**

Chapter 1: Introduction **1**

1.0 Introduction 1

1.1 Epidemiology 1

1.2 Aetiology 2

1.3 Treatment 3

1.4 Rates of Survival and Recurrence 4

1.5 The Psychosocial Transition Post-Treatment 5

1.6 The Role of Developmental Stage in Children's Experiences 7

1.7 Late and Long-Term Effects 8

1.7.1 Effects on Childhood Leukaemia Survivors 9

1.7.2 Effects on Parents and the Family Unit 10

1.8 Quality of Life 12

1.8.1 Quality of Life in the Context of Childhood Cancer 13

1.9 Social Support 16

1.9.1 Social Support in the Context of Childhood Cancer 18

1.10 Resilience 20

1.10.1 Resilience in the Context of Childhood Cancer 22

1.11 National and International Policy Context 24

1.12 Researcher Positionality 26

1.13 Rationale for Present Study 27

1.14 The Present Thesis 29

1.15 Thesis Conspectus 30

Chapter 2: Systematic Review 31

2.0 Overview 31

2.1 Introduction 31

2.2 Method 32

2.2.1 Search Strategy & Study Selection Criteria 33

2.2.2 Data Screening & Extraction 34

2.2.3 Quality Appraisal 35

2.2.4 Synthesis of Results 35

2.3 Results 35

2.3.1 Quality Appraisal 43

2.3.2 Study Characteristics 43

2.3.3 Social Support Measures 43

2.3.4 Social Support Findings 46

2.3.4.1 Levels of Social Support 46

2.3.4.2 Sources of Social Support 46

2.3.4.3 Gender differences relating to Social Support 47

2.3.4.4 Age Differences Relating to Social Support 48

2.3.4.5 Social Support in Childhood Cancer Survivors Compared to Other Groups 48

2.3.4.6 Relationship of Social Support to Other Outcomes 49

2.4 Discussion 51

2.4.1 Clinical Implications 55

2.4.2 Study Limitations 56

2.4.3 Conclusion and Implications for Thesis 57

Chapter 3: Methodology 59

3.0 Introduction 59

3.1 Study Aims 59

3.1.1 Quantitative Strand Objectives 59

3.1.2 Qualitative Strand Objectives 60

3.2 Mixed-Methods Approach 60

3.2.1 Philosophical Orientation 61

3.2.2 Advantages and Disadvantages of Mixed-Methods Research 62

3.3 Present Study Design 64

3.3.1 Rationale for Using a Convergent Parallel Design 65

3.3.2 Timing of Study Phases 66

3.3.3 Weighting of Study Phases 66

3.3.4 Data Integration Approach 67

3.4 Conclusion 68

Chapter 4: Quantitative Strand 70

4.0 Introduction 70

4.1 Aims and Hypotheses 72

4.2 Participants 73

4.2.1 Selection Criteria 73

4.3 Recruitment 73

4.3.1 Leukaemia Clinic 74

4.3.2 Cancer Organisations 74

4.3.3 Social Media 75

4.4 Procedure 75

4.5 Questionnaires 76

4.5.1 Social Support 77

4.5.2 Resilience 78

4.5.3 Quality of Life 79

4.5.4 Socio-Demographic and Clinical Questions 80

4.6 Ethical Considerations 81

4.7 Data Analysis 81

4.8 Results 87

4.9 Child Data 87

4.9.1 Child Demographic Characteristics and Clinical Characteristics 87

4.9.2 Objective - To Establish Self-Reported Levels of Social Support, Resilience and Quality of Life Among Childhood Leukaemia Survivors. 89

4.9.3 Objective - To Examine the Relationship Between Children's Social Support, Resilience and Quality of Life with their Self-Reported Demographic and Clinical Factors..... 93

4.9.4 Objective - To Explore the Relationship Between Children's Social Support, Resilience and Quality of Life. 99

4.10 Parent Data 104

4.10.1 Parent Demographic Characteristics and their Child's Clinical Characteristics 104

4.10.2 Objective - To Establish Self-Reported Levels of Social Support, Resilience and Quality of Life Among Parents of Childhood Leukaemia Survivors. 106

4.10.3 Objective - To Examine the Relationship Between Parents' Social Support, Resilience and Quality of Life with their Self-Reported Demographic Factors and their Child's Clinical Factors (parent-reported). 108

4.10.4 Objective - To Explore the Relationship Between Parents' Social Support, Resilience and Quality of Life. 115

4.11 Discussion 118

4.12 Children 118

4.12.1 Objective 1 - To Establish Self-Reported Levels of Social Support, Resilience and Quality of Life..... 118

4.12.2 Objective 2 - To Examine Relationship Between Children's Social Support, Resilience and Quality of Life with their Self-Reported Demographic and Clinical Factors..... 120

4.12.3 Objective 3 - To Explore the Relationship Between Children' s Social Support, Resilience and Quality of Life 123

4.13 Parents 125

4.13.1 Objective 1 - To Establish Self-Reported Levels of Social Support, Resilience and Quality of Life 126

4.13.2 Objective 2 - To Examine the Relationship Between Parents' Social Support, Resilience and Quality of Life with their Self-Reported Demographic Factors and their Child's Clinical Factors (parent-reported) 128

4.13.3 Objective 3 - To Examine the Relationship Between Parents' Social Support, Resilience and Quality of Life 130

4.14 Strengths and Limitations of the Quantitative Strand 131

4.15 Conclusions of the Quantitative Strand 133

Chapter 5: Qualitative Strand 134

5.0 Introduction 134

5.1 Aims 135

5.2 Study Design 135

5.3 Selection Criteria 136

5.4 Recruitment 136

5.5 Procedure 137

5.6 Ethical Considerations 138

5.7 Data Analysis 139

5.8 Sample Characteristics 141

5.9 Child Findings 142

5.9.1 Memories as a Bridge: From Deeply Ingrained to Absent 145

5.9.2 A Tale of Two Recoveries: Swift Rebound vs. Persistent Struggles 146
5.9.3 Who I Am Now: Identity Beyond Cancer 149
5.9.4 Through Thick & Thin: Who Stayed, Who Went & Who was Found 150
5.10 Discussion of Children's Findings 152
5.10.1 Memories as a Bridge: From Deeply Ingrained to Absent 153
5.10.2 A Tale of Two Recoveries: Swift Rebound vs. Persistent Struggles 154
5.10.3 Who I Am Now: Identity Beyond Cancer 157
5.10.4 Through Thick & Thin: Who Stayed, Who Went & Who was Found 159
5.11 Strengths and Limitations of the Qualitative Strand for Children 161
5.12 Parent Findings 162
5.12.1 The Past Tugs, the Future Pulls 164
5.12.1.1 Time Heals but Fear Lingers 164
5.12.1.2 "Stuck in No Man's Land" 166
5.12.2 Cast Adrift, Yet Anchored 167
5.12.2.1 Navigating the Unknown 168
5.12.2.2 Fading Support, Persistent Need 170
5.12.2.3 Bridging the Gap to Support 172
5.12.2.4 Ties that Strengthen, Connections that Fade 174
5.12.3 "Finding the Play Button" Again 175
5.12.3.1 The Challenges of Adjustment in a 'New Normal' 175
5.12.3.2 Guilts Hold on Moving Forward 177
5.12.4 Self-Discovery through Adversity 179

5.12.4.1 Clarity and Strength through Adversity: Reaffirming what Truly Matters 179

5.12.4.2 Empowered by Adversity, Driven to Advocate 181

5.13 Discussion of Parents Findings 182

5.13.1 The Past Tugs, the Future Pulls 183

5.13.2 Cast Adrift, Yet Anchored 186

5.13.3 “Finding the Play Button” Again 189

5.13.4 Self-Discovery through Adversity 192

5.14 Strengths and Limitations of the Qualitative Strand for Parents 193

5.15 Conclusions of the Qualitative Strand 194

Chapter 6: Integrative Discussion 196

6.0 Introduction 196

6.1 Integrating the Qualitative and Quantitative Findings 196

6.1.1 Convergence 197

6.1.2 Complementarity 201

6.1.3 Dissonance 206

6.1.4 Silences 210

6.1.5 Summary of the Integrated Analysis 215

6.2 Discussion of the Integrated Findings 216

6.2.1 Study Rationale and Aim 216

6.2.2 The Hidden Labour of Negotiating Support and Normalcy 218

6.2.3 Symbolic and Identity-Affirming Dimensions of Peer and Parent Support 222

6.2.4 The Hidden Emotional and Ethical Labour of Parents After Treatment 226

6.2.5 Unseen Dimensions of Identity and Existential Meaning-Making After Treatment 228

6.3 Conclusion of the Integrative Analysis 231

Chapter 7: Conclusions 232

7.0 Introduction 232

7.1 The Original Contribution of the Present Study 232

7.2 Study Implications 241

7.2.1 Practice Implications 241

7.2.2 Research Implications 243

7.2.3 Policy Implications 245

7.3 Researcher Reflections 246

7.4 Strengths and Limitations of the Present Thesis 247

7.5 Conclusion 249

List of Figures

Figure 2.1: PRISMA Diagram: Overview of Search Results Included and Excluded at Each Stage of Review 36

Figure 3.1: Visual Diagram of Convergent Parallel Design Process 69

Figure 7.1: Geographical Distribution of Participants 142

Figure 8.1: Child Qualitative Themes 144

Figure 9.1: Parent Qualitative Findings: Themes and Sub-Themes 163

List of Tables

Table 2.1: Search Strategy Used for Each Database 34

Table 2.2: Extracted Studies 37

Table 2.3: Social Support Instruments 44

Table 4.1: Questionnaire Measures 77

Table 4.2: Tests of Normality 82

Table 4.3: Child Demographic and Clinical Characteristics 88

Table 4.4: Means and Standard Deviations of Scales & Related Domains by Age Group 91

Table 4.5: Group Differences in Child Reported Social Support, Resilience and Quality of Life by Age Group and Gender 94

Table 4.6: Correlations Between Social Support, Resilience and Quality of Life Variables and Age at Time of Study: Child Reported 96

Table 4.7: Correlations Between Social Support, Resilience and Quality of Life Variables and Months Since Diagnosis: Child Reported 98

Table 4.8: Correlations Between Social Support, Resilience and Quality of Life Variables and Months Since End of Treatment: Child Reported 99

Table 4.9: Correlations Between Younger Children (aged 12 years and younger) Social Support, Resilience and Quality of Life 102

Table 4.10: Correlations Between Older Children (aged 13-17 years) Social Support, Resilience and Quality of Life 102

Table 4.11: Parent Demographic Characteristics and their Child's Clinical Characteristics 105

Table 4.12: Parent Reported Social Support, Resilience and Quality of Life Variables 107

Table 4.13: Differences Between Male and Females on Self-Reported Social Support, Resilience and Quality of Life 110

Table 4.14: Differences Between Parents With and Without Third-Level Education on Self-Reported Social Support, Resilience and Quality of Life 111

Table 4.15: Correlations Between Social Support, Resilience and Quality of Life Variables and Parent Age 112

Table 4.16: Correlations Between Social Support, Resilience and Quality of Life Variables and Months Since Child's Diagnosis: Parent Reported 114

Table 4.17: Correlations Between Social Support, Resilience and Quality of Life Variables and Months Since Child's End of Treatment: Parent Reported 115

Table 4.18: Correlations Between Parents Social Support, Resilience and Quality of Life 117

Table 6.1: Convergence Between Quantitative and Qualitative Findings 198

Table 6.2: Complementarity Between Quantitative and Qualitative Findings 202

Table 6.3: Dissonance Between Quantitative and Qualitative Findings 207

Table 6.4: Silences Between Quantitative and Qualitative Findings 212

Table 7.1: Original Contribution of the Present Study 237

List of Appendices

Appendix A: Quality Appraisal for the Systematic Review 304

Appendix B: Recruitment Materials (Quantitative Strand) 306

Appendix B1. Cover Letter 306

Appendix B2. Parent/Guardian Plain Language Statement/Information Leaflet 307

Appendix B3. Child 8-12 Years Plain Language Statement/Information Leaflet 313

Appendix B4. Child 13-17 Years Plain Language Statement/Information Leaflet 315

Appendix B5. Parent/Guardian Consent Form 317

Appendix B6. Child 8-12 Years Assent Form 319

Appendix B7. Child 13-17 Years Assent Form 321

Appendix B8. Parent/Guardian Questionnaire 323

Appendix B9. Child 8-12 Years Questionnaire 336

Appendix B10. Child 13-17 Years Questionnaire 347

Appendix C: Resources/Supports 359

Appendix C1. Parent/Guardian Resources/Supports 359

Appendix C2. Child Resources/Supports 360

Appendix D: Recruitment Advertisements 361

Appendix D1. Poster 362

Appendix D2. Email Message 363

Appendix D3. Social Media 365

Appendix E: Ethical Approval 366

Appendix E1. CHI Ethical Approval 367

Appendix E2. DCU Ethical Approval 368

Appendix F: Recruitment Materials (Qualitative Strand) 369

Appendix F1. Recruitment Email 369

Appendix F2. Interview Scheduling Form 370

Appendix F3. Parent/Guardian Plain Language Statement/Information Leaflet 371

Appendix F4. Child 8-12 Years Plain Language Statement/Information Leaflet 377

Appendix F5. Child 13-17 Years Plain Language Statement/Information Leaflet 379

Appendix F6. Parent/Guardian Consent Form 381

Appendix F7. Child 8-12 Years Assent Form 383

Appendix F8. Child 13-17 Years Assent Form 384

Appendix F9. Parent/Guardian Interview Topic Guide 386

Appendix F10. Child Interview Topic Guide 388

Appendix G: Risk Protocol for In-Person Interviews 390

Appendix H: Safety Protocols 392

Appendix H2. Protocol if a child protection issue arises 393

Appendix H3. Protocol if a participant discloses suicidal ideations or there are concerns regarding mood and/or safety 394

Appendix I: Research Dissemination 395

Appendix I1: Publications 395

Appendix I2: Conference Proceedings 395

List of Abbreviations

Abbreviation	Associated Word
ALL	Acute Lymphoblastic Leukaemia
APML	Acute Promyelocytic Leukaemia
AML	Acute Myeloid Leukaemia
CAR-T therapy	Chimeric Antigen Receptor T-cell Therapy
CASSS	The Child and Adolescent Social Support Scale (Malecki et al., 2000)
CAYA	Children, Adolescents and Young Adults
CBT	Cognitive Behavioural Therapy
CHI	Children's Health Ireland
CML	Chronic Myeloid Leukaemia
DCU	Dublin City University
GDPR	General Data Protection Regulation
MCS	Mental Component Summary
MSPSS	The Multidimensional Scale of Perceived Social Support (Zimet et al., 1988)
NCCP	National Cancer Control Programme
NG Tube	Nasogastric Tube
PCS	Physical Component Summary
PedsQL	The Pediatric Quality of Life Inventory (Varni et al., 2001)
PLS	Plain Language Statement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses framework
PTSS	Posttraumatic Stress Symptoms
QoL	Quality of Life
RS10	The Resilience Scale for Children (Wagnild, 2012)
RS25	The Resilience Scale (Wagnild & Young,

Abbreviation	Associated Word
	1993)
SF-36	The 36-Item Short Form Survey (Ware & Sherbourne, 1992)
WHO	World Health Organisation
YPAG	Young Persons' Advisory Group

Abstract

Thesis Title: Life After Childhood Leukaemia: Exploring the Relationship Between Social Support, Resilience and Quality of Life Amongst Children and their Parents.

PhD Candidate: Avril Deegan

Background: The post-treatment period for childhood leukaemia survivors and their parents is a critical yet under-researched time, marked by challenges that impact quality of life. Social support is crucial for maintaining a good quality of life but tends to decline after treatment ends. Resilience, closely linked to social support, also plays a key role in maintaining well-being. However, few studies have explored the relationship between social support, resilience and quality of life among survivors and their parents.
Aims: The study aims to gain a deeper understanding of the post-treatment experiences of childhood leukaemia survivors and their parents, focusing on the relationship between social support, resilience and quality of life.
Methods: A systematic review of social support among child and adolescent cancer survivors was conducted. A convergent parallel mixed-methods design followed, combining cross-sectional surveys with 70 parents and 35 children and qualitative interviews with 19 parents and 11 children.
Results: Quantitative findings showed that for parents, greater social support was linked to higher resilience and better mental well-being. For children, greater social support was associated with higher resilience, which in younger children related to better overall quality of life and psychosocial health, while in older children resilience was linked mainly to psychosocial health. Qualitative findings highlighted the emotional complexity of parents' recovery and the developmentally diverse experiences of children. Integrative findings revealed survivorship as a dynamic, relational process, with longer time since treatment completion associated with lower levels of perceived support, despite persistent emotional and practical needs.
Conclusions: The post-treatment period is complex and evolving. Sustained, developmentally tailored support is needed to promote resilience and quality of life. Care delivery should incorporate routine psychosocial screening and timely interventions, and policy should embed structured survivorship care pathways to ensure equitable, ongoing access to psychosocial support.

Chapter 1: Introduction

1.0 Introduction

With more and more children surviving cancer, there has been an increased interest in understanding the longer-term outcomes of survivorship, including the physical, emotional and social effects of treatment (Eroglu & Hazar, 2023; Keller et al., 2024; Muskat et al., 2017; Racine et al., 2018; Wilford et al., 2019). This research explores the post-treatment experiences of childhood leukaemia survivors aged 7-17 years and their parents, with a particular focus on the relationship between social support, resilience and quality of life as these factors are closely linked to how children and parents cope, adapt and thrive after the challenges of cancer treatment (Marbot et al., 2025; Melguizo-Garín et al., 2019; Hofman et al., 2021; Seiler & Jenewein, 2019). In this introductory chapter, background information is provided on childhood leukaemia, its epidemiology and aetiology, as well as its treatment and prognosis. I will then discuss the transition to life after successful treatment for leukaemia and the three main variables of interest: social support, resilience and quality of life.

1.1 Epidemiology

Leukaemia is the most common childhood cancer in Ireland, accounting for about 1 in every 3 cancers in children (Irish Cancer Society, 2021). An average of 191 cancers were diagnosed every year in Ireland in children aged under 15 between 2011 and 2020 (National Cancer Registry, 2023). Leukaemia accounted for 27% of all childhood cancers in each time period since 2011, with approximately 51 children under the age of 15 years diagnosed annually in Ireland (National Cancer Registry, 2023). There are two main types of childhood leukaemia: acute lymphoblastic leukaemia (ALL) and acute myeloid leukaemia (AML), with ALL being the most common. Other rare forms of childhood leukaemia can also occur, such as chronic myeloid leukaemia (CML), but they are very uncommon. Most children are diagnosed with ALL between the ages of 1-4 years old and with AML under the age of 2 years, with another peak during adolescence (Redaelli et al., 2005). According to the National Cancer Registry (2023) incident rates for

leukaemia in children aged under 15 years in Ireland between 2011 and 2020 were slightly higher in males compared to females (49.8/million vs 46.7/million).

1.2 Aetiology

Leukaemia is a cancer affecting white blood cells. White blood cells fight off infection and normally grow and divide in an orderly way but in children with leukaemia the bone marrow produces an excessive amount of abnormal white blood cells that crowd out healthy blood cells (Clarke et al., 2016). This can occur at a number of different stages in blood cell production (Clarke et al., 2016). Blood is made up of three main types of cells - red blood cells, white blood cells and platelets. Red blood cells are the most abundant cell in the blood and their function is to carry oxygen around the body. Platelets, or thrombocytes, are small cells that form clots to prevent bleeding.

The formation of blood cells takes place through stem cells in the bone marrow, where a cell may become a myeloid stem cell or a lymphoid stem cell. ALL occurs when too many lymphoid stem cells become lymphoblasts, B lymphocytes, or T lymphocytes and do not mature into normal functioning lymphocytic white blood cells (Erber, 2010). When this occurs an excessive amount of these abnormal cells form in the blood and bone marrow, making less room for healthy white blood cells, red blood cells and platelets (Erber, 2010). This significantly reduces the body's immunity to disease and infection. In AML, myeloid stem cells develop into myeloblasts or myeloid blasts, instead of healthy granulocytic white blood cells, which are needed to fight off foreign bodies such as bacteria and parasites (Erber, 2010). Instead myeloblasts continue to multiply, leaving less room for healthy white blood cells, red blood cells and platelets (Erber, 2010). As with ALL, this reduces the body's resistance to disease and infection. This is why frequent infections and high temperatures are one of the main symptoms of leukaemia in children (Clarke et al., 2016; Shahverdi et al., 2020). Other symptoms of leukaemia include swollen lymph nodes, bone or joint pain, swelling of the abdomen, excessive bleeding, bruising, tiredness, shortness of breath and pale skin (Fragkandrea et al., 2013).

In essence, leukaemia develops as a result of genetic mutations that occur in the DNA of progenitor blood cells during development. These changes cause these abnormal cells to divide uncontrollably without fully maturing. What causes these changes remains largely unknown. However, it is likely to be linked to environmental factors and genetic factors (Azzwali & Azab, 2019). A family history of first degree relatives with chronic lymphoid leukaemia or identical twins who have/had AML or ALL may increase the risk of developing leukaemia (Sud et al., 2019; Tebbi, 2021). Genetic abnormalities associated with syndromes such as Down syndrome, black fan-diamond syndrome, Bloom syndrome and Fanconi anaemia may also increase the risk of developing leukaemia (Azzwali & Azab, 2019). Other possible risk factors for leukaemia include the long-term exposure to high levels of radiation energy and industrial chemicals such as benzene (C. Lin et al., 2020). Parental smoking has also been linked to a greater risk of AML (Devi et al., 2025). Furthermore, lower physical activity, increased caffeine intake and alcohol consumption were identified as significant risk factors for leukaemia (Devi et al., 2025).

1.3 Treatment

Treatment for ALL is typically 2-3 years, while treatment for AML is generally more intensive but shorter, lasting up to 6 months. Upon diagnosis children are immediately admitted to hospital to begin treatment to prevent further spreading of the cancer cells (Cancer Research UK, 2021). A number of invasive procedures are commonly used during the treatment process, including lumbar punctures, blood tests and catheter insertions, to facilitate diagnosis, drug delivery and ongoing monitoring. Chemotherapy is the major form of treatment for leukaemia (Cancer Research UK, 2021). This form of treatment uses chemicals to kill leukaemia cells and restore normal blood functioning. Chemotherapy drugs may be administered in tablet form or injected directly into the vein, often through a central or peripheral venous catheter, allowing drugs to be administered routinely without the need for repeated venipuncture procedures.

Typically, a repeated series and combination of chemotherapy and steroids are given to children in the treatment of ALL (Inaba et al., 2013), while those with AML may receive stem cell transplantation earlier in treatment, particularly in high-risk cases. In certain situations, radiation therapy may also be used, particularly for central nervous system involvement or as part of the preparation for stem cell transplantation. If children do not respond to this treatment, they may be offered a stem cell or bone marrow transplant (Cancer Research UK, 2021). Before transplantation, higher doses of chemotherapy are given to destroy leukaemia cells. These cells are then replaced with cells from a healthy matched donor via a central line into the bloodstream. Following a stem cell transplant, a blood transfusion will be required to replace red blood cells (Cancer Research UK, 2022).

In recent years, advances in immunotherapy have significantly improved outcomes for children with relapsed or refractory ALL. Therapies such as chimeric antigen receptor T-cell (CAR-T) therapy and monoclonal antibodies like blinatumomab and inotuzumab ozogamicin offer targeted immune-mediated approaches to attack leukaemia cells (Aureli et al., 2023; McCall et al., 2025). While these therapies are primarily used for ALL, their application in AML is an active area of research. Furthermore, RNA-based therapies are an emerging area of interest, with the potential to disrupt cancer related gene expression pathways, RNA therapeutics hold the potential to provide more personalised and less toxic treatment options in the future (Zhou et al., 2019).

1.4 Rates of Survival and Recurrence

Survival rates for childhood leukaemia have dramatically improved due to significant advancements in cancer treatment, with 5-year survival now exceeding 90% for ALL and reaching 60–70% for AML (Devilli et al., 2021; Kiem Hao et al., 2020; Pui et al., 2015). These promising prognosis rates are due to significant improvements in risk classification, drug regimes, chemotherapy and additional supportive care (Rubnitz, 2017). With ever improving survival rates comes an increasing number of survivors of childhood leukaemia (Rubnitz, 2017). Relapse, defined as the return of cancer cells after remission, remains a significant challenge. Relapse rates for ALL has been reported to be between 15-20% in

developed countries over the last two decades (Mengxuan et al., 2022). In contrast, relapse rates for AML are higher, often around 30–40%, reflecting the more aggressive nature and poorer prognosis of AML relapses (Conneely & Stevens, 2021).

1.5 The Psychosocial Transition Post-Treatment

While the literature is quite expansive relating to the impacts of cancer while on active treatment and in long-term survivorship (typically 5+ years post-treatment), there is much less known about the initial few months and early years following the end of treatment for childhood cancer, a distinct and often challenging transition period for both survivors and their parents (Keller et al., 2024; Wilford et al., 2019). In particular, the experiences of children and their parents following the successful completion of leukaemia treatment has been relatively under-researched (McCarthy et al., 2021; Muskat et al., 2017). The experience of active treatment is a highly disrupting and stressful time for children and their parents which leads to the expectation that the end of treatment will be marked solely with feelings of relief, joy, happiness and elation (Ljungman et al., 2016; Muskat et al., 2017).

However, the transition to life after treatment is a time of great uncertainty and fear for children and their parents even if it is situated in a context of positive emotions and feelings (Keller et al., 2024; Ljungman et al., 2016; Wakefield et al., 2011). This emotional ambivalence reflects the disorienting shift from the structured, high-contact environment of treatment to the ambiguity of survivorship. A study by Greenzang and colleagues (2016) reported that approximately 87% of parents felt prepared for their child's cancer treatment, while only 62% felt prepared for life after treatment. The regular routine of formal support within the hospital, contact with nurses/physicians and lab appointments abruptly ends and this is followed by ever increasing intervals between follow-up appointments and survivorship clinics for leukaemia survivors (Muskat et al., 2017). For some, this loss of the treatment "safety net" is distressing and heightens feelings of vulnerability (Muskat et al., 2017). This period has been considered a crisis period for families in determining long-term quality of life outcomes (Cantrell & Conte, 2009; Greenzang et al. 2016; Muskat et al., 2017).

Qualitative research has further highlighted the complexity of this post-treatment transition by examining how survivors and parents make sense of the cancer journey beyond treatment completion. For example, a qualitative study by Cho and colleagues (2024) exploring autobiographical memories among paediatric ALL survivors and their caregivers found that survivorship was characterised by fragmented recall, protective communication, and enduring psychosocial impact. Survivors often reported difficulty remembering their cancer experience or felt that information had been withheld, while caregivers described intentionally limiting what they shared in an effort to protect their child. Similarly, Winzig and colleagues (2024) examined the burden and support needs of adolescent childhood cancer survivors in long-term follow-up care and reported ongoing physical, cognitive, social, and psychosocial challenges even years after treatment completion. Parents often remained central to adolescents' cancer-related concerns, maintaining responsibility for health management and daily support, which constrained adolescents' opportunities to develop autonomy. Despite these differences in age and developmental stage, both studies emphasised the lasting impact of cancer and the importance of social support. These findings highlight that recovery extends beyond medical completion and involves ongoing psychological, relational, and developmental adjustment for children and adolescents, as well as their parents, during the post-treatment phase.

Although clinical treatment may have concluded, emotional, psychological, and social recovery often continues well beyond the end of treatment. Children and their parents may experience a sense of disequilibrium, balancing the idea that life is "normal" again with the recognition that it will never be quite the same (Conway Keller et al., 2020). Parents often feel they are left with the burden of responsibility for their child's adherence to health behaviours, care and management of late effects and possible recurrence (Greenzang et al., 2016; Vetsch et al., 2018). At the same time as this, parents may be trying to reintegrate back into their communities and work, while also renegotiating relationships with others (Peikert et al., 2020). Likewise, children must reintegrate back into school and their social circle of friends (Vanclooster et al., 2019). This can be difficult for some children who may depend more on their parents, become less sociable, lack self-confidence and experience social isolation following treatment for

cancer (Wakefield et al., 2010). Despite these well-documented challenges, survivors and their parents often feel they are left to face these challenges alone and are not supported during this transition (Inhestern et al., 2020; Labay et al., 2004; Muskat et al., 2017).

This disconnect highlights the growing recognition in psycho-oncology that recovery is not merely medical, but deeply psychosocial. Recent literature has called for a broader understanding of survivorship that addresses the lasting emotional and social consequences of childhood cancer (Darlington et al., 2022). Building on this recognition, research needs to go beyond purely medical markers of recovery and explore the social and emotional resources that shape survivorship experiences. In this context, a range of psychological constructs have been explored, such as coping strategies (Castellano-Tejedor et al., 2016; Fisher et al., 2021), post-traumatic growth (Halldorsdottir et al., 2022; Yi et al., 2015) and illness perceptions (Parker et al., 2023; Schwartz-Attias et al., 2024). However, three constructs have been consistently identified as particularly salient to post-treatment adjustment; social support, resilience and quality of life (Celik et al., 2021; Chen at al., 2023; Zhang et al., 2017). These constructs are central because they capture key aspects of survivors' and parents' psychosocial functioning and are often interrelated, with social support influencing resilience, and both shaping longer-term quality of life (Seiler & Jenewein, 2019; Hofman et al., 2021). While each has been explored to varying degrees, they remain under examined when considered together and in relation to the lived experiences of both survivors and their parents, particularly in the context of childhood leukaemia. Therefore, this study focuses specifically on these three interlinked variables to provide a more holistic and developmentally attuned account of the post-treatment experience.

1.6 The Role of Developmental Stage in Children's Experiences

Understanding the post-treatment experience requires a developmental perspective, as childhood and adolescence are periods of rapid and complex growth across biological, cognitive and socioemotional domains, processes that profoundly shape how survivors perceive and navigate their recovery journey (Kuther, 2018). These domains are deeply interwoven, each influencing and modifying the others across

time, especially in the context of significant life events such as a cancer diagnosis and treatment. Developmental stage plays a pivotal role in shaping how illness is experienced, understood and integrated into a child's ongoing psychosocial trajectory (Greenblatt & Saini, 2019; van Driessche et al., 2025).

Children and adolescents differ markedly in their cognitive capacities, emotional regulation and social expectations, which means that the experience and interpretation of illness, and subsequently, survivorship are deeply embedded in developmental context (Greenblatt & Saini, 2019; van Driessche et al., 2025). Younger children, typically 12 years and younger, often rely heavily on their parents or caregivers (B. Lin et al., 2020). These parental figures play a significant role in ensuring treatment plans are followed and appropriate lifestyle choices are made (Ferraz et al., 2025; Schepers et al., 2019). By contrast, during adolescence (approximately 13-17 years), adolescents grapple with rapid social, biological and psychological changes while also striving for increased independence and autonomy from their parents or caregivers (Mastorci et al., 2024). Parents of adolescents therefore face the challenge of balancing ongoing vigilance regarding late effects and relapse with respect for their child's growing need for autonomy, often renegotiating family roles and boundaries (Kim et al., 2024; Yu et al., 2024). Adolescents with a history of leukaemia must navigate these normative developmental tasks while simultaneously dealing with the residual effects of treatment and the psychological aftermath of serious illness. Recognising these developmental nuances is essential to providing age-appropriate, psychologically informed survivorship care. This study therefore focuses on children aged 7-17 years, capturing both younger children (aged 12 years and younger) and older children (13-17 years) to explore how developmental stage shapes post-treatment experiences.

1.7 Late and Long-Term Effects

Cure often comes at a cost, with childhood cancer survivors being at greater risk for physical and psychosocial late and long-term effects from the disease and the aggressive treatments they were subjected to (Erdmann et al., 2021; Hudson et al., 2003). Late effects are health problems or complications that arise months or years after cancer treatment, while long-term effects are ongoing

issues that persist continuously during and after treatment (Kızılocak & Okcu, 2019; Stein et al., 2008; Al-Mahayri et al., 2021).

1.7.1 Effects on Childhood Leukaemia Survivors

Childhood leukaemia survivors often face a range of late and long-term effects as a consequence of the aggressive treatments required to fight the disease (Douvas et al., 2022; Kızılocak & Okcu, 2019). Neurocognitive late effects include impaired attention and executive function, working memory deficits and below age-adjusted norms for fine motor skills, visual-motor integration skills, verbal skills and visual short-term memory, which can affect their ability to perform well academically (Chipeeva et al., 2022; Moore et al., 2016). Psychological late effects are also a concern, with survivors facing a greater risk of depression, anxiety, post-traumatic stress symptoms and other mental health issues compared to population norms or peers without a history of cancer (Al-Saadi et al., 2022; Kanellopoulos et al., 2013). The emotional toll of a life-threatening illness, coupled with the pressures of ongoing health monitoring, also contributes to the increased prevalence of these psychological conditions (Al-Saadi et al., 2022). These effects can significantly impact survivors' cognitive, physical, social and emotional well-being, and their impact often varies by developmental stage, with younger children especially vulnerable to neurocognitive late effects that disrupt schooling and learning (Patel et al., 2016; Phillip et al., 2023).

In terms of physical health, survivors of childhood leukaemia are at a heightened risk for developing a secondary malignancy later in life (Demoor-Goldschmidt & de Vathaire, 2019; Maule et al., 2007). Moreover, long-term treatment-related side effects include cardiac problems, osteoporosis, neuropathies and an increased risk of obesity, all of which can further compromise quality of life (Al-Mahayri et al., 2021). Fertility is also an additional concern for adolescent survivors of leukaemia (Karalexi et al., 2023). Some treatments, particularly chemotherapy with alkylating agents, can cause permanent damage to reproductive organs, leading to infertility (Karalexi et al., 2023). For survivors transitioning into adulthood, this can have profound personal and emotional implications, underscoring the importance of fertility preservation methods (Karalexi et al., 2023).

Beyond these cognitive, psychological and physical challenges, children are also faced with significant long-lasting social challenges which can persist well into adulthood and shape overall quality of life and social integration (Larsen et al., 2022). A systematic review by Pahl and colleagues (2021) highlighted how prolonged hospital stays, missed school and disrupted peer interactions during treatment can lead to persistent social isolation, reduced confidence and difficulty reintegrating with peers. Over time, such disruptions may not only affect psychosocial adjustment but also increase the risk of engaging in problem behaviours, such as smoking, alcohol use and substance use (Bitsko et al., 2016; Lown et al., 2008). Difficulties in establishing and maintaining intimate and peer relationships are common, further compounding psychosocial strain and adversely affecting long-term well-being (Pahl et al., 2021).

1.7.2 Effects on Parents and the Family Unit

Childhood leukaemia is a life-altering experience not only for the child but also for their parents and wider family, who often face significant psychological, social and financial challenges (Kumari et al., 2018; Vercasson et al., 2020). One of the most profound long-term effects on parents of childhood cancer survivors is psychological distress (Carlsson et al., 2019; Wijnberg-Williams et al., 2006). A recent meta-analysis by van Warmerdam and colleagues (2019) found that prevalence rates of post-traumatic stress disorder, depression and anxiety among parents of children with cancer was 26%, 28%, and 21%, respectively, which were significantly higher than those observed in parents of children without cancer. While most parents adapt well and recover from the distress, some parents continue to experience heightened levels of anxiety, depression and post-traumatic stress symptoms after the end of curative treatment, having a negative knock-on effect on their overall quality of life (Carlsson et al., 2019; Kumari et al., 2018; Malpert et al., 2015). Moreover, many parents of childhood cancer survivors worry about relapse, late toxicities and late effects for their child (Sisk et al., 2019). This heightened health vigilance can lead to excessive worry about minor symptoms and decreased peace of mind among parents of childhood cancer survivors (Barrett et al., 2020; Sisk et al., 2019). While some degree of worry about late effects is natural, excessive or disproportionate worry can negatively interfere with parental coping and

quality of life, which in turn may exacerbate their children's anxiety and quality of life (Greenzang et al., 2021). This heightened familial stress can also affect siblings and other family members, leading to increased emotional distress and disruptions in family functioning (Greenzang et al., 2021; Van Schoors et al., 2017).

Beyond psychological distress, the experience of childhood leukaemia can also reshape social dynamics among parents of survivors (Vercasson et al., 2020). Parents often report feeling socially isolated due to the intense caregiving responsibilities during treatment, and this isolation can persist long after the end of treatment (Davies & O'Connor, 2023; Kelada et al., 2019; Peikert et al., 2020; Slater, 2020). Some parents struggle to reintegrate into social circles and activities, particularly if there is a lack of understanding from others about their experiences (Peikert et al., 2020). Within the family unit, the effects of childhood leukaemia can be long-lasting and lead to changes in parental roles and responsibilities. Some parents describe feeling overprotective towards their child even years after treatment has ended, which can lead to strained parent-child relationships and increase parenting stress (Kim et al., 2024; Yu et al., 2024). Moreover, some parents may feel guilty about prioritising the child who had cancer, potentially leaving their siblings feeling overlooked (Davies & O'Connor, 2023; Van Schoors et al., 2018). Furthermore, marital relationships can be significantly impacted (Silva-Rodrigues et al., 2016; Wiener et al., 2017). While some parents find that the experience strengthens their relationship, others experience increased tension, communication difficulties and emotional disconnection, which in some cases can lead to marital breakdowns (Silva-Rodrigues et al., 2016; Wiener et al., 2017).

Finally, the financial burden of childhood leukaemia can have long-term effects on parents, particularly for those who had to leave their job, work reduced hours or take unpaid leave to care for their child during treatment (Kelada et al., 2020; Vercasson et al., 2020). Even years after treatment, some parents continue to experience financial strain, especially if their child requires ongoing medical care (Peikert et al., 2020). This strain is often exacerbated by accumulated medical expenses, lost income and challenges in re-entering the workforce (Peikert et al., 2020).

1.8 Quality of Life

Quality of life has emerged as a critical construct in this context, both as an outcome and as a lens through which to understand ongoing challenges for survivors and their families (Larsen et al., 2023; Savage et al., 2009). In the present study, quality of life is examined as a core psychosocial outcome to capture the broader impact of cancer and treatment beyond clinical indicators of health, especially during the post-treatment period when medical oversight declines and psychosocial adjustment becomes central.

Despite being a widely used term there is no universally accepted definition of quality of life (McDougall & Tsonis, 2009). Traditionally, the impact of cancer and its treatment was assessed through clinical endpoints such as survival rates, morbidity and mortality. However, as survival has improved, researchers have turned to understanding the long-term psychosocial and functional impacts of treatment (Eiser, 2007; Eiser & Morse, 2001; Wilson et al., 2015). Researchers often examine and measure quality of life in objective terms (e.g., presence or absence of illness/disability) or in subjective or perceived terms (i.e., satisfaction with life) (Livingstone et al., 2007). The World Health Organisation (WHO) in 1948 provided one of the very first definitions of quality of life, describing quality of life as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (Krahn et al., 2021). In 1995, the WHO elaborated further on their definition of quality of life referring to it as an individual's perception of their life in the context of their culture and their own values, expectations, standards and goals (WHOQOL, 1995). These formulations underscore quality of life as a multidimensional and subjective experience, typically encompassing physical, psychological, social relationships and environmental domains (WHOQOL, 1995). These domains have since been widely adopted, although some researchers have expanded them to include elements such as personal development, spirituality, safety and human rights (Verdugo et al., 2005).

The conceptualisation of quality of life in the literature generally falls into two theoretical perspectives: a health-related model and a global, multidimensional model (Register & Herman, 2006). The former focuses on how illness and treatment affect quality of life, while the latter adopts a more holistic perspective, encompassing broader life experiences, relationships and subjective well-being

(Anderson & Burckhardt, 1999; Ferrans et al., 2005). This thesis adopts a multidimensional framework in line with the WHOQOL (1995) definition, as it best reflects the complex and interrelated psychological, social and developmental processes that shape post-treatment life for both survivors of childhood leukaemia and their parents. Understanding these theoretical perspectives is critical in ensuring that measures and interpretations of quality of life meaningfully reflect lived experience, particularly in populations like childhood cancer survivors, where theory remains underdeveloped (Savage et al., 2009; Wallander, 2001).

Likewise, a number of terms have been used to describe the concept, including quality of life, health-related quality of life, functional status and health status (Klassen et al., 2011). Health-related quality of life is a multidimensional concept that emerged in part due to the broadening definition of health from the WHO (McDougall & Tsonis, 2009). However, health-related quality of life should not be differentiated from quality of life as although health is a separate domain it is also an interrelated domain of quality of life and therefore is referred to quality of life hereafter (McDougall & Tsonis, 2009). For the purpose of this study, quality of life is defined as a state of complete physical, psychological and social well-being or satisfaction that may be influenced by an individual's health status (i.e., presence or absence of disease), personal factors (e.g., age, sex) and environmental factors (e.g., social support from others) (McDougall & Tsonis, 2009; WHOQOL, 1995). This multidimensional concept is particularly important in the context of childhood leukaemia survivorship, where treatment impacts extend beyond physical health to affect emotional and social development.

1.8.1 Quality of Life in the Context of Childhood Cancer

Quality of life is considered an important outcome measure for children with cancer, both during treatment and the years following treatment (Savage et al., 2009). However, findings on survivor quality of life have been mixed, with some studies reporting worse quality of life among survivors, and others reporting equivalent or better quality of life compared with population norms or matched controls (Larsen et al., 2023; McDougall & Tsonis, 2009; Klassen et al., 2011). Similarly, a systematic review by Vetsch

and colleagues (2018) on survivors of childhood ALL found that only thirteen studies reported worse quality of life, eight found no difference and three reported greater quality of life in survivors compared to healthy controls or norms. Moreover, a systematic review by Garas and colleagues (2019) reported mixed results on children's quality of life up to five years post-treatment completion for ALL, though some survivors experienced marked declines. These inconsistencies underscore the need for more nuanced, contextually grounded research to identify which survivors and families remain vulnerable and why.

Recent qualitative research provides further insight into the lived experiences underlying these mixed quantitative outcomes. For example, a narrative study conducted by Neris and colleagues (2025) with 18 adolescents and young adults who survived childhood cancer explored their meanings and conceptualisations of quality of life using semi-structured interviews and reflexive thematic analysis. The study identified four sub-themes that converged into a central theme of a 'New self', reflecting the profound impact of cancer and survivorship on participants' identity and sense of self. Survivors described experiences of having a 'second chance' and integrating this transformed self into daily life as central to their quality of life. These findings highlight that quality of life encompasses more than physical or functional health, extending into psychological adaptation, identity reconstruction, and the development of personal meaning after cancer. Such qualitative insights complement quantitative findings and emphasise the importance of recognising and supporting the evolving psychosocial needs of childhood cancer survivors during the post-treatment phase. Despite the richness of these insights, qualitative research exploring quality of life among childhood cancer survivors remains limited, highlighting the ongoing need for contextually grounded studies.

Following treatment for leukaemia, regular monitoring is recommended for approximately five years, however the level of support from healthcare services gradually declines over this period compared to when the child is on active treatment (Garas et al., 2019). This is worrying given that some long-term survivors of childhood leukaemia report persistent late effects, such as fertility issues, secondary cancers, psychosocial issues, cognitive late effects and higher incidence of psychopathology that can significantly

compromise quality of life (Fardell et al., 2017; Vetsch et al., 2018). Predictors of poorer quality of life include clinical factors (e.g., older age at diagnosis, CNS involvement, relapse, treatment intensity), socio-demographic characteristics (e.g., sex), and personal or family-level variables (e.g., parental distress, income, education) (McDougall & Tsonis, 2009; Klassen et al., 2011). In contrast, factors such as resilience, optimism, healthy lifestyle behaviours and strong social networks have been associated with more favourable quality of life outcomes (Chou & Hunter, 2009; Eiser et al., 2005).

The impact of childhood cancer on the quality of life of parents is also understudied (Innasimuthu et al., 2022). The quality of life of parents is often overlooked and forgotten about during the child's cancer journey as all of the focus is directed towards caring for and treating the sick child (Mondal et al., 2020). However, the cancer experience can have an effect on the quality of life of parents both during the child's treatment and even years after the child's treatment has ended (Innasimuthu et al., 2022). Caring for a child with cancer can have a significant effect on a parent's physical, social, financial and psychological well-being (Barrett et al., 2020; Ibrahim et al., 2025; Litzelman et al., 2011; Witt et al., 2010). Factors such as distress, economic constraints, marital disharmony and difficulties adapting have been shown to have a negative impact on the quality of life of parents of a child with cancer or a child who has survived cancer (Ibrahim et al., 2025; Litzelman et al., 2011; Witt et al., 2010). Parents have little time to prioritise their own well-being and health as they are required to care for their child at all times (Klassen et al., 2008; Nielsen et al., 2024). Previous studies have reported poorer quality of life in parents of children with chronic diseases such as congenital heart disease (Gregory et al., 2018), cerebral palsy (Okurowska-Zawada et al., 2011), sickle cell anaemia (Van den Tweel et al., 2008) and pervasive developmental disorders (Yamada et al., 2012) when compared with healthy norms. In relation to cancer a number of studies have reported poorer quality of life in parents of children with cancer compared to healthy norms (Abdulkareem et al., 2020; Eiser et al., 2005; Klassen et al., 2008; Witt et al., 2010).

1.9 Social Support

As highlighted in the preceding section, quality of life in the aftermath of childhood leukaemia is influenced not only by individual health outcomes but also by the broader psychosocial environment surrounding both survivors and their parents. Social support has been identified as an important factor associated with more favourable post-treatment quality of life among childhood cancer survivors and their families (Castellano-Tejedor et al., 2015; Gise & Cohen, 2022; Klassen et al., 2011; Litzelman et al., 2011). However, while the concept of social support is widely cited, it is often inconsistently defined and measured across studies (French et al., 2018). Sarason and colleagues (1983) defined social support as the presence of people one can depend on for care, love and reassurance. It has typically been examined either as the perceived availability and adequacy of supportive relationships (House et al., 1985; Sherbourne & Stewart, 1991) or as a coping strategy in which individuals actively seek support to manage challenges (Carver et al., 1989). For the purpose of this study, social support is defined as a multidimensional concept, referring to the interpersonal relationships we have with others (Melguizo-Garín et al., 2019; Uchino, 2004).

There are four general types of social support: emotional support, instrumental support, informational support, and/or appraisal support (Langford et al., 1997). Emotional support is concerned with expressions of empathy, love, care and understanding from others. Instrumental support refers to tangible assistance from others. Informational support is concerned with the sharing of information and advice, particularly during decision making and appraisal support is concerned with the availability of information for self-evaluation and affirmation. These types can be further divided into structural and functional measures of support (Uchino, 2004). While structural models of social support assess the availability and frequency of support from an individual's social network (i.e., direct and indirect social connections with others such as family, friends, neighbours), they do not capture whether these ties are perceived as supportive or helpful in practice (Lakey & Cohen, 2000; Uchino, 2004). In contrast, functional models of social support assess the functionality or degree to which these networks provide social support to the individual, though they rely on subjective evaluations that may vary across time,

context and individual disposition (Lakey & Cohen, 2000). This study is grounded primarily in the functional model of social support, focusing on parents' and survivors' evaluations of support, while also recognising structural shifts in networks as important contextual influences.

Support can come from multiple sources within the child and parents environment, such as family, peers and teachers. Adults play an important role in providing social support to children throughout childhood (Zimmer-Gembeck & Skinner, 2010). As children progress to adolescence and young adulthood there is a widening of social networks (Collins & Laursen, 2004). In middle childhood or around the ages of 7-8 years friends become increasingly more important to children as providers of support, a shift that continues through adolescence and into young adulthood (Branje et al., 2021; Fuligni, 2019; Zimmer-Gembeck & Skinner, 2010). This developmental transition is important to consider when exploring how social support is experienced by childhood cancer survivors at different ages. A further distinction can be made between perceived social support and received social support. Perceived social support refers to an individual's own appraisal of their social support, while received social support refers to evaluations of actual levels of support received (Haber et al., 2007).

Two prominent theoretical models typically guide social support research: the main/direct model and the buffering model (Cohen & Wills, 1985; Cohen et al., 2000). The main or direct effect model proposes a generalised beneficial effect of social support, where social support has a direct effect on well-being/quality of life regardless of whether or not the person is under stress. This is believed to occur as a result of the strong feelings of self-worth, positive experiences, and predictability a strong social network can provide. While the buffering model hypotheses that social support moderates, buffers or protects an individual from the psychological impact of stress, such as fear of relapse or uncertainty about the future, themes that are common in the post-treatment experience (Cohen et al., 2000; Fardell et al., 2017). In the context of this study, both models are relevant for understanding how social support influences the post-treatment experiences of childhood leukaemia survivors and their families. However, the buffering model is particularly salient, as survivors and parents often grapple with uncertainty, fear of relapse and psychosocial adjustment (Bitsko et al., 2016; Fardell et al., 2017; Keller et al., 2024; Larsen et al., 2022;

Muskat et al., 2017). At the same time, the enduring, day-to-day benefits of support for resilience and quality of life highlight the continued relevance of direct effects, suggesting that a combined lens best captures the post-treatment experience.

1.9.1 Social Support in the Context of Childhood Cancer

In the context of childhood cancer, social support has been shown to play a critical protective role (Çavuşoğlu & Sağlam, 2015; Shin et al., 2019). Studies report that higher social support is associated with reduced anxiety, depression and behavioural problems, as well as greater self-esteem and optimism among survivors (Brinkman et al., 2018; Decker, 2007; Woodgate, 2006). Key sources of support include family members, peers, healthcare professionals and teachers (Ingersgaard et al., 2021; Pennant et al., 2019). Notably, most research relies on parent proxy reports, which may not fully capture the child's experience, highlighting the need for direct child perspectives (Inhestern et al., 2020). Parents may overestimate or underestimate their child's level of social support based on their own perceptions and biases, highlighting the need for direct child self-reports (Inhestern et al., 2020; Morino et al., 2021).

In relation to parents, a systematic review by Gise and Cohen (2022) on 37 published studies between 2010 and 2021 examining social support in parents of children with cancer found that social support was positively related to well-being and quality of life, while negatively related to distress, anxiety and posttraumatic stress. More specifically, the review found that high levels of social support were linked with positive psychological outcomes, such as resilience, post-traumatic growth and the ability to find meaning in the cancer experience. Additionally, most studies in the review found that greater perceived social support was associated with lower levels of distress, anxiety, post-traumatic stress symptoms and depression.

Studies have indicated that children and parents receive the most support at diagnosis and that this support reduces significantly overtime as the child overcomes their illness (Hoekstra-Weebers et al., 2001; Merz et al., 2024; Wijnberg-Williams et al., 2006). During the early stages of treatment children and parents receive high levels of support from their extended families, friends, communities and

healthcare professionals, however, this support tends to decline overtime, leaving children and parents particularly vulnerable at the end of treatment phase (Kelada et al., 2019; Melguizo-Garín et al., 2019; Wakefield et al., 2010). Continued support for children and their parents when treatment ends is critical to relieve psychological distress and ease the transition back to 'normal' life (Maurice-Stam et al., 2007).

Qualitative research with survivors has further highlighted the influence of social support in psychosocial adjustment and long-term coping. A study by Steinberg and colleagues (2020) found that young adult survivors of childhood cancer highlighted the transformative role of social support in fostering optimism, resilience, and a positive mind-set, both during treatment and into survivorship. Similarly, a study by Foster and colleagues (2017) exploring situational coping among young adult survivors identified social support as a central theme, with family and peers providing emotional, practical, and distraction-based support both during and after treatment. Survivors particularly valued the consistent presence of family and the shared understanding offered by friends, while some highlighted the negative impact of losing or not receiving support. Together, these studies highlight that social support extends beyond immediate protection against distress and continues to influence identity formation, adaptive coping and psychosocial well-being post-treatment.

Importantly, this thesis foregrounds social support as a key psychosocial variable that not only influences quality of life but also underpins resilience in both survivors and their parents. There is limited understanding of how social support contributes to resilience and overall quality of life in the post-treatment phase, particularly from the child's own perspective. While the studies mentioned above do not explicitly apply social support theory, their findings are broadly consistent with both the main effect model (support as directly beneficial to well-being) and the stress-buffering model (support as protective in times of stress) (Cohen & Wills, 1985). Addressing these gaps is essential for understanding the role of social support in supporting quality of life following childhood leukaemia. The next section will explore resilience in depth, with attention to its interaction with social support and quality of life.

1.10 Resilience

Resilience is increasingly recognised in psycho-oncology as a critical protective factor influencing how children and parents cope with the adversity of childhood cancer (Rosenberg et al., 2014; Marbot et al., 2025; Seiler & Jenewein, 2019). Yet, despite its growing prominence, resilience remains a complex and contested concept, with disagreements about whether it should be conceptualised as a stable trait, an outcome, or a dynamic, context-dependent process, and about how it should be measured (Luthar et al., 2000; Seiler & Jenewein, 2019). Broadly, it refers to the capacity to adapt well to adversity, to recover from distressing experiences, and in some cases, to emerge stronger as a result (Seiler & Jenewein, 2019; Wagnild & Young, 1993). Conceptualisations of resilience span from viewing it as a fixed personality trait (Jacelon, 1997), to a psychosocial outcome (Galatzer-Levy et al., 2018), or more recently, as a dynamic, context-dependent process influenced by psychological, physiological and environmental factors (Luthar et al., 2000; Brewer et al., 2019).

For the purpose of this study, resilience is conceptualised through a strengths-based lens, emphasising the personal characteristics and capacities that enable children and parents to cope effectively with the challenges of survivorship and maintain emotional well-being following the disruption of childhood leukaemia (Brewer et al., 2019; Luthar et al., 2000; Marbot et al., 2025; Seiler & Jenewein, 2019; Wagnild & Young, 1993). This operational focus highlights trait-like personal strengths observable at the post-treatment phase, while recognising that these strengths are shaped by and interact with broader contextual factors such as social support, consistent with the dynamic nature of resilience. By focusing on these capacities, the study examines the relationship between social support, resilience and quality of life in survivorship, without implying that resilience is fixed or independent of environmental influences.

Several theoretical models reinforce this dynamic, multidimensional understanding of resilience. Polk (1997) developed a middle range theory, for instance, which frames resilience as the capacity to transform disaster into growth and forward movement, capturing the potential for positive transformation in the wake of trauma. Rew and Horner's (2003) Youth Resilience Framework takes a developmental

approach, emphasising the interaction between individual vulnerabilities, sociocultural risk factors and protective resources, particularly during adolescence, supporting the study's focus on how personal strengths operate within broader social contexts. Similarly, the Adolescent Resilience Model (Haase et al., 1999) offers a triangulated perspective based on studies of young people (typically 13–18 years) with chronic illnesses, including cancer. The model identifies three key protective factors: individual (courageous coping, hope and spiritual perspective), family (family atmosphere, family support and resources), and social (health resources and social integration) which jointly shape both resilience and quality of life, providing a conceptual foundation for examining these constructs in both children and parents. To capture a broader developmental range, Masten's (2001, 2014) Developmental Systems Model views resilience as emerging from normative adaptive systems (e.g., caregiver relationships, cognitive development) across childhood and adolescence. Similarly, Luthar and colleagues (2000) Developmental Psychopathology Framework and Ungar's (2011) Social Ecological Model emphasise how individual, familial and contextual factors interact to support resilience across diverse developmental stages. Together, these frameworks inform the study's conceptualisation of resilience as personal strengths embedded within a social context and closely linked to psychosocial outcomes such as well-being and quality of life.

Conceptualisations of resilience in childhood cancer are closely linked with broader theoretical models of psychosocial adjustment to chronic illness. Lazarus and Folkman's (1984) stress and coping model conceptualises adjustment as an ongoing process shaped by individuals' cognitive appraisals of illness-related stressors and their available coping resources. Within this framework, social support functions as a key external coping resource, while resilience-related capacities influence how challenges are appraised and managed over time. Similarly, Leventhal's common-sense model (Leventhal et al., 2016) and Livneh's stage model of chronic illness adjustment (2022) highlight how cognitive representations, illness perceptions, and successive stages of adaptation influence coping and well-being. Building on these, Dekker's (2024) general model integrates previous frameworks, proposing that illness stressors trigger parallel cognitive, emotional, behavioural and physiological responses that interact

dynamically to influence outcomes. Together, these models offer insight into the multifaceted processes involved in adjustment to childhood chronic illness, highlighting the interplay of cognitive appraisal, coping strategies, social support and physiological responses.

1.10.1 Resilience in the Context of Childhood Cancer

In the context of childhood cancer, resilience plays an especially critical role. The treatment journey is often long and invasive, marked by prolonged hospitalisations, physical discomfort, emotional uncertainty and disruptions to normal life trajectories. Yet despite these challenges, survivors and their parents demonstrate resilience in their ability to adapt, cope and maintain psychological well-being in the aftermath of trauma (Phipps et al., 2015; Howard Sharp et al., 2015). Resilience, in this context, is not merely about 'bouncing back' but about navigating a long-term process of adjustment marked by highs and lows, progress and setbacks and ongoing uncertainty (Slater, 2020; Testoni et al., 2023).

Psycho-oncology research tends to primarily focus on the negative psychosocial outcomes associated with cancer, such as distress, anxiety, depression and posttraumatic stress (Molina et al., 2014; Seiler & Jenewein, 2019; van Erp et al., 2021). While these areas are important for understanding the challenges children and their parents face, it risks overlooking protective psychosocial factors, like resilience, that may be useful in promoting positive psychosocial outcomes (Rosenberg et al., 2013; Seiler & Jenewein, 2019). A recent literature review by Seiler & Jenewein (2019) found that resilience may indirectly buffer against the negative effects of stress on quality of life in cancer patients. By broadening the scope of psycho-oncology research to include protective psychosocial factors such as resilience, we can move beyond a deficit-based model to one that actively promotes well-being, positive psychosocial outcomes and healthy survivorship (Chung et al., 2021; Park et al., 2021).

A recent systematic review was carried out by Marbot and colleagues (2025) on psychological resilience among childhood cancer survivors and their parents. The review identified 13 studies, highlighting the lack of research conducted in this area. The review found that the psychosocial impact of cancer differs between childhood cancer survivors and their parents. For childhood cancer survivors,

resilience was strongly influenced by emotional problems, self-esteem and social support. Survivors who experienced emotional difficulties found it harder to be resilient, whereas those with higher self-esteem and strong social support tended to adapt and cope more successfully. For example, Chen and colleagues (2014) found that adolescent brain tumor survivors with emotional problems were at greater risk of having poor resilience, while Okado and colleagues (2018) reported that perceived social connectedness and optimism contributed to better psychosocial adjustment. Scrignaro and colleagues (2016) highlighted the importance of meaning-making and posttraumatic growth in fostering resilience, while Shin and Oh (2021) found that resilience was enhanced by courageous coping and hope. The single qualitative study by Hinton and colleagues (2022) further illustrates that adult survivors retain vivid memories of family support and coping strategies during their childhood cancer experience, which continue to influence their present sense of strength and resilience. Notably, the review found a disproportionate focus on adult survivors of childhood cancer, with only three of the included studies specifically examining resilience in survivors under the age of 18. The remaining studies examined adult survivors of childhood cancer and parents or caregivers, highlighting a critical gap in understanding resilience in young survivors.

In contrast, the resilience of parents was largely influenced by anxiety, fears of recurrence and their sense of life purpose (Marbot et al., 2025). Greater levels of resilience in parents was associated with less psychological distress and greater positive psychosocial functioning, along with greater coping and perceived social support (Rosenberg et al., 2014; Ye et al., 2015). Given the integral caregiving role parents play and the emotional demands placed upon them, understanding and fostering resilience in parents is vital not only for their own mental health, but for the well-being of their children (Marbot et al., 2025; Rodriguez et al., 2012; Rosenberg et al., 2013).

Building on the pivotal role of social support, resilience emerges as a closely intertwined concept that further deepens our understanding of how childhood leukaemia survivors and their parents adapt, recover and maintain well-being after treatment. While social support provides crucial external resources, resilience reflects the dynamic process by which individuals harness these resources and their own psychological strengths to overcome the complex challenges posed by cancer and survivorship. Taken

together, the literature on social support, resilience and quality of life highlights both the progress in understanding post-treatment survivorship and the persistent gaps in knowledge. Existing studies emphasise the importance of these constructs during the post-treatment phase. However, most research examines these factors in isolation, often focuses on either the child or the parent rather than both, and frequently includes mixed cancer populations rather than focusing specifically on childhood leukaemia. Integrating these constructs and perspectives is therefore necessary to fully understand the complex interplay of social support, resilience and quality of life in post-treatment recovery. These insights highlight the need for research that examines these psychosocial variables together amongst childhood leukaemia survivors and their parents, providing a clear rationale for the integrated focus of the present study.

1.11 National and International Policy Context

The psychosocial impacts of childhood cancer has gained increased attention within health policy frameworks both internationally and in Ireland. This growing recognition is reflected in the National Model of Care for Psycho-Oncology Services for Children, Adolescents and Young Adults (CAYA) with Cancer and Their Families, published by the National Cancer Control Programme (NCCP) under the National Cancer Strategy 2017-2026 (Greally et al., 2023). This policy framework represents a major step forward in embedding psychosocial care across all phases of the cancer trajectory, including the often-overlooked post-treatment survivorship period.

The model emphasises the need for the delivery of developmentally appropriate, family-centred psycho-oncology services, acknowledging the distinctive emotional, cognitive and social needs of both survivors and their families. Of particular relevance to this study is the model's identification of the post-treatment period as a unique phase, marked by heightened psychological vulnerability and long-term adjustment challenges for both survivors and their families. Another key feature of the model is the establishment of multidisciplinary psycho-oncology teams within specialist cancer centres, including Children’s Health Ireland (CHI) at Crumlin for paediatric care. These teams reflect an institutional

commitment to addressing the complex psychosocial needs of families. The model also supports continuity of care, including the integration of hospital-based services with community mental health supports, an important consideration given that many families 'cut off' from formal support networks following the end of active treatment. However, despite its progressive design, implementation challenges persist, and significant challenges persist in translating policy into consistent practice.

Internationally, similar frameworks advocate for comprehensive psychosocial care across the cancer continuum. The Standards for the Psychosocial Care of Children with Cancer (Wiener et al., 2015) recommend routine psychosocial assessments and interventions throughout the cancer trajectory, including the post-treatment phase. These standards highlight the importance of addressing the psychosocial needs of both survivors and their families, emphasising the necessity for developmentally appropriate care that considers the unique challenges faced at different stages of development. Furthermore, the International Society of Paediatric Oncology (SIOP) and the Pan American Health Organization (PAHO) have developed guidelines that underscore the importance of integrating psychosocial care into survivorship programs (Trigoso et al., 2023). These guidelines advocate for continuous psychosocial support, recognising that the needs of survivors evolve over time and require ongoing attention (Trigoso et al., 2023). However, despite the progressive design of these frameworks, implementation challenges persist. Variability in resources, training, and institutional support can hinder the consistent application of these policies, leading to disparities in care delivery. Addressing these challenges is crucial to ensure that all survivors receive the comprehensive psychosocial support they need.

This policy landscape provides an essential context for the present study, which seeks to explore post-treatment experiences of childhood leukaemia survivors and their parents in depth. By situating this research within the national model of psycho-oncology care, it aligns with broader health system objectives and has the potential to contribute to the refinement of survivorship services in Ireland, particularly by highlighting the lived realities that persist beyond the hospital setting.

1.12 Researcher Positionality

In undertaking this study, I also draw on my own lived experience as a survivor of childhood leukaemia. This positionality as an expert-by-experience researcher offers first-hand experience of the emotional and psychological complexities that can emerge once treatment ends, even if my own direct memories are limited due to my young age at diagnosis. From my personal experience, and what I have learnt from my parents experiences, the end of treatment felt like being abruptly discharged into a new reality with little guidance or continuity of support. The structured networks of care and attention that had surrounded us during treatment seemed to fade away and in the eyes of others life had returned to normal. In reality, however, the absence of sustained support amplified feelings of vulnerability and uncertainty. My parents carried the weight of constant caregiving, uncertainty and fear, often setting aside their own needs to protect mine. Observing their resilience has profoundly shaped my understanding of survivorship. Their ability to remain strong and supportive, despite the emotional burden, highlighted for me how resilience can operate as both an individual and relational resource. These experiences underscore the importance of social support in sustaining well-being and illuminate how resilience contributes to coping with the disruptions of cancer treatment. They also bring into focus the broader concept of quality of life, which encompasses not only physical recovery but also emotional and psychosocial adjustment during the post-treatment phase. Reflecting on these experiences has guided the focus of this study and reinforced the need to centre the perspectives of children and parents. In particular, they illustrate why social support, resilience, and quality of life are critical to examine specifically in the post-treatment context, where formal support structures are reduced but the psychological and social challenges of survivorship remain. By situating the research within the lived realities of those directly affected, the study ensures that these factors are explored in ways grounded in real-world experiences, capturing the ongoing processes that shape well-being after treatment.

1.13 Rationale for Present Study

As discussed in the previous sections, the transition to life after successful treatment can be challenging for both the child and parent (Keller et al., 2024; Muskat et al., 2017). While the completion of treatment marks a significant milestone, it does not signify the end of the cancer experience. Beyond the medical treatment, children and their parents must navigate emotional, social and psychological adjustments, including fears of recurrence, late and long-term effects, uncertainty about the future, shifting family dynamics, changes in identity and reintegrating into daily life (Keller et al., 2024; Muskat et al., 2017). Despite the growing recognition of these challenges, significant gaps remain in our understanding of the post-treatment phase, particularly in relation to the psychosocial factors that may facilitate or hinder recovery during this critical post-treatment phase.

Central to addressing this gap is a closer examination of the relationship between social support, resilience and quality of life. Each of these factors play a distinct yet interconnected role in the overall well-being of both the child and the parent. Social support can serve a buffering function, helping to protect children and parents from the psychological impact of stressors commonly experienced in the post-treatment phase, such as fear of relapse, uncertainty about the future, and challenges in reintegrating into daily life (Bitsko et al., 2016; Cohen & Wills, 1985; Fardell et al., 2017; Keller et al., 2024; Larsen et al., 2022; Muskat et al., 2017). Resilience, in turn, enables individuals to maintain a positive outlook and cope effectively with adversity, while quality of life reflects overall well-being, including physical, emotional and social aspects of life (Marbot et al., 2025; McDougall & Tsonis, 2009). Exploring these factors in tandem allows for a more holistic and ecologically valid understanding of survivorship, that goes beyond medical outcomes to consider the broader context of life after childhood leukaemia. To date, however, these constructs have not been examined together within a single study, particularly in relation to the post-treatment experiences of childhood leukaemia survivors and their parents.

Drawing on my lived experience as a survivor, this study is both academically informed and personally motivated, aiming to produce findings that are contextually grounded and meaningfully informed by lived experience. Understanding the perceptions and needs of those directly affected is

essential for guiding research and developing interventions grounded in real-world challenges (Udlis, 2011). By situating the research within these lived realities, the study seeks to explore how social support, resilience and quality of life interact during the critical post-treatment phase, providing insights that extend beyond medical recovery to encompass broader psychosocial well-being.

This research is further situated within both national and international policy context. Nationally, the National Model of Care for Psycho-Oncology Services for Children, Adolescents and Young Adults (CAYA), developed under Ireland's National Cancer Strategy 2017–2026, explicitly identifies the post-treatment period as a critical phase of vulnerability and unmet need (Greally et al., 2023). The model calls for developmentally appropriate, family-centred psycho-oncology support throughout the cancer continuum, including the survivorship phase. However, while the policy offers a progressive vision, implementation remains uneven and there is limited empirical data on how families actually experience the post-treatment phase. This study directly aligns with the aims of national policy by generating context-specific data that can inform the design and delivery of post-treatment psychosocial care for survivors and their families in Ireland. Internationally, similar frameworks reinforce these priorities. The Standards for the Psychosocial Care of Children with Cancer (Wiener et al., 2015) recommend routine psychosocial assessments and interventions across the cancer trajectory, including the post-treatment phase. Likewise, the International Society of Paediatric Oncology (SIOP) and the Pan American Health Organization (PAHO) advocate for continuous, developmentally appropriate psychosocial support addressing both survivor and family needs (Trigoso et al., 2023). Together, national and international policies underscore the importance of examining post-treatment experiences and psychosocial factors such as social support, resilience and quality of life, highlighting the global relevance of this research.

Importantly, this study focuses exclusively on childhood leukaemia, the most common type of childhood cancer. The majority of studies to date have included children with a wide variety of cancer types and often fail to separate the results according to cancer type (Marbot et al., 2025). This is problematic because different cancer types can have varying treatment approaches, medical interventions and prognoses, which can significantly influence the experiences of children and their parents. By failing

to separate cancer types, previous research may overlook these differences, leading to overly generalised findings and conclusions that may not be fully applicable to childhood leukaemia survivors and their parents. Focusing specifically on childhood leukaemia will ensure that the unique needs and experiences of these children and their parents are accurately reflected, leading to more precise findings and enabling the development of more tailored support strategies and interventions that address the specific challenges faced by childhood leukaemia survivors and their parents.

In sum, this study responds to pressing gaps in both the research literature and national service provision by examining the post-treatment experiences of childhood leukaemia survivors and their parents through the integrated lens of social support, resilience and quality of life. It adopts a developmentally sensitive, family-focused approach and is grounded within a nationally relevant policy framework and is shaped by the lived insights of an expert-by-experience researcher. By examining how these psychosocial factors interact rather than in isolation, the study provides a nuanced understanding of post-treatment recovery. In doing so, the study aims to contribute to the growing field of psycho-oncology by deepening our understanding of the psychosocial dimensions of survivorship and informing the development of evidence-based, person and family-centred care pathways. Ultimately, this study aims to offer valuable guidance for healthcare professionals and policymakers striving to improve the quality of life and emotional recovery of childhood leukaemia survivors and their families.

1.14 The Present Thesis

The present thesis sets out to gain a deeper understanding of the post-treatment experiences of childhood leukaemia survivors and their parents relating to social support, resilience and quality of life. Recognising that survivorship is a dynamic and evolving process that impacts both the child and the wider family unit, this research comprises two main components: a systematic review of the existing literature and an empirical mixed-methods study.

The first part of the study was a systematic review designed to synthesise existing quantitative literature on social support from the perspective of child and adolescent cancer survivors, with a specific

focus on studies involving participants aged 18 years or younger to ensure developmental relevance. The review aimed to clarify how support is defined and measured and to examine its associations with psychosocial outcomes such as well-being, quality of life and stress.

Building on insights from the review, the thesis then employs a mixed-methods empirical design to explore psychosocial recovery and adjustment during the post-treatment phase. The quantitative strand aims to investigate the relationships between social support, resilience and quality of life among children who completed treatment for leukaemia within the past five years and their parents. Complementing this, the qualitative strand draws on in-depth interviews to explore the lived experiences of both children and parents, providing richer insights into their lived experiences of support, resilience and quality of life. Supplementing the quantitative data with the qualitative data will bring this project in line with recommendations for mixed-method research in the area of childhood cancer survivorship (Wiener et al, 2015).

1.15 Thesis Conspectus

This thesis consists of eleven chapters. Following on from the current introductory chapter, Chapter 2 outlines a systematic review of social support in child and adolescent cancer survivors. Chapter 3 presents the mixed-methods study design. In Chapter 4, methodological details pertaining to the quantitative strand of the study are presented. The quantitative findings are presented in Chapter 5 and critically discussed in Chapter 6. In Chapter 7, methodological details pertaining to the qualitative strand of the study are described. The qualitative findings are presented within Chapter 8 and critically discussed in Chapter 9. In Chapter 10, an integrative analysis of the findings from both the qualitative and quantitative strands is presented, alongside a critical discussion of the key findings of the mixed-method study. Concluding the thesis, in Chapter 11, the study's unique contribution, strengths and limitations, and implications for practice, research and policy are highlighted.

Chapter 2: Systematic Review

2.0 Overview

This chapter presents a systematic review of studies that have quantitatively explored social support from the perspective of child and adolescent cancer survivors aged 18 years or younger. The review directly contributes to the broader thesis aims by clarifying how social support is defined, measured and linked to psychosocial outcomes such as well-being, quality of life and stress. The research presented in this chapter was published as the paper "Social Support and Childhood Cancer Survivors: A Systematic Review (2006-2022)", in Psycho-Oncology (Deegan et al., 2023).

2.1 Introduction

Social support is widely recognised as a key psychosocial resource for children and adolescents undergoing and recovering from cancer treatment (Çavuşoğlu & Sağlam, 2015; Shin et al., 2019). It has been shown to buffer the effects of stress, promote emotional adjustment and support the broader developmental needs of young people facing illness-related disruptions (Çavuşoğlu & Sağlam, 2015; Shin et al., 2019). However, despite its crucial role, social support tends to reduce over time as children overcome their illness despite its ongoing importance even years after treatment has finished (Kelada et al., 2019; Melguizo-Garín et al., 2019; Wakefield et al., 2010).

A number of reviews to date have undertaken investigations of social support in families of children with cancer (Pedro et al., 2008), parents of children with cancer (Gise & Cohen, 2022), and siblings of children with cancer (Wawrzynski et al., 2021). Christiansen and colleagues (2015) conducted a literature review with children and adolescents with cancer to investigate social interaction as a standard of care in paediatric oncology and found evidence to suggest that youth with cancer should be provided with opportunities for social interaction, an important unmet need shown to improve adjustment, increase knowledge and decrease isolation; hence, implying the importance of social support. Woodgate (1999) carried out a literature review on research examining the varying dimensions of social support in children with cancer. However, Woodgate (1999) noted that the majority of studies included in their review

predominantly relied on parent or medical staff proxies of children's social support rather than studies examining social support from the perspective of the child. Taking this into consideration, Decker (2007) conducted a systematic review on studies examining social support from the perspective of adolescent cancer survivors aged 10–21 years. However, Decker's review focussed solely on studies with adolescents and was conducted almost 16 years ago. Since then, to our knowledge, no systematic review has been carried out on social support from the perspective of child and adolescent cancer survivors who were diagnosed with cancer as a child and aged 18 or under at the time of the study only. We believe this latter point is important because children and adolescents aged 18 or younger tend to have different needs/responsibilities than those aged over 18, where care may be predominantly parent-led, therefore it is important to disaggregate and focus solely on those aged 18 or younger.

Therefore, we aimed to synthesise and evaluate quantitative research exploring social support in childhood cancer survivors from the child and adolescents' perspective and examine the relationship between social support and outcomes such as quality of life, well- being and stress. Furthermore, given the wide disparity in approaches to social support noted in Decker's review (2007), a secondary aim of the review was to examine how social support in the above context is measured in the literature. Findings from this review may offer greater insight into social support in child and adolescents cancer survivors and may also inform future support interventions and provide recommendations to clinicians working in this area in relation to promoting adaptive social support approaches.

2.2 Method

This review followed the guidelines outlined by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework (Page et al., 2021). The review was submitted and registered with PROSPERO (No. CRD42022314715). The review has been conducted in accordance with that protocol.

2.2.1 Search Strategy & Study Selection Criteria

Searches were conducted on the 5th of February 2022 on the following five electronic databases: PsycINFO, PubMed, CINAHL, EMBASE and Web of Science using search terms related to: social support, childhood cancer, cancer and child/adolescent. Mesh terms were used for social support, childhood cancer, cancer, child and adolescent where they existed, as well as free text terms to ensure a comprehensive search of the literature was conducted. A comprehensive search strategy for each database is provided in Table 2.1.

Articles were included if they were full-text, peer reviewed journal articles published in English between 2006 and 2022. Only quantitative studies or mixed-methods studies with a quantitative element that could be clearly separated were included. Perceived or received social support had to be described as a variable in the study and measured by a dedicated social support instrument. Included studies had to measure perceived or received social support from the perspective of the child or adolescent with cancer (i.e., not by someone else e.g., family member or friend) in any stage of survivorship from the timepoint of diagnosis on. Children and adolescents of all genders up to the age of 18 years old who were diagnosed with any type of cancer under the age of 18 were included. Studies evaluating a social support instrument were excluded.

Table 2.1: Search Strategy Used for Each Database

Database	Search Strategy
PsycInfo	((“Childhood cancer”) OR ((DE "Neoplasms" OR DE "Benign Neoplasms" OR DE "Breast Neoplasms" OR DE "Endocrine Neoplasms" OR DE "Leukemias" OR DE "Melanoma" OR DE "Metastasis" OR DE "Nervous System Neoplasms" OR DE "Terminal Cancer" OR “neoplasm*” OR “cancer*”)) AND ("child*" OR "adolesce*"))) AND ((DE "Social Support" OR DE "Social Networks" OR DE "Online Social Networks" OR DE "Emotional Support" OR DE "Social Connectedness" OR "social support" OR "social network*” OR “emotional support”))
CINAHL	((MH "Childhood Neoplasms") OR (“childhood cancer”) OR (((MH "Neoplasms+") OR ("neoplasm*") OR ("cancer*")) AND ((MH "Child+") OR (MH "Adolescence+") OR (“child*”) OR (“adolesce*”)))) AND ((MH "Support, Psychosocial+") OR (MH "Social Support Index") OR (MH "Norbeck Social Support Questionnaire") OR (MH "Caregiver Support") OR “social support” OR “social network*” OR “emotional support”)
EMBASE	('social support' OR 'social network*' OR ‘emotional support’ OR 'social support'/exp OR 'social network'/exp OR ‘emotional support’/exp) AND (('neoplasm'/exp OR 'neoplasm*' OR 'cancer*') AND ('child*' OR 'adolesce*' OR 'child'/exp OR 'adolescent'/exp) OR 'childhood cancer'/exp OR 'childhood cancer')
PubMed	("childhood cancer"[All Fields] OR (("Neoplasms"[MeSH Terms] OR "cancer*"[All Fields] OR "neoplasm*"[All Fields]) AND ("Child"[MeSH Terms] OR "Adolescent"[MeSH Terms] OR "child*"[All Fields] OR "adolesce*"[All Fields]))) AND ("Social Support"[MeSH Terms] OR "Social Networking"[MeSH Terms] OR "Social Support"[All Fields] OR "social network*"[All Fields] OR “emotional support”[All Fields])
Web of Science	“social support*” OR “social network*” OR “emotional support*” AND child* OR adolesce* OR “childhood cancer*” OR “neoplasm*” OR “cancer*”

2.2.2 Data Screening & Extraction

The review was conducted with a team of two reviewers (AD & CB) and two supervisors (SD & PG). After searches were completed, the results were exported to the reference management system, Zotero (Corporation for Digital Scholarship, 2021), where duplicates were removed before being exported to Covidence (Veritas Health Innovation, 2021) where abstract/title and full text screening took place. Each reviewer independently screened titles and abstracts of the retrieved studies for inclusion, while a third reviewer (SD or PG) was available to consult where disagreement occurred. In cases of disagreement, a consensus approach was taken and the study was included in the full-text screening stage. At the full-text screening stage, studies that did not meet the eligibility criteria were excluded with the reason for

exclusion recorded. Where the full text of a study was not available, the author was contacted and the reviewers independently screened the texts and, similarly, a third reviewer was available to consult for any disagreements. Data was extracted by the first author from each paper included in the review onto a standardised, prepared data extraction form that included general characteristics (e.g., authors names, year of publication, title, study design), unique demographic and clinical factors of interest (e.g., age, gender breakdown, setting, cancer diagnosis) and information and major findings relating to social support.

2.2.3 Quality Appraisal

Quality appraisal was conducted by both reviewers (AD & CB) using the quantitative quality appraisal tool developed by Dunne and colleagues (2017). Items marked 'yes' received a score of 2, items marked 'partially' received a score of 1 and items marked 'no' received a score of 0. Articles were scored out of a maximum of 24, with those scoring 17 or above considered high quality, those scoring between 9 and 16 considered adequate quality and those scoring below 9 considered poor quality. See Appendix A for full details.

2.2.4 Synthesis of Results

A narrative synthesis approach was selected to analyse the data due to the heterogeneity of social support definitions and measures included. Narrative synthesis is useful for integrating the results of studies to organise and identify patterns across studies from the data extracted (Popay et al., 2006).

2.3 Results

A total of 8682 abstracts across five databases were identified, 4959 after duplicates were removed, 171 for full-text screening and 10 met the inclusion criteria and were included in this review (see Figure 2.1). Of those included, seven studies employed quantitative analyses only and three studies employed mixed-methods. Table 2.2 provides a summary of the sample, purpose and social support findings for the reviewed studies.

Figure 2.1: *PRISMA Diagram: Overview of Search Results Included and Excluded at Each Stage of Review*

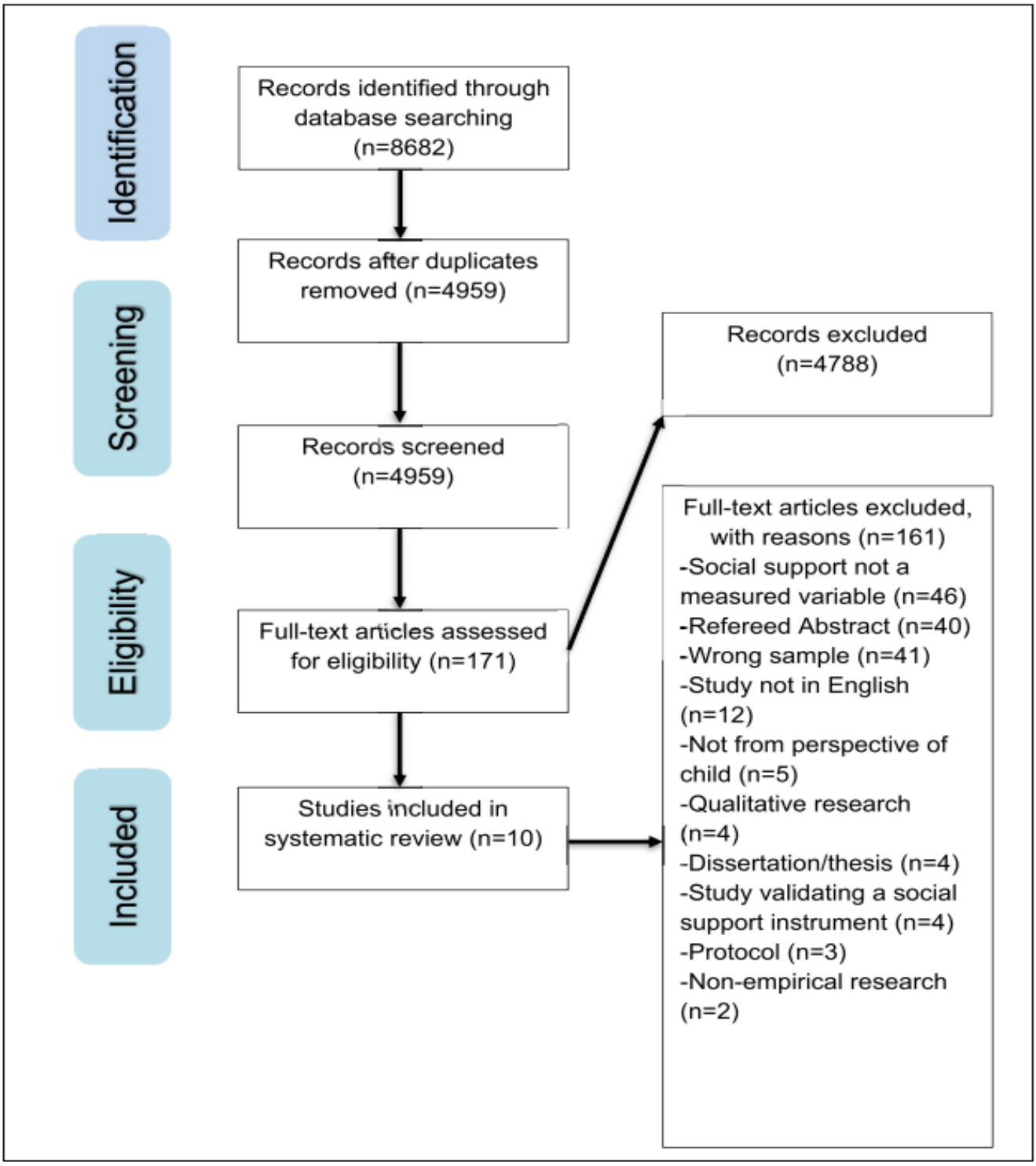


Table 2.2: *Extracted Studies*

Study	Aim related to Social Support	Country	Setting	Participants	Age/Gender of Cancer Survivors	Cancer Diagnosis	Stage	Social Support Instrument	Social Support Finding
Bikmazer et al., 2020	To evaluate and compare social support perceived by children with cancer (HO), Bronchiectasis (B) and healthy controls (C)	Turkey	Hospital	114 participants divided into 3 groups: HO (n=47), B (n=25), and C (n=41).	9-15 years 59.5% male	Leukaemia/Lymphoma (56.8%), Solid tumor (43.2%)	Active treatment	Social Support Appraisal Scale (Dubow et al., 1991)	B survivors perceived significantly less support from friends (p=.002) and family (p=.007) than HO patients and C. HO & B survivors had significantly lower scores on the teacher subscale (p=.04) than C participants
Conrad & Altmaier, 2009	To assess the types of social support children report receiving at camp and the relationship between social support and adjustment	America	Summer Camp	25 survivors & their parents	9-18 years 56% female	Brain tumor, Hodgkin's, Acute Lymphoblastic Leukaemia, Wilms tumor, Ewing sarcoma, and other cancers	Active treatment & In remission	The Survey of Children's Social Support (Dubow & Ullman, 1987)	Campers perceived emotional/informational support, emotional/esteem-enhancing support and tangible support more frequently than children in the general population. No significant relationship found between social support & adjustment

Study	Aim related to Social Support	Country	Setting	Participants	Age/Gender of Cancer Survivors	Cancer Diagnosis	Stage	Social Support Instrument	Social Support Finding
D'Urso et al., 2018	To explore the impact of perceived social support on posttraumatic stress symptoms (PTSS)	UK	Hospital	60 participants: 34 survivors, 26 siblings & 1 parent per family	8-18 years 62% female	Acute Lymphoblastic Leukaemia (53%), Other Leukaemia's (3%), Hodgkin's and Non-Hodgkin's (12%), Solid tumor (17%) and Brain tumor (15%)	Active treatment & Off treatment	The Multidimensional Scale of Perceived Social Support (Zimet et al., 1988)	Perceived social support was not predictive of PTSS in cancer survivors.
Ekim & Ocakci, 2015	To examine the relationship between the reaction to cancer and perceived social support	Turkey	Hospital	108 survivors	12-18 years 52% female	Leukaemia/Lymphoma, Solid tumor	Active treatment	The Multidimensional Scale of Perceived Social Support (Zimet et al., 1988)	Survivors perceived social support from families as the greatest, followed by social support from friends and a special person. A positive correlation was found between perceived social support and posttraumatic growth.

Study	Aim related to Social Support	Country	Setting	Participants	Age/Gender of Cancer Survivors	Cancer Diagnosis	Stage	Social Support Instrument	Social Support Finding
Gilliam et al., 2012	To investigate social support as a predictor of physical activity in childhood cancer survivors	America	Telephone survey, recruited from hospital	105 survivors and their caregivers; plus 36 caregivers of younger survivors (aged 6–7 years) alone	6-16 years 51% male	Leukaemia (32%), CNS tumor (21%), Soft tissue sarcoma (14%), Kidney tumor (11%), Non-Hodgkin's Lymphoma (9%), Neuroblastoma (6%), Hodgkin's (4%), Osteosarcoma (3%), and other cancers (3%)	Off treatment	Family & Peer Support Scale (Taylor et al., 2002)	Social support from family and peers emerged as significant predictors of physical activity

Study	Aim related to Social Support	Country	Setting	Participants	Age/Gender of Cancer Survivors	Cancer Diagnosis	Stage	Social Support Instrument	Social Support Finding
Gilliam et al., 2013	To evaluate the relationship between social support and survivor physical activity levels	America	Telephone survey, recruited from hospital	105 survivors and their parents	8-16 years 51% female	Leukaemia (36%), CNS tumor (19%), Soft tissue sarcoma (11%), non-Hodgkin's lymphoma (11%), Kidney tumor (9%), Neuroblastoma (5%), Osteosarcoma (4%), Hodgkin's lymphoma (3%), and other cancers (2%)	Off treatment	Family & Peer Support Scales (Taylor et al., 2002)	Both family and peer support had a significant direct and indirect effect on survivor physical activity, mediated through increases in self-efficacy
Greszta, 2006	To analyse perceptions of social support derived from the narrative stories of children in	Poland	Hospital	67 survivors and healthy controls	6-16 years 59.7% male	Acute Lymphoblastic Leukaemia (100%)	In remission	Narrative stories	Healthy controls perceived significantly more social support than survivors ($p<0.001$)

Study	Aim related to Social Support	Country	Setting	Participants	Age/Gender of Cancer Survivors	Cancer Diagnosis	Stage	Social Support Instrument	Social Support Finding
	Leukaemia remission and healthy children								Parents were the primary source of social support
Liu et al., 2020	To explore the relationship between social support, self-efficacy & psychological stress	China	Hospital	141 survivors	8-16 years 58 % male	Leukaemia (63.2%), Lymphoma (14.8%), Sarcoma (9.93%), and others (12.77%)	Active treatment	Social Network Questionnaire (Zuo et al., 2005)	Social support could directly and indirectly predict the psychological stress of survivors through self-efficacy or coping style.
Soejima et al., 2015	To explore the relationship between support for school re-entry and social support from peers and teachers	Japan	Hospital	36 survivors and their caregivers	9-18 years 50% male	Leukaemia (42%), Lymphoma (39%), Osteosarcoma (11%), and others: Wilms tumor, Ovarian tumor, Nasopharyngea	Off treatment	The Scale of Expectancy for Social Support (Okayasu et al., 1993)	Survivors reported receiving social support from both teachers and peers Social support was associated with successful school re-entry

Study	Aim related to Social Support	Country	Setting	Participants	Age/Gender of Cancer Survivors	Cancer Diagnosis	Stage	Social Support Instrument	Social Support Finding
						l carcinoma (8%)			
Wright et al., 2013	To examine the influence of social support on survivor physical activity levels	Canada	Hospital	48 survivors and healthy controls	13-18 years 60.5% male	Leukaemia (66.6%), Lymphoma (18.7%), Solid tumor (12.5%), CNS tumor (2.1%)	Off treatment	Adapted version of the Amherst Health & Activity Study: Student Survey	Physical activity levels were positively correlated with adult social support factors for survivors, but not for healthy controls.

2.3.1 Quality Appraisal

All the included studies were deemed to have acceptable quality according to the quality appraisal tool, the details of which are provided in Appendix A. The reviewed studies were all deemed to be of high quality. The main methodological concerns identified through quality appraisal were the lack of justification for sample size, failing or only partially describing non-respondents and studies lacking the presence of a control group.

2.3.2 Study Characteristics

All of the studies were exploratory and cross-sectional in design. Studies were conducted in the United States (n = 3), Turkey (n = 2), China (n = 1), the United Kingdom (n = 1), Canada (n = 1), Japan (n = 1) and Poland (n = 1). Nine studies recruited survivors from paediatric hospitals and centres, while one study recruited participants through a summer camp for children with cancer (Conrad & Altmaier, 2009). Total sample size of survivors for included studies was 716, with samples ranging from 25 to 141. The age range of studies was 8–18 years of age. Samples ranged from 38% to 60.5% male and 39.5%–62% female. Leukaemia was the most common type of cancer across samples (n = 10). Time since diagnosis varied across samples, with some studies focussing only on those recently diagnosed with cancer to other studies including children from diagnosis through completion of treatment.

2.3.3 Social Support Measures

Table 2.3 displays the seven dedicated measures of social support used in the studies reviewed. One of the studies used narrative techniques to assess social support (Greszta, 2006).

Table 2.3: *Social Support Instruments*

Instrument	Components Measured	Number of Items	Instrument Design	Reliability/Validity	Studies employing this instrument
Social Support Appraisal Scale (Dubow et al., 1991)	Comprises three subscales measuring child and adolescent's appraisal of friend, family, and teacher support	41	5-point Likert scale ranging from 1=always to 5=never. High scores indicate greater support	Internal consistency of total scale =.93	Bikmazer et al., 2020
The Survey of Children's Social Support (Dubow & Ullman, 1987)	Consists of 3 subscales 1) Scale of Available Behaviours (SAB), 2) Social Support Appraisals Scale 3) Support Network. Only the subscale of the SAB was used in Conrad & Altmaier's (2009) study; this measures how frequently children perceive receiving three separate types of social support: emotional/informational support, emotional/esteem and tangible support	38 on the SAB subscale	5-point Likert scale ranging from 1=never to 5=always. Higher scores indicate less support	Internal consistency of subscales range from .74 to .88	Conrad & Altmaier, 2009
Multidimensional Scale of Perceived Social Support (Zimet et al., 1988)	Measures perception of social support obtained from three separate sources (family, friends, and a special person)	12 (4 on family, 4 on friends, 4 on special person)	7-point Likert scale ranging from 1=not at all to 4=I agree entirely. Higher scores indicate greater support	Internal consistency of total scale =.88	Ekim & Ocacki, 2015; D'Urso et al., 2018
Family & Peer Support Scales (Taylor et al., 2002)	This scale was developed to measure perceived frequency of encouragement, support & engagement from family & peers for physical activity. Responses were summed to create a family support score	19 & 3 items respectively	5-point Likert scale	Internal consistency of family scale =.88 and peers scale =.78	Gilliam et al., 2012 Gilliam et al., 2013

Instrument	Components Measured	Number of Items	Instrument Design	Reliability/Validity	Studies employing this instrument
	and a peer support score.				
Social Network Questionnaire (Zuo et al., 2005)	Evaluates the relationship between child and parents/ friends/teachers etc. describing 4 dimensions: affirmation & support; company & intimacy; satisfaction; conflict & punishment	36	5-point Likert scale ranging from 1=never to 5=almost. Higher total scores mean heavier degree of social support	Internal consistency of subscales range from 0.64 and 0.90.	Liu et al., 2020
The Scale of Expectancy for Social Support (Okayasu et al., 1993)	Measures perceived availability of support from mothers, fathers, siblings, peers, and teachers to handle future problems (peer and teacher subscales only), each source is evaluated separately.	16 *in total*	4-point Likert scale ranging from 1=not at all to 4=very often. Total scores for each subscale range from 16 to 64.	Internal consistency of the subscales range from 0.96–0.97	Soejima et al., 2015
The Amherst Health & Activity Study: Student Survey (adapted)	To identify physical activity choices, sport team participation, social support, environmental, & personal barrier factors that may impact physical activity. Specific social support domain.		6-point Likert scale ranging from 0=never to 5=everyday		Wright et al., 2013

2.3.4 Social Support Findings

2.3.4.1 Levels of Social Support

None of the reviewed studies distinguished between social support perceived and actual levels of social support received. All of the reviewed studies (n = 10) examined children and adolescent's perceptions of social support. Three studies clearly distinguished between different types: Liu and colleagues (2020) explored four dimensions of social support; affirmation and support, company and intimacy, satisfaction and, conflict and punishment; Conrad and Altmaier (2009) distinguished between emotional, informational and tangible support; while Greszta (2006) distinguished between emotional and instrumental support.

2.3.4.2 Sources of Social Support

Four studies reported on sources of social support. Ekim and Ocakci (2015) compared children and adolescents perceptions of social support from their family, their friends and a special person or significant other while receiving treatment for cancer in hospital and found that social support from families, particularly parents was perceived as the greatest (M = 28.64, SD = 2.53), followed by social support from friends (M = 18.82, SD = 7.61) and then social support from a special person (M = 9.50, SD = 5.47). Greszta (2006) also reported that parents were the greatest source of social support for 94% of leukaemia survivors and 70% of healthy children in their study. The remaining 6% of leukaemia survivors perceived strangers to be another source of social support to them (Greszta, 2006).

Bikmazer and colleagues (2020) compared survivors' perception of social support from their family, friends and their teacher and found that friends were the most prevalent source of social support (M = 81.33, SD = 12.03), followed by social support from one's family (M = 55.29, SD = 5.15) and then social support from one's teacher (M = 41.94, SD = 7.39). Friends and teachers were also reported as sources of social support by Soejima and colleagues (2015). In their study, social support from friends was associated with home visits during temporary discharge (r = 0.384), understanding of hospital experiences (r = 0.376) and positive interactions (r = 0.471). Furthermore, teachers' understanding of physical appearance (r = 0.453), academic performance (r = 0.466), the hospital experience (r = 0.422)

and how to interact with children ($r = 0.417$) was related to social support from peers. Likewise, social support from teachers was associated with understanding of the disease/treatment ($r = 0.386$), academic performance ($r = 0.439$) and the teacher's role as a liaison between the school and the hospital ($r = 0.422$).

2.3.4.3 Gender differences relating to Social Support

Four studies examined gender differences relating to social support in child and adolescent cancer survivors, where mixed findings were reported. D'Urso and colleagues (2018) examined potential gender differences in perceived social support scores and levels of posttraumatic stress symptoms (PTSS) between siblings and childhood cancer survivors and found no significant differences with respect to gender. Furthermore, Ekim and Ocakci (2015) found no significant gender differences in perceived family social support. However, the same study found statistically significant differences ($p < 0.05$) in social support from friends between girls and boys, with girls ($M = 20.46$, $SD = 6.25$) reporting significantly more social support from friends than boys ($M = 16.73$, $SD = 4.86$). Similarly, Conrad and Altmaier (2009) reported a significant main effect for gender in their study (F (3,19) = 3.352, $p = 0.041$). They found that girls perceived more social support than boys on all three subscales of social support [(emotional/informational ($p = 0.021$), emotional/esteem-enhancing ($p = 0.298$) and tangible support ($p = 0.074$))], while this relationship was found to be statistically significant for the subscale of emotional/ informational support only ($F(1, 21) = 6.188$; $p = 0.021$). Furthermore, there was a significant main effect for the type of social support reported among the males in this study ($F(2,9) = 5.295$, $p = 0.030$). Pairwise comparisons showed that males in this study reported emotional/esteem enhancing support more frequently than tangible support. Similarly, females yielded a significant main effect for type of support reported ($F(2,12) = 8.517$, $p = 0.005$). Pairwise comparisons showed that emotional/esteem enhancing support and emotional/informational support were reported significantly more frequently than tangible support among the females in this study. Finally, Gilliam and colleagues (2013) reported that male survivors were physically more active than females (p=0.04).

2.3.4.4 Age Differences Relating to Social Support

Three studies examined age differences relating to social support in childhood cancer survivors, where mixed findings were reported. Conrad and Altmaier (2009) found no significant differences between cancer survivors aged 9-12 years and older survivors aged 13-18 years. However, Gilliam and colleagues (2013) reported that younger age at the time of assessment was associated with greater levels of family support for physical activity ($r = -0.023$, $p < 0.05$) and peer support for physical activity ($r = -0.21$, $p < 0.05$). Likewise, younger age at diagnosis was associated with greater levels of family support ($r = -0.027$, $p < 0.001$) and peer support for physical activity ($r = -0.25$, $p < 0.001$). Notably, Gilliam and colleagues (2012) found that survivors aged 8-11 years reported family support (p=.04) as the greatest predictor of physical activity, while older survivors aged 12-16 years reported both family (p=.01) and peer support (p=.02) as strong predictors of physical activity.

2.3.4.5 Social Support in Childhood Cancer Survivors Compared to Other Groups

Five studies examined social support in childhood cancer survivors compared to other groups, where mixed findings were reported. Bikmazer and colleagues (2020) found that social support from family ($p = 0.002$) and friends ($p = 0.007$) was significantly greater for childhood cancer survivors and healthy controls when compared with children with Bronchiectasis. However, they also found in the same study that both childhood cancer survivors and Bronchiectasis patients perceived significantly less support from their teacher ($p = 0.04$) than healthy children. Greszta (2006) reported that 88% of healthy children perceived greater social support compared to 49% of leukaemia survivors ($p < 0.001$). On the other hand, Conrad and Altmaier (2009) reported that children who attended a summer camp for children with cancer perceived greater levels of social support than children in the general population. Greszta (2006) also found that the intensity of parental support was significantly lower for leukaemia survivors ($M = 1.2$) than healthy children ($M = 2.5$, $p < 0.001$). Specifically, paternal support was significantly less intense for survivors ($M = 0.4$) than healthy children ($M = 1.1$, $p < 0.001$). Likewise, maternal support was significantly less intense for leukaemia survivors ($M = 0.8$) than healthy children ($M = 1.4$, $p < 0.01$). Greszta (2006) also reported that leukaemia survivors reported less ‘proximity support’ (29%, $p < 0.01$)

and ‘confidant support’ (23%), than healthy children (68% and 27% respectively). In other words, nearly all of the healthy children and half of all leukaemia survivors perceived emotional support from their parents. Finally, in the same study, Greszta (2006) reported that 48% of leukaemia survivors perceived instrumental support compared to only 5% of healthy children ($p < 0.001$). Wright and colleagues (2013) reported no significant differences (p = NS) in perceived social support total scores between cancer survivors ($M = 19.1$, $SD = 5.7$) and healthy comparisons ($M = 19.1$, $SD = 6.2$).

2.3.4.6 Relationship of Social Support to Other Outcomes

The relationship of social support to other outcomes was examined in eight of the reviewed studies. Ekim and Ocakci (2015) found a strong positive relationship between perceived social support and posttraumatic growth total scores ($p = 0.00$). Moreover, there was a significant negative correlation between extending the duration of treatment and total perceived social support scores. Soejima and colleagues (2015) found that social support from peers and teachers was positively associated with school re-entry.

Three studies found evidence to support a positive relationship between social support and physical activity levels (Gilliam et al., 2012; Gilliam et al., 2013; Wright et al., 2013). Firstly, Gilliam and colleagues (2012) reported that greater levels of family ($p = 0.004$) and peer ($p = 0.013$) support were significant predictors of greater physical activity levels among childhood cancer survivors. Likewise, Gilliam and colleagues (2013) reported that the total effect of family support on survivor physical activity levels was significant ($c = 0.48$, <0.001; overall $R^2 = 0.41$). Similarly, the total effect size of peer support on survivor physical activity was significant ($c = 0.46$, $p < 0.001$; overall R^2=0.43). Finally, Wright and colleagues (2013) indicated a moderately positive correlation between social support and survivor physical activity levels. The following adult social support factors were significantly and positively correlated with physical activity in the group of cancer survivors: encouragement ($z = -3.13$, $p = 0.002$), having an adult telling them physical activity was good for their health ($z = -3.26$, $p = 0.001$), having a sibling or friend do physical activities or sports with them ($z = -0.237$, p = 0.018) and transportation to a place they could do physical activity ($z = -3.29$, $p = 0.001$).

Gilliam and colleagues (2013) applied a multiple mediation model to their analysis and found that family and peer support were both directly and indirectly linked with physical activity. The total effect of family support ($c = 0.48$, $p < 0.001$; overall $R^2 = 0.41$) and peer support ($c = 0.46$, $p < 0.001$; overall $R^2 = 0.43$) on survivor physical activity levels were significant. Self-efficacy partially mediated the relationship between social support and physical activity. In other words, survivors who reported greater family support ($c' = 0.38$, $p < 0.001$) and peer support ($c' = 0.38$, $p < 0.001$), endorsed greater self-efficacy for physical activity and in turn reported higher physical activity levels. Liu and colleagues (2020) found similar mediation effects between perceived social support, self-efficacy, coping style and psychological stress in children with cancer. Social support was found to be the largest direct negative predictor of psychological stress ($r = -0.371$, $p < 0.01$), while also having an indirect negative effect on psychological stress through improvements in self-efficacy and adopting positive coping strategies ($r = -0.055$, $p < 0.05$). Liu and colleagues (2020) also reported that severity of depression was negatively correlated with some aspects of social support including affirmation and support ($r = -0.331$, $p < 0.01$) ($M = 143.22$, $SD = 29.24$), company and intimacy ($r = -0.360$, $p < 0.01$) ($M = 99.62$, $SD = 21.22$) and satisfaction ($r = -0.213$, $p < 0.05$) ($M = 62.44$, $SD = 11.33$), while being positively correlated with conflict and punishment ($r = 0.178$, $p < 0.05$) ($M = 81.25$, $SD = 18.47$). Moreover, anxiety was negatively correlated with the dimensions of 'affirmation and support' ($r = -0.176$, $p < 0.05$) and 'company and intimacy' ($r = -0.199$, $p < 0.05$). Likewise, stress was also negatively correlated with the dimensions of "affirmation and support" ($r = -0.220$, $p < 0.01$) and "company and intimacy" ($r = -0.213$, $p < 0.01$).

Studies also reported non-significant relationships between social support and some outcome variables. D'Urso and colleagues (2018) found no significant relationship between perceived social support and PTSS in childhood cancer survivors, despite finding a significant relationship among the siblings of these survivors. Likewise, no significant relationship was found between child reported perceived social support and the behavioural/emotional adjustment of children as rated by parents following a specialised summer camp for children with cancer (Conrad & Altmaier, 2009).

2.4 Discussion

The current review is the first to synthesise the current literature from 2006 on social support from the perspective of child and adolescent cancer survivors. The review extends on Decker's (2007) review by focussing exclusively on survivors of childhood cancer aged 18 or under. The findings highlight the value of social support for childhood cancer survivors and how it is related, both positively and negatively, to a number of outcome variables, such as posttraumatic growth, school re-entry, physical activity, psychological symptoms and a number of other psychosocial outcomes. This review also highlights that social support for childhood cancer survivors can come from a number of sources, with support from family and friends reported as the most influential among the reviewed studies.

The review highlighted that there is a lack of consistency in the measurement and conceptualisation of social support in the literature. Definitions of social support often lack clarity, making it difficult to carry out a review with social support as the central concept. From the initial screening stages, it was noted that researchers often refer to any type of 'help' as social support and/or examine this support as part of a larger construct that is, social quality of life or social support as a coping strategy. As a result, research in the area is being diluted by studies that do not look specifically at social support as a singular construct but rather as part of a bigger construct. This may be one of the reasons for the small number of studies that met the eligibility criteria, highlighting the importance of examining social support in more meaningful and efficient ways using dedicated social support measures, as well as defining social support clearly in this context.

The way social support was measured across the childhood cancer survivorship literature varied considerably across studies. No single measure of social support was used more than twice across all 10 studies, highlighting that there is a lack of dedicated social support instruments available for children who have cancer or have previously experienced cancer. Not having a single set of dedicated social support measures for childhood cancer survivors makes it increasingly more difficult to compare findings across studies. The majority of social support instruments used were also developed using 'healthy' populations for example, the Multidimensional Scale of Perceived Social Support (Zimet et al., 1988) and The Scale

of Expectancy for Social Support (Okayasu et al., 1993). As a result, these instruments may be missing out on key aspects relating to the cancer experience that may not be captured otherwise. Moreover, social support was generally not the main variable of focus in the reviewed studies. Future research should use measures specifically designed for children and adolescents only, such as the Survey of Children's Social Support (Dubow & Ullman, 1987) or, better still, instruments specifically designed for those with childhood cancer. To our knowledge, there are no instruments specifically designed to measure social support in children and adolescents with cancer, thus highlighting the need for the development of a new measure, which will help increase consistency across studies and advance our knowledge in the area. With this in mind, researchers should design, modify, adapt and pilot/validate instruments to incorporate key elements of the cancer experience, such as diagnosis, treatment, hospital stays, relapse etc. These measures should assess all four types of social support (emotional, informational, instrumental and appraisal), both received and perceived from the child's social network, that is, parents, peers, healthcare professionals etc. Likewise, social support measures are often dependent on proxy reports from parents or caregivers, rather than from the child or adolescent themselves.

The review highlighted that there are limited studies examining the child's experience of social support during cancer survivorship. This may relate to our definition of a child being anyone up to the age of 18 years old only, therefore excluding studies that classified 19- year-olds, for example, as children. Moreover, studies often group survivors aged 18 or younger with survivors over the age of 18 and, as a result, these studies were excluded if they did not disaggregate the data separately which may have resulted in valuable findings being excluded. However, it is important to consider those aged 18 or under distinctly from those over the age of 18, particularly in relation to consent and responsibility. Furthermore, the majority of studies had small sample sizes, limiting the ability to interpret the true effect size of social support due to power limitations.

Family and friends were reported as the major sources of social support for childhood cancer survivors (Ekim & Ocakci, 2015; Greszta, 2006; Bikmazer et al., 2020). Friends become increasingly more important during middle to late childhood, while family support is important at all stages of

childhood (Spitz et al., 2020). Parents were indicated as the most important sources of social support by survivors in two of the reviewed studies (Ekim & Ocakci, 2015; Greszta, 2006). This is not surprising, as previous research has indicated that family members, particularly parents, are major sources of social support for children/adolescents with cancer (Haluska et al., 2002; Ritchie, 2001). Family members typically live in the same household as the child and, therefore, may spend considerably more time with the child than anyone else. Furthermore, children who are ill tend to have restricted social support systems and/or networks due to their illness and treatment despite having greater social support needs than healthy children (Nestmann & Hurrelmann, 2012). As a result, ill children may be highly dependent on the support they receive from their family and friends even more so than healthy children.

Mixed findings were found in relation to gender differences. While some studies reported no differences between genders (D'Urso et al., 2018; Ekim & Ocakci, 2015), others found that girls tend to report more social support than boys (Conrad & Altmaier, 2009; Ekim & Ocakci, 2015). Additional studies are needed using larger and more evenly dispersed samples to elucidate the mixed and inconsistent findings in relation to gender differences for social support among childhood cancer survivors.

Similarly, mixed findings were found in relation to age related differences. Only three of the 10 reviewed studies explored potential age-related differences of included children and adolescents (Conrad & Altmaier, 2009; Gilliam et al., 2012; Gilliam et al., 2013). These studies differentiated between younger children (8-11 and 9-12 years) and older children/adolescents (12-16 and 13-18 years); however, it is difficult to draw conclusions from these studies and generalise findings due to the limited number of studies analysing age-related differences. Conrad and Altmaier (2009) reported no significant differences in social support scores between younger children and older children, while Gilliam and colleagues (2013) reported that younger age at diagnosis and assessment was associated with greater family and peer support for physical activity. Moreover, Gilliam and colleagues (2012) found that younger children reported family support as the greatest predictor of physical activity, while older children reported both family and peer support as strong predictors of physical activity. This may be because peer support

becomes increasingly more important to us as we grow older, particularly during late childhood and early adolescence, while family support remains important throughout all stages of our life. Future studies should consider trying to use standardised ages for developmental stages to enable synthesis and comparisons across ages to identify specific age-related differences.

Childhood cancer survivors' self-reports on social support were compared with healthy comparison children reports in four of the reviewed studies (Bikmazer et al., 2020; Conrad & Altmaier, 2009; Greszta, 2006; Wright et al., 2013). Mixed findings were reported with some studies indicating no differences between childhood cancer survivors and healthy children (Wright et al, 2013), some indicating that survivors perceive greater social support (Bikmazer et al., 2020; Conrad & Altmaier, 2009) and others reporting that healthy children perceive greater social support than survivors (Greszta, 2006). It is difficult to draw concrete conclusions in relation to differences between these groups due to the number of studies lacking the presence of a control for comparison across groups and the mixed findings. This points towards a need to conduct additional studies exploring differences in social support between childhood cancer survivors and healthy children. Another possible reason for the lack of consistency in results may relate to the fact that the measures were not developed specifically for the paediatric oncology population.

Social support was positively related to posttraumatic growth (Ekim & Ocacki, 2015), school re-entry (Soejima et al., 2015) and physical activity (Gilliam et al., 2012; Gilliam et al., 2013; Wright et al., 2013), and negatively related to psychological stress (Liu et al., 2020), depression (Liu et al., 2020), anxiety (Liu et al., 2020) and stress (D'Urso et al., 2020; Liu et al., 2020) in the reviewed studies. More studies exploring the relationship of social support to various outcomes need to be conducted in order to gain a deeper understanding of the role of social support in these relationships. Likewise, more research into the moderating and mediating effects of types of social support on key psychosocial outcomes is necessary to draw out the nuanced relationship between variables. Additional research needs to be conducted exploring both the positive outcomes associated with social support such as well- being, resilience and posttraumatic growth, as well as the more negative outcomes such as distress, anxiety and

depression. The reviewed studies have examined a number of these outcomes already; however, the limited number of studies conducted and limited number of outcomes explored makes it difficult to draw definitive conclusions. Furthermore, none of the reviewed studies utilised the stress-buffering model of social support (Cohen & Wills, 1985) in their analysis, despite the strong theoretical knowledge that social support could buffer the potentially negative effects of stress on these outcomes. The review highlights that there is a lack of theoretically informed studies conducted in the area, such studies would help inform and direct research. With this in mind,there is a clear opportunity for future research to evaluate social support as a buffer in the relationship between stress and psychological outcomes.

2.4.1 Clinical Implications

Additional research in the area would help in the development of interventions that enhance social support and psychosocial outcomes for childhood cancer survivors. Some potential intervention approaches could include social recreational interventions such as camps and group-based programmes, educational interventions such as social skills training and cognitive-behavioural interventions such as CBT (Meyler et al., 2010). These interventions need to encompass the entire social support network of the child/adolescent, including their parents, siblings, healthcare professionals and the other significant people in their life. Researchers must be careful not to stereotype the cancer survivorship experience as a one size fits all. Depending on the situation and stage of the cancer journey, social support required may vary considerably from one child to the next. Children and adolescents should be carefully assessed in relation to their own individual social support needs and preferences at all stages of the cancer journey as part of their routine standard of care (Christiansen et al., 2015). As highlighted by Ekim and Ocakci (2015) the support children and adolescents receive tends to decline over time as they successfully manage their illness, however this does not mean that the social support they receive should be halted or given less of a priority than as before. As such, children and adolescents should be provided with opportunities for social interaction at all stages of the cancer journey (Christiansen et al., 2015). It is also likely that social support will be more important at certain stages of a survivor's life; for example, when

transitioning from primary to secondary school, as there can be huge gaps in school attendance between survivors and their peers making the transition more difficult for survivors (Stam et al., 2005). This highlights the importance of having strong social support during this transition. Likewise, the cancer experience and related late effects can have an impact on the development and maintenance of romantic relationships in young adulthood and beyond, again highlighting the importance of continued support beyond the end of treatment (Thompson et al., 2013). Moreover, all of the studies were cross-sectional in nature, limiting the ability to make conclusions about the pattern and long-term impact of social support throughout the child's cancer experience. Future research should prioritise longitudinal research design studies that examine social support over time.

2.4.2 Study Limitations

Despite following recommended practice for conducting systematic reviews, a number of limitations were inherent in this review. Firstly, the possibility that relevant papers might have been missed cannot be excluded despite employing a deliberately inclusive search strategy across multiple databases. Secondly, the exclusion of non-English language studies may have resulted in publication bias. Thirdly, because of the limited number of quantitative studies and the heterogeneity in the measures employed to assess social support from the perspective of the child/adolescent, it was not feasible to formally pool results across studies and perform meta-analyses or meta syntheses. Finally, it was not possible to draw any conclusions in relation to differences in social support for those in active treatment versus off treatment or differences in social support between various cancer types due to the dearth of studies in this area examining these differences.

Despite these limitations, this review syntheses the evidence pertaining to the topic of social support among childhood cancer survivors. Social support has been shown to play a protective role in the face of stress, therefore it is important to gain a clearer understanding of social support from the perspective of childhood cancer survivors. This will facilitate the development of interventions and

promote the importance of strong social support for children and adolescents at all stages of the cancer journey.

2.4.3 Conclusion and Implications for Thesis

The systematic review offers greater insight into the current state of the literature on social support among childhood cancer survivors aged 18 or younger. The evidence from the review highlights that social support, particularly from family and friends, is highly valued by cancer survivors. The findings also demonstrate that social support is related both positively and negatively to a number of psychosocial variables (i.e., posttraumatic growth, psychological stress, physical activity etc). However, mixed findings in relation to gender, age and group differences indicates the need for more research elucidating these findings further. Like previous reviews conducted by Woodgate (1999) and Decker (2007), this review further highlights the methodological challenges that researchers face when studying social support in childhood cancer survivorship literature, including small sample sizes and an overreliance on cross-sectional designs. Furthermore, despite a growing emphasis on survivor well-being, many studies still treat social support as a secondary variable, limiting our understanding of its dynamic and potentially protective role in long-term psychosocial adjustment.

Importantly, these findings directly informed the design and direction of the mixed-methods study that follows. First, the review highlighted consistent evidence that social support plays a pivotal role in shaping psychosocial outcomes for children, while also revealing that it is often underexamined relative to resilience and quality of life. This justified the need to centre social support, alongside resilience and quality of life, as a core variable of interest within the thesis's empirical investigation. Given the diversity in measurement approaches observed in the literature, particular attention was paid to selecting validated, age-appropriate instruments capable of capturing these constructs from the perspective of children. The review also reinforced the importance of capturing the subjective experience of support, which in turn informed the decision to adopt a qualitative component to complement the quantitative strand and explore the contextual meaning of support during the post-treatment period. Building on the insights and gaps

identified in the systematic review, the following chapter outlines the methodological approach adopted in this thesis.

Chapter 3: Methodology

3.0 Introduction

This chapter presents the methodology of the present study. Initially, the study aims and objectives are outlined. This is followed by an overview of mixed-methods research, the philosophical paradigm underpinning the design of the study, and the strengths and challenges associated with implementing mixed-methods research designs. Finally, the specific design to be utilised in the present study will be discussed, including the rationale for implementing this study design.

3.1 Study Aims

As mentioned in the introduction, the overarching aim of this study is to gain a deeper understanding of the post-treatment experiences of childhood leukaemia survivors (aged 7-17 years) and their parents relating to social support, resilience and quality of life. The aims of this mixed-methods inquiry are two-fold:

1. to explore the relationship between, and factors related to social support, resilience and quality of life among children who finished treatment for leukaemia within the past 5 years[1] and their parents (quantitative strand).
2. to explore the post-treatment experiences of childhood leukaemia survivors and their parents, with a particular focus on social support, resilience and quality of life (qualitative strand).

3.1.1 Quantitative Strand Objectives

The objectives of the quantitative strand are to:

1) Establish self-reported levels of social support, resilience and quality of life among children and parents.

[1] The decision to focus on those within the first 5 years post-treatment reflects the recognition that this period typically represents the initial post-treatment phase and is distinct from long-term survivorship, which is generally defined as 5 years or more beyond treatment completion.

2) Explore the relationship between children's social support, resilience and quality of life with their self-reported demographic and clinical factors.
3) Examine the relationship between parents' social support, resilience and quality of life with their self-reported demographic factors and their child's clinical factors (parent-reported).
4) Explore the relationship between children's social support, resilience and quality of life.
5) Explore the relationship between parents' social support, resilience and quality of life.

3.1.2 Qualitative Strand Objectives

The objective of the qualitative strand is to:

1) Explore how children experience the transition to post-treatment life, particularly in relation to social support, resilience and quality of life.
2) Explore how parents of childhood leukaemia survivors experience the transition to post-treatment life, particularly in relation to social support, resilience and quality of life.

3.2 Mixed-Methods Approach

A mixed-methods research design was deemed most suitable to address the aims of this study. Mixed-methods research continues to gain popularity and is often referred to as the third methodological movement, combining both quantitative and qualitative approaches (Creswell & Plano, 2018; Johnson et al., 2019; Olsen, 2004). Essentially, mixed-methods research seeks to draw on insights from both quantitative and qualitative perspectives (Johnson et al., 2007) and involves the collection, analyses and mixing of both quantitative and qualitative data in a single programme of inquiry (Creswell & Plano Clark, 2018).

There are a number of reasons why researchers opt for a mixed-methods approach. Qualitative research collects open-ended information to gain an in-depth understanding of the experiences, views and contexts of individuals (Mason, 2017). Conversely, quantitative research uses close-ended questions, such as those found in validated scales and instruments, to answer research questions statistically (Creswell &

Plano Clark, 2018). Combining quantitative and qualitative data allows for a more comprehensive understanding of research questions than either qualitative or quantitative approaches alone could offer (Shorten & Smith, 2017; Wasti et al., 2022). Other reasons for selecting a mixed-methods approach include the need to clarify initial findings. In quantitative research, the underlying meanings and factors behind statistical relationships are often unclear. Using a mixed-methods approach allows for a deeper understanding of these quantitative results by incorporating a qualitative strand, which can provide new insights and interpretations (Shorten & Smith, 2017; Wasti et al., 2022).

A mixed-methods approach was considered the most appropriate for the current study to explore the post-treatment experiences of children and parents, particularly regarding their social support, resilience and quality of life. A key consideration when conducting mixed-methods research is whether it is suitable for addressing the research questions being explored. Relying solely on a quantitative or qualitative approach in the current study would not fully address the research objective. While quantitative data can reveal patterns, relationships, and statistical significance, it often lacks the ability to explain the 'how' and 'why' behind these results (Shorten & Smith, 2017; Wasti et al., 2022). In the context of this thesis, while a quantitative strand alone may highlight significant and non-significant relationships and factors related to social support, resilience and quality of life, it would not explain how or why these relationships occur, nor would it reveal factors that may be influencing them. To complement and enrich the interpretation of these findings, a qualitative strand was conducted in parallel, offering deeper insight into lived experiences. By integrating both approaches, this study provides a more holistic understanding of social support, resilience and quality of life in childhood cancer survivors and their parents. Therefore, a convergent parallel mixed-methods approach was deemed most suitable methodology for addressing the aims of this research.

3.2.1 Philosophical Orientation

The decision to use a mixed-methods research design is underpinned by a pragmatic approach. Pragmatism does not restrict the researcher to a specific method but instead supports the use of whichever

method best addresses the research question (Dawadi et al., 2021; Robson, 2002). For example, pragmatism acknowledges that alongside quantitative data, qualitative data may provide greater insight into explaining the quantitative results from the individual's perspective and experience (Creswell & Plano Clark, 2018). Choosing an appropriate paradigm is important for justifying the use of mixed-methods research (Hall, 2013). Tashakkori and Teddlie (2010) argue that pragmatism offers the best foundation for this type of design. It advocates for drawing on the strengths of both quantitative and qualitative methods to best answer research questions (Creswell & Plano Clark, 2018; Dawadi et al., 2021; Johnson & Onwuegbuzie, 2004).

Therefore, the present study adopts a pragmatic approach, combining quantitative and qualitative methods to generate the greatest level of information relating to the topic and address the research topic of interest. This is particularly relevant to the current study given the complex and multi-layered nature of the constructs under investigation: social support, resilience and quality of life in childhood leukaemia survivors and their parents. These are constructs that are both measurable and shaped by personal context. As such, pragmatism aligns with the study's aim to produce nuanced, relevant and actionable insights into post-treatment survivorship.

3.2.2 Advantages and Disadvantages of Mixed-Methods Research

Researchers use mixed-method approaches for a number of reasons. Applying a mixed-method design to examine a research topic allows for a more insightful, complete and comprehensive investigation (Farquhar et al., 2011). Further, adopting a mixed-methods approach allows the researcher to capitalise on the strengths and offset the weaknesses of using either quantitative or qualitative methods alone (Creswell & Plano Clark, 2018). In this study, quantitative methods capture measurable patterns in social support, resilience and quality of life, while qualitative methods provide contextual depth and insight into the lived experiences behind these patterns. As such, the research questions, centred on both what these psychosocial outcomes look like and how they are experienced, cannot be fully addressed by either method alone.

Likewise, another reason for using a mixed-methods approach is that both methods can complement each other and can be used to further explain findings. For example, while the quantitative strand identifies patterns and associations between social support, resilience and quality of life, the qualitative strand offers insight into how these constructs are experienced by survivors and their parents (Creswell & Plano Clark, 2018). Moreover, the integration of quantitative and qualitative findings, allows for a richer interpretation, whether the results converge, complement, or diverge, each scenario offers valuable insight. Converging findings can enhance the credibility of conclusions, while complimentary or divergent results may reveal complexity or contextual nuances that a single method alone could not capture (Creswell & Plano Clark, 2018; Lund, 2012).

Mixed-methods research, despite its many strengths, also has its limitations. The terminology used in mixed-methods research and the definition of mixed-methods research itself remains a persistent challenge. Several terms, such as multiple methods, mixed research and mixed methodology, have been used to describe the approach (Creswell & Plano Clark, 2018; Tashakkori & Teddlie, 2010). Similarly, there is no universally accepted definition of mixed-methods research, with multiple variations proposed. This lack of clarity makes it difficult to make comparisons between studies using mixed-methods designs (Creswell & Plano Clark, 2018; Tashakkori & Teddlie, 2010). To address this, researchers should clearly define the terms and approach they are using to ensure better understanding and improve compatibility across research (Creswell & Plano Clark, 2018). In this thesis, mixed-methods research is defined as the purposeful integration of quantitative and qualitative approaches to gain a fuller understanding of the post-treatment experiences of childhood leukaemia survivors and their parents, with a particular focus on the relationship between social support, resilience and quality of life.

Furthermore, mixed-methods research can be costly and time consuming due to the collection and analysis of different data types (Johnson & Onwuegbuzie, 2004). Researchers need to be highly competent and proficient in multiple methods of data collection and analysis (Johnson & Onwuegbuzie, 2004). It has also been noted that publishing mixed-methods studies can be challenging due to their lengthy nature and the tendency of some journals to favour either quantitative or qualitative findings

(Bryman, 2007; Malina et al., 2011). Finally, conflicting findings between quantitative and qualitative results can be difficult to assess, however, this can be resolved through careful data integration (Creswell & Plano Clark, 2018).

Despite these limitations, the decision to adopt a mixed-methods approach was driven by the complexity of the research topic and the need for both breadth and depth in understanding the post-treatment experiences of childhood leukaemia survivors and their parents. The quantitative component offered measurable insights into the relationships between social support, resilience and quality of life, while the qualitative component offered deeper, personal insights into these constructs and the post-treatment phase. By weighing the additional time, resources and analytical demands against the potential for richer, more meaningful findings, the benefits of methodological complementarity ultimately justified the use of a mixed-methods design in this study.

3.3 Present Study Design

This study employed a mixed-methods convergent parallel design consisting of two strands: a quantitative strand and a qualitative strand. The quantitative cross-sectional questionnaires were conducted with childhood leukaemia survivors and their parents to explore the relationship between, and factors related to social support, resilience and quality of life, from both a child and parent perspective. While qualitative semi-structured interviews with parents and children were conducted to capture in-depth perspectives on their post-treatment experiences relating to social support, resilience and quality of life. To ensure the qualitative strand was appropriate and relevant for children and young people, the study consulted with the Young Persons' Advisory Group (YPAG) affiliated with the National Children's Cancer Service at CHI Crumlin. YPAG comprises children and young people with lived experience of childhood cancer who contribute to research design to ensure study designs and methods are relevant, acceptable, and responsive to the needs of young people affected by cancer. Their feedback informed the development and refinement of child-focused interview topic guides, ensuring they were age-appropriate, sensitive and grounded in lived experience. The findings from the quantitative and qualitative strands are analysed and

presented separately. They are then integrated to identify points of convergence, complementarity, divergence, or silences which forms the basis for the final interpretation and discussion.

3.3.1 Rationale for Using a Convergent Parallel Design

Mixed-methods research designs are typically categorized into six main types: convergent parallel, explanatory sequential, exploratory sequential, embedded, transformative, and multi-phase designs (Sharma et al., 2023). For this study, the convergent parallel design was used because it best aligns with the research objectives and the need for a comprehensive understanding of the post-treatment experiences of childhood leukaemia survivors and their parents, particularly in relation to the relationship between social support, resilience and quality of life. The convergent parallel design is well-suited for this study as it gives equal weighting to qualitative and quantitative data, allowing both to be collected and analysed separately before being merged together. This approach ensures that the strengths of both data types complement each other, offering a deeper and more holistic understanding of survivors' and parents' perspectives.

While other mixed-methods approaches were considered, they were less suitable for the study's objectives. The explanatory sequential design, which begins with a quantitative phase followed by a qualitative phase, would not have allowed for equal emphasis or simultaneous insight from both strands. Conversely, the exploratory sequential design, which begins with a qualitative phase and is followed by a quantitative phase, was similarly limiting because the qualitative findings would have overly shaped the quantitative inquiry, rather than treating both as equally valuable from the outset. Next, in an embedded design, one data type (qualitative or quantitative) is prioritised, while the other is used to supplement it, which conflicts with the study's aim to give equal weight to both. Next, a transformative design integrates qualitative and quantitative data sets within a specific theoretical or conceptual framework which was not the intent of the current study. Finally, multi-phase designs involve multiple phases of both qualitative and quantitative data collection and analysis, often over an extended period, which again did not align with the scope or timeline of this project.

Other factors that informed the decision to use a convergent parallel design include the timing of study phases, the weighting of qualitative and quantitative components, the planned data integration approach, and consideration of the advantages and limitations of this method. These factors are discussed in the following sections.

3.3.2 Timing of Study Phases

The timing of the study phases refers to when each strand was conducted, which can be either concurrent or sequential (Creswell & Plano Clark, 2018). Concurrent designs are when qualitative and quantitative strands occur at approximately the same time. While sequential designs are when study strands occur chronologically (quantitative strand followed by a qualitative strand, or vice versa). In the present study, concurrent timing was chosen, whereby the collection and analysis of quantitative and qualitative data took place at approximately the same time. Since neither the quantitative or qualitative strand relies on the other to be completed first, they were collected simultaneously. This design was particularly valuable in capturing a real-time, multifaceted understanding of the post-treatment experiences of childhood leukaemia survivors and their parents. Collecting both data concurrently ensured that the findings reflected the same psychosocial context, thereby enhancing the coherence and comparability of the integration process, allowing for a more comprehensive interpretation of how social support, resilience and quality of life are both measured and lived.

3.3.3 Weighting of Study Phases

The weighting of study phases refers to the level of priority assigned to each phase within the overall study (Creswell & Plano Clark, 2018). In the present study, both the quantitative and qualitative data are given equal priority or weighting as it is envisaged that both strands will uncover rich findings. The quantitative data will provide numerical data on the relationship between, and factors related to social support, resilience and quality of life among childhood leukaemia survivors and their parents, while the qualitative data will offer an in-depth exploration of their lived experiences of social support, resilience

and quality of life during the post-treatment phase. By giving equal priority to both strands, the study ensures that it captures both quantitative trends and qualitative experiences, providing a more comprehensive understanding of the research topic.

3.3.4 Data Integration Approach

Data integration is a critical element of mixed-methods research (Creswell & Plano Clark, 2018). The process of integration involves merging both qualitative and quantitative methods together in one study (Creswell & Plano Clark, 2018). A wide range of guides and frameworks have been developed to facilitate the integration of findings from mixed-methods research (Tashakkori & Teddlie, 2010; O'Cathain et al., 2010). O'Cathain and colleagues (2010) identified three approaches to data integration of quantitative and qualitative findings. These included 1) triangulation protocol, 2) following a thread, and 3) the use of a mixed-methods matrix.

The triangulation protocol was considered the most suitable method of integration for this study as it allows for the interpretation of quantitative and qualitative findings after independently analysing both datasets. By contrast, following a thread involves identifying key themes in one data set to guide the analysis of the other dataset (O'Cathain et al., 2010). This approach risks prioritising one data type over the other, which is inconsistent with the study's convergent parallel design which aims to equally prioritise both data types. Similarly, the mixed-methods matrix was not chosen as it requires organising findings within a structured framework, using predefined categories that may limit the flexibility of data interpretation (O'Cathain et al., 2010). Given the study aims to explore the complex and dynamic relationships between social support, resilience and quality of life, a rigid matrix structure may constrain the depth of interpretation.

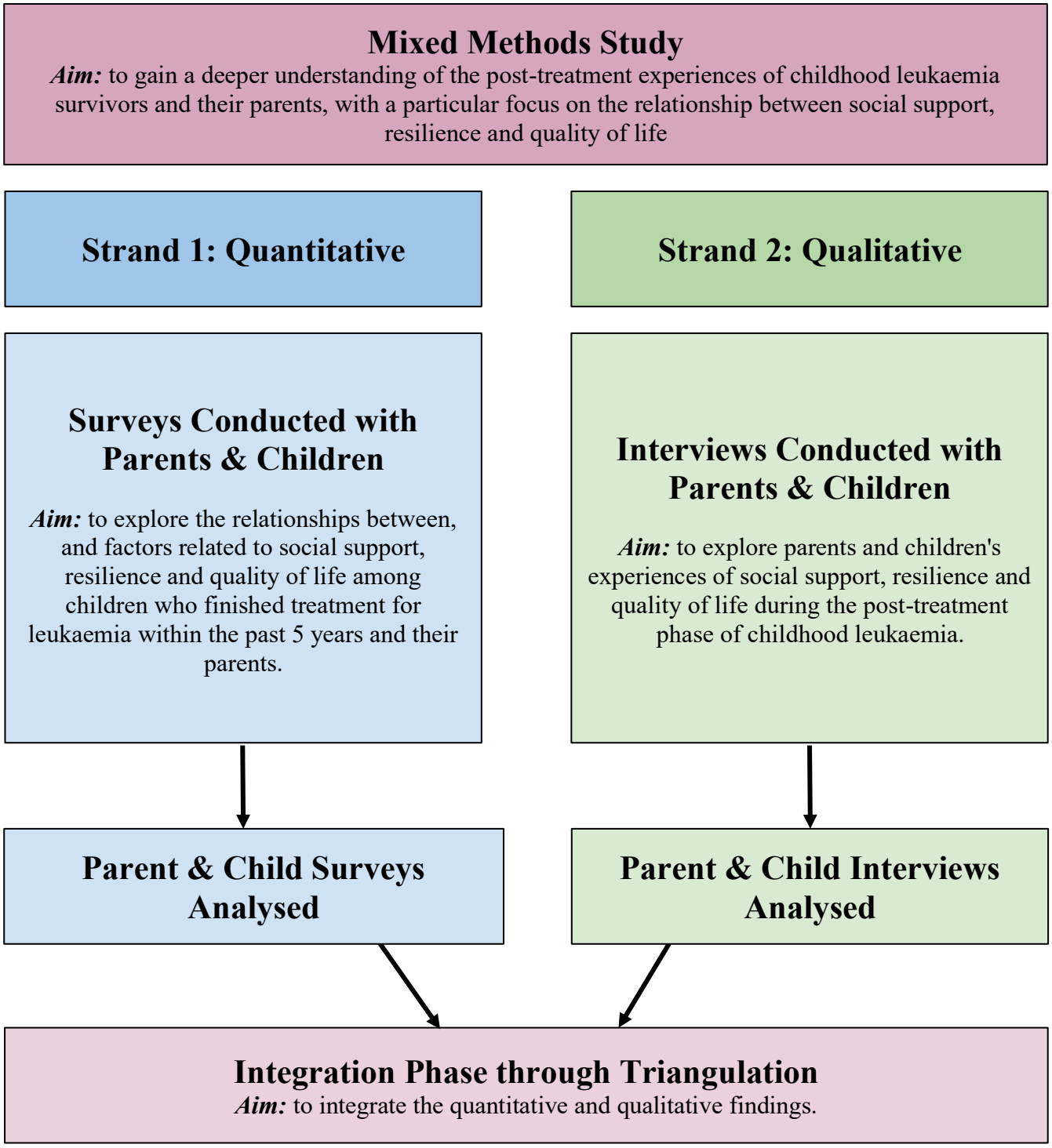
For these reasons and in accordance with the recommendations of O'Cathain and colleagues (2010) and Farmer and colleagues (2006), the triangulation protocol was selected for data integration, as it allows for the independent analysis of both datasets before comparing and interpreting them together. This process of integration allows for several possible outcomes, including; convergence (where both sets

of findings produce the same finding on a theme); complementarity (where both sets of findings feature a theme but have differing perspectives or elaborated on different dimensions of the same theme); dissonance (where the sets of findings have conflicting findings on a theme); and silence (where one set of findings uncovers a theme whereas it appears silent in the other set). By employing a triangulation protocol, this study ensures a comprehensive, nuanced and in-depth understanding of the research topic.

3.4 Conclusion

To conclude, in the present study, in order to address the research aims and to answer the specific research questions, a convergent parallel design, grounded in the philosophical paradigm of pragmatism, is employed. A visual representation of the overall study design is presented in Figure 3.1.

Figure 3.1: *Visual Diagram of Convergent Parallel Design Process*



Chapter 4: Quantitative Strand

4.0 Introduction

Childhood leukaemia, once associated with a poor prognosis, now has a high survival rate due to significant medical advances (Devilli et al., 2021; Kiem Hao et al., 2020; Pui et al., 2015). However, survival does not necessarily signal the end of its impact. A growing body of research has highlighted the enduring psychosocial challenges that persist beyond the completion of treatment for many survivors and their families (Conway Keller et al., 2020; Inhestern et al., 2020; Muskat et al., 2017; Tremolada et al., 2017). As survivorship becomes a more prominent and prolonged phase of the cancer trajectory, increasing attention has turned to the psychosocial dimensions of recovery, particularly the roles of social support, resilience and quality of life. These constructs are critical for understanding the long-term well-being of childhood leukaemia survivors and their parents. Parents often carry the emotional, practical and financial burdens of their child's illness and recovery (Greenzang et al., 2016; Vetsch et al., 2018), while children and adolescents must navigate reintegration into school, friendships and routines, often with a changed sense of self (Collins et al., 2019; Vanclooster et al., 2019). Yet, despite the centrality of these psychosocial factors, support needs are frequently overlooked or unmet (Inhestern et al., 2020; Labay et al., 2004; Muskat et al., 2017).

Social support, defined as the interpersonal relationships we have with others (Melguizo-Garín et al., 2019), has been shown to buffer stress and promote psychological adjustment in childhood cancer survivors. Despite its known protective role, support networks often diminish once treatment ends, even as psychosocial needs remain high or even intensify (Hoekstra-Weebers et al., 2001; Merz et al., 2024; Wijnberg-Williams et al., 2006). Similarly, resilience, defined as the ability to cope effectively with stress and adversity, maintain emotional well-being, and adapt in the face of challenges (Wagnild & Young, 1993) varies widely among survivors and parents. While quality of life, a multidimensional construct encompassing physical, psychological and social well-being (McDougall & Tsonis, 2009; WHOQOL, 1995), remains a key indicator of successful survivorship.

Importantly, both social support and resilience have been associated with better quality of life outcomes (Larsen et al., 2023; McDougall & Tsonis, 2009; Klassen et al., 2011), suggesting these factors may play an interdependent role in post-treatment adjustment. A number of studies have shown that higher perceived social support is associated with greater resilience among paediatric cancer survivors and their families, suggesting that support networks may reinforce adaptive coping mechanisms and emotional regulation (Marbot et al., 2025; Rosenberg et al., 2014; Ye et al., 2015). Conversely, resilience may enable survivors and parents to sustain, seek out and mobilise social support, highlighting a reciprocal relationship between the two constructs (Marbot et al., 2025; Rosenberg et al., 2014; Ye et al., 2015). Both social support and resilience have independently been linked to improved quality of life outcomes, including reduced psychological distress, better emotional functioning and greater social engagement (Kazak et al., 2010; Tremolada et al., 2017; McDonnell et al., 2021). These findings suggest that social support may function as a protective resource that not only enhances psychological resilience but also directly and indirectly contributes to better quality of life. Likewise, resilient coping strategies may allow families to manage the stress of late effects, uncertainty and reintegration challenges, thereby preserving or improving perceived quality of life. Despite this growing body of evidence, few studies have explored these constructs together or considered the interrelationships between them across both child and parent perspectives, particularly in the context of childhood leukaemia survivorship. This leaves an important gap in our understanding of how children and their parents adjust after treatment and how psychosocial resources operate.

This quantitative study seeks to address this gap by investigating the interrelationships between social support, resilience and quality of life in a cohort of children who have completed treatment for leukaemia within the past five years, alongside their parents. The following chapter outlines the methodological details of the quantitative strand of the study, including: 1) aims and specific objectives; 2) participants; 3) study procedure; 4) key ethical considerations; and 5) data analysis.

4.1 Aims and Hypotheses

The overall aim of this quantitative strand was to explore the relationship between, and factors related to social support, resilience and quality of life among children who finished treatment for leukaemia within the past 5 years and their parents.

The objectives were to:

1) Establish self-reported levels of social support, resilience and quality of life among children and parents of childhood leukaemia survivors.
2) Explore the relationship between children's social support, resilience and quality of life with their self-reported demographic and clinical factors.
3) Examine the relationship between parents' social support, resilience and quality of life with their self-reported demographic factors and their child's clinical factors (parent-reported).
4) Explore the relationship between children' s social support, resilience and quality of life.
5) Explore the relationship between parents' social support, resilience and quality of life.

Based on previous research we hypothesised the following among children and parents of childhood leukaemia survivors:

1) Higher levels of resilience will be associated with greater social support, while lower levels of resilience will be associated with poorer social support (Marbot et al., 2025; Rosenberg et al., 2014; Ye et al., 2015).
2) Higher levels of social support will be associated with a greater quality of life, while lower levels of social support will be associated with poorer quality of life (Castellano-Tejedor et al., 2015; Melguizo-Garín et al., 2023; Tremolada et al., 2016).
3) Higher levels of resilience will be associated with a greater quality of life, while lower levels of resilience will be associated with poorer quality of life (Chung et al., 2021; Luo et al., 2021; Marbot et al., 2025).

4.2 Participants

The sample for the quantitative strand consisted of 35 children and 70 parents[2] of childhood leukaemia survivors. Originally, we planned for a longitudinal component to the study, inviting participants who had finished treatment within the past 6 months and assented/consented for follow up at 6- and 12-months post-treatment. However, the number of participants who agreed to or completed follow-up assessments was insufficient to conduct longitudinal analyses. A detailed breakdown of the child and parent participants' characteristics is provided in chapter 5 in section 5.1.

4.2.1 Selection Criteria

Participants were eligible for the quantitative study if they were (1) children aged under 18 years at the time of the study who had successfully completed treatment for any type of leukaemia within the past 5 years, or (2) parents/guardians of children who had successfully completed treatment for any type of leukaemia within the past 5 years. If both parents wanted to complete the questionnaire, an additional copy could be requested from the researcher. Individuals presenting with significant neurodiversity or mental health needs were ineligible to participate e.g., Down syndrome, intellectual disabilities. Individuals who were not competent in the English language and/or did not have the capacity to provide informed assent/consent were also ineligible to participate.

4.3 Recruitment

Data was collected over a 9-month period (October 2023 - June 2024). Potential participants were recruited via three main recruitment routes: 1) through the leukaemia clinic in Children's Health Ireland (CHI) at Crumlin, 2) contacting various cancer organisations, and 3) through social media. Specific recruitment details are outlined below.

[2] The term 'parents' is used throughout the text to refer inclusively to both parents and guardians.

4.3.1 Leukaemia Clinic

CHI at Crumlin is the largest paediatric hospital in Ireland and also home to the National Paediatric Haematology Oncology Centre. Children and parents who met the inclusion criteria for the study were informed about the study details during leukaemia clinic hours by a consultant/nurse on-site at CHI Crumlin. If parents and/or children expressed an interest in hearing more about the study, they were then directed to the researcher who was on site to provide further information about the study and seek participation. A survey packet (i.e. cover letter, plain language statements/information sheets, consent forms, questionnaires) was distributed to those interested in participating (see Appendices B1–B10). Contact details for relevant support services were also provided to all participants (see Appendix C). If children and/or their parents decided to participate in the study, they either: 1) completed the hard-copy questionnaires at the hospital, 2) completed the questionnaires at home and returned them directly to the postgraduate researcher in the stamped and addressed envelope provided, or 3) completed the questionnaire online via the Qualtrics survey platform. These three completion formats were offered for the purpose of facilitating greater response rates. Additionally, a poster/flyer advertising the study and the postgraduate researcher's contact details was displayed in the leukaemia clinic (see Appendix D1). If children and/or parents wished to participate, they could either: 1) scan the QR code on the poster, which brought them directly to the questionnaire, or 2) contact the researcher directly for further information using the contact details provided. In all cases, parental assent was also required for the child's participation.

4.3.2 Cancer Organisations

Potential participants were also recruited via various cancer organisations such as Breakthrough Cancer Research, Childhood Cancer Ireland, CanTeen Ireland, the Irish Cancer Society, Solving Kids Cancer UK, Cancer Fund for Children, Daisy Lodge and Hand in Hand Children's Cancer Charity. Organisations were contacted by email with details of the study and information to share with potential participants (see Appendix D2). Many of the organisations shared details of the study via their social media platforms,

emailed potential participants via their email lists, and/or shared a poster/flyer in their centres. The researcher's contact details were included so that those who wished to participate could contact the researcher directly regarding any queries or concerns they had. Participants were provided with information regarding the study and were offered the opportunity to either: 1) complete the questionnaire online via the Qualtrics survey link provided; or 2) request a hard copy through email.

4.3.3 Social Media

A study-specific Instagram, Facebook and Twitter page - "Life After Childhood Leukaemia" page was set up to share details of the study, as well as recruitment messages (see Appendix D3). These pages were managed by the postgraduate researcher. Paid advertisements were used on Facebook to target specific audiences and groups, i.e., those following childhood cancer related content. A Qualtrics survey link was included on all posts directing participants to the online questionnaire.

4.4 Procedure

Data was collected through quantitative questionnaires assessing social support, resilience and quality of life. Participants had the option of completing the questionnaires either online via the Qualtrics survey platform (Qualtrics, Provo, UT) or by pen and paper. Three versions of the questionnaire were designed; a version for children aged 8-12 years, a version for children aged 13-17 years and a version for parents/guardians. For all three of the above recruitment routes, in addition to being able to complete hard copy or online versions of the questionnaire, all participants were also offered the option of telephone assistance with survey completion. The questionnaire took approximately 30 minutes to complete. In the case of hard copy completion, a separate envelope was enclosed in the survey packet for child participants should they wish to keep their responses private from their parents.

Participation was completely voluntary. In terms of hard-copy participation, each participant was given a pre-packed survey pack marked with a unique identifying code (see Appendices B1-B10). The pack included a plain language statement/information leaflet, consent/assent forms, the questionnaire

booklet, a resource sheet outlining details of available services and an additional envelope marked with the same unique ID code. Participants were given instructions to first review the plain language statement/information leaflet, and if interested in participation to then complete the consent form and questionnaire, and to seal them in the separate numbered envelopes provided. If consent/assent was not obtained from the participant, their participation was complete. Parents were also made aware that they were under no obligation to share details of the study with their child, however doing so implied that they consented for their child to participate. Parents were encouraged to discuss the details of the study with their child if they were happy for them to participate. Furthermore, children were reminded that just because their parents consented for them to participate, it was ultimately up to themselves whether they wanted to take part or not. Children and parents completed the questionnaires separately from each other; however, it was recommended that parents assisted children if they required help. The unique code on the forms enabled the researcher to match participant consent forms and contact details with their questionnaire data, thus ensuring appropriate consent was provided.

In terms of online participation, upon clicking the link to the survey, participants were directed to the plain language statement/information leaflet. Those interested in participation could then select the option to progress to the consent/assent form. If participants answered 'no' to any of the questions on the consent/assent form, they were automatically directed to the end of the questionnaire. Those who consented to participation were then automatically directed onto the questionnaire.

4.5 Questionnaires

The questionnaires for children and parents were developed from an amalgamation of existing valid and reliable age-appropriate child and parent instruments. The measures used to assess the variables of interest (social support, resilience and quality of life) are presented in Table 4.1 below.

Table 4.1: *Questionnaire Measures*

	Social Support	Resilience	Quality of Life
Parents/Guardians	MSPSS	RS25	SF-36
Children 12 years and younger	CASSS	RS10	PedsQL (ages 8-12 version)
Children 13-17 years	CASSS	RS25	PedsQL (ages 13-18 version)

MSPSS: The Multidimensional Scale of Perceived Social Support (Zimet et al., 1988)
CASSS: The Child and Adolescent Social Support Scale (Malecki et al., 2000)
RS25: The Resilience Scale (Wagnild & Young, 1993)
RS10: The Resilience Scale for Children (Wagnild, 2012)
SF-36: The 36-Item Short Form Survey (Ware & Sherbourne, 1992)
PedsQL: The Pediatric Quality of Life Inventory (Varni et al., 2001)

4.5.1 Social Support

The Child and Adolescent Social Support Scale (CASSS) (Malecki et al., 2000) was used to measure social support in children aged 12 years and younger and in children aged 13-17 years. The CASSS is a 60 item measure consisting of five 12-item subscales (parent, teacher, classmate, close friend and people in my school). For the purpose of this study, we used four of these subscales in our measure of social support, namely the parent, teacher, classmate and close friend subscales. Therefore, children were asked to respond to 48 statements. On every subscale, items 1-3 pertain to emotional support, 4-6 informational support, 7-9 appraisal support, and 10-12 instrumental support. Children are asked to read each statement and rate (1) how often they perceive that support and (2) how important it is to them that they perceive that support. The frequency ratings are on a 6-point scale, ranging from (1), never to (6), always. A higher score indicates that the support is perceived more frequently. The importance ratings are on a 3-point scale, from (1), not important to (3), very important. A higher score indicates that the support is very important to them. The CASSS has demonstrated strong validity and reliability, with Cronbach's alpha values > .80 across subscales (Malecki et al., 2000).

The Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988) was used to measure parent/guardian perceived social support. The MSPSS is a 12-item measure, with a 7-point Likert scale, ranging from (1), very strongly disagree, to (7), very strongly agree. The MSPSS is concerned with an individual's perception of the availability of emotional support (empathy, trust) and instrumental support (advice, help) to them across three different subscales (a) their family, (b) their friends and (c) a significant other or special person. Variability between these factors is captured in the MSPSS. The minimum subscale score possible is 4 and the maximum subscale score possible is 28. Furthermore, the minimum total score is 12 and the maximum total score is 84. Higher scores represent higher levels of perceived social support (Landeta & Calvete, 2002). The MSPSS demonstrates high psychometric qualities with strong internal consistency and test-retest reliability scores (Zimet et al., 1988; Landeta & Calvete, 2002; Clara et al., 2003). The coefficient alpha for the total scale is 0.85, with reported coefficient alphas for each of the subscales also demonstrating high internal consistency (Significant Other = 0.91; Family = 0.87; and Friends = 0.85) (Zimet et al., 1988). Both total scores and subscale scores demonstrated high stability over 2-3 weeks, with correlations ranging from .72 and .85, representing strong internal reliability. Construct validity has been established for the MSPSS via the confirmation of hypothesised negative correlations between perceived social support and anxiety and depression symptoms (Zimet et al., 1998).

4.5.2 Resilience

The Resilience Scale for Children (RS10) (Wagnild, 2012) was used to measure resilience in children aged 12 years and younger. It is a 10-item strengths-based tool that helps children recognise their strengths and capacity to respond in a positive way to challenges across five core elements: (1) sense of purpose and meaning, (2) authenticity, (3) equanimity, (4) self-reliance, and (5) perseverance. Children respond on a 4-point Likert scale, ranging from (1) not at all like me, to (4) a lot like me. The RS10 uses a total score rather than scores for each of the five elements. Total possible scores ranged from 10 to 40, with higher scores indicating higher levels of resilience. The RS10 demonstrates high psychometric

qualities with strong validity and reliability (Cronbach's alpha > .80) (Cajada et al., 2023; Chung et al., 2021).

The Resilience Scale (Wagnild & Young, 1993) was used to measure resilience in parents/guardians and children aged 13 years and older. The Resilience Scale is a 25-item strengths-based tool, with a 7-point Likert scale ranging from (1) strongly disagree, to (7) strongly agree. The measure consists of five core characteristics: purpose, perseverance, equanimity, self-reliance and existential aloneness. The Resilience Scale uses a total score rather than scores for each of the five characteristics. Total possible scores range from 25 to 175, with higher scores indicating greater levels of resilience. Internal consistency of the scale is good with alpha coefficients reported to be between 0.85 and 0.94 (Wagnild & Young, 1993).

4.5.3 Quality of Life

The Pediatric Quality of Life Inventory (PedsQL) (Varni et al., 2001) was used to measure quality of life in children aged 12 years and younger and children aged 13-17 years. The PedsQL is a brief measure that asks children to respond to 23 different statements relating to their health-related quality of life, on a 5-point Likert scale, ranging from (0), 'never', to (4), 'almost always'. Two versions of the scale were used, the 8–12 year old version for younger children and the 13-18 year old version for the older children. The 23 items in the PedsQL comprise four generic core scales: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items) and school functioning (5 items). Two summary scores can be computed: a psychosocial health summary score and a physical health summary score, as well as a total scale score. The psychosocial health summary score is the mean score of the emotional, social and school functioning scales (15 items). The physical health summary score is the same as the physical functioning scale score (8 items). While the total scale score is the mean of all 23 items. Items are reversed scored and transformed to a 0-100 scale, with higher scores indicating better health related quality of life. The PedsQL has been shown to be reliable (Cronbach's alpha > .80) and valid,

distinguishing between healthy children and children with acute and chronic conditions, as well as distinguishing between disease severity within chronic health conditions (Varni et al., 2001).

The 36-Item Short Form Survey (SF-36) (Ware & Sherbourne, 1992) was used to measure quality of life in parents/guardians. The SF-36 asks participants to respond to 36 different statements relating to their health-related quality of life. The SF-36 has eight individual subscales: physical functioning (10 items), role limitations resulting from physical health problems (4 items), bodily pain (2 items), general health perception (5 items), energy and vitality (4 items), social functioning (2 items), role limitations resulting from emotional problems (3 items), and mental health (5 items). For each domain, a score ranging from 0 to 100 is calculated with a higher score indicating better health. By use of factor score coefficients, the domain scores can be combined into two higher-order summary scores, the physical component summary (PCS) and mental component summary (MCS). The MCS includes the subscales of energy and vitality, social functioning, emotional role functioning and mental health. While the PCS includes the subscales of physical functioning, physical role functioning, bodily pain and general health perception. Both the PCS and MCS are reported as norm-based T scores and normalised to a mean of 50 and standard deviation of 10. A higher standardised score indicates better quality of life parameters. The SF-36 has also demonstrated good reliability and validity (Bunevicius, 2017; Wu et al., 2023).

4.5.4 Socio-Demographic and Clinical Questions

The following socio-demographic and clinical details were recorded for both children and parents: age, gender (male, female, prefer not to say, other), ethnicity (e.g., white, black or black Irish, Asian or Asian Irish, other or mixed background), geography (county), type of leukaemia (e.g., ALL, AML, CML), treatment received (e.g., chemotherapy, radiotherapy, surgery, targeted therapy, immunotherapy, bone marrow/stem cell transplant, CAR-T cell therapy, other), age at diagnosis, duration of time since diagnosis, age at end of treatment, duration of time since end of treatment and any history of relapse (yes, no). Parents were also asked about their child's gender and age, relationship to the child, education level, marital status and working status. See Appendices B8-B10 for questionnaires.

4.6 Ethical Considerations

The study was approved by the Research Ethics Committees in Children's Health Ireland (CHI) at Crumlin (REC-261-23) and Dublin City University's Research Ethics Committee (DCUREC/2023/091) (see Appendix E). Ethical approval from CHI at Crumlin covered recruitment that took place through the hospital, while ethical approval from Dublin City University's Research Ethics Committee covered recruitment that took place through social media and the various cancer organisations and charities. Key ethical considerations included informed consent and assent, confidentiality and data protection. Informed consent was obtained from all participating parents, while child participants provided assent alongside parental consent. All participants received clear, accessible information about the study's purpose, their right to withdraw at any time, and how their data would be handled. Substantial steps were taken to ensure confidentiality and protect identifying information (e.g., names and email addresses) collected for data tracking. This included the separation of both online and hard-copy consent/assent forms from questionnaire data and replacing all identifying details with unique ID codes. All data were handled in a private, confidential and GDPR compliant manner at all times. Furthermore, participants were fully informed of issues related to anonymity, confidentiality, and data storage in the plain language statement/information leaflet.

4.7 Data Analysis

Quantitative analyses were conducted using SPSS 29.0 statistical analysis software package. First, descriptive statistics were performed in order to provide an overview of the sample's demographic and clinical characteristics. Subsequently, normality testing was performed to investigate whether the various data points merited parametric or non-parametric statistics. The decision regarding whether parametric or non-parametric statistics were appropriate for analysis of data was made by visual inspection of the histograms, analysing the skewness and kurtosis of the data, as well as the Kologorov-Smirnov and Shapiro-Wilks tests. Skewness values falling outside of the range of +/-1 are indicative of a skewed

distribution and may warrant further investigation (Hair et al., 2019). Kurtosis values between +/-2 were considered normal; whilst values above or below +/-2 were considered non-normal. While a p value greater than 0.05 for the Kologorov-Smirnov and Shapiro-Wilks test was considered normal; whilst a p value less than 0.05 was considered non-normal. See Table 4.2 for tests of normality for children and parent data. Transformations (square root and logarithm) were performed on skewed data to see if normality could be improved. However, no significant improvements were made. Where a transformation did result in a normal distribution the direction of the skew changed therefore non-parametric tests were deemed the most suitable.

A series of correlational analyses and group differences were performed on the data arising from both child and parent questionnaires in order to examine the specific objectives of the quantitative strand of this mixed-method study. One-tailed correlational analyses were conducted where there was existing empirical evidence on which to base hypotheses (see section 4.1). Although several correlational analyses were conducted to explore associations among social support, resilience and quality of life, formal correction for multiple comparisons (e.g., Bonferroni) was not applied. This decision reflects the exploratory nature of the study; applying such corrections would reduce the likelihood of detecting potentially meaningful associations. The increased risk of Type I error is acknowledged, and findings were interpreted cautiously, considering effect sizes, consistency with prior research, and triangulation with qualitative data.

Table 4.2: *Tests of Normality*

Children

A. Children aged 12 years and younger

Outcome Variable	Histogram	Kolmogorov-Smirnov	Shapiro-Wilk	Skewness Statistic	Kurtosis Statistic	Decision
Social Support (CASSS)						
Freq. Parent	Satisfactory	.200*	.224	-.862	.467	Parametric
Freq. Teacher	Negatively skewed	.071	.002	-1.939	5.605	Non-Para.
Freq. Classmate	Satisfactory	.200*	.930	-.327	.185	Parametric
Freq. Close Friend	Satisfactory	.200*	.540	-.437	-.438	Parametric
Freq. Total	Satisfactory	.200*	.347	-.821	.977	Parametric
Imp. Parent	Satisfactory	.200*	.502	-.146	-.605	Parametric
Imp. Teacher	Satisfactory	.200*	.052	-.380	-1.160	Parametric
Imp. Classmate	Satisfactory	.188	.822	-.009	.023	Parametric
Imp. Close Friend	Satisfactory	.200*	.966	-.076	-.383	Parametric
Imp. Total	Satisfactory	.200*	.974	-.125	-.017	Parametric
Resilience						
RS10	Negatively skewed	.002	.004	-1.429	2.303	Non-Para.
Quality of Life (PedsQL)						
Physical Health	Negatively skewed	.142	.004	-1.541	2.479	Non-Para.
Emotional Functioning	Satisfactory	.200*	.470	-.448	-.529	Parametric
Social Functioning	Negatively skewed	.084	.003	-1.558	2.703	Non-Para.
School Functioning	Satisfactory	.013	.021	-.949	-.107	Parametric
Psychosocial Health	Satisfactory	.200*	.074	-1.079	1.112	Parametric
Total	Satisfactory	.190	.066	-.675	-.671	Parametric

B. Children aged 13-17 years

Outcome Variable	Histogram	Kolmogorov-Smirnov	Shapiro-Wilk	Skewness Statistic	Kurtosis Statistic	Decision
Social Support (CASSS)						
Freq. Parent	Satisfactory	.200*	.257	-.309	-1.263	Parametric
Freq. Teacher	Satisfactory	.200*	.859	.208	-.945	Parametric
Freq. Classmate	Positively skewed	.200*	.649	.369	-.919	Parametric
Freq. Close Friend	Satisfactory	.200*	.848	.213	-.403	Parametric
Freq. Total	Positively skewed	.200*	.287	.744	-.528	Parametric
Imp. Parent	Satisfactory	.200*	.931	.142	-.586	Parametric
Imp. Teacher	Positively skewed	.200*	.309	.799	-.323	Parametric
Imp. Classmate	Satisfactory	.200*	.913	.328	.147	Parametric
Imp. Close Friend	Positively skewed	.025	.037	1.332	1.213	Non-Para.
Imp. Total	Positively skewed	.005	.031	1.382	1.276	Non-Para.
Resilience						
RS25	Negatively skewed	.050	.172	-.944	.277	Parametric
Quality of Life (PedsQL)						
Physical Health	Negatively skewed	.200*	.007	-1.995	4.828	Non-Para.
Emotional Functioning	Satisfactory	.200*	.996	-.183	-.368	Parametric
Social Functioning	Satisfactory	.045	.110	-.699	-.862	Parametric
School Functioning	Satisfactory	.200*	.948	-.253	-.725	Parametric
Psychosocial Health	Negatively skewed	.200*	.183	-.671	-.487	Parametric
Total	Satisfactory	.200*	.220	-.250	-1.650	Parametric

C. Full Child Sample

Outcome Variable	Histogram	Kolmogorov-Smirnov	Shapiro-Wilk	Skewness Statistic	Kurtosis Statistic	Decision
Social Support (CASSS)						
Freq. Parent	Satisfactory	.040	.022	-.752	-.269	Parametric
Freq. Teacher	Negatively skewed	.028	.005	-.919	-.154	Non-Para.
Freq. Classmate	Satisfactory	.200*	.667	-.351	-.360	Parametric
Freq. Close Friend	Negatively skewed	.200*	.366	-.402	-.426	Parametric
Freq. Total	Satisfactory	.200*	.165	-.545	-.564	Parametric
Imp. Parent	Negatively skewed	.200*	.370	-.220	-.542	Parametric
Imp. Teacher	Negatively skewed	.200*	.025	-.004	-1.375	Parametric
Imp. Classmate	Negatively skewed	.200*	.694	-.335	.289	Parametric
Imp. Close Friend	Positively skewed	.149	.365	.273	-.764	Parametric
Imp. Total	Positively skewed	.200*	.621	.128	-.870	Parametric
Resilience						
RS10 (12 yrs & younger)	Negatively skewed	.002	.004	-1.429	2.303	Non-Para.
RS25 (13-17 yrs)	Negatively skewed	.050	.172	-.944	.277	Parametric
Quality of Life (PedsQL)						
Physical Health	Negatively skewed	.054	<.001	-1.484	2.384	Non-Para.
Emotional Functioning	Satisfactory	.200*	.574	-.288	-.540	Parametric
Social Functioning	Negatively skewed	.020	.002	-1.146	1.129	Non-Para.
School Functioning	Satisfactory	.065	.115	-.496	-.695	Parametric
Psychosocial Health	Satisfactory	.200*	.149	-.748	.316	Parametric
Total	Negatively skewed	.200*	.096	-.377	-.984	Parametric

Parent/Guardians

Outcome Variable	Histogram	Kolmogorov-Smirnov	Shapiro-Wilk	Skewness Statistic	Kurtosis Statistic	Decision
Social Support (MSPSS)						
Total	Negatively skewed	.026	<.001	-1.108	.951	Non-Para
Family	Negatively skewed	<.001	<.001	-1.053	.292	Non-Para.
Friend	Negatively skewed	.086	.001	-.715	.147	Non-Para.
Sig. other	Negatively skewed	<.001	<.001	-1.497	2.100	Non-Para.
Resilience						
RS25	Satisfactory	.012	.047	-.620	.415	Parametric
Quality of Life (SF-36)						
Physical Functioning	Negatively skewed	<.001	<.001	-2.585	6.465	Non-Para.
Physical Role Functioning	Negatively skewed	<.001	<.001	-1.291	.052	Non-Para.
Bodily Pain	Negatively skewed	<.001	<.001	-1.310	1.191	Non-Para.
General Health Perception	Negatively skewed	.002	<.001	-.919	.424	Non-Para.
Energy and Vitality	Satisfactory	.198	.159	-.094	.256	Parametric
Social Functioning	Negatively skewed	<.001	<.001	-1.196	.587	Non-Para.
Emotional Role Functioning	Negatively skewed	<.001	<.001	-.882	-1.062	Non-Para.
Mental Health	Satisfactory	.005	.035	-.605	.053	Parametric
PCS	Negatively skewed	<.001	<.001	-1.458	1.910	Non-Para.
MCS	Satisfactory	.002	.002	-.618	-.527	Parametric

4.8 Results

The findings from the quantitative strand of this mixed-methods study will now be presented. Results pertaining to the child data will be presented first, followed by the parent data. The aims of this quantitative strand have been outlined in section 4.1.

4.9 Child Data

4.9.1 Child Demographic Characteristics and Clinical Characteristics

In total, 35 children completed a questionnaire, 23 were aged 12 years and younger (range = 7-17 years), while 12 were aged between 13-17 years. Overall, the average age of participating children was 11.34 years (*SD* = 3.18) (range = 7-17 years). Twenty (57.1%) of the participating children were male and 15 (42.9%) were female. Thirty of the participating children (85.7%) had acute lymphoblastic leukaemia (ALL), four (11.4%) had acute myeloid leukaemia (AML) and one child did not know what type of leukaemia they had. The main form of treatment children reported having was chemotherapy, with 32 (91.4%) reporting they received chemotherapy. Other forms of treatment reported by children included surgery (14.3%), bone or stem cell transplant (5.7%) and non-chemotherapy drugs (5.7%). One (2.9%) child reported having a cancer relapse, while 34 (97.1%) reported not having a relapse. The average age of children at diagnosis was 6.37 years (range = 1-14 years). The average number of months since diagnosis was 55.71 months (*SD* = 27.28) (range = 8-97 months). The average age of children at the end of treatment was 9.03 years (*SD* = 3.76) (range = 4-16 years). The average number of months since the end of treatment was 28.71 (*SD* = 18.55) (range 0-60 months). Table 4.3 below shows the age-related breakdown of the child demographic and clinical characteristics.

Table 4.3: *Child Demographic and Clinical Characteristics*

	Aged ≤12 yrs (n = 23)	***Aged 13-17 yrs (n = 12)***	***Total (n = 35)***
Gender			
Male	12 (52.2%)	8 (66.7%)	20 (57.1%)
Female	11 (47.8%)	4 (33.3%)	15 (42.9%)
Prefer not to say	0 (0%)	0 (0%)	0 (0%)
Other	0 (0%)	0 (0%)	0 (0%)
Leukaemia Type			
ALL	20 (87.0%)	10 (83.3%)	30 (85.7%)
AML	2 (8.7%)	2 (16.7%)	4 (11.4%)
CML	0 (0%)	0 (0%)	0
Don’t know	1 (4.3%)	0 (0%)	1 (2.9%)
Treatment Received			
Chemotherapy	21 (91.3%)	11 (91.7%)	32 (91.4%)
Radiotherapy	0 (0%)	0 (0%)	0 (0%)
Surgery	4 (17.4%)	1 (8.3%)	5 (14.3%)
Targeted Therapy	0 (0%)	0 (0%)	0 (0%)
Immunotherapy	0 (0%)	0 (0%)	0 (0%)
Bone or Stem Cell Transplant	1 (4.3%)	1 (8.3%)	2 (5.7%)
Chimeric antigen receptor (CAR)-T cell therapy	0 (0%)	0 (0%)	0 (0%)
Non-Chemotherapy Drugs	1 (4.3%)	1 (8.3%)	2 (5.7%)
I don’t know	0 (0%)	0 (0%)	0 (0%)
History of Relapse			
Yes	1 (4.3%)	0 (0%)	1 (2.9%)

No	22 (95.7%)	12 (100%)	34 (97.1%)
Age at Diagnosis (yrs), Mean (SD)	3.96 (1.99)	11.00 (2.05)	6.37 (3.93)
Months Since Diagnosis	58.04 (27.62)	51.25 (27.22)	55.71 (27.28)
Age at End of Treatment (yrs), Mean (SD)	6.65 (1.58)	13.58 (2.07)	9.03 (3.76)
Months Since End of Treatment	31.43 (18.76)	23.50 (17.73)	28.71 (18.55)

4.9.2 Objective - To Establish Self-Reported Levels of Social Support, Resilience and Quality of Life Among Childhood Leukaemia Survivors.

Table 4.4 presents age-related breakdowns of the descriptive statistics for each of the child reported social support, resilience and quality of life variables examined. Overall children perceived the most social support from their parents (M = 62.29, SD = 7.39), followed by teachers (M = 57.20, SD = 12.84), close friends (M = 55.83, SD = 11.41) and classmates (M = 52.06, SD = 12.44). Similarly, children indicated support from their parents (M = 29.22, SD = 4.36) as the most important support to them, followed by teachers (M = 28.56, SD = 5.35), close friends (M = 27.50, SD = 4.33) and classmates (M = 25.72, SD = 5.50). Younger children[3] perceived greater overall support (M = 240.61, SD = 25.67) compared to older children[4] (M = 202.00, SD = 41.580). This trend was consistent across support sources, including teachers, classmates and close friends. Younger children also rated all sources of support as more important than older children.

In terms of resilience, older children (M = 138.25, SD = 12.86) scored between 121-145 indicating a moderate-to-high level of resilience. Based on interpretive guidelines provided by the scale's author, scores between 131 and 145 reflect a moderate-to-high level of resilience. Likewise, younger children (M = 34.22, SD = 4.07) scored between 31-37 on the RS10, which has a possible range of 10 to 40. Based on

[3] Younger children is used throughout the text to refer to children aged 8-12 years
[4] Older children is used throughout the text to refer to children aged 13-17 years

the authors guidelines, this also indicates a moderate-to-high level of resilience. In terms of quality of life, children perceived their physical health (M = 74.44, SD = 22.60) to be greater than their psychosocial health (M = 67.33, SD = 18.75). Younger children rated their physical health (M = 76.73, SD = 22.84) higher than their psychosocial health (M = 70.87, SD = 19.47). Similarly, older children rated their physical health (M = 70.05, SD = 22.43) higher than their psychosocial health (M = 60.56, SD = 15.88). Within the psychosocial health domain, social functioning (M = 76.57, SD = 21.85) was rated the greatest, with younger children (M = 78.91, SD = 22.41) reporting slightly better social functioning than older children (M = 72.08, SD = 20.94). Emotional functioning was the next highest rated (M = 62.86, SD = 20.98), with younger children (M = 65.00, SD = 22.31) again reporting slightly higher scores than older children (M = 58.75, SD = 18.36). Finally, school functioning was rated the lowest (M = 62.57, SD = 22.47), with younger children (M = 68.70, SD = 22.97) again reporting slightly higher scores than older children (M = 50.83, SD = 16.63).

Table 4.4: *Means and Standard Deviations of Scales & Related Domains by Age Group*

Variable	*Aged ≤12 yrs*	*Aged 13-17 yrs*	*Total*
	M (SD) **Min-Max**	**M (SD)** **Min-Max**	**M (SD)** **Min-Max**
Social Support (CASSS)			
Frequency of Total Support	240.61 (25.67) 175-284	202.00 (41.580) 151-280	227.37 (36.49) 151-284
Frequency of Parent Support	63.39 (6.22) 48-72	60.17 (9.15) 47-72	62.29 (7.39) 47-72
Frequency of Teacher Support	62.91 (8.97) 32-72	46.25 (12.24) 27-67	57.20 (12.84) 27-72
Frequency of Classmate Support	55.26 (9.77) 34-72	45.92 (15.00) 24-72	52.06 (12.44) 24-72
Frequency of Close Friend Support	59.04 (9.47) 39-72	49.67 (12.64) 30-72	55.83 (11.41) 30-72
Importance of Total Support	116.00 (13.70) 89-144	101.45 (17.60) 83-140	111.00 (16.44) 83-144
Importance of Parent Support	30.10 (3.82) 22-36	27.55 (5.01) 20-36	29.22 (4.36) 20-36
Importance of Teacher Support	30.33 (4.94) 21-36	25.18 (4.54) 20-34	28.56 (5.35) 20-36
Importance of Classmate Support	27.10 (4.15) 19-36	23.09 (6.92) 12-36	25.72 (5.50) 12-36
Importance of Close Friend Support	28.48 (3.80) 21-36	25.64 (4.82) 20-36	27.50 (4.33) 20-36
Resilience			
Total Resilience (RS10)	34.22 (4.07) 22-39	-	-
Total Resilience (RS25)	-	138.25 (12.86) 113-156	-
Quality of Life (PedsQL)			
Total Quality of Life Summary Score	72.78 (18.30) 33.70-95.65	63.86 (14.94) 40.22-82.61	69.72 (17.53) 33.70-95.65
Physical Health Summary Score	76.73 (22.84) 9.38-100	70.05 (22.43) 9.38-90.63	74.44 (22.60) 9.38-100
Emotional Functioning Score	65.00 (22.31) 15-100	58.75 (18.36) 25-90	62.86 (20.98) 15-100

Variable	*Aged ≤12 yrs*	*Aged 13-17 yrs*	*Total*
	M (SD) **Min-Max**	**M (SD)** **Min-Max**	**M (SD)** **Min-Max**
Social Functioning Score	78.91 (22.41) 10-100	72.08 (20.94) 40-100	76.57 (21.85) 10-100
School Functioning Score	68.70 (22.97) 15-100	50.83 (16.63) 20-75	62.57 (22.47) 15-100
Psychosocial Health Summary Score	70.87 (19.47) 16.47-96.67	60.56 (15.88) 28.33-78.33	67.33 (18.75) 16.67-96.67

4.9.3 Objective - To Examine the Relationship Between Children's Social Support, Resilience and Quality of Life with their Self-Reported Demographic and Clinical Factors.

A series of correlations and group difference analyses were performed in order to address the research objective of examining the relationship between children' s social support, resilience and quality of life with their self-reported demographic and clinical factors. Independent samples t-tests and Mann Whitney U tests were performed between child reported social support, resilience, quality of life variables and their gender. These gender-based analyses were additionally stratified by developmental stage (younger children aged 12 years and younger, and older children aged 13–17 years) to explore potential age-related differences. Pearson's product moment and Spearman's rho correlations were conducted between child reported social support, resilience, quality of life variables and their age at the time of the study. These analyses were conducted in the total sample, as age at the time of study is inherently related to developmental stage, and stratifying further would introduce conceptual redundancy. Two-tailed correlations were used in order to investigate any relationships between variables.

No significant gender differences were observed between boys and girls in relation to their self-reported perceptions of social support, resilience and quality of life for both younger and older children, as well as the total group. The results of these analyses are displayed in Table 4.5.

Table 4.5: *Group Differences in Child Reported Social Support, Resilience and Quality of Life by Age Group and Gender*

Variable (Scale)	*Aged ≤12 yrs*	*Aged 13-17 yrs*	*Total*
Social Support (CASSS)			
Frequency of Total Support	$t(21) = .394$, $p = .698$	$t(10) = -.527$, $p = .610$	$t(33) = -.523$, $p = .605$
Frequency of Parent Support	$t(21) = .217$, $p = .830$	$t(10) = -.473$, $p = .646$	$t(33) = -.352$, $p = .727$
Frequency of Teacher Support	$U = 63.500$, $p = .877$	$t(10) = -.287$, $p = .780$	$U = 138.500$, $p = .701$
Frequency of Classmate Support	$t(21) = -.383$, $p = .706$	$t(10) = -.406$, $p = .694$	$t(33) = -.824$, $p = .416$
Frequency of Close Friend Support	$t(21) = .853$, $p = .403$	$t(10) = -.628$, $p = .544$	$t(33) = -.135$, $p = .894$
Importance of Total Support	$t(19) = 1.055$, $p = .305$	$U = 12.500$, $p = .776$	$t(30) = .191$, $p = .850$
Importance of Parent Support	$t(19) = .799$, $p = .434$	$t(9) = .381$, $p = .712$	$t(30) = .585$, $p = .563$
Importance of Teacher Support	$t(19) = 1.420$, $p = .172$	$t(9) = -.167$, $p = .871$	$t(30) = .553$, $p = .584$
Importance of Classmate Support	$t(19) = -.304$, $p = .764$	$t(9) = -.314$, $p = .761$	$t(30) = -.717$, $p = .479$
Importance of Close Friend Support	$t(19) = 1.576$, $p = .131$	$U = 11.000$, $p = .561$	$t(30) = .363$, $p = .719$
Resilience			
Total Resilience (RS10)	$U = 60$, $p = .740$	-	-
Total Resilience (RS25)	-	$t(10) = -.136$, $p = .894$	-
Quality of Life (PedsQL)			
Total Quality of Life Summary Score	$t(21) = -1.188$, $p = .248$	$t(10) = 1.505$, $p = .163$	$t(33) = -.521$, $p = .606$
Physical Health Summary Score	$U = 48.000$, $p = .267$	$U = 9.000$, $p = .232$	$U = 134$, $p = .610$

Emotional Functioning Score	$t(21) = -.183, p = .857$	$t(10) = 1.390, p = .195$	$t(33) = .367, p = .716$
Social Functioning Score	$U = 50.000, p = .321$	$t(10) = -.046, p = .964$	$U = 117.000, p = .268$
School Functioning Score	$t(21) = -.524, p = .605$	$t(10) = 1.487, p = .168$	$t(33) = -.171, p = .865$
Psychosocial Health Summary Score	$t(21) = -.788, p = .439$	$t(10) = .984, p = .348$	$t(33) = -.420, p = .677$

Significant correlations were observed between the child's age and perceived frequency of teacher support (CASSS), perceived frequency of classmate support (CASSS), perceived frequency of close friend support (CASSS), perceived importance of parental support (CASSS), perceived importance of teacher support (CASSS), perceived importance of classmate support (CASSS), perceived importance of close friend support (CASSS), total perceived frequency of social support (CASSS), total perceived importance of social support (CASSS), school functioning (PedsQL) and psychosocial health (PedsQL). Older age was significantly associated with less perceived frequency of teacher support ($r_s = -.573$, $p < .001$), classmate support ($r = -.429$, $p < .05$), close friend support ($r = -.342$, $p < .05$) and overall total social support ($r = -.525$, $p < .01$). Older age was also associated with less perceived importance of parental support ($r = -.395$, $p < .05$), teacher support ($r = -.534$, $p < .05$), classmate support ($r = -.494$, $p < .01$), close friend support ($r = -.368$, $p < .05$) and overall total social support ($r = -.541$, $p < .01$). Moreover, older age was associated with less school functioning ($r = -.375$, $p < .05$), and psychosocial health ($r = -.348$, $p < .05$). In essence, these findings indicate that, as the child's age increased, they tended to perceive that they received less support, both in terms of frequency and importance of that support. Additionally, older children report lower school functioning and psychosocial health. The results of these analyses are displayed in Table 4.6.

Table 4.6: *Correlations Between Social Support, Resilience and Quality of Life Variables and Age at Time of Study: Child Reported*

Variable (Scale)	*N*	*r or* r_s	*p*
Social Support (CASSS)			
Frequency of Total Support	35	*r* = -.525**	.001
Frequency of Parent Support	35	*r* = -.273	.112
Frequency of Teacher Support	35	r_s = -.573**	<.001
Frequency of Classmate Support	35	*r* = -.429*	.010
Frequency of Close Friend Support	35	*r* = -.342*	.044
Importance of Total Support	32	*r* = -.541**	.001
Importance of Parent Support	32	*r* = -.395*	.025
Importance of Teacher Support	32	*r* = -.534*	.002
Importance of Classmate Support	32	*r* = -.494**	.004
Importance of Close Friend Support	32	*r* = -.368*	.038
Resilience			
Total Resilience (RS10) (younger children)	23	r_s = -.242	.266
Total Resilience (RS25) (older children)	12	*r* = .071	.826
Quality of Life (PedsQL)			
Total Quality of Life Summary Score	35	*r* = -.286	.096
Physical Health Summary Score	35	r_s = -.062	.724
Emotional Functioning Score	35	*r* = -.233	.177
Social Functioning Score	35	*r* = -.285	.097
School Functioning Score	35	*r* = -.375*	.026
Psychosocial Health Summary Score	35	*r* = -.348*	.041

*p <.05. **p = <.01.

Following on from this, a series of analyses were performed between child reported social support, resilience, quality of life variables and their self-reported clinical factors, including months since diagnosis and months since end of treatment. Pearson's product moment and Spearman's rho correlations were conducted between child's perceived social support, resilience, quality of life and their self-reported

months since diagnosis and months since end of treatment. Two-tailed correlations were used in order to investigate any relationships between variables. These analyses were conducted in the total sample and were not stratified by developmental stage, as months since diagnosis and months since end of treatment are time-based variables that apply across age groups.

No significant correlations were observed between child reported social support, resilience and quality of life variables and their self-reported number of months since diagnosis. See Table 4.7 for a full breakdown of results. There were also no significant correlations observed between child reported social support, resilience and quality of life variables and their self-reported months since end of treatment. See Table 4.8 for a full breakdown of results.

Table 4.7: *Correlations Between Social Support, Resilience and Quality of Life Variables and Months Since Diagnosis: Child Reported*

Variable (Scale)	***N***	***r or r_s***	***p***
Social Support (CASSS)			
Frequency of Total Support	35	r = -.218	.208
Frequency of Parent Support	35	r = -.133	.446
Frequency of Teacher Support	35	r_s = -.200	.249
Frequency of Classmate Support	35	r = -.240	.165
Frequency of Close Friend Support	35	r = -.146	.401
Importance of Total Support	32	r = -.257	.156
Importance of Parent Support	32	r = -.078	.673
Importance of Teacher Support	32	r = -.228	.210
Importance of Classmate Support	32	r = -.331	.064
Importance of Close Friend Support	32	r = -.195	.286
Resilience			
Total Resilience (RS10) (younger children)	23	r_s = -.036	.870
Total Resilience (RS25) (older children)	12	r = -.411	.185
Quality of Life (PedsQL)			
Total Quality of Life Summary Score	35	r = -.077	.658
Physical Health Summary Score	35	r_s = .061	.729
Emotional Functioning Score	35	r = -.046	.792
Social Functioning Score	35	r = -.281	.102
School Functioning Score	35	r = .047	.789
Psychosocial Health Summary Score	35	r = -.108	.538

Table 4.8: *Correlations Between Social Support, Resilience and Quality of Life Variables and Months Since End of Treatment: Child Reported*

Variable (Scale)	***N***	***r or r_s***	***p***
Social Support (CASSS)			
Frequency of Total Support	35	r = -.123	.482
Frequency of Parent Support	35	r = -.106	.543
Frequency of Teacher Support	35	r_s = .008	.966
Frequency of Classmate Support	35	r = -.157	.369
Frequency of Close Friend Support	35	r = -.115	.509
Importance of Total Support	32	r = -.217	.232
Importance of Parent Support	32	r = -.038	.838
Importance of Teacher Support	32	r = -.158	.387
Importance of Classmate Support	32	r = -.320	.074
Importance of Close Friend Support	32	r = -.185	.311
Resilience			
Total Resilience (RS10) (younger children)	23	r_s = -.217	.319
Total Resilience (RS25) (older children)	12	r = -.442	.151
Quality of Life (PedsQL)			
Total Quality of Life Summary Score	35	r = -.076	.666
Physical Health Summary Score	35	r_s = .103	.554
Emotional Functioning Score	35	r = -.130	.458
Social Functioning Score	35	r = -.159	.362
School Functioning Score	35	r = -.070	.690
Psychosocial Health Summary Score	35	r = -.138	.429

4.9.4 Objective - To Explore the Relationship Between Children's Social Support, Resilience and Quality of Life.

Correlational analyses were performed separately for younger children and older children on the data arising from the children's questionnaires to address the research objective of exploring the relationship

between social support, resilience and quality of life. Pearson's product moment and Spearman's rho correlations were performed in order to investigate any links between social support, resilience and quality of life within each age group. One-tailed correlations were performed in order to assess the existence of previously hypothesised relationships between variables. For the variable of social support, we specifically analysed the frequency of social support rather than importance ratings, due to missing data in the latter caused by incomplete questionnaire responses. Three children did not complete any of the importance items, meaning their entire subscale was missing and a total score could not be calculated. According to the CASSS (Malecki et al., 2000) scoring instructions, participants with a missing subscale must be excluded from analyses of that variable. Excluding these participants would have reduced the sample, and the frequency items were completed consistently by all participants, so analyses focused solely on social support frequency, allowing for more reliable and interpretable quantitative analysis. Similarly, for the variable of quality of life, we analysed the total quality of life score, the physical health summary score and the psychosocial health summary score to provide a comprehensive assessment of a child's overall well-being, capturing both physical and psychosocial aspects of quality of life that are most relevant to understanding the impact of social support and resilience. The total quality of life score provides an aggregated measure of overall functioning, and the summary scores were used instead of the individual subscales to reduce statistical redundancy and the risk of Type I error, given the small sample size. Results from these separate analyses are presented in Table 4.9 (younger children) and Table 4.10 (older children).

In line with hypothesis 1, significant correlations were found between resilience for older children (RS25) and perceived frequency of total social support (CASSS) ($r = .499$, $p < .05$) and parent support (CASSS) ($r = .545$, $p < .05$). These findings indicate that the older children with higher resilience tend to perceive greater social support, particularly from parents. In terms of the younger children, significant correlations were found between resilience (RS10) and perceived frequency of social support (CASSS) ($r_s = .623$, $p < .01$), parent support (CASSS) ($r_s = .592$, $p < .01$), teacher support (CASSS) ($r_s = .384$, $p < .05$) and classmate support (CASSS) ($r_s = .539$, $p < .01$). These findings indicate that the younger children with

higher resilience tend to perceive greater social support, particularly from parents, teachers and classmates.

Consistent with hypothesis 2, significant correlations were found between perceived social support (CASSS) and quality of life (PedsQL). Among younger children, close friend support (CASSS) was significantly correlated with total quality of life (PedsQL) ($r = .426$, $p < .05$), as well as with both psychosocial health (PedsQL) ($r = .355$, $p < .05$) and physical health summary scores (PedsQL) ($r = .374$, $p < .05$). These results indicate that social support from close friends was linked to better quality of life, in both physical and psychosocial domains, amongst younger children. Among the older children, perceived frequency of total social support (CASSS) ($r = .582$, $p < .05$), teacher support (CASSS) ($r = .619$, $p < .05$), classmate support (CASSS) ($r = .597$, $p < .05$) and close friend support (CASSS) ($r = .531$, $p < .05$) were significantly correlated with total quality of life. These results suggest that higher perceived frequency of support, especially from teachers, classmates and close friends, were linked to better overall quality of life for older children. Looking more closely at the quality of life domains, psychosocial health showed particularly strong associations with perceived frequency of classmate support ($r = .592$, $p < .05$), close friend support ($r = .665$, $p < .05$), teacher support ($r = .664$, $p < .01$), and total support ($r = .640$, $p < .05$).

Finally, hypothesis 3 was partially supported. A significant correlation was found between resilience for younger children (RS10) and total quality of life (PedsQL) ($r_s = .484$, $p < .01$) and psychosocial health (PedsQL) ($r_s = .546$, $p < .01$). This result indicates that amongst the younger children, those with higher resilience tend to report a better quality of life, especially in psychosocial aspects. Moreover, a significant correlation was found between resilience for older children (RS25) and psychosocial health (PedsQL) ($r = .623$, $p < .05$), indicating that those with higher resilience tend to report better psychosocial health. However, there was no significant correlation observed between resilience for older children (RS25) and total quality of life (PedsQL).

Table 4.9: *Correlations Between Younger Children (aged 12 years and younger) Social Support, Resilience and Quality of Life*

Variables	1	2	3	4	5	6	7	8	9
1. Frequency of Total Support	1	-	-	-	-	-	-	-	-
2. Frequency of Parent Support	.555**	1	-	-	-	-	-	-	-
3. Frequency of Teacher Support	.654 $_s$ **	.526$_s$**	1	-	-	-	-	-	-
4. Frequency of Classmate Support	.825**	.345	.471$_s$*	1	-	-	-	-	-
5. Frequency of Close Friend Support	.775**	.152	.292 $_s$	.571**	1	-	-	-	-
6. Resilience (RS10)	.623 $_s$ **	.592$_s$**	.384$_s$*	.539$_s$**	.347$_s$	1	-	-	-
7. Total QoL	.307	.163	.031$_s$	.330	.426*	.484$_s$**	1	-	-
8. Physical Health Summary Score	.269 $_s$	.046 $_s$	-.095 $_s$	.237$_s$	.374 $_s$*	.231$_s$	.788 $_s$ **	1	-
9. Psychosocial Health Summary Score	.302	.173	.062$_s$	.308	.355*	.546 $_s$ **	.929**	.661$_s$ **	1

Table 4.10: *Correlations Between Older Children (aged 13-17 years) Social Support, Resilience and Quality of Life*

Variables	1	2	3	4	5	6	7	8	9
1. Frequency of Total Support	1	-	-	-	-	-	-	-	-
2. Frequency of Parent Support	.425	1	-	-	-	-	-	-	-
3. Frequency of Teacher Support	.915**	.155	1	-	-	-	-	-	-
4. Frequency of Classmate Support	.969**	.282	.881**	1	-	-	-	-	-
5. Frequency of Close Friend Support	.946**	.190	.884**	.943**	1	-	-	-	-
6. Resilience (RS25)	.499*	.545*	.363	.379	.444	1	-	-	-
7. Total QoL	.582*	.104	.619*	.597*	.531*	.495	1	-	-
8. Physical Health Summary Score	.366 $_s$	-.012 $_s$	.482 $_s$	.387 $_s$	.204 $_s$	.192 $_s$	.886 $_s$ **	1	-
9. Psychosocial Health Summary Score	.640*	.132	.664**	.592*	.665**	.623*	.871**	.641 $_s$*	1

4.10 Parent Data

This section presents the analysis of the questionnaires completed by the parent/guardians.

4.10.1 Parent Demographic Characteristics and their Child's Clinical Characteristics

Sixty-nine parents and one legal guardian (82.9% female; 17.1% male) returned questionnaires. This included one mother and father of the same child, meaning responses reflect 69 unique child survivors. The average age of parents was 43.09 years (*SD* = 6.28), with the oldest parent being 60 and the youngest parent being 28. The majority of parents identified themselves as Irish (77.1%), followed by any other white background (21.4%) and Chinese (1.4%). While, geographically, 62 parents were from Ireland, the majority (31.4%, *n* = 22) being from Dublin, 6 were from the UK, 1 from the USA and 1 from Canada. With regard to parental level of education, the majority had either attained an Honours Bachelor's Degree (27.1%, *n* = 19) or the Leaving Certificate (17.1%, *n* = 12). Other forms of educational achievements included a postgraduate diploma, a professional accreditation, and a qualified solicitor. 72.9% of parents were employed and 12.9% were unemployed. Other employment statuses (14.3%) included those on career breaks, carers, stay at home parents, self-employed and one person with a disability.

Acute lymphoblastic leukaemia (ALL) (85.7%) was reported as the most common type of leukaemia their child had, followed by acute myeloid leukaemia (AML) (12.9%) and one parent reported their child had acute promyelocytic leukaemia (APML) (1.4%). 68% of parents reported chemotherapy as the main form of treatment their child received, followed by surgery (11.4%), immunotherapy (8.6%), bone or stem cell transplant (8.6%), radiotherapy (7.1%), non-chemotherapy drugs (2.9%) and targeted therapy (1.4%). Additionally, 94.3% of parents reported no history of relapse for their child. In terms of timing, the number of months since the child's initial diagnosis ranged from 6 to 168 months, with a mean of 52.19 months (*SD* = 28.70). Time since completion of treatment ranged from 0 to 60 months, with a mean of 26.31 months (*SD* = 18.68). Table 4.11 below shows the breakdown of the parent's demographic characteristics and their child's clinical characteristics.

Table 4.11: *Parent Demographic Characteristics and their Child's Clinical Characteristics*

	N	**%**
Parent Gender		
Male	12	17.1
Female	58	82.9
Prefer not to say	0	0
Other	0	0
Parent Marital Status		
Single	3	4.3
Married	51	72.9
Divorced	3	4.3
Separated	2	2.9
Widowed	2	2.9
Unmarried partner/living as a couple	9	12.9
Parent Education Level		
Less than Junior Certificate	2	2.9
Junior Certificate	2	2.9
Leaving Certificate	12	17.1
Higher Certificate	9	12.9
Ordinary Bachelors Degree	4	5.7
Honours Bachelors Degree	19	27.1
Higher Diploma	6	8.6
Masters Degree	11	15.7
Doctoral Degree	2	2.9
Other	3	4.3
Parent Working Status		
Employed	50	71.4
Unemployed	9	12.9
Student	0	0
Retired	0	0

	N	%
Other	11	15.7
Child's Gender		
Male	12	17.1
Female	58	82.9
Prefer not to say	0	0
Other	0	0
Child's Leukaemia Type		
ALL	60	85.7
AML	9	12.9
CML	0	0
APML	1	1.4
Treatment Child Received		
Chemotherapy	68	97.1
Radiotherapy	5	7.1
Surgery	8	11.4
Targeted Therapy	1	1.4
Immunotherapy	6	8.6
Bone or Stem Cell Transplant	6	8.6
Chimeric antigen receptor (CAR)-T cell therapy	0	0
Non-Chemotherapy Drugs	2	2.9
Does Child Have a History of Relapse		
Yes	4	5.7
No	66	94.3

4.10.2 Objective - To Establish Self-Reported Levels of Social Support, Resilience and Quality of Life Among Parents of Childhood Leukaemia Survivors.

Table 4.12 presents descriptive statistics for each of the parent reported social support, resilience and quality of life variables examined. Parents perceived the most social support from their significant other

(*M* = 5.80, *SD* = 1.36), followed by family (*M* = 5.28, *SD* = 1.63) and followed by friends (*M* = 5.09, *SD* = 1.48). In terms of resilience, parent's mean score on the Resilience Scale was (*M* = 140.66, *SD* = 18.05), with observed scores ranging from 93 to 175. Based on interpretive guidelines provided by the scale's author, scores between 131 and 145 reflect a moderate-to-high level of resilience. Therefore, these findings place the majority of parents within the moderate-to-high resilience range. In terms of quality of life for parents, the physical functioning domain had the highest mean score (*M* = 88.21, *SD* = 21.99), whereas the energy and vitality domain had the lowest mean score (*M* = 49.21, *SD* = 20.41). The physical component score (PCS) (*M* = 51.78, *SD* = 9.54) was slightly above the general population norm (*M* = 50, *SD* = 10), indicating relatively good physical health. In contrast, the mental component score (MCS) (*M* = 43.82, *SD* = 12.23) was below the normative mean, suggesting reduced mental health-related quality of life among parents' post-treatment.

Table 4.12: *Parent Reported Social Support, Resilience and Quality of Life Variables*

Variable	*N*	*M*	*SD*	*Min*	*Max*
Social Support (MSPSS)					
Total Support	70	5.39	1.28	1	7
Family Support	70	5.28	1.63	1	7
Friend Support	70	5.09	1.48	1	7
Significant Other Support	70	5.80	1.36	1.25	7
Resilience (RS25)					
Total Resilience	70	140.66	18.05	93	175
Quality of Life (SF36)					
Physical Functioning	70	88.21	21.99	0	100
Physical Role Functioning	70	77.86	36.25	0	100
Bodily Pain	70	79.01	25.89	0	100
General Health Perception	70	67.26	22.73	5	100
Energy and Vitality	70	49.21	20.41	0	100
Social Functioning	70	78.21	26.12	0	100
Emotional Role Functioning	70	70.00	42.52	0	100
Mental Health	70	66.11	17.78	12	100
Physical Component Score (PCS)	70	51.78	9.54	19.28	67.21
Mental Component Score (MCS)	70	43.82	12.23	15.73	65.85

4.10.3 Objective - To Examine the Relationship Between Parents' Social Support, Resilience and Quality of Life with their Self-Reported Demographic Factors and their Child's Clinical Factors (parent-reported).

A series of correlations and group difference analyses were performed in order to address the research objective of examining the relationship between parents' social support, resilience and quality of life with their self-reported demographic factors and their child's clinical factors. Specifically, independent samples t-tests and Mann Whitney U tests were performed between parents reported social support, resilience, quality of life variables and their gender and level of education. Pearson's product moment and

Spearman's rho correlations were conducted between parents reported social support, resilience, quality of life variables and their age. Two-tailed correlations were used in order to explore any relationships between variables.

A significant difference was observed for parent gender with fathers (M = 51.28, SD = 10.71) of childhood leukaemia survivors significantly more likely to report a greater mental component score (MCS) (SF-36) than mothers (M = 42.28, SD = 12.07) of childhood leukaemia survivors, $t(68) = 2.394$, $p < .05$. Furthermore, mothers of childhood leukaemia survivors were more likely to report a greater physical component score (PCS) (SF-36) than fathers of childhood leukaemia survivors, $U = 155.000$, $p < .01$. No other significant differences were observed for parents' gender. See Table 4.13 for a full breakdown of results.

Table 4.13: *Differences Between Male and Females on Self-Reported Social Support, Resilience and Quality of Life*

Variable (Scale)	***df***	***t or U***	***Sig. 2-tailed***
Social Support (MSPSS)			
Total Support	-	$U = 314$	$p = .596$
Family Support	-	$U = 288.500$	$p = .352$
Friend Support	-	$U = 323$	$p = .696$
Significant Other Support	-	$U = 322.500$	$p = .687$
Resilience (RS25)			
Total Resilience	68	$t = 1.546$	$p = .127$
Quality of Life (SF-36)			
Physical Functioning	-	$U = 238.500$	$p = .070$
Physical Role Functioning	-	$U = 335.000$	$p = .805$
Bodily Pain	-	$U = 300.000$	$p = .430$
General Health Perception	-	$U = 286$	$p = .332$
Energy and Vitality	68	$t = 1.160$	$p = .250$
Social Functioning	-	$U = 282.00$	$p = .284$
Emotional Role Functioning	-	U = 261.500	$p = .117$
Mental Health	68	$t = 1.711$	$p = .092$
Physical Component Score (PCS)	-	$U = 155.000$	$p = .003$**
Mental Component Score (MCS)	68	$t = 2.394$	$p = .019$*

*p <.05. **p <.01.

A significant difference was observed for education level, with parents who had attained third-level education significantly more likely to report greater support from friends, ($U = 247.500$, $p < .05$), fewer limitations in physical role functioning ($U = 311.500$, $p < .05$), and fewer limitations in emotional role functioning ($U = 307.500$, $p < .05$), compared to parents without third-level education. No other significant differences were observed. See Table 4.14 for a full breakdown of results.

Table 4.14: *Differences Between Parents With and Without Third-Level Education on Self-Reported Social Support, Resilience and Quality of Life*

Variable (Scale)	***df***	***t or U***	***Sig. 2-tailed***
Social Support (MSPSS)			
Total Support	-	$U = 331.00$	$p = .158$
Family Support	-	$U = 410.500$	$p = .763$
Friend Support	-	$U = 247.500$	$p = .010$*
Significant Other Support	-	$U = 308.500$	$p = .080$
Resilience (RS25)			
Total Resilience	68	$t = -.826$	$p = .412$
Quality of Life (SF-36)			
Physical Functioning	-	$U = 342.500$	$p = .183$
Physical Role Functioning	-	$U = 311.500$	$p = .040$*
Bodily Pain	-	$U = 418.000$	$p = .836$
General Health Perception	-	$U = 382.000$	$p = .483$
Energy and Vitality	68	$t = .452$	$p = .653$
Social Functioning	-	$U = 395.000$	$p = .590$
Emotional Role Functioning	-	U = 307.500	$p = .043$*
Mental Health	68	$t = .544$	$p = .588$
Physical Component Score (PCS)	-	$U = 414.000$	$p = .801$
Mental Component Score (MCS)	68	$t = 1.169$	$p = .246$

There were no significant correlations observed between parents' social support, resilience and quality of life variables and their age. See Table 4.15 for a full breakdown of results.

Table 4.15: *Correlations Between Social Support, Resilience and Quality of Life Variables and Parent Age*

Variable (Scale)	***N***	***r or r_s***	***p***
Social Support (MSPSS)			
Total Support	70	r_s = -.042	.733
Family Support	70	r_s = -.070	.563
Friend Support	70	r_s = -.004	.976
Significant Other Support	70	r_s = -.036	.768
Resilience (RS25)			
Total Resilience	70	r = .130	.285
Quality of Life (SF-36)			
Physical Functioning	70	r_s = -.107	.379
Role Physical	70	r_s = .004	.975
Bodily Pain	70	r_s = -.215	.075
General Health	70	r_s = -.074	.542
Vitality	70	r = -.090	.459
Social Functioning	70	r_s = -.081	.505
Role Emotional	70	r_s = .014	.910
Mental Health	70	r = .017	.889
Physical Component Score (PCS)	70	r_s = -.143	.236
Mental Component Score (MCS)	70	r = .032	.791

Following on from this, a series of analyses were performed between parent-reported social support, resilience, quality of life variables and their child's clinical factors, including the number of months passed since child's diagnosis and the number of months passed since their child's end of treatment. Pearson's product moment and Spearman's rho correlations were conducted between parents perceived social support, resilience, quality of life and the number of months passed since their child's diagnosis and the number of months passed since their child's end of treatment. Two-tailed correlations were used in order to investigate any relationships between variables.

The number of months passed since their child's diagnosis significantly negatively correlated with parents perceived total support (MSPSS), family support (MSPSS), friend support (MSPSS) and significant other support (MSPSS), indicating that as the number of months since diagnosis increased, parents perceived total support (r_s = -.353, p <.01), family support (r_s = -.310, p <.01), friend support (r_s = -.266, p <.05) and significant other support (r_s = -.323, p <.01) decreased. In other words, the longer it had been since their child was diagnosed, the less support parents felt they were receiving. No other significant correlations were observed. See Table 4.16 for a full breakdown of results.

Table 4.16: *Correlations Between Social Support, Resilience and Quality of Life Variables and Months Since Child's Diagnosis: Parent Reported*

Variable (Scale)	***N***	***r or r_s***	***p***
Social Support (MSPSS)			
Total Support	70	r_s = -.353**	.003
Family Support	70	r_s = -.310**	.009
Friend Support	70	r_s = -.266*	.026
Significant Other Support	70	r_s = -.323**	.006
Resilience (RS25)			
Total Resilience	70	r = -.155	.200
Quality of Life (SF-36)			
Physical Functioning	70	r_s = .118	.332
Role Physical	70	r_s = -.013	.914
Bodily Pain	70	r_s = -.022	.859
General Health	70	r_s = .084	.490
Vitality	70	r = .076	.532
Social Functioning	70	r_s = .071	.562
Role Emotional	70	r_s = -.055	.649
Mental Health	70	r = -.092	.450
Physical Component Score (PCS)	70	r_s = .080	.510
Mental Component Score (MCS)	70	r = -.060	.621

*p <.05. **p <.01.

Finally, the number of months passed since their child's end of treatment significantly negatively correlated with parents perceived total support (MSPSS), family support (MSPSS), friend support (MSPSS), significant other support (MSPSS) and total resilience (RS25), indicating that as the number of months passed since their child's end of treatment increased, perceived total support (r_s = -.377, p <.01), family support (r_s = -.316, p <.01), friend support (r_s = -.324, p <.01), significant other support (r_s = -.367, p <.01) and resilience (r = -.244, p <.05) decreased. No other significant correlations were observed. See Table 4.17 for a full breakdown of results.

Table 4.17: *Correlations Between Social Support, Resilience and Quality of Life Variables and Months Since Child's End of Treatment: Parent Reported*

Variable (Scale)	*N*	*r or* r_s	*p*
Social Support (MSPSS)			
Total Support	70	r_s = -.377**	.001
Family Support	70	r_s = -.316**	.008
Friend Support	70	r_s = -.324**	.006
Significant Other Support	70	r_s = -.367**	.002
Resilience (RS25)			
Total Resilience	70	*r* = -.244*	.042
Quality of Life (SF36)			
Physical Functioning	70	r_s = .145	.231
Role Physical	70	r_s = .066	.585
Bodily Pain	70	r_s = -.075	.538
General Health	70	r_s = .005	.969
Vitality	70	*r* = -.070	.565
Social Functioning	70	r_s = .076	.533
Role Emotional	70	r_s = .067	.583
Mental Health	70	*r* = -.029	.811
Physical Component Score (PCS)	70	r_s = .036	.769
Mental Component Score (MCS)	70	*r* = -.008	.948

*p <.05. **p <.01.

4.10.4 Objective - To Explore the Relationship Between Parents' Social Support, Resilience and Quality of Life.

Pearson's product moment and Spearman's rho correlations were performed in order to investigate any links between social support, resilience and quality of life amongst parents. One-tailed correlations were performed in order to assess the existence of previously hypothesised relationships between variables. Quality of life was conceptualised as the outcome variable and was assessed using the Physical

Component Summary (PCS) and Mental Component Summary (MCS) scores from the SF-36. These scores provide validated, higher-order summary scores that provide a comprehensive, efficient measure of overall physical and mental health, which are the key dimensions of quality of life. The use of the PCS and MCS scores in this context serves to reduce the number of comparisons and the associated risk of Type I error stemming from correlations among multiple SF-36 domains, thereby improving statistical robustness. This approach also aligns with prior research that employs these composite scores as global indicators of physical and mental quality of life. In earlier sections of the analysis, individual SF-36 domain scores were included in descriptive and group comparisons to yield a more granular understanding of specific functional areas influenced by demographic factors such as gender, age and education. Thus, both the summary scores and domain-level scores serve complementary roles: domain scores offer detailed insights into particular aspects of functioning, while summary scores allow focused analysis of overarching physical and mental health constructs in relation to social support and resilience. The results of these analyses are displayed in Table 4.18.

Consistent with hypothesis 1, significant correlations were found between resilience (RS25) and perceived levels of total social support (MSPSS) (r_s = .399, p <.001), family support (MSPSS) (r_s = .310, p <.001), friend support (MSPSS) (r_s = .435, p <.001) and significant other support (MSPSS) (r_s = .223, p <.05). These results indicate that higher resilience is associated with greater social support across all sources (family, friends, significant others).

Hypothesis 2 was partially supported with significant correlations observed between parents' MCS (SF-36) and perceived levels of total social support (MSPSS) (r_s = .267, p <.05), family support (MSPSS) (r_s = .299, p <.01) and friend support (MSPSS) (r_s = .293, p <.01). There was no significant correlation observed between social support (MSPSS) and PCS (SF-36). These results indicate that social support, especially from friends and family, is linked to better mental well-being (MCS), but not significantly to physical health (PCS).

Similarly, hypothesis 3 was partially supported with a significant correlation observed between resilience (RS25) and parents' MCS (SF-36) (r = .514, p <.01). There was no significant correlation

observed between resilience (RS25) and PCS (SF-36). These results indicate that more resilient parents report better mental well-being (MCS), but their resilience was not significantly associated with their physical health (PCS).

In summary, among the parents in this study, higher perceived social support, especially from family and friends, was positively associated with higher mental well-being and greater resilience. Parents who were more resilient were more likely to report receiving more social support, which, in turn, was positively associated with their mental health. However, neither social support nor resilience showed a significant association with physical health within this sample.

Table 4.18: *Correlations Between Parents Social Support, Resilience and Quality of Life*

Variables	1	2	3	4	5	6	7
1. Frequency of Total Support	1	-	-	-	-	-	-
2. Frequency of Family Support	$.881_s$**	1	-	-	-	-	-
3. Frequency of Friend Support	$.834_s$**	$.599_s$**	1	-	-	-	-
4. Frequency of Significant Other Support	$.767_s$**	$.573_s$**	$.500_s$**	1	-	-	-
5. Resilience (RS25)	$.399_s$**	$.310_s$**	$.435_s$**	$.223_s$*	1	-	-
6. MCS	$.267_s$*	$.299_s$**	$.293_s$**	$-.006_s$	.514**	1	-
7. PCS	$.161_s$	$.162_s$	$.121_s$	$.145_s$	$.106_s$	$-.129_s$	1

*p <.05. **p <.01.
$_s$ = Spearman's rho correlation coefficient

4.11 Discussion

In this section, the findings from the quantitative strand of this mixed-methods study will be discussed. The aim of the quantitative strand was to explore the relationship between, and factors related to social support, resilience and quality of life among children who finished treatment for leukaemia within the past 5 years and their parents. Findings pertaining to the children will be discussed first, followed by findings pertaining to the parents. Strengths and limitations of this quantitative strand will also be outlined.

4.12 Children

This section discusses the findings of the children's questionnaires in line with the objectives of the quantitative strand of this mixed-methods study.

4.12.1 Objective 1 - To Establish Self-Reported Levels of Social Support, Resilience and Quality of Life

Children reported the highest level of support from their parents, followed by teachers, close friends, and classmates. This finding echoes previous literature emphasising the primary role of parents in providing a foundational sense of support and emotional security in childhood (Bowlby, 2008). According to attachment theory, strong parental bonds contribute to a child's ability to form healthy relationships and manage stress (Ainsworth, 1989). Beyond parental support, teachers also play a significant role in children's emotional well-being. The relatively strong support from teachers reinforces previous research on the importance of positive teacher-student relationships in promoting emotional well-being (Lin et al., 2022; Saxer et al., 2024). In contrast, the comparatively lower scores for support from close friends and classmates in this sample suggest that, while peer relationships are valuable, they may play a less central role in the perceived social support structures of children recovering from leukaemia. Peer relationships, particularly in early childhood, tend to be more transient and less reliable than the support provided by adult caregivers (Rubin et al., 2015).

These patterns were further reflected in the developmental differences observed within the current study. Younger children reported not only higher levels of support from all sources but also rated these sources as more important than older children. This likely reflects younger children's greater dependence on adult caregivers for emotional security, guidance and routine, especially in the context of recovery from a serious illness. In contrast, older children may be more discerning in how they perceive and appraise support, influenced by their heightened sense of autonomy, evolving identities and increasing focus on peer relationships. This shift aligns with Erikson's (1982) psychosocial development theory, specifically the stage of "identity vs. role confusion", whereby adolescents strive to establish their own sense of self and personal identity. While parental support remains important, adolescents begin to assert greater independence from caregivers and increasingly turn to peers for validation, support and social belonging (Branje et al., 2021; Scott & Saginak, 2016; Zhang & Qin, 2023). Taken together, these findings underscore the importance of considering developmental stage when evaluating social support, as the structure, source and perceived value of support may vary significantly between younger children and adolescents navigating post-treatment recovery.

Finally, the findings revealed a difference in how children perceive their quality of life in the physical and psychosocial health domains, with children rating their physical health more positively than their psychosocial health. This suggests that, while children may feel relatively capable in their physical abilities, they may continue to face more subtle challenges in their emotional, social, and school functioning. This pattern suggests that, although physical recovery may progress steadily after treatment, psychosocial recovery may be more complex and uneven. This aligns with existing literature indicating that survivors of childhood cancer often face ongoing challenges related to emotional adjustment, social reintegration, and academic performance (Bitsko et al., 2016; Hendriks et al., 2022; Huang et al., 2017; Kazak et al., 2010; McDougall & Tsonis, 2009; van Erp et al., 2021; Vetsch et al., 2018). While the present findings do not indicate severe psychosocial difficulties, they highlight areas where children may be more vulnerable and in need of continued support. Prior research has identified issues such as posttraumatic stress, anxiety and difficulties adjusting to life after treatment as common among survivors,

which may help explain the comparatively lower scores in psychosocial domains observed in the current study (Maurice-Stam et al., 2007; Okado et al., 2018). Similarly, social isolation and academic difficulties have also been noted as factors that can affect children's overall well-being and may be relevant for interpreting these results (Delehaye et al., 2024; Pahl et al., 2021).

Importantly, developmental differences were also reflected in these quality of life outcomes, with younger children tending to report more positive perceptions of quality of life across all domains when compared to older children. One possible explanation is that younger children, who also reported higher perceived social support, may benefit from the emotional security and buffering effects of close adult relationships, particularly in the immediate years following treatment. In contrast, older children may face more complex psychological demands, as they begin to grapple with a greater awareness of long-term risks, disrupted academic and social trajectories, and evolving concerns about identity and the future (Scott & Saginak, 2016; Zhang & Qin, 2023). These developmental factors may contribute to older children's comparatively lower ratings of psychosocial well-being, even as their physical health perceptions remain relatively positive.

4.12.2 Objective 2 - To Examine Relationship Between Children's Social Support, Resilience and Quality of Life with their Self-Reported Demographic and Clinical Factors

No significant gender differences in self-reported perceptions of social support, resilience and quality of life were found across both age groups (≤12 years and 13–17 years) and in the overall sample. The absence of significant gender differences contradicts previous research suggesting that girls typically report higher levels of social support, particularly from friends and family, whereas boys tend to rely more on instrumental support and be less likely to express emotional needs (Camara et al., 2017; Rose & Rudolph, 2006; Rueger et al., 2010). The absence of such differences in the present study suggests that the experience of leukaemia and its treatment may create a more uniform psychosocial impact across boys and girls, possibly due to shared reliance on family and healthcare support systems during and after treatment. These common support structures may reduce the expression of gendered coping patterns,

leading to more similar perceptions of support, resilience and quality of life among boys and girls. However, this interpretation should be made with caution given the modest sample size, which may have limited the ability to detect gender differences. Furthermore, no non-binary children or adolescents were represented in the sample, highlighting an important gap for future research.

A key finding of this study is the significant negative association between age and children's perceptions of social support both in terms of its frequency and importance. As children grew older, they reported receiving support less frequently and rated it as less important, across multiple sources, including teachers, classmates, close friends and parents. As mentioned earlier, this aligns with developmental theories suggesting that, as children grow older, they strive for greater independence and autonomy, potentially leading them to perceive social support as less important (Branje et al., 2021). Moreover, the observed decline in school functioning and psychosocial health with age suggests that as children get older, they may face increasing academic and social demands that may contribute to diminished well-being. As children progress through school they encounter greater academic pressures, more complex social relationships and greater expectations for emotional self-regulation, all of which can have a negative impact on their psychosocial well-being (Jiang et al., 2022; Wang & Eccles, 2012). The concurrent decline in perceived social support suggests that the buffering effects of support may weaken as children grow older, but this may also reflect the unique challenges of adolescence, such as hormonal changes, difficulties with emotional regulation, evolving peer relationships, and shifts in self-esteem and self-confidence that shape how support is sought, received, and valued (Branje et al., 2021; Collins & Larsen, 2004; Kent et al., 2012; Zhang & Qin, 2023). Together, these factors may leave older children more vulnerable to stressors, even when support remains present. The decline in psychosocial health with age also indicates that psychological support may be even more critical as children get older. Furthermore, qualitative exploration of children's lived experiences, especially in relation to peer dynamics, school reintegration, and shifting emotional needs could offer critical insights into the psychosocial mechanisms underlying these patterns.

The findings that no significant correlations were observed between child-reported social support, resilience and quality of life with the number of months since diagnosis or since the end of treatment suggests that psychosocial recovery in childhood cancer survivors does not appear to be solely dependent on the passage of time. While it might be expected that more time would facilitate greater psychological adjustment and social reintegration, these results indicate that recovery is influenced by a wider range of factors beyond time alone. Given the cross-sectional nature of the data, no conclusions can be drawn about the trajectory of psychosocial recovery. However, the lack of association at this single time point highlights the importance of considering individual variation and the potential influence of other contextual, relational, or developmental factors that shape recovery experiences in childhood leukaemia survivors.

Some research suggests that psychological distress tends to decrease over time as children adjust and become more resilient (Wakefield et al., 2010), other studies have shown that many survivors continue to encounter ongoing challenges, which may not be fully captured by time since treatment alone (Barrett et al., 2020; Castellano-Tejedor et al., 2016; Hendriks et al., 2021; Patterson et al., 2024). This suggests that factors other than time may be influencing children's social support experiences. For example, ongoing medical complications, social stigma related to having cancer, late effects of treatment and barriers to social reintegration may complicate access to social support regardless of how long it has been since treatment ended. Similarly, the concept of resilience, which is often assumed to naturally develop with time, has been shown to be shaped by a number of external factors beyond just the passage of time, such as family coping mechanisms, psychological support and individual characteristics (Castellano-Tejedor et al., 2016; Greeff et al., 2014; Sumrall et al., 2024). Given the complexity and individuality of these experiences, qualitative research could offer valuable insights into the lived experiences of survivors to better understand how these factors interact and affect psychosocial outcomes.

Taken together, these findings suggest that, while time is an important contextual factor in recovery, it is not sufficient on its own to explain variations in social support, resilience and quality of

life. As such, future research should adopt longitudinal studies to explore how individual factors interact over time to help shape recovery.

4.12.3 Objective 3 - To Explore the Relationship Between Children' s Social Support, Resilience and Quality of Life

The findings from this study provide valuable insights into the relationships between social support, resilience and quality of life among children in the post-treatment phase following treatment for leukaemia. Amongst the younger children, greater social support, especially from parents, teachers, and classmates, was associated with higher resilience, and both social support and resilience were independently associated with better quality of life, particularly in psychosocial aspects. These findings suggest that both social support and resilience may play important roles in shaping post-treatment quality of life in younger children. In contrast, among older children, greater social support, particularly from parents, was associated with higher resilience, and social support was independently associated with better quality of life. However, resilience was significantly correlated with psychosocial health but not with overall quality of life or physical health.

Consistent with previous research examining children with chronic illnesses and childhood cancer survivors, both older and younger children with higher resilience perceived greater social support, particularly from parents (Castellano-Tejedor et al., 2016; Greeff et al., 2014; Ingersgaard et al., 2021). The findings align with previous research highlighting the important role of parents in providing practical and emotional support to children across all stages of development (Gudmundsdottir et al., 2011; Ingersgaard et al., 2021; Pennant et al., 2019). According to attachment theory (Ainsworth, 1989), primary caregivers, typically parents, serve as foundational sources of support for children, fostering resilience and effective coping mechanisms. However, the finding that greater resilience was significantly associated with greater perceived social support from teachers and classmates for younger children, but not for older children, contradicts some existing research, which suggests that peer support from friends becomes increasingly important as children grow older (Branje et al., 2021; Fuligni, 2019; Ingersgaard et

al., 2021; Zimmer-Gembeck & Skinner, 2010). This discrepancy between younger and older children suggests that older children may face more struggles reintegrating back into their school environments and socialising with peers post-treatment. These findings suggest that social support needs may vary across developmental stages and highlights the need for further research into how different types of social support interact with resilience across various age groups and stages of recovery. Furthermore, qualitative research exploring the lived experiences of school reintegration and peer relationships could offer valuable insights into these age-related differences.

Another key finding was that social support, particularly from teachers, classmates, and close friends, was associated with better overall quality of life, is consistent with previous research involving children with cancer or chronic illness (Conrad & Altmaier, 2009; Ingersgaard et al., 2021; Klassen et al., 2011; Pennant et al., 2019; Woodgate, 1999). While several of these studies focused on children undergoing active cancer treatment or included mixed diagnostic groups, the present findings specifically highlight the importance of social support during the post-treatment phase of childhood leukaemia survivors. Social support from these sources helps to buffer against the negative effects of stress and struggles that survivors face post-treatment, including isolation, anxiety, and difficulties reintegrating into normal life (Brinkman et al., 2018; Calhoun et al., 2022; Cohen & Wills, 1985; Ingersgaard et al., 2021). Teachers and classmates provide a sense of normalcy and belonging, while close friends offer empathy and companionship for survivors (Ingersgaard et al., 2021; Tremolada et al., 2016). However, the non-significant finding for parental support is unexpected, as prior studies have consistently highlighted the influential role of parents in shaping children's quality of life both during and after illness (Azak et al., 2025; Jantien Vrijmoet-Wiersma et al., 2008). One possible explanation is that as children, particularly older survivors, grow and seek more autonomy, they may rely more heavily on peers for emotional validation and social connection, while viewing parental support as expected (Branje et al., 2021; Fladeboe et al., 2021; Jones et al., 2011; Kent et al., 2012). Additionally, the post-treatment period may be marked by altered family dynamics or parental distress, which can affect the perceived availability or effectiveness of support (Keller et al., 2024; Muskat et al., 2017). In essence, these findings reinforce the

importance of strong social networks in promoting positive psychosocial outcomes in childhood leukaemia survivors.

Finally, important age-related differences were found in the relationship between resilience and quality of life among childhood cancer survivors. For younger children, higher resilience was significantly associated with better quality of life, particularly in psychosocial health aspects, reinforcing its role as a key protective factor in helping to mitigate against emotional distress. This finding aligns with previous research linking resilience to a better quality of life (Castellano-Tejedor et al., 2016; Greeff et al., 2014; Rosenberg et al., 2015). However, among older children, resilience was significantly correlated with psychosocial health but not with overall quality of life or physical health. This discrepancy suggests that, while resilience may support psychosocial adjustment among older children, it alone may not be sufficient to account for the broader quality of life outcomes of older children. It is possible that other factors known to negatively impact these groups, such as reintegration into school, body image concerns, peer relationships, long-term treatment side-effects and fatigue may play a greater role in shaping older children's overall quality of life (Larsen et al., 2022; Tremolada et al., 2017). Future research should investigate the mediating influence of such factors between resilience and quality of life, particularly amongst older children. Additionally, qualitative research exploring the lived experiences of post-treatment reintegration and social adjustment could provide valuable insight into the developmental and contextual challenges faced by older children.

4.13 Parents

This section discusses the findings of the parent questionnaires in line with the objectives of the quantitative strand of this mixed-methods study. The results provide a nuanced picture of the post-treatment experiences of parents of childhood leukaemia survivors. The key findings show that parents reported the highest levels of social support from their significant other, followed by family, and then friends. Resilience scores were moderate-to-high, and quality of life scores indicated higher levels of physical functioning compared to mental well-being. Notable gender differences were observed, with

fathers reporting higher mental well-being and mothers reporting better physical functioning. Social support and resilience both declined as the number of months since diagnosis and end of treatment increased. Finally, a significant positive correlation was found between social support, resilience, and mental well-being, but no significant relationship was found between social support, resilience, and physical health. The following sections present a more detailed discussion of these findings in relation to each of the study's quantitative objectives.

4.13.1 Objective 1 - To Establish Self-Reported Levels of Social Support, Resilience and Quality of Life

Parents reported the highest frequency of social support from their significant other, followed by family, and then friends. These findings broadly align with previous research paediatric cancer research, which suggests that intimate partners typically serve as the primary source of both emotional and instrumental support for parents (Gise & Cohen., 2022; Melguizo-Garín et al., 2023). However, the current study contributes specificity by documenting these patterns within the context of childhood leukaemia post-treatment survivorship, highlighting the perceived hierarchy of support during this critical phase. The comparatively lower support from friends suggests that friendships, while valuable, may not offer the same depth of support. Some friends might feel unable to provide adequate support or may struggle to fully relate to the unique experiences parents face in this context (Nielsen et al., 2024), which qualitative inquiry may further elucidate.

Parents demonstrated a moderate-to-high levels of resilience, implying an ability to cope with adversity but also suggesting that some individuals may be vulnerable to psychological difficulties. A recent study by Sharp and colleagues (2022) on trajectories of resilience and posttraumatic stress in children and their parents across a 5 year period, identified two distinct trajectories of posttraumatic stress among parents of childhood cancer survivors: a 'resilient trajectory' with consistently low and decreasing levels of posttraumatic stress (71.5% of parents), and an 'elevated posttraumatic stress trajectory' with higher and increasing posttraumatic stress overtime (28.5% of parents). Understanding what factors contribute to higher resilience, such as coping strategies, socioeconomic status, or access to psychosocial

resources is essential for advancing knowledge of parents' varied experiences following childhood leukaemia.

Finally, the findings on quality of life for parents revealed an interesting disparity between physical and mental well-being. The highest mean score was in the physical functioning domain, suggesting that parents generally perceive a relatively high level of ability to perform everyday physical activities, while the lowest score was in the energy and vitality domain, suggesting a greater level of fatigue, which aligns with previous findings on caregiver burden (Chaghazardi et al., 2022; Heller & Melnikov, 2025; Junkins et al., 2020; Salvador et al., 2015). Notably, these findings are specific to the post-treatment phase of childhood leukaemia survivorship, highlighting that despite the conclusion of medical treatment, parents may continue to experience persistent fatigue and mental health challenges. However, it is important to note that other factors, such as family circumstances, work demands, and broader psychosocial stressors may also influence these outcomes (Chaghazardi et al., 2022; Salvador et al., 2015). Moreover, the physical component score (PCS) was notably higher than the mental component score (MCS), suggesting that parents experience greater mental strain than physical limitations. This is consistent with previous research indicating that parents of children with serious illnesses experience heightened levels of anxiety, depression, and post-traumatic stress symptoms (Ljungman et al., 2014; Meeske et al., 2007; van Warmerdam et al., 2019). What is particularly novel in this study is the focus on the post-treatment phase of childhood leukaemia survivorship, illustrating that mental health challenges persist even after successful treatment completion. This highlights the need for targeted and accessible mental health support, including counselling and peer support groups, to improve mental well-being. These findings also point to the value of qualitative exploration to better understand how parents make sense of their experiences and adjust in the longer term.

4.13.2 Objective 2 - To Examine the Relationship Between Parents' Social Support, Resilience and Quality of Life with their Self-Reported Demographic Factors and their Child's Clinical Factors (parent-reported)

The findings suggest significant differences in mental and physical health outcomes among fathers and mothers of childhood leukaemia survivors. Fathers reported significantly higher MCS than mothers, while mothers had significantly higher PCS. Consistent with previous research, the lower mental well-being reported by mothers aligns with research indicating that mothers often experience higher levels of psychological distress due to their primary caregiving role (Pinquart, 2018; Sultan et al., 2016; Kuswanto et al., 2018). However, the lower mental health scores among fathers should be interpreted with caution. Rather than indicating the absence of distress, it is possible that fathers' psychological difficulties may be underreported or manifest differently, as previous studies suggest that men are more likely to adopt avoidance-based coping strategies and less likely to express emotional vulnerability (Lundgren et al., 2025; Seidler et al., 2016). This highlights the need for further investigation into the coping mechanisms used by fathers, as well as how mental health outcomes may be shaped by gendered patterns of emotional expression, caregiving involvement, and identification with societal norms of masculinity and femininity.

Conversely, mothers reported higher PCS scores than fathers, suggesting better perceived physical health. This finding challenges previous research that typically associates caregiving responsibilities with increased physical strain and fatigue, particularly for mothers who often assume primary caregiving roles (Mensah et al., 2023; Olsavsky et al., 2024). In the context of post-treatment survivorship, higher PCS scores among mothers may reflect differences in self-perception, reporting tendencies, or coping strategies developed during the caregiving period, rather than a phenomenon unique to childhood leukaemia. Alternatively, mothers may have a different baseline for assessing their physical health compared to fathers, potentially leading them to rate their physical health more optimistically. Notably, despite these differences in quality of life scores, no significant gender differences were found in levels of social support or resilience, suggesting that mothers and fathers report similar experiences of support and resilience. Qualitative research could usefully explore these possibilities by examining parents lived

experiences, helping to disentangle the complex interplay between caregiving roles, resilience, and gendered perceptions of health.

Consistent with previous research, parents perceived a decrease in social support as the number of months since their child's diagnosis and end of treatment increased (Inhestern et al., 2020; Kelada et al., 2019; Melguizo-Garín et al., 2019; Wakefield et al., 2010; Wijnberg-Williams et al., 2006). This pattern likely reflects the natural decline in perceived support as the acute crisis phase transitions into long-term caregiving (Davies & O'Connor, 2023; Inhestern et al., 2020). Parents typically receive extensive support from family, friends, healthcare providers and the broader community when their child is first diagnosed (Gage, 2013; Melguizo-Garín et al., 2019; Nielsen et al., 2024). However, as time passes, others may assume that the most challenging period has passed and that the family no longer requires the same level of support. This assumption, however, may not align with the ongoing support needs of parents (Jantien Vrijmoet-Wiersma et al., 2008). Additionally, the decline in significant other support aligns with findings showing that the stress of caring for a child with an illness can strain marital relationships over time (Kearney et al., 2015; Lavi et al., 2018; Wiener et al., 2017). These dynamics warrant further exploration, particularly through qualitative research, to better understand parents lived experiences with shifting social support and its impact on resilience and quality of life.

Furthermore, the observed decrease in resilience over time as the number of months passed since their child finished treatment is concerning given its important role in helping individuals cope with adversity (Melguizo-Garín et al., 2019; Rosenberg et al., 2014). Resilience often depends on the availability of strong social support networks, suggesting that the decline of support over time may contribute to a weakening of parents' ability to adapt and cope with stress effectively (Melguizo-Garín et al., 2019; Rosenberg et al., 2014). Later analysis will further explore how resilience and social support interact in this context. Another possible explanation for the reduction in parents' perceptions of resilience is that they may initially feel a sense of relief and strength when treatment is over but, as time goes on, new challenges may emerge, such as fear of relapse or difficulty adjusting to a 'new normal', which may challenge parents' resilience and sense of adaptive capacity (Mckenzie & Curle, 2012; Muskat

et al., 2017). Overall, these findings underscore the importance of ongoing support for parents beyond the initial diagnosis and treatment phase.

4.13.3 Objective 3 - To Examine the Relationship Between Parents' Social Support, Resilience and Quality of Life

The results from this study provide valuable insights into the relationships between social support, resilience and quality of life in parents. Findings revealed a significant positive relationship between social support, resilience and mental well-being among parents. However, contrary to expectations, no significant relationships were found between social support, resilience and physical health.

The finding that social support is positively associated with greater resilience and mental well-being aligns with previous research, emphasising the protective role of social support in fostering resilience and psychological health (Cohen & Wills, 1985; Luthar et al., 2000; Rosenberg et al., 2014; Uchino, 2009). Social support has long been recognised as a key protective factor for psychological outcomes, serving as both a buffer against stress and a resource for adaptive coping (Cohen & Wills, 1985; Melguizo-Garín et al., 2019). However, what this study contributes is a focused examination of this relationship within the underexplored context of the post-treatment phase of childhood leukaemia survivorship. This adds a valuable perspective by showing that even after the intensity of active treatment subsides, support continues to play a vital role in sustaining resilience and promoting mental well-being in parents. Furthermore, this study offers new insights into the sustained psychosocial needs of parents beyond the completion of treatment. To fully capture the nuances of how parents experience and make sense of these interrelated processes over time, qualitative research is needed to explore their lived experiences in greater detail.

However, the absence of a significant relationship between social support, resilience, and physical health is noteworthy and contrasts with some prior research suggesting links between social relationships and resilience with physical health outcomes (Ha et al., 2022; Thoits, 2011; Uchino, 2006). One possible explanation for this discrepancy is that other factors may mediate or moderate the relationship between

social support, resilience and physical health. Factors such as biological processes, lifestyle behaviours, access to healthcare and pre-existing health conditions may play a more significant role in determining physical health outcomes than social support or resilience alone (Braveman & Gottlieb, 2014; Holt-Lunstad, 2024).

Future research should consider potential mediating and moderating factors to better understand the nuanced relationship between social support, resilience and quality of life among parents of childhood leukaemia survivors. While this study highlights important associations, it was not sufficiently powered to explore mediation or moderation effects. Moreover, long-term support interventions designed to support parents should aim to strengthen social networks and promote resilience building strategies, while considering the multifaceted nature of well-being, which includes both mental and physical health dimensions. Such interventions could include peer support groups, psychoeducational workshops focused on coping skills, family-centered counselling, or access to community resources that address ongoing caregiving challenges. Addressing these complexities by tailoring interventions to the diverse and evolving needs of parents may enhance the effectiveness of support interventions by improving engagement and fostering more meaningful and sustained support. This comprehensive approach ensures that support reflects the holistic nature of parental well-being, ultimately improving quality of life outcomes.

4.14 Strengths and Limitations of the Quantitative Strand

To the author's knowledge, this is the first study to quantitatively examine the relationship between, and factors related to social support, resilience and quality of life among children who successfully finished treatment for leukaemia and their parents. A key strength of this study is that it focused exclusively on childhood leukaemia, rather than including a broader range of paediatric cancer types. By concentrating on this specific diagnosis, the study ensures that its findings are more specific and relevant to the unique experiences of children recovering from leukaemia and their parents. Focusing exclusively on childhood leukaemia is important because its treatment protocols, duration, late effects, and psychosocial impacts

differ from other paediatric cancers. This specificity allows for more precise insights into the unique recovery experiences and support needs of these families, enabling the development of tailored interventions rather than broad approaches applied across varied cancer types. Another major strength of this research is the inclusion of both children's and parents perspectives, rather than relying on parent-proxy reports, which are typically used in illness related psychosocial research (Eiser & Morse, 2001; Fisher et al., 2021; Inhestern et al., 2020; Klassen et al., 2006; Sherifali & Pinelli, 2007). While parent-proxy reports provide valuable insights, they may not fully reflect children's own perceptions of their social support, resilience and quality of life.

Despite the notable strengths outlined above, as with all studies, there were also limitations. Firstly, the majority of parent participants in this quantitative strand were mothers, which may limit the applicability of these findings to fathers of childhood leukaemia survivors. Secondly, the relatively small sample size for this strand of the study did not allow for the investigation of interrelationships between all variables of interest within a single hierarchical multiple regression model. With a larger sample, it would have been possible to investigate more complex interrelationships, such as potential mediating or moderating effects, such as whether parental quality of life mediates the link between social support and child quality of life, or whether these relationships vary depending on factors like the child's age or time since treatment completion. Despite the implementation of a number of strategies to maximise recruitment (e.g., the utilisation of a three way recruitment pathway, the option for children and parents to complete the surveys in hard copy format or online, the inclusion of follow-up reminders), recruitment numbers remained relatively small. However, this reflects the inherently small population of childhood leukaemia survivors in any given year, which naturally constrains the number of eligible participants. The small sample size did not allow for the originally planned longitudinal design. The cross-sectional nature of this study did not allow for the identification of causal relationships over time. Future research should adopt larger sample sizes and employ a longitudinal design.

4.15 Conclusions of the Quantitative Strand

Overall, this quantitative strand of this mixed-methods enquiry represents the first quantitative investigation into the relationship between, and factors related to social support, resilience and quality of life among childhood leukaemia survivors and their parents. When considered collectively, the findings highlight the intricate ways in which these factors interact, emphasising that without adequate social support and resilience, both children and their parents risk facing ongoing challenges that can impact their quality of life. Addressing these elements is essential not only for helping children and their parents navigate life after leukaemia, but also ensuring they have the resources needed to thrive in the long-term. A holistic, multidimensional approach to support is key to overall health, happiness, and well-being for both children and their parents. Ensuring that children and their parents receive continued care beyond treatment is essential in fostering resilience and improving quality of life. The integration of these quantitative findings with the qualitative strand of this study will provide a deeper, more comprehensive understanding of the experiences of childhood leukaemia survivors and their parents, offering valuable guidance for future research, support programs, and interventions aimed at enhancing long-term quality of life.

Chapter 5: Qualitative Strand

5.0 Introduction

As survival rates for childhood leukaemia continue to improve due to significant advances in medical care and treatment, there is growing recognition that the end of treatment does not mark the end of the cancer experience (Keller et al., 2024; Muskat et al., 2017). While medical care may cease, the emotional, psychological, and social impacts of the cancer experience often continue to persist long after treatment completion for both children and their parents (Conway Keller et al., 2020; Inhestern et al., 2020; Tremolada et al., 2017). These impacts can include ongoing concerns, such as fear of relapse, changes in self-identity, altered family dynamics, and challenges or adjustments in reintegrating into social, educational and community settings.

For many, life after treatment is not just simply a return to 'normal', but rather an ongoing process of adjustment marked by emotional, developmental, and relational shifts (Davies & O'Connor, 2023; Hendriks et al., 2021; Muskat et al., 2017). These multifaceted adjustments underscore the need to consider survivorship as a distinct and dynamic phase of the cancer trajectory rather than a fixed endpoint. Despite increasing awareness of these post-treatment challenges, existing research tends to focus predominantly on either the acute treatment phase or long-term survivorship, often defined as five or more years post-treatment (Keller et al., 2024; Davies & O'Connor, 2023; Inhestern et al., 2020; Wilford et al., 2019). Consequently, the immediate post-treatment period is relatively under-explored.

Moreover, the key constructs of social support, resilience and quality of life, widely acknowledged as central to psychosocial adjustment are often examined in isolation, or through quantitative tools that may fail to capture their fluid, context-dependent, and meaning-laden nature. This qualitative strand was therefore designed to explore the lived experiences of children who have completed treatment for leukaemia and their parents. Specifically, it seeks to understand how they interpret and navigate the evolving dynamics of social support, resilience and quality of life as they adjust to life beyond treatment. Understanding these experiences is vital not only for improving psychosocial care, but

also for informing support systems, policy, and survivorship services that better reflect the realities families face.

This chapter outlines the methodological details of the qualitative strand of the study, including: 1) aims and specific objectives; 2) study design; 3) participants; 4) study procedure; 5) key ethical considerations; and 6) data analysis.

5.1 Aims

The overall aim of this qualitative strand was to explore the post-treatment experiences of childhood leukaemia survivors and their parents, with a particular focus on social support, resilience and quality of life.

The objectives were to:

1) Explore how children experience the transition to post-treatment life, particularly in relation to social support, resilience and quality of life.
2) Explore how parents of childhood leukaemia survivors experience the transition to post-treatment life, particularly in relation to social support, resilience and quality of life.

5.2 Study Design

The qualitative strand of this mixed-method study adopted an exploratory qualitative design, which was appropriate for investigating under-researched, complex experiences, such as the post-treatment experiences of childhood leukaemia survivors and their parents. This qualitative component was conducted within a convergent parallel mixed-methods design (Creswell & Plano Clark, 2018), wherein quantitative and qualitative data were collected and analysed independently but concurrently, with integration occurring at the interpretation stage. This qualitative approach allowed the study to capture the nuanced perspectives and contextualised experiences of survivors and parents, providing insight into how

social support, resilience, and quality of life are experienced and understood in everyday life, beyond what could be captured by standardised instruments.

5.3 Selection Criteria

Children and parents/guardians who participated in the quantitative strand and consented to be contacted for an interview were eligible for the interview strand. This included participants from families in which both a child and parent had taken part, regardless of time since treatment completion, as well as individual participants whose child had finished treatment within the past six months

5.4 Recruitment

A recruitment email was sent to eligible participants who, after completing the quantitative survey, had agreed to be contacted for an interview. Of those contacted, 11 children and 19 parents agreed to participate in the interviews, while 18 did not respond or declined the invitation to participate. This email included information sheets/plain language statements and a link to an online form for interview scheduling preferences, as well as consent/assent forms (see Appendices F1- F10 for recruitment material). To accommodate varying comprehension and reading levels, two separate information sheets were devised for child participants - one for younger children aged under 12 years and one for older children aged 13-17 years. If parents and/or their child expressed an interest and willingness to participate, the researcher arranged to meet with the consenting/assenting parent and/or child at a time and location convenient to them (via Zoom, over the phone, onsite at DCU or CHI Crumlin, at their home, or at a neutral venue of their choice). Twenty-four hours prior to the interview the researcher emailed the parent as a reminder and to ensure that the parent and/or child were still satisfied with their decision to participate.

5.5 Procedure

Two separate semi-structured interview topic guides were developed; a parent version (see Appendix F9) and a child version (see Appendix F10). The topic guides were developed collaboratively with the research team who had expertise in interviewing children/young people and their parents, and also with the Young Persons' Advisory Group (YPAG) affiliated with the National Children's Cancer Service at CHI Crumlin. YPAG is a group of children and young people who are actively involved in research and help ensure research being conducted is relevant and meets the needs of the young people affected. Every effort was made to ensure the interview schedules were flexible and not rigid, allowing for the elicitation of rich, diverse and in-depth data. The interview topic guides were developed to elicit information on participants' insights into their experience of the end of treatment phase and transition to life after childhood leukaemia, particularly in relation to their lived experience of social support, resilience and quality of life. Parent and child interviews were conducted separately unless the child chose to have their parent present during the interview, or vice versa; his/her wishes were respected in this regard.

Interviews took place via Zoom (n = 27), over the phone (n = 1), or at a neutral venue of their choice (n = 2). Participants were required to complete an online assent/consent form and return it online before the interview took place. Participation was completely voluntary. Parents were also made aware that they were under no obligation to share details of the interview with their child, however doing so implied that they consented for their child to participate. Parents were encouraged to discuss the details of the interview with their child if they were happy for them to participate. Furthermore, children were reminded that just because their parents consented for them to participate, it was ultimately up to themselves whether they wanted to take part or not.

On the day of the interview, for participants who opted to be interviewed via Zoom or over the phone the researcher contacted the participant from a private room at the agreed time, ensuring confidentiality and minimising interruptions. Participants were also asked in advance to join from a private space wherever possible, so that they could speak freely. In the case of in-person interviews the researcher met the participant at the prearranged time and location. See Appendix G for risk protocol for

interviews. Prior to commencing with the interview process, the researcher engaged in general conversation with the parent and/or child participants to develop rapport. Furthermore, participants were invited to raise any queries about partaking in the interview process and reminded that although they consented/assented to participate, their participation was voluntary, and they could stop the interview at any time. Interviews only commenced when participants were entirely satisfied and comfortable to do so.

All interviews were recorded using an electronic recording device for later transcription and analysis. Only audio data was recorded, there was no video recording across any interview format. The interviews took around 45 minutes to complete but ultimately the length of the interview was entirely dependent on the amount of information participants wished to relay about their experiences, as well as their level of engagement with the interview process. Once the interview was complete, the recording was downloaded in soft-copy format on the DCU Google Drive and labelled with the participant's unique ID code. The recording was then deleted from the recording device. The interview recording was then transcribed verbatim and saved to the DCU Google Drive under the participant's unique ID code. The researcher then removed any identifiable information from the transcript.

5.6 Ethical Considerations

The study was approved by the Research Ethics Committees in Children's Health Ireland (CHI) at Crumlin (REC-261-23) and Dublin City University's Research Ethics Committee (DCUREC/2023/091) (see Appendix E). Informed consent/assent, confidentiality and data protection were taken into consideration.

All participants were fully informed about the nature of the interviews through age appropriate information sheets and were given the opportunity to make their own decision about whether or not they wanted to participate. Informed consent/assent was sought from all parent and child participants prior to the interview process. As children could not provide legal consent, assent was sought from all child participants via age appropriate assent forms, alongside parental consent for their child's participation (see Appendices F6 - F8). Parents who participated in the study themselves also provided separate

informed consent for their own participation. Additionally, prior to the commencement of interviews, the researcher clarified that participants were fully informed about the study details and what their involvement would entail by doing a verbal check with them and answering any further questions that they may have had. Participants were also informed that if they wished to withdraw at any time, interviews would be stopped and there would be no repercussions for doing so. No participants chose to withdraw from the study.

If children desired to have their parent(s) present with them during the interview, this wish was respected and facilitated. In total, seven interviews were conducted with a parent present and four without their parent present. In some cases, the child requested this and in others, the parent expressed a desire to remain nearby, and this was accommodated. While most parents remained largely passive, there were occasional moments when they contributed more actively than anticipated and sometimes responded on behalf of their child. However, this was managed sensitively by the researcher, and every effort was made to ensure the child's voice remained central, using gentle redirection and follow-up questions. Nonetheless, the presence and level of parental involvement present a potential limitation, as children's responses may have been shaped, consciously or unconsciously, by parental influence, particularly in families with more directive or authoritarian parenting styles.

In order to protect participants anonymity and confidentiality, any identifiable information was removed from transcripts and unique ID codes provided from the onset of the study were used. Finally, safety protocols were devised to outline the actions the researcher should take if 1) a participant became upset, 2) a child protection issue arose, and/or 3) a participant disclosed suicidal ideations or there were concerns regarding mood and/or safety. These protocols are outlined in Appendix H. Contact details for relevant support services were also provided to all participants (see Appendix C).

5.7 Data Analysis

All interviews were transcribed verbatim and analysed using reflexive thematic analysis following Braun and Clarke's (2006) framework. The six step process involved 1) becoming familiar with the data, 2)

generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and finally, 6) producing a report of the thematic findings. This approach involved an inductive and iterative process in which meaning was actively interpreted by the researcher through a process of reflexive engagement with the data, rather than themes being passively "discovered" (Braun & Clarke, 2019). To begin thematic analysis, the researcher listened to the audio files and read/re-read the transcripts to become familiar with the data. Next, all transcripts were entered into NVivo 20 computer software (QSR International Pty Ltd, 2012). This software allows for the storage, retrieval and manipulation of large quantities of qualitative data. Next, the researcher coded the data line-by-line in each transcript. Once all data was coded in NVivo, codes were collated and synthesised into potential themes and sub-themes. Parent and child data were analysed separately to preserve the distinctiveness of their experiences and ensure that thematic development remained grounded in each group's unique perspective. Within the child dataset, data were analysed collectively as a single group; however, developmental differences between younger (aged 12 years and younger) and older children (aged 13–17 years) were noted and reflexively considered during coding and theme development.

Throughout the analytic process, the researcher engaged in memo-writing and regular critical reflection on how their own positioning shaped the interpretation of the data. All codes, themes, and subthemes were then reviewed by members of the research team where interpretations were validated through discussion and repeated referral to the coded extracts and original dataset. Each theme and sub-theme was then appropriately named and defined in relation to the data it sought to capture. Finally, all of this culminated in the production of a written analysis report.

To further enhance the trustworthiness of the analysis, Lincoln and Guba's (1985) evaluative criteria were applied. Credibility was supported through prolonged engagement with the data, repeated review of transcripts, and collaborative discussions with the research team, which enabled robust exploration and validation of interpretations. Transferability was enhanced by providing rich, contextualised accounts of participants' experiences, allowing readers to assess the relevance of findings in other settings. Dependability was addressed through careful documentation of the analytic process,

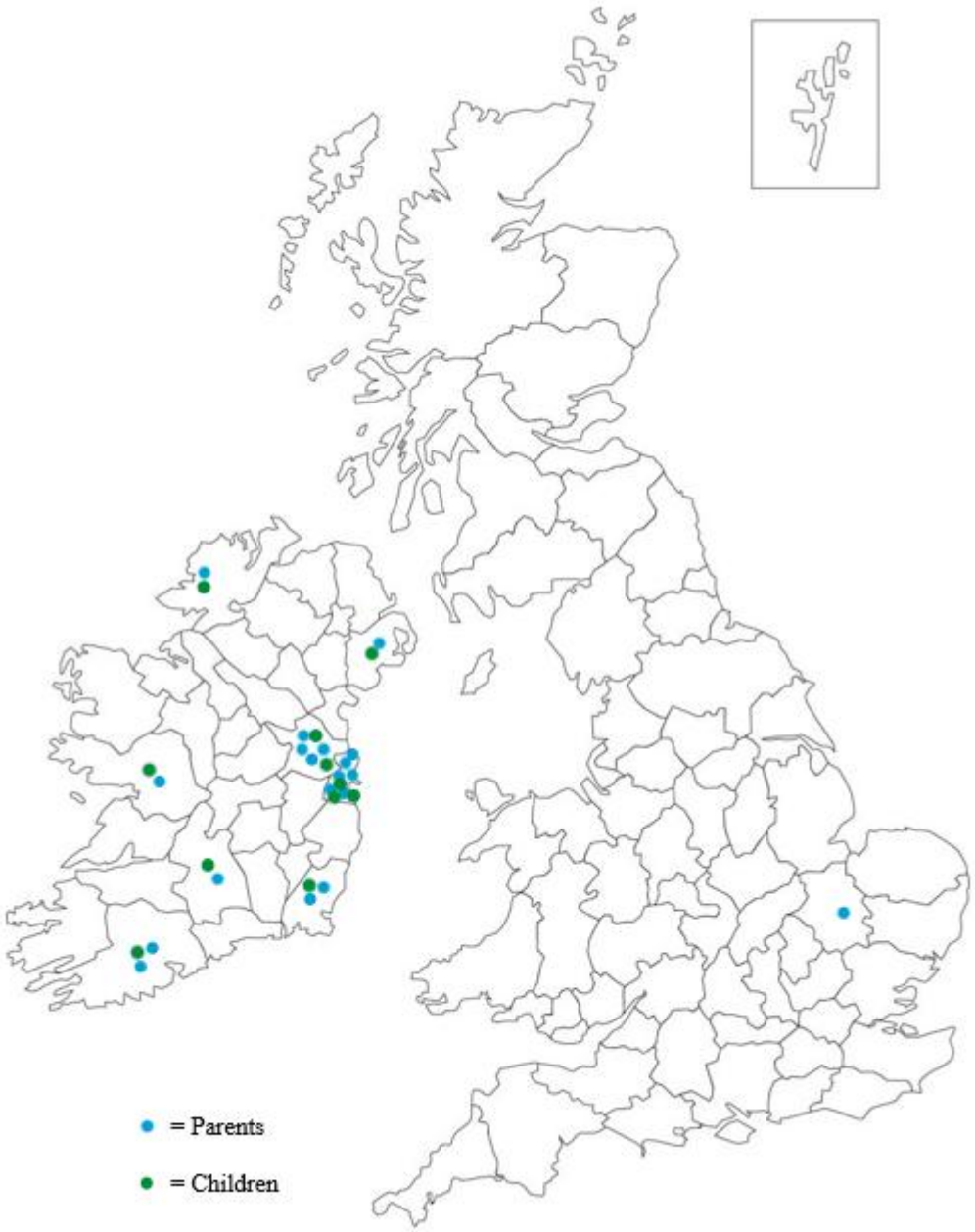
including coding decisions, theme development, and team-based review. Confirmability was strengthened through reflexive thinking and peer debriefing, ensuring that findings were grounded in participants' accounts rather than shaped solely by researcher assumptions. Reflexive memo-writing and regular peer debriefing with the research team were used to question assumptions, refine interpretations, and ensure that findings remained grounded in participants' voices rather than researcher expectations. This reflexive stance did not aim to remove subjectivity, but to recognise and manage it thoughtfully, thereby strengthening the transparency and trustworthiness of the analytic process.

5.8 Sample Characteristics

In total, 11 interviews were conducted with children (5 male, 6 female) aged 7-17 years (M = 11.73, SD = 3.61). Seven children were aged 12 years and younger, and 4 were aged 13-17 years. While 19 interviews were conducted with parents (4 male, 15 female) aged 34-53 years (M = 43.21, SD = 5.09). Parent interviews lasted between 27 minutes and 2 hours 16 minutes, with an average interview time of 63 minutes. Child interviews lasted between 13 minutes and 59 minutes, with an average interview time of 33 minutes. Interviews with younger children lasted an average of 25 minutes, while interviews with older children lasted an average of 46 minutes.

Participants were recruited from 9 counties across Ireland including Dublin, Meath, Cork, Armagh, Donegal, Galway, Tipperary, Waterford and Wexford. One participant was from the UK. The geographical distribution of participants is illustrated in Figure 7.1. The majority of the interviews (child and parent) were conducted via Zoom (n = 19 families). For one family, child and parent interviews were conducted in a hotel lobby. For child interviews, if children desired to have their parent(s) present with them during the interview, this wish was respected. Most children (n = 7, 63.64%) opted to be interviewed with their parents present, with 4 children (36.36%) opting to be interviewed separately from their parents. Further detail on the qualitative findings and discussion is provided in the next two chapters, beginning with children and followed by parents.

Figure 7.1: *Geographical Distribution of Participants*

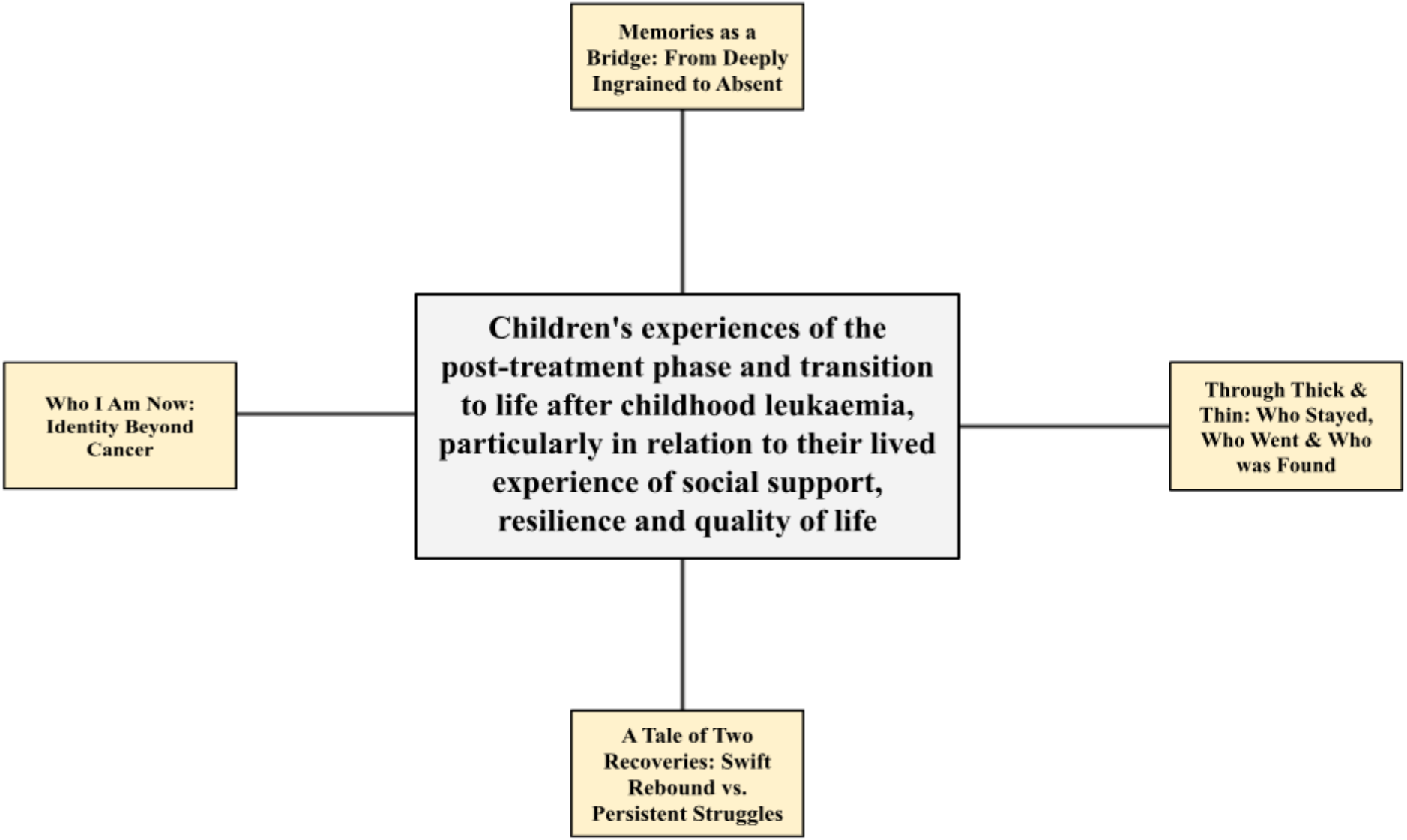


5.9 Child Findings

In this section, the experiences of childhood leukaemia survivors regarding the post-treatment phase and transition to life after the illness, particularly in relation to their lived experience of social support, resilience and quality of life will be presented. Four overarching themes were identified that reflect the nuanced and multifaceted nature of children's post-treatment journeys (see Figure 8.1 for a full visual

representation). Each theme explores different facets of children's lived realities, revealing the complex and multifaceted nature of their journeys beyond treatment. Although the thematic titles often employ dichotomous language to highlight contrasting or varied experiences, these should not be interpreted as rigid categories separating children into distinct groups. Rather, they reflect the complexity and diversity of experiences, including changes over time, the coexistence of differing feelings, and developmental differences between younger and older children. Italicised quotations from participants will be used throughout the following sections to illustrate and support the identified themes. To protect the privacy and confidentiality of participants, all names have been replaced with pseudonyms.

Figure 8.1: *Child Qualitative Themes*



5.9.1 Memories as a Bridge: From Deeply Ingrained to Absent

This theme captures the range of children's memories of their illness and treatment, spanning a continuum from deeply ingrained and vivid recollections to more fragmented or absent memories. Children who were diagnosed at a younger age tended to have fewer or more fragmented memories, whereas those diagnosed at an older age were more likely to retain vivid and detailed recollections. The metaphor of a 'bridge' in this theme refers to the way in which memories or, in cases of fragmented recall, external cues, link past experiences of illness and treatment to children's present-day understanding and adjustment.

Older children typically reported vivid and emotionally charged memories of their leukaemia and treatment. These memories often included specific details of medical procedures, hospital routines, and restrictions. For example, Molly (aged 16 years) was able to recall the exact number of days she was in transplant and the restrictions she faced while there; *"I was in transplant for 73 days so I wasn't allowed to leave the room for 73 days"*. Similarly, Harry (aged 16 years) shared his memories of the nasogastric (NG) tube, a medical procedure that caused him significant distress, leaving lasting traumatic memories. He recounted, *"I hated it so much that I just started eating"*. These narratives illustrate how strongly embedded these experiences were in older children's memory, often shaping the way they reflected on their treatment in the present.

In contrast, younger children often described their memories as more generalised, fragmented, or in some cases nearly absent. When memories were described, they tended to focus on more positive or neutral aspects of their hospital experience rather than the illness itself. For instance, James (aged 12 years) remembered the hospital playroom fondly, saying; *"there was a massive playroom where the nurses would bring you sometimes...we had to do this art thing with someone in the playroom"*. Similarly, Alex (aged 8 years) recalled, *"all I remember is playing with my Nintendo"* as his most vivid hospital memory. Conor (aged 7 years) expressed a belief that *"everybody survives cancer…you never die of cancer…how can they die just because they are taking medicine?"*, indicating a limited awareness of the severity of his illness. These more positive and less detailed memories appeared alongside accounts of

smoother emotional adjustment and fewer expressions of fear or distress, suggesting a potentially protective role in supporting resilience and quality of life during recovery. While no direct connections were made by children themselves, the co-occurrence of limited recall and emotional ease likely reflects differences in memory development at the time of their illness, with children diagnosed at a younger age having fewer or more fragmented memories because their cognitive and emotional capacities for encoding and retaining these experiences were still developing.

For younger children with more fragmented or absent memories, external cues such as photographs, videos, or stories shared by family members often helped in bridging the gap between fragmented memories and present experiences. For example, Chloe (aged 8 years) explained, *"if I look at photos of me with the yellow thing my brain can move all of those pictures back to what's happening"*. Similarly, Conor (aged 7 years) recalled feeling very hungry after coming off steroids only after his mother reminded him; *"I do remember now. I was so hungry"*. These examples illustrate how memory in younger children was sometimes supported or reactivated by external sources, helping them situate their past experiences within their present understanding.

5.9.2 A Tale of Two Recoveries: Swift Rebound vs. Persistent Struggles

This theme captures the contrasting post-treatment recovery experiences of children, highlighting how social support, resilience and quality of life shaped their individual recovery trajectories. The notion of a 'swift rebound' reflects the accounts of children who were younger at the time of their diagnosis and returned quickly to normal activities with minimal disruption. In contrast, the 'persistent struggles' refer to the experiences of children who were older at diagnosis and faced ongoing physical, emotional and psychosocial challenges that continued to affect their quality of life long after treatment ended.

Younger children typically described a return to school, sports, and social activities with little difficulty. In many cases, the transition back to everyday life was so seamless that it appeared unremarkable or even unmemorable. As Sophie (aged 12 years) admitted, *"I can't really remember that actually"*, when asked about her return to school. James (aged 12 years) described his classmates'

reaction: *"I had a big party when I finished it and everyone was like 'well done'"*. For these younger children, social support from parents and school appeared to ease the transition, although their reflections were often brief or vague.

While their descriptions of recovery lacked detail, some younger children offered glimpses into highly active and socially integrated lives post-treatment. Chloe (aged 8 years) described her weekly routine, saying; *"On Tuesdays I have speech and drama, on Wednesdays I have swimming, on Fridays I have gymnastics, Saturdays I have Gaelic and music and then Fridays hockey"*. These accounts suggested a return to structure and engagement, possibly indicating adaptive functioning or resilience, though these children did not explicitly articulate any struggle or effort in doing so. The return to school often involved phased reintegration and gradually increasing to full days as they regained their strength. As Sophie (aged 12 years) explained, *"I'm pretty sure I did like half days at the start, I was only in for like one or two hours, so I found that helpful because I got to like build myself back up almost"*.

In contrast, older children recounted post-treatment experiences characterised by fatigue, compromised immunity, pain, and ongoing limitations, all of which significantly disrupted their quality of life. Molly (aged 16 years) shared her frustration, saying; *"there's no point in my day where I'm not tired, which I hate so much, like, I'm never not tired so it's kinda, constantly just that tiredness and fatigue and there's nothing you can do like. There's no magic pill that you can take"*. She also described vulnerability to illness, saying; *"my immune system is like a newborn's immune system, I'm getting sick the whole time"*. These ongoing health challenges affected school attendance, participation in social life, and emotional well-being. Molly continued; *"I haven't been able to go to school recently because I've been sick so that is just a pain"*.

Beyond fatigue and immunity issues, chronic pain and physical limitations further complicated recovery among older children. Megan (aged 17 years) shared her struggle with chronic pain saying; *"I'm glad I'm finished treatment but it's done a lot of damage to my body. At the moment, I have a really bad pain in my knee so it hurts to walk, so I'm using a wheelchair at the moment"*. Similarly, Harry (aged 16 years) spoke about lasting side effects, saying; *"I had flat footedness after it as well so I had to wear*

braces and stuff". These limitations interfered with their ability to participate fully in activities they once enjoyed. As Harry (aged 16 years) shared; *"I don't think I'll ever go back to playing that much sport or anything like that"*.

Despite these challenges, older children often described efforts to rebuild their routines, indicating the presence of resilience, albeit under strain. Megan (aged 17 years) reflected; *"I'm not doing as much as I used to, but I'm getting closer to it"*, while Molly (aged 16 years) shared; *"I've been in the gym since December, like it doesn't sound like long but like I'm slowly starting to build myself back up and hitting new personal bests is like the best feeling ever"*. In these cases, rebuilding routines seemed to support a sense of progress and self-worth.

Older children also described the need for sustained social support, particularly in academic and psychological domains. Megan (aged 17 years) expressed frustration at the lack of academic accommodations, saying; *"online school, it's been very hard to get teachers to do online classes but because I'm in and out a bit at the moment still it would be a big help to keep on top of work"*. Similarly, Molly (aged 16 years) highlighted the importance of the emotional support she received from counselling, saying; *"I kind of was protecting my family in a way that I didn't really tell them anything that was going on with me, so having someone that wasn't, like it was her job kind of, it was nice"*. These accounts underscore how persistent struggles, whether physical, emotional, or academic, necessitated ongoing formalised support to sustain resilience and manage emotional well-being. In contrast, younger children rarely described needing or receiving additional post-treatment support. James (aged 12 years) simply reflected, *"I think it's enough, I don't need any more support"*. Their accounts did not suggest an absence of support, but rather an unawareness of any additional needs, a finding which may reflect their more rapid physical recovery and developmental differences in insight or memory.

5.9.3 Who I Am Now: Identity Beyond Cancer

This theme captures children's evolving identity and sense of self following the end of treatment. Within this theme, developmental differences became apparent, with older children being more likely to actively distance themselves from a 'cancer survivor' identity, expressing a desire to move forward and be known for who they had become beyond their diagnosis. By contrast, younger children tended to integrate their cancer history with a sense of ease, viewing it as just one chapter in their lives rather than a defining characteristic.

For many older children, the label 'cancer survivor' felt limiting, confining them to an identity shaped by an experience they did not choose. Megan (aged 17 years) described this tension when asked how it felt to be a survivor, saying; *"ahm strange like I wouldn't have thought it a few years ago that I would've but now that I am it's... it's weird"*. She explained, *"it's easier to talk about it to people who know but when someone doesn't I'm having to explain it a lot and then it's a lot harder... I wouldn't really bring it up, with a lot of people they know anyways but I wouldn't be advertising it like"* underscoring her wish to be seen as a whole person beyond her medical history rather than defined by the survivor label. Similarly, Molly (aged 16 years) expressed a desire to avoid being socially defined by her past illness, saying; *"I really don't want people to see me as like oh the girl who had cancer"*. This reflects not only a wish to steer social perceptions away from illness but also an internal resistance to being reduced to a singular, illness-based identity. Harry (aged 16 years) reflected on how his experience set him apart from his peers, saying; *"it's kind of a bit strange because you have to mature more because of the cancer, but then no one else does"*. This heightened maturity seemed to contribute to his desire to resist being defined solely by his cancer experience, as it enabled him to see himself as more than his illness, a person who has endured adversity but was not limited by it.

Such reflections also brought about a broader perspective and greater appreciation for life. Molly (aged 16 years) shared, *"to go through what I went through, I feel like it's better than a normal kind of thing cause you have a completely different outlook on everything"*. This shift in outlook was central to their resilience, helping them navigate life after treatment with renewed determination. Megan (aged 17

years) elaborated; *"I know a lot of stuff no kid should ever have to know…I'm a lot more aware of stuff, like how unsafe certain things are… not every day is guaranteed, no matter what age you are, something bad can happen"*. While such awareness could lead to fear, for Megan it appeared to foster a sense of perspective and personal growth, helping her navigate life after treatment with greater awareness of risks and priorities.

In contrast, many younger children described their cancer survivor status with a straightforward acceptance, often simplifying their experience rather than attaching emotional weight to it. Chloe (aged 8 years) reflected optimism, saying; *"I would say it's a good thing because then maybe you won't get it again"*, suggesting cancer was a challenge that once overcome would not return. Similarly, Conor (aged 7 years) shared; *"everybody survives cancer"*, assuming recovery was the norm, reflecting a simplified understanding of cancer similar to illnesses like chickenpox, where having it once means you won't get it again. For some younger children, however, survivorship was not only accepted but also incorporated into their sense of identity. When Alex (aged 8 years) was asked how it felt to be a leukaemia survivor, he simply said, *"cool"*, adding; *"nobody else in my school had it"*. This suggests that, while younger children generally integrated their experience with ease, for some, their cancer experience became a unique part of their identity, something that set them apart without necessarily carrying hardship or stigma.

5.9.4 Through Thick & Thin: Who Stayed, Who Went & Who was Found

This theme explores how surviving leukaemia reshaped children's social worlds, highlighting shifts in friendships, family connections, and new relationships formed after treatment. While many children experienced changes in their social ties, the process of re-evaluating friendships and peer relationships was especially pronounced among older children. For these children, the experience had become a lens through which they re-evaluated their social connections, which played a key role in their ongoing adjustment and well-being.

Friendships that endured beyond treatment were highly valued and appreciated. For example, Molly (aged 16 years) described the significance of her best friend's ongoing presence; *"my best friend, she's been around for years now, she's gone nowhere luckily…she's like one friend that I'll never lose, you know that kind of way? Even after going through cancer, there's like a connection still left"*. At the same time, the experience also revealed the fragility of some relationships, with not all friendships withstanding the test of illness. Some connections inevitably faded as peers drifted away or cut contact completely. These changes often occurred without warning or explanation, leaving children to make sense of the silence or distance on their own. Molly recalled; "*only one person has stayed around since, like everyone just stopped, like cut contact off with me, and like I didn't see anyone my age for like a year, which was so strange"*.

This social withdrawal was often accompanied by a sense of frustration towards those who had attempted to relate without truly understanding. Megan (aged 17 years) expressed this frustration, saying; *"I don't think anybody should have to know what it's like, but for those who don't it's like "ok, that's fine". I don't like when people act like they know, when they don't know anything at all, that's the worst for me"*. For some, the end of these relationships led to a sense of clarity over time. Looking back, children sometimes felt that these changes, though painful, helped them understand who truly cared for them. As Molly (aged 16 years) put it; *"people that you lose are kind of, kind of good that they're gone because you see them for their true selves when you're sick…looking back on it now, I'm grateful that they're out of my life but, like, if I could have died and, imagine like, that's what they were left with, completely leaving me, so I'm happy they are out of my life anyway"*.

While friendships changed, family support remained constant. Across ages, children spoke about the importance of their parents in helping them through and beyond treatment. Sophie (aged 12 years) simply shared; *"I'd say probably my mum and dad definitely"*. Molly (aged 16 years) similarly reflected; *"my parents were really good to me, like I actually couldn't have better support at home".* Children also formed meaningful bonds beyond family and peers, particularly with healthcare staff and others who had gone through similar experiences. These relationships were often described with a deep sense of

appreciation. Conor (aged 7 years) tried to explain his connection with a nurse; *"there's too many reasons, there's too many reasons"*, a heartfelt attempt to convey the depth of that support.

Support organisations, such as CanTeen Ireland, were especially important to many of the older children. While some were initially hesitant to join groups that centred on cancer, they quickly found comfort in the shared understanding they offered. As Molly (aged 16 years) explained; *"it's literally a group of friends that happen to be either going or have gone through the same thing"*. Megan (aged 17 years) echoed; *"we all can talk about our experiences without having to explain it"*. These groups allowed children to connect with others who instinctively understood their situation, without the need for explanation or justification. As Megan further explained; *"I wouldn't have met as many people with similar experiences, I'd still be trying to meet people with the same experiences"*.

5.10 Discussion of Children's Findings

This study offers rich and nuanced insights into the post-treatment experiences of childhood leukaemia survivors, demonstrating that survivorship is neither uniform nor linear. Rather, it unfolds as a complex, evolving process shaped by shifting memories, variable recovery trajectories, changing identities, and dynamic social relationships. Importantly, this study highlights how these experiences are deeply embedded within the developmental context of the child. Younger children's memories tended to be more fragmented or positively reframed, typically aligning with relatively swift physical recovery, while older children more frequently carried vivid, sometimes distressing memories alongside ongoing challenges related to identity, health and social belonging. Distinctively, this study highlights how memory, identity and social connection emerged as interconnected aspects of children's experiences across developmental stages, offering a more integrated understanding than has previously been reported in survivorship research. This analytic approach goes beyond simple groupings of survivors, instead capturing the complexity and variability of children's post-treatment experiences, including the ways they continually adapt to changes in their health, identity, and social relationships. These insights highlight aspects of post-treatment support that participants found valuable or lacking, suggesting areas where care could better

meet survivors' psychosocial needs. The following sections explore each key theme in depth, offering a window into the multifaceted realities of life after treatment.

5.10.1 Memories as a Bridge: From Deeply Ingrained to Absent

The findings of this study highlight a critical and previously under-explored function of memory in childhood leukaemia survivorship as a cognitive and emotional bridge linking past treatment experiences to present-day understanding and adjustment. Although younger children generally did not explicitly narrate their memories, older children demonstrated a greater capacity to recall specific events in a structured and reflective manner. This suggests that memory plays an active, integrative role in adolescent survivors' processing of their experiences, and highlights how developmental stage and age at diagnosis shape the ways survivors reflect on their illness. These findings extend general theories of autobiographical memory development (Bauer, 2015; Merín et al., 2024) to the specific context of leukaemia survivorship, providing nuanced insight into how structured recollection can contribute to meaning-making and coherence, a key component of psychological resilience (Tedeschi & Calhoun, 2004; Vanderveren et al., 2020).

In contrast, younger children exhibited more fragmented, incomplete or even absent memories of their illness and treatment. When present, these memories often centred on the less threatening elements of treatment, such as hospital playrooms, toys or supportive healthcare staff, rather than aspects of their illness. This aligns with Piaget's (1971) framework, where children in the preoperational (2-7 years) and concrete operational stages (7-11 years) have emerging but still limited capacities for abstract reasoning, perspective-taking, and temporal understanding, which affect how they encode complex medical events. Older children, by contrast, generally demonstrated more coherent and structured recollections, consistent with the cognitive abilities associated with the formal operational stage (11+ years). Contemporary critiques of Piaget's stage model emphasise that cognitive development is gradual and shaped by socio-cultural and environmental factors (Miller, 2022), highlighting that children's memory and reflective

capacities are influenced both by developmental stage and by the specific context of their illness experience.

For younger children, the bridge between past and present was not internalised through recall alone but constructed socially through external cues and adult scaffolding. Parents played a key role in co-constructing memory via photographs, videos, or shared stories, echoing Vygotsky's (1978) sociocultural theory of cognitive development. This theory posits that higher cognitive functions, including memory, are mediated through social interactions and cultural tools. The current findings extend this understanding by demonstrating how, in the specific context of childhood leukaemia, parents actively facilitate memory-building, helping children reconstruct and engage with past experiences that they might otherwise recall only partially or fragmentedly (Gyollai, 2025; Sridhar et al., 2023). Memory thus emerges not as a purely individual process but as a dynamic, socially co-constructed activity embedded in everyday interactions and familial support, with parents and external cues guiding children's recollection.

Framing children's memories as a cognitive and emotional bridge between past treatment and present experience offers a novel contribution to the understanding of childhood leukaemia survivorship. While previous research has described developmental differences in autobiographical memory, this study highlights memory's active role in shaping how survivors make sense of their experiences and engage with their current lives. Older children's internally coherent and emotionally resonant memories illustrate how they recall and relate to past events, whereas younger children's reliance on social scaffolding points to alternative ways of integrating and understanding their treatment experiences.

5.10.2 A Tale of Two Recoveries: Swift Rebound vs. Persistent Struggles

A key insight emerging from the data is the striking difference in recovery experiences between younger and older children. Younger children often reported a relatively smooth reintegration into everyday life, returning to school, extracurricular activities, and social engagement with minimal difficulty. This pattern aligns with prior research indicating fewer psychosocial difficulties among children diagnosed at younger

ages (Barrett et al., 2020; Brinkman et al., 2018). The current study extends this understanding by highlighting potential mechanisms underlying these observed differences. Younger children's developmental stage may limit their capacity to fully process or articulate the challenges they face, while adult support and structured routines may buffer them from the broader psychosocial impact of post-treatment life. By situating these recovery trajectories within both developmental and social contexts, the findings provide a more nuanced perspective on why younger children may appear to experience a swift rebound, enriching our understanding of the interplay between age at diagnosis, developmental stage, and post-treatment experiences.

In contrast, older children described a far more complex and challenging recovery process. Their accounts included vivid recollections of treatment, ongoing concerns about health, and the lasting impact of their illness on daily routines and social relationships. These findings align with previous research indicating that late effects and diminished quality of life are prevalent among adolescent cancer survivors (Barrett et al., 2020; Brinkman et al., 2018; Ernst et al., 2023; Larsen et al., 2022). Fatigue, in particular, stood out as a prominent and debilitating issue, reinforcing previous research identifying it as one of the most prevalent and challenging long-term effects of cancer treatment (Abd El-Khalek et al., 2025; Larsen et al., 2022; van Deuren et al., 2020). Therefore, the transition back to normalcy may be more psychologically and socially complex for older children, as they carry a greater awareness of what was lost, changed, or threatened.

Applying Bronfenbrenner's (1979) ecological systems theory offers one lens through which to understand why younger children often experience smoother reintegration, while older children encounter more persistent challenges following treatment for childhood leukaemia. Younger children benefited from close parental support, structured routines, and social scaffolding (microsystem), while older children navigated greater personal responsibility and awareness of their illness. Limited communication between parents, schools and healthcare providers (mesosystem) sometimes hindered reintegration. These findings align with prior research on ecological influences in childhood cancer survivorship (Barrett et al., 2020; Brinkman et al., 2018) and extend it by showing how interactions across environmental layers may

contribute to divergent recovery trajectories, highlighting potential targets for more coordinated, multi-level support.

Despite ongoing post-treatment difficulties such as ongoing fatigue, disrupted routines, and difficulties reintegrating socially, many children demonstrated notable resilience, gradually re-engaging with physical activity or academic goals, demonstrating forms of resilience in how they navigated post-treatment life. This reflects the multidimensional nature of resilience, characterised not by the absence of adversity but the ability to respond adaptively to it (Davydov et al., 2010; Tan et al., 2019; Wagnild & Young, 1993). Factors such as supportive parents and peer connections appeared to facilitate children's re-engagement with daily activities and social life, potentially mitigating the psychosocial burdens of survivorship. These findings align with previous research suggesting that self-motivation, social support and access to suitable resources can alleviate the psychosocial burdens of survivorship and encourage post-traumatic growth (Calhoun et al., 2022; Yi et al., 2015). Recognising resilience in this way points to the importance of nurturing survivors' strengths and adaptive capacities alongside addressing their vulnerabilities, thereby promoting growth and well-being over time.

However, the findings also exposed gaps in psychosocial support. Despite recognition in the literature that adolescent survivors are particularly vulnerable to psychosocial difficulties, the older children in this study reported unmet needs, particularly in accessing mental health care, obtaining academic accommodations and receiving adequate transitional support (Barnett et al., 2016; Jin et al., 2021; Warner et al., 2016; Zhang et al., 2023). These reports highlight perceived gaps in post-treatment support from the perspective of participants. While this does not allow for definitive conclusions about systemic provision, it suggests that survivors may experience difficulties accessing or navigating existing services. These findings align with current initiatives to enhance care coordination for child, adolescent and young adult with cancer in Ireland, notably the CAYA Model of Care, which aims to improve psychosocial support and care (Greally et al., 2023). Efforts such as expanding psychological services, increasing flexibility in educational settings, and strengthening care coordination during critical

developmental transitions are essential steps to improve long-term quality of life for these survivors (Chan et al., 2021; Ehrhardt et al., 2023; Hudson et al., 2021).

5.10.3 Who I Am Now: Identity Beyond Cancer

This theme focuses on how children reconstructed their sense of self after treatment, with identity and existential meaning-making emerging as a key dimension of their post-treatment experiences. Children's accounts suggested that their sense of identity was shaped not only by developmental stage but also by their social relationships and by the ways they made sense of their illness and recovery.

The findings revealed that identity negotiation after childhood leukaemia is both developmental and self-directed, with older children actively resisting an illness-centred identity and younger children more readily integrating the experience into their sense of self. This difference reflects differences in cognitive maturity, social priorities, and the degree of narrative control survivors can exercise over their experience. For older children, the 'cancer survivor' label was not only uninvited but also potentially restrictive, threatening to fix their identity in a single, past-oriented frame. This mirrors findings in adult cancer survivorship literature, where the 'survivor' label can similarly be experienced as limiting, prompting ongoing efforts to integrate the illness experience without allowing it to define the self (O'Callaghan et al., 2025; Rashidi et al., 2021). It also aligns with Erikson's (1968) theory of adolescent identity formation, particularly the stage of 'identity versus role confusion', in which self-definition is heavily negotiated in relation to peer belonging and autonomy. The present findings enrich this theoretical perspective by highlighting how the externally imposed 'cancer survivor' label intersects with developmental identity work. For adolescents, the label risked constraining identity by anchoring it in past illness, prompting strategies of resistance and redefinition in order to protect autonomy and align with peer norms. For younger children, by contrast, the survivor identity was more readily absorbed without such tension, suggesting that developmental stage shapes not only the capacity for identity negotiation but also the ways illness experiences are integrated into the self.

The older children's accounts also resonate with sociological theories such as labelling theory (Becker, 1963), which highlights the potential for externally imposed identities to shape self-perception and social interaction in constraining ways. Many of the older children in the current study sought to move away from this label in an effort to reassert control over their identity. This distancing also reflects a broader desire for normalcy, peer acceptance and social belonging (Ingersgaard et al., 2021, Yi & Lee, 2024). Many older children deliberately avoided conversations about their leukaemia history with others in a deliberate effort to avoid being stigmatised, pitied, or perceived as different. These behaviours align with previous findings suggesting that adolescents often seek to blend in with their peers and resist identities that set them apart from their peers (Jones et al., 2011; Kent et al., 2012).

Importantly, this resistance to being defined by their past illness was not about denying their cancer experience but reflected a form of existential meaning-making, as they sought to integrate the experience without allowing it to overshadow other aspects of the self. At the same time, these young people often demonstrated heightened maturity and perspective, a feature consistent with post-traumatic growth models (Castellano-Tejedor et al., 2015; Duran, 2013; Seiler & Jenewein, 2019; Tedeschi & Calhoun, 2004). In this sense, identity reconstruction was both an act of resilience and a means of reclaiming agency. Importantly, however, such resilience and growth does not diminish the emotional burden of being labelled by illness. Rather, it highlights the complexity of post-treatment identity formation, where individuals may experience personal growth and development as a result of their illness experiences, yet still resist being wholly defined by it (Seiler & Jenewein, 2019).

Conversely, younger children integrated their cancer experience into their emerging self-concept with relative ease, often described as one chapter among many rather than a defining feature. This aligns with Erikson's (1968) earlier stage of psychosocial development, 'industry versus inferiority', during which children are primarily concerned with gaining competence and social acceptance rather than on abstract self-conceptualisation. This also corresponds with Piagetian developmental stages (Piaget, 1971), where younger children's limited cognitive capacity restricts engagement with illness as a life-defining or existential event. As a result, younger children's accounts rarely expressed emotional or identity-driven

narratives about their cancer, consistent with prior findings that younger survivors report fewer psychological disturbances post-treatment (Barrett et al., 2020; Hudson et al., 2021).

What is distinctive in the current study is the interplay between developmental stage, agency in identity negotiation, and how children positioned their cancer experience within their emerging sense of self. The findings show that older children's distancing and younger children's integration are not binary endpoints but points on a dynamic trajectory, influenced by cognitive maturity, memory of illness, and ongoing health effects. This positions survivor identity as a flexible construct, actively shaped and reshaped in response to personal, social and temporal contexts.

5.10.4 Through Thick & Thin: Who Stayed, Who Went & Who was Found

Consistent with previous research, this study confirms that strong social support plays a central protective factor in childhood cancer survivorship, buffering against psychological distress and promoting adaptive coping (Castellano-Tejedor et al., 2015; Çavuşoğlu & Sağlam, 2015; Maurice-Stam et al., 2007; Shin et al., 2019). However, the findings presented here go further by demonstrating that social support is not a static variable but rather it is emotionally evaluated. In the aftermath of treatment, many of the older children re-evaluated the depth and authenticity of their relationships with others, often interpreting those who stayed or left as a reflection of personal loyalty and emotional understanding. Friendships that endured were particularly meaningful for survivors, reflecting their own evaluation of loyalty and emotional connection, which aligns with previous research suggesting that enduring friendships serve as key sources of resilience and well-being (Sampson et al., 2025). Conversely, the unexplained fading of some friendships was not always experienced as a source of pain or loss but rather a clarifying process that revealed the superficial nature of some connections. This nuanced understanding challenges the traditionally negative framing of peer withdrawal as isolating and lonely (Cantrell & Conte, 2009; Ingersgaard et al., 2021; Kent et al., 2013). Instead and consistent with concepts of post-traumatic growth, it highlights how adversity can act as a catalyst for relational growth and psychological maturation, distinguishing the superficiality of some friendships from the meaningful ones (Tedeschi & Calhoun,

2004). Older children in particular expressed a sense of relief at having seen the true-colours of friends who drifted away and feeling greater self-assurance about who they could trust and what was important to them, reinforcing a greater sense of personal strength, agency and emotional maturity.

In line with previous research, family support consistently emerged as the most significant and consistent source of emotional and practical support for children both during and after treatment (Cetin, 2023; Ingersgaard et al., 2021; McDonnell et al., 2020; Pennant et al., 2019). Parents, in particular, were frequently described as unwavering sources of comfort and support (Cetin, 2023; McDonnell et al., 2020; Pennant et al., 2019). These findings also echo family systems theory (Bowen, 1978), which posits that the family functions as an interdependent emotional system, where the well-being of each member is closely interconnected. The resilience and emotional functioning of parents, therefore, plays a crucial role in shaping a child's adjustment and recovery, highlighting the family as a central factor in shaping survivors' psychosocial outcomes.

Beyond longstanding relationships, many survivors also described forming new, meaningful connections with medical staff, fellow survivors, and peers within cancer-specific support groups. These relationships were viewed as uniquely meaningful because they were grounded in shared lived experience, which reduced the need for explanation, something that was generally absent in friendships with peers unaffected by cancer. Peer support groups, such as CanTeen Ireland, were seen not only as therapeutic interventions but as crucial social networks that fostered connection, mutual understanding and improved quality of life. These findings support previous research highlighting the protective and therapeutic value of peer-based support for survivors, where survivors feel safe expressing vulnerability without the burden of explanation or fear of being misunderstood (Ingersgaard et al., 2021; Kent et al., 2013; Soejima et al., 2015). Notably, some survivors described an initial reluctance to join a cancer-focused support group, often due to concerns about reinforcing their 'cancer survivor' identity, a tension reflected in the preceding theme of *'Who I Am Now: Identity Beyond Cancer'*. However, once involved, these groups provided safe and secure spaces where they could speak openly without fear of judgement or

misunderstanding. This reflects the dual desires of survivors wanting to move on with their lives while also wanting to connect with others who understand (Cantrell & Conte, 2009; Larsen et al., 2022).

In summary, this theme illustrates that post-treatment recovery from childhood leukaemia is deeply relational and developmentally influenced. The findings affirm existing research on the importance of strong social support and resilience but extend it further by illustrating how survivors actively rebuild their social lives post-treatment. While some relationships fade under the weight of absence or misunderstanding, others deepen, and new connections are often formed to fill the void. This reconstructive process is central to survivors' resilience and overall quality of life. The findings suggest that psychosocial support services and interventions should not only focus on preserving pre-existing relationships but should also facilitate opportunities for survivors to form new, meaningful social bonds that enhance both their resilience and long-term quality of life.

5.11 Strengths and Limitations of the Qualitative Strand for Children

The qualitative strand of this mixed-methods study offers rich insight into children's experiences during the post-treatment period and their transition to life after childhood leukaemia. A major strength is the inclusion of children's self-reported perspectives, which allows their voices to be heard directly. While much existing research in paediatric psychosocial oncology has relied on parent-proxy reports (e.g., Fisher et al., 2021; Inhestern et al., 2020; Klassen et al., 2006; Kunin-Batson et al., 2016; Sherifali & Pinelli, 2007), which are valuable but may not fully capture children's subjective experiences, this study builds on the involvement of children's own voices by providing in-depth qualitative accounts. It explores not only their experiences of social support, resilience and quality of life, but also the ways in which they interpret and integrate these experiences into their post-treatment lives.

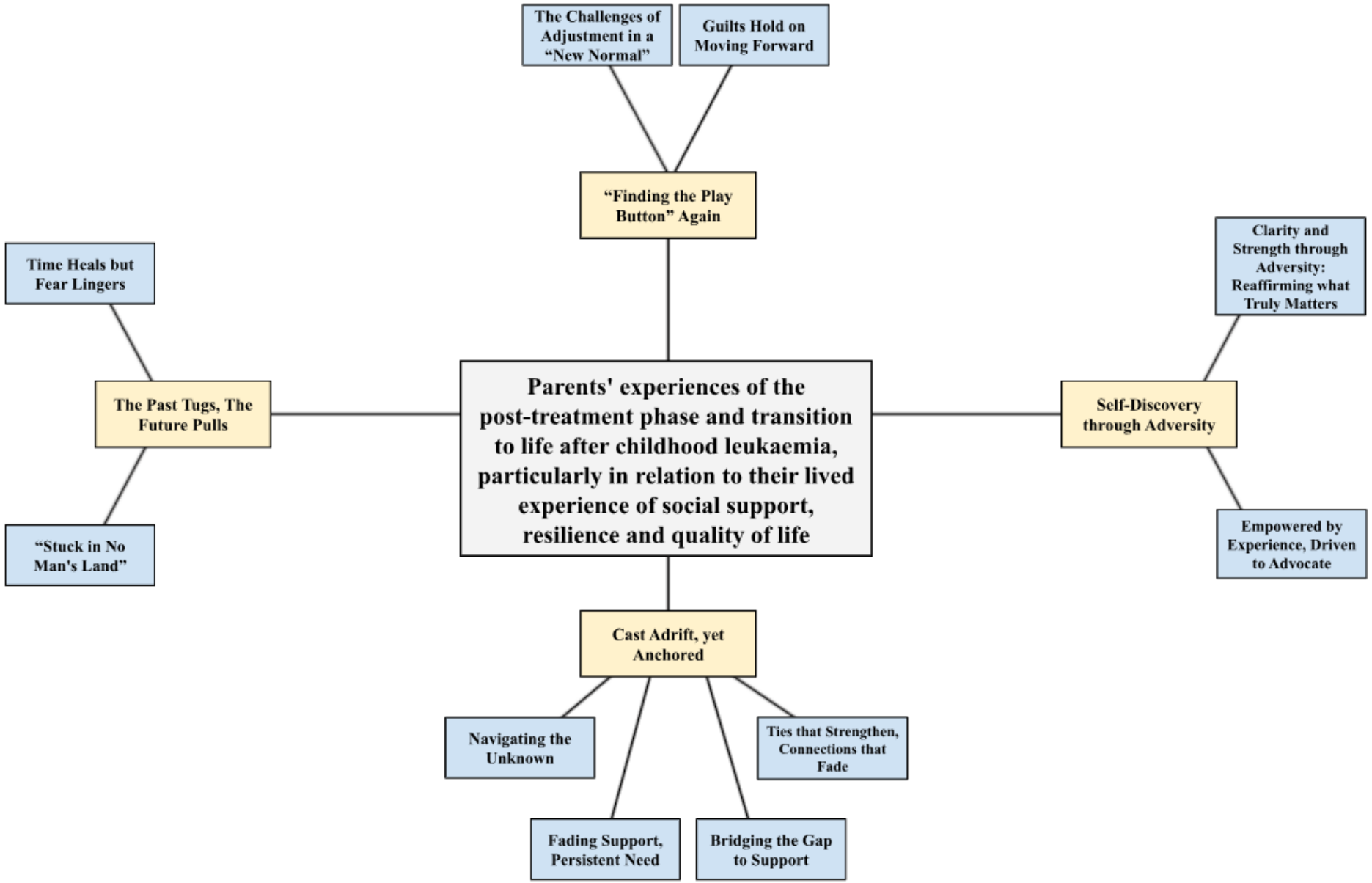
Despite these strengths, some limitations also exist. Firstly, the majority of children were of Irish origin/descent, limiting the transferability of findings to more ethnically diverse populations. Secondly, the responses of some younger children were at times brief or clipped, and in a few cases, their comfort may have been influenced by the presence of a parent during the interview. While these factors may have

constrained the depth of insight for some participants, the study nonetheless provides rich, nuanced accounts of children's post-treatment experiences. Future research could build on this work by exploring approaches that further optimise participation among younger children and include more diverse populations, thereby broadening understanding of childhood leukaemia survivorship.

5.12 Parent Findings

In this section, the experiences of parents of childhood leukaemia survivors regarding the post-treatment phase and transition to life after the illness, particularly in relation to their lived experience of social support, resilience and quality of life will be presented. Four overarching themes were identified, each comprising several sub-themes that reflect the nuanced and multifaceted nature of parents' post-treatment journeys. See Figure 9.1 for a full visual representation of these themes and sub-themes from the parent data. Italicised quotations from participants will be used throughout the following sections to illustrate and support the identified themes. To protect the privacy and confidentiality of participants, all names have been replaced with pseudonyms.

Figure 9.1: *Parent Qualitative Findings: Themes and Sub-Themes*



5.12.1 The Past Tugs, the Future Pulls

This theme represents the emotional tightrope that parents walk in the aftermath of their child's leukaemia treatment, suspended between a traumatic past they could not fully leave behind and a future marked by both hope and lingering uncertainty. The past tugs refers to the emotional attachment to the past, including pre-cancer life and memories of their child's treatment, as well as the fear, trauma and pain experienced. Many parents shared how, even as time passes, fear continues to shadow their lives, sometimes even years after treatment ends. The sub-theme of *'Time Heals but Fear Lingers'* captures how the trauma of treatment continues to linger, with anxiety and hyper-vigilance persisting over time. In contrast, *'Stuck in No Man's Land'* reflects the sense of emotional liminality, parents feel neither fully anchored in the past nor secure in the future. Together, these subthemes illustrate the complex and non-linear process of adjustment, where parents must navigate an evolving identity and emotional landscape shaped by both what has been endured and what still lies ahead.

5.12.1.1 Time Heals but Fear Lingers

This sub-theme captured the emotional paradox many parents experienced in the aftermath of their child's treatment, where profound relief and gratitude co-existed with persistent fear and uncertainty. These dual emotional forces, emotional recovery and lingering anxiety, reflected the broader dynamic of being pulled forward by hope and the desire for normalcy, while still tethered to the psychological aftermath of the illness experience.

For many parents, the end of treatment brought an overwhelming sense of relief. After months or even years of constant hospital visits and medical interventions, many parents felt an emotional weight had been taken off their shoulders. Parents spoke of a renewed appreciation for everyday life, a deepened bond within the family, and a strong sense of gratitude. As Lorna (mother of a 16 year old girl) explained; *"I don't believe in any Gods or anything like that but I feel truly blessed, thoroughly grateful. My little girl is still alive and we got through this as a family and the four of us are a solid box"*. Others spoke about how time had brought emotional perspective and allowed them to begin healing. As Peter (father of

a 9 year old girl) shared; *"look, it's like any trauma, the effects of it lessen as time goes on and, you know, time does kind of help you come to terms with it"*.

However, this forward momentum was frequently interrupted. Lingering fear and anxiety remained just beneath the surface, manifesting in moments of anxiety, hyper-vigilance, and emotional reactivity to health scares or hospital visits. As Jessica (mother of a 6 year old girl) said; *"I can envision it lessening and then a trigger coming up and then remembering it in that you know a symptom that was similar or going back to hospital or whatever it is you know"*. Fear of relapse was one of the most profound and persistent emotional responses, leaving parents feeling emotionally vulnerable, even after their child was declared cancer free. For instance, Mary (mother of an 8 year old girl) shared;

"you're uptight, because you are always on edge. During the first few months because you are looking at temperatures, you are looking at all that kind of stuff. Is he ok?, is he ok?, and that knot you have in your throat when he's not and he's a bit sick and you kind of jump to conclusions, you know "what if we are back there again?"".

This lingering fear complicated parents' perceived quality of life. Even during moments of joy and normalcy, the past continued to exert its emotional pull, reactivating trauma in unexpected ways. Rebecca (mother of an 8 year old boy) captured this fragility; *"all he has to say is "my leg hurts" or something hurts and you're just, you orbit, it's fall over again [sic]"*. Similarly, Charlotte (mother of a 5 year old girl) shared; *"everything is lovely and then you get a little tiny wobble and your back goes up and you're like "okay prepare yourself""*. Even when statistics offered reassurance, the emotional imprint of the past remained difficult to shake. Peter (father of a 9 year old girl) reflected; *"the fact that now she's five years in remission, like it's two and a half years since she rang the bell, five years in remission, I'm hoping that science will tell me to kind of cop myself on and you know we know that she's, I'll never say that this is not going to come back but we know she's in the .0001% of you know chances of relapsing"*. Taken together, these accounts illustrated the emotional tightrope that defined post-treatment life. While time offered healing and a gradual return to everyday routines, the trauma of the past continued to exert its pull, particularly through persistent fear and anticipatory anxiety. At the same time, parents were pulled

forward by hope, gratitude, and a desire to secure a stable future for their child and family. It is within this emotional tension that parents learned to live, not free from fear, but with it, while still finding ways to move forward.

5.12.1.2 "Stuck in No Man's Land"

This sub-theme explored the psychological liminality many parents described experiencing after their child's leukaemia treatment ended. While the acute medical crisis had passed, it did not necessarily bring the relief or closure they had anticipated. Instead, parents often felt emotionally suspended, no longer in survival mode but not yet at peace. Being *"stuck in no man's land"*, as described by Nicole (mother of a 9 year old boy), became an apt metaphor to describe this unsettling state of in-betweenness. This sense of psychological liminality left many parents in a state where neither the past could be fully released nor the future fully embraced. As Nicole (mother of a 9 year old boy) explained; *"you finish treatment and you sit there and you look back and it's really hard, then you start trying to look forward and that's really hard too"*. Many parents described this transitional phase as emotionally destabilising. Although many parents had anticipated a sense of elation and closure after treatment, some were met with feelings of deflation, confusion, and isolation instead. Rebecca (mother of an 8 year old boy) conveyed this unexpected sense of anti-climax; *"I do feel a bit deflated and a bit - I don't know how to feel finishing it, you know? I thought I'd feel more elated than I do but you can just feel like "oh God I'm supposed to just go back to normal life after that absolutely mental experience?""*.

In this suspended state, many parents also wrestled with complex feelings of grief, not for a lost child but for the life that had been irreversibly disrupted for both themselves and their child. As Lorna (mother of a 16 year old girl) shared;

"life is different, that old life is gone, you're never going to get that back, that pre-cancer diagnosis life is gone and I found there's a grieving process to it. You know, the grieving for the life that we had prior to cancer. Ahm, you know there's been so many opportunities that she's missed out on during treatment regarding her football because she wants to do this professionally. Ahm and it's well F

cancer. If it hadn't of been for cancer she would have been in a different position now but look it's happened, we've accepted that it's happened but you still have that niggle in the back of your mind, you know that had she not gone through it she would have been on a, a completely different path".

For Lorna, and others like her, this sense of grief contributed to feeling stuck, unable to return to the life that once was, yet uncertain how to step into the life that now lay ahead. While their child's survival was deeply cherished, the emotional residue of what had been lost made it difficult to fully move forward. In this way, grief became one of the emotional forces that kept parents "stuck in no man's land", tethered to a disrupted past while cautiously navigating an uncertain future.

In this emotional no man's land, grief often co-existed with guilt. Some parents described carrying a lingering emotional weight despite their child's survival. As Jessica (mother of a 6 year old girl) shared; "*I definitely feel like I carry a wound around in my heart, like it's not an open wound but it's like scar tissue. You feel, you feel it as a mum, like an ache, like a slight sadness just because of what we've gone through"*. The past, while technically 'over', was not psychologically behind them. Finally, some parents also expressed concern about losing or forgetting the lessons learnt during their cancer journey. As Rebecca (mother of an 8 year old boy) shared, *"I hope that we don't lose that, I hope we don't lose sight of that and fall back into old habits",* highlighting that there is often a sense of not belonging to either the world they left behind or the world they are trying to create. Moving forward requires balancing the past with the uncertainties of the future while not forgetting the insights and lessons gained during their cancer journey. In this way, "no man's land" was not just a place of loss or paralysis, but also one of emotional ambiguity.

5.12.2 Cast Adrift, Yet Anchored

This theme captures the emotional paradox many parents face in the post-treatment phase; the sense of feeling adrift and alone, coupled with feeling held and supported. The metaphor of feeling 'cast adrift' reflects feelings of isolation and uncertainty, like a boat drifting aimlessly on the water. In contrast, 'yet

anchored' signifies the enduring presence of stabilising forces, such as supportive relationships and personal resilience, that provide a sense of security amidst the unknown.

During cancer treatment, life is often consumed by appointments, hospital visits, medical decisions and constant worry. Once treatment ends, many parents expressed how they felt adrift and unsure of how to navigate the future with no clear path forward. This is captured in the sub-theme *'Navigating the Unknown'*, where many parents described the post-treatment phase as if they were stepping into unknown waters, with a lack of clear guidance, unanswered questions and the disorientation of adjusting to life beyond treatment. This uncertainty was compounded by *'Fading Support, Persistent Need'*, where the abrupt withdrawal of support and medical oversight often left parents feeling abandoned at a time when psychological and emotional needs remain high.

Despite these challenges, *'Bridging the Gap to Support'* illustrates how parents actively sought alternative forms of support, such as peer support groups, charities, and informal social connection. These efforts were not without barriers, such as long wait times or financial constraints, yet they reflect a determination to restore stability and regain a sense of control. Lastly, the sub-theme, *'Ties that Strengthen, Connections that Fade'* highlights the shifting dynamics of interpersonal relationships post-treatment. While some relationships became sources of enduring strength, others deteriorated under the emotional strain or misunderstanding of survivorship.

5.12.2.1 Navigating the Unknown

Several parents described the post-treatment phase as a disorientating journey through unchartered territory. Emma (mother of a 5 year old girl) captured this vividly; *"[you are] thrown into the great unknown, right, [you are left thinking] "she did have cancer, she doesn't have cancer anymore but what the fuck could potentially happen next? What am I supposed to look out for?""*. Unlike the emotional weight of fear explored in the previous theme, this sub-theme reflects the profound sense of disorientation and cognitive burden experienced by parents as they emerged from the highly structured world of treatment into a post-treatment phase defined by ambiguity. This was not fear in its raw emotional form

but a grappling with the absence of information, direction, and clarity. Parents were left with many unanswered questions at the end of treatment and felt adrift in the unknowns and unpredictability of the path ahead but they continued to move forward and actively navigate it. As Jessica (mother of a 6 year old girl) shared;

"you kind of adapt quickly once you're finished but, like I said, anticipating the end, that was almost the hardest bit. [I] was wondering "what on earth? It's going to be the end of treatment [sic]", and being scared of, "what happens to our support network?, can I contact the doctor?", you know? All those questions and anxieties were at their peak maybe one or two months before the end and I wonder if the doctor had said [that] then that might have been more helpful to anticipate rather than once you're off treatment you kind of get into the groove you know, we adapt don't we?".

Many parents felt isolated and alone in managing the unknowns of the post-treatment phase, creating a landscape of uncertainty and ambiguity. As Lauren (mother of an 8 year old girl) shared; *"you're left on a ledge to survive by yourselves".* For many parents it was no longer having concrete answers to their questions anymore that left them feeling disorientated and adrift from the highly medicalised world they were accustomed to while their child was on treatment. Emma (mother of a 5 year old girl) articulated this sense of loss of certainty; *"it's the great unknown that upsets me, right? That's what would get me now, I didn't have any of that, I had every answer I wanted".* Several parents also described difficulty in knowing what constituted 'normal' in the aftermath of cancer. Behaviours, developmental changes, or physical symptoms triggered confusion and anxiety, often in the absence of professional reassurance. As Emma (mother of a 5 year old girl) shared; *"d'you know and like that, I'm like "is that normal?" Like, I just don't know what normal is but I think only time will let me figure out what is normal".* Despite these uncertainties, parents felt anchored by the hope that the worst was over and they were managing and adapting to new challenges and uncertainties head-on. For some, resilience took the form of pragmatic hope; managing the present while preparing for future challenges. As Emma (mother of a 5 year old girl) explained; *"we get her to survive cancer and then we deal with whatever pops up, that'll pop up, right?".*

At times, the process of navigating the unknown was complicated by their child's own growing awareness and curiosity. A number of parents shared that, after treatment, their child began asking more questions about their illness, which was often difficult for parents as it resurfaced painful memories, making them relive the child's suffering and triggering strong emotional reactions. As Nicole (mother of a 9 year old boy) explained;

"he talks about it a lot more now [interviewer's name] than he used to and he's asking loads of questions - "why was I in hospital?, why did I have a Freddie? (a Hickman line used for administering chemotherapy, blood products and other medication), why was I so sick?, remember my medicine tube?", you know his NG tube [Nasogastric tube], "why did I have that?" And you know every time he mentions something like this you are taken right back to the first time they passed the NG tube or you know the first time he got those injections, the first time they held a bag of chemo, and I'm going for everything I remember. He remembers a lot of it too, even though he was two and a half/three and up in ICU not able to move, not able to breathe".

This illustrates a distinct facet of navigating the unknown, separate from the lingering fear of relapse or ongoing health threats explored earlier. It is not simply that fears persist over time, but that parents continually confront new uncertainties and ambiguities that require ongoing management.

5.12.2.2 Fading Support, Persistent Need

This sub-theme reflects the emotional journey many parents faced when they experienced the fading and often withdrawal of their *'safety net'* of support following their child's successful treatment. The 'fading' reflects the reduction or loss of support they received during active treatment, while the 'persistent need' emphasises that, even though support may have diminished, the desire and need for ongoing support remained high, leaving them feeling cast adrift at a time when their need for guidance, reassurance, and connection was still acute. Although this ongoing need could be experienced as unsettling or isolating, many parents remained anchored by stabilising factors such as supportive relationships, personal

resilience, or their child's recovery, which provided a sense of security amidst the uncertainty of post-treatment life.

During treatment, parents described being surrounded by 24/7 access to emergency care, having regular interactions with healthcare professionals, and having access to a variety of resources like social workers, therapists, and other support groups. However, once treatment ends, the safety net often fades, which can be daunting for some. As Mary (mother of an 8 year old girl) shared; *"we were like in this bubble in the hospital and we had everyone looking out for all of us and doing everything and whatever we needed they did, and then, you know, it was down to us, we were home and I was nervous about that, kind of taking her home"*.

Despite the fading of support, the 'persistent need' for emotional and practical support remained. Many parents missed the frequent routine check-ins, support and reassurance from the hospital as they transitioned to post-treatment life. The reduction of emotional support from the hospital, which often felt quite sudden, was difficult for some parents to process as they felt forgotten about, especially when there was no one to check in on their emotional state or offer guidance through the transition back to everyday life. As Nicole (mother of a 9 year old boy) explained; *"I suppose it's the people around you, and I think it's just when you finish your treatment for anything like this, it's like stepping off a cliff, you have everyone around you helping you and suddenly then there's no psychologists, there's no one to kind of ask you how you're doing or ask how is your child doing?, what are your worries?, do you have any fears?"*. Although the treatment was over, many parents continued to feel emotionally vulnerable as they tried to navigate the future without the close guidance of their medical team. Yet, the memories of past support and the reassurance previously received acted as an invisible anchor, providing a psychological tether that helped parents maintain a sense of stability and connection during this uncertain transition.

Additionally, a number of parents felt like they were no longer the main priority for hospital staff following their child's successful treatment for cancer. With treatment complete, the child is typically considered out of immediate danger, and focus generally shifts toward monitoring for any signs of relapse. Some parents found this transition difficult, experiencing a sense of loss as they felt they were not

receiving the same level of attention as they were during active treatment. For instance, Jessica (mother of a 6 year old girl) shared; *"my feeling on Monday was very much that this is what end of treatment is like, ahm, that you are not the priority which I think is a hard transition period to go through that when you were a high priority and you would be admitted straight to ward and you can talk to your doctor anytime"*.

5.12.2.3 Bridging the Gap to Support

This sub-theme captures the complex emotional and practical journey that parents face when actively seeking out support in the aftermath of their child's successful treatment. While the fading of structured support left many parents cast adrift, this phase is uniquely marked by parents' determined efforts to rebuild stability, reclaim direction. In doing so, parents actively sought out new anchors, such as resources, emotional support, and guidance, that functioned as stabilising forces, helping them regain a sense of control and security during the post-treatment period. Many parents felt unprepared for how abrupt the withdrawal of structured care would feel. Amy (mother of a 16 year old boy) reflected bluntly; *"I don't think there really was any support afterwards".* The lack of clear guidance or direction to available support and resources post-treatment was a significant challenge for many parents. While they were not expecting all answers or services to be handed to them, they hoped for at least some guidance to help navigate the unfamiliar terrain. As Kim (mother of a 16 year old girl) explained; *"it's signposting, I always call it it's just signposting. I don't expect anybody to do the work for me, it's just helpful when someone says you should go and talk to this or try that department"*. This lack of signposting left parents not only unsure of what support existed, but also uncertain of whether their continued emotional struggles were valid or visible to anyone beyond themselves. As Ryan (father of a 13 year old boy) explained; *"I think you are left to your own devices, just to get on with it"*.

Unlike previous sub-themes that highlighted the gradual loss of available support, this sub-theme focused on parents' proactive attempts to reconstruct support and regain agency for themselves and their families. Even the idea of being offered a simple resource list was described as powerful. Andrew (father

of a 12 year old girl) suggested that; *"even if people were offered a list of, you know, if you wanted to talk to people about it or you know or "here's x, y and z, or here's a list of resources", I think that would be very, very beneficial to families"*.

The feeling of being adrift was further compounded by the various barriers to accessing support post-treatment. Long wait times, fragmented services, and the financial cost of post-treatment care created further obstacles to accessing support. With limited options, many parents were forced to choose between waiting months, or even years, for the needed services or referrals, or else opt for private care which was not financially feasible for all parents. As Peter (father of a 9 year old girl) explained; *"if you are not prepared to wait and if you don't have access to private healthcare, there's nothing, there's nothing there for you like"*. This made the already difficult process of bridging the gap to support even more daunting.

Despite the obstacles, many parents showed remarkable resilience, persistence, and self-direction to gradually re-anchor themselves by seeking out counselling, peer networks, and community support. Jessica (mother of a 6 year old girl) described the impact of counselling for her, saying;

"yeah, so, honestly, since having counselling, it has improved hugely, ahm the first I'd say maybe four or five sessions of counselling was just me crying over the slightest thing and now I feel I can talk about things without tearing up, I mean that's not to say that I can't not cry (laughing) ahm but I feel much more like I've, I've worked through those emotions and I you know I can still feel sad about them but I don't feel overwhelmed by those emotions. Ahm counselling has been invaluable. I'm really grateful I've had that opportunity to do it". She added; *"counselling was really helpful just to kind of sift through the memories and cry and kind of ahm make peace with it (laughing) so that, when we were actually there, I can focus on [child name], you know supporting her"*.

Thus, while parents initially felt cast adrift in the face of limited support and unclear pathways, this sub-theme highlights their agency in locating or creating new sources of support, such as counselling, peer networks, and community resources, which helped them regain emotional balance, practical direction, and a sense of control during the post-treatment period.

5.12.2.4 Ties that Strengthen, Connections that Fade

This sub-theme reflects the emotional tension parents experienced between feeling anchored by strengthened relationships and feeling adrift due to damaged or lost connections. Many parents shared how they grew closer to family members and friends who were by their side throughout their child's cancer experience. Jessica (mother of a 6 year old girl) shared; *"I certainly, with my closest friends, I felt like they've been a support and they've been a constant ahm in a really positive way"*, highlighting the comfort found in ongoing, reliable connection. Additionally, many parents spoke about how they developed supportive companionships with other families affected by cancer. For instance, Lorna (mother of a 16 year old girl) said; *"I've gained more friends now yeah if you know what I mean through our little cancer community"*. These newfound bonds are often crucial in the post-treatment phase, as only those who have experienced childhood cancer before truly understand what the experience is like. As Rebecca (mother of an 8 year old boy) shared; *"nobody really understands it like, even though they are all so different and there might be different outcomes for different kids depending on what you're dealing with, like they are the only people, like I made great friends in there"*.

However, on the other hand, many parents also acknowledged that some relationships were damaged or even lost. Some parents described how friends or family members distanced themselves, avoided the topic of cancer, or failed to provide support during or after treatment. These absences were often characterised by social discomfort and silence, particularly in the post-treatment phase when the outside world expected a return to normality. As Rebecca (mother of an 8 year old boy) reflected; *"I think too, people don't like the idea, like children aren't meant to get leukaemia and cancer and all that sort of stuff, people hate talking about it, ahm and people just want your child to be better and everything to go back to normal"*. A number of parents also shared how friends who had been distant during treatment, or did not provide any support during their child's cancer treatment, reappeared once their child was cancer free, often leaving them confused and conflicted. As Lauren (mother of an 8 year old girl) shared; *"now I have friends saying to me "oh, I'm really sorry I wasn't there for you then" and I'm, you know I'm kind of like "but if you were that sorry, you would have been", so I don't know. It's kind of funny, d'you know?"*.

Moreover, for some parents, those who they expected to be supported by were not there for them, leaving them feeling abandoned and disappointed, and subsequently damaging relationships they once had. For example, Lorna (mother of a 16 year girl) shared; *"my sisters didn't know what to do. They didn't know what to say. You know and that hurt, that really hurt and that kind of (pause) I suppose there's irreparable damage done there. You know that we didn't- I didn't have my sisters to fall back on. You know, so it's quite sad really"*.

5.12.3 "Finding the Play Button" Again

This theme describes parents' journey of reactivating and reengaging with their everyday lives after the prolonged pause caused by their child's treatment. During treatment, life felt paused or on hold as parents focused solely on survival. The metaphor of 'finding the play button' captures the emotional and practical process of restarting a transformed life, pressing 'play' on a 'new normal' where previous routines and identities may no longer fit. The sub-theme *'The Challenges of Adjustment in a 'New Normal''* highlights that restarting life was not straightforward. Parents encountered practical and emotional difficulties in re-establishing routines and renegotiating family dynamics in a context that expected normalcy. Similarly, the sub-theme *'Guilts Hold on Moving Forward'* reflects the lingering emotional burden of survivor guilt about their child's survival when others did not, or the impact on siblings, which complicated the process of fully pressing 'play'. These challenges were integral to the re-engagement process, shaping how parents paced their return to everyday life and selectively reconnected with activities, relationships and responsibilities.

5.12.3.1 The Challenges of Adjustment in a 'New Normal'

This sub-theme captures the complex journey of parents as they navigate life after treatment; adjusting to a 'new normal' while working to restore familiar routines that were disrupted during their child's cancer experience. As the treatment phase came to an end, many parents found themselves not only celebrating the end of a difficult medical journey but also facing the difficult task of adjusting to a 'new normal'. As

Adam (father of a 12 year old boy) reflected; *"I remember the cliche at the time was the 'new normal' and that was a really cheesy thing to say but it just, it does describe it well".*

During treatment, many parents adopted a full-time caregiver identity, with everything else in life placed on pause. Once treatment ended, this identity was suddenly no longer needed in the same way, leaving some parents feeling directionless or even lost. Jessica (mother of a 6 year old girl) described this disorientation; *"my overwhelming feeling is "now I feel like an imposter". So like, while your child has treatment, you feel like that becomes part of your identity, [it] is that you have a child who has leukaemia, and then, once you're post-treatment, you aren't that parent anymore"*. For some, connecting with their pre-cancer self was emotionally complex and challenging to process. For example, Lorna (mother of a 16 year old girl) shared; *"you're trying to come up with, as you said a "new you". Ahm but I don't think there is a new you per se, you know, life is different, that old life is gone, you're never going to get that back that pre-cancer diagnosis life".*

Despite these challenges, many parents described purposeful efforts to 'press play' again, gradually reclaiming parts of their lives and identities outside the caregiving role. For Rachel (mother of a 7 year old boy), returning to work and the gym were important in her adjustment; *"I think going back to work and having another outlet, you know going to the gym, going back to work, you need - if I didn't push myself to do those things, I never would have been able to return to society"*. She added; *"I remember thinking I'll never go back but, after two years, I was ready to go back then and I think it gave me another outlet, it gave me other things to think about it, it gave me other things to moan about. Yeah, just kind of another sense of normality back. Yeah it totally was the best thing for me"*. Similarly, Mary (mother of an 8 year old girl) reclaimed time for herself through pilates and exercise, describing these small acts as pivotal to her recovery; *"I go to pilates once a week now so that's my kind of, I've been doing that for two years now, so I just made a point of getting out of the house and that's it and I have my hour and it's great you know and then I was, like I actually did start walking and jogging".*

For many, their child's return to school also symbolised a major milestone in re-establishing normalcy, but it was not without emotional strain. Parents remained deeply attuned to their child's energy

levels, side effects, and emotional readiness. As Rebecca (mother of an 8 year old boy) explained; *"he's back now, he didn't do a full day today, we're easing him in because I think ahm even though he's well I think he, you probably know this, it leaves you kind of tired and so we don't want to push it."*. Yet, the post-treatment period remained demanding, with frequent medical appointments and ongoing side effects complicating any sense of closure. These ongoing disruptions often impeded parents' efforts to fully 'press play' again, revealing that the 'new normal' was not a return to the past, but an ongoing negotiation of life permanently reshaped by illness. As Nicole (mother of a 9 year old boy) reflected; *"many people think the work is done once you get through the treatment but of course there are after effects, side effects, the long-term effects, the psycho-oncological side of things"*. Ryan (father of a 13 year old boy) similarly noted; *"it's a new normal. [child's name] still has his physio appointments and they're quite often, and his check ups"*.

Financial strain also emerged as a barrier to fully pressing 'play' on everyday life. Kim (mother of a 17-year-old girl) voiced her frustration over having to pay for treatments related to her daughter's cancer-induced menopause, saying; *"all of her other meds, I have to get, every month, you know, I have to pay. It all adds up so it does, it does all add up 'cause even the other medications that she's on - it's like you pay your 150, and I have no problem paying that, but why should I have to pay for her HRT as a result of the treatment?"*.

Yet, despite these obstacles, many parents described small but meaningful steps toward reclaiming their lives, demonstrating resilience and determination in "finding the play button" again. Nicole (mother of a 9 year old boy) captured this sentiment, saying; *"resilient 100%, like yourself [interviewer name], anyone who's come through it, you have to give yourself a pat on the back"*.

5.12.3.2 Guilts Hold on Moving Forward

This sub-theme captures how deeply internalised feelings of guilt complicated the process of finding the play button again and moving forward. For some parents, joy, and relief that treatment had ended were shadowed by the emotional weight of survival. A quiet, persistent guilt lingering in the knowledge that

while their child had survived, others had not. Nicole (mother of a 9 year old boy) reflected on this tension, saying; *"I suppose that is for me, that's one thing I still can't cope with, that's the one thing I find really hard, how to talk to a parent who's lost a child when your child has the same diagnosis, ahm you know it's the roll of the dice, isn't it? You just don't know when you start your treatment; are you going to be in that 10% who have complications and don't do well or will you be in that 90% who will be cured and you know ride off into the sunset, successful completion?"*. Even though parents were overjoyed at the completion of treatment, they often found it difficult to simply move on, burdened by an ongoing emotional tension. Rebecca (mother of an 8 year old boy) reflected on this saying; *"sometimes I feel an odd guilt you know when other children are not doing well and you're doing well and you're thinking "Jesus, I don't want my kid to be sick, what's wrong with me?" but ahm it's just incredible the suffering that other children go through as well you know"*.

In addition to survivor guilt, many parents described a persistent parental guilt over siblings, reflecting on how the intensity of treatment had drawn their attention away from other children in the family. As parents attempted to recover a sense of balance, these feelings often resurfaced. Lauren (mother of an 8 year old girl) shared; *"I feel guilty because I haven't, like, as strong a connection to her as much as I have to [child' name] ahm but I do, I work on that myself and I hope that that'll change"*. Parents also described how this dynamic affected sibling relationships and family harmony. Peter (father of a 9 year old girl) shared; *"resentment is the wrong word but you definitely get the sense that her two older sisters would, I guess, notice a bit of favouritism towards [child's name] and that can sometimes braid a bit of friction as well"*. Given the profound impact that cancer can have on siblings, many parents expressed a strong desire for professional support for siblings. For example, Jessica (mother of a 6 year old girl) shared; "*I can't think of anything where I would like more support apart from maybe supporting [child's name], ahm for me to have support to support him, so kind of indirectly siblings, you know- if hospital did something for parents on how to support siblings, I would jump at that opportunity"*. In this way, guilt, whether related to their child's survival or its impact on siblings, emerged as a prominent

aspect of parents' post-treatment experiences, highlighting the emotional challenges they navigated during this period.

5.12.4 Self-Discovery through Adversity

This theme captures the profound self-reflection and growth that many parents experienced in the aftermath of their child's cancer treatment. While the journey was marked by immense hardship and adversity, it also became a powerful catalyst for self-discovery. At the core of this theme is the process of self-reflection that often began once treatment had ended. As captured in the sub-theme *'Clarity and Strength through Adversity: Reaffirming what Truly Matters'*, parents described how their perspectives, priorities and values often shifted in light of the traumatic experience they endured. Furthermore, for some parents, this self-discovery extended beyond personal insight and became a foundation for meaningful outward-facing action. In the sub-theme, *'Empowered by Adversity, Driven to Advocate',* parents described how they turned their lived experience into platforms for change by supporting other families, raising awareness, contributing to fundraising, and speaking publicly about their experiences.

5.12.4.1 Clarity and Strength through Adversity: Reaffirming what Truly Matters

This sub-theme captures the transformative impact of childhood cancer on parents' perspectives, priorities, and personal resilience. The adversity led many parents to a profound realisation of their own strength, what was truly important in life, and a greater understanding of themselves and the world around them. Despite the emotional toll, parents often discovered untapped reserves of resilience and personal strength, as reflected by Lauren (mother of an 8 year girl); *"you wonder how the hell you just kept going cause you just did and you do when you're in that mode"*. At the time, this strength often went unrecognised, with parents focused entirely on getting through each day. Yet in retrospect, many came to appreciate the depth of their inner strength and resilience. For example, Rachel (mother of a 7 year old boy) reflected; *"I look back now and I probably don't know how we did it and people, friends say to me all the time "oh my God, you're amazing. How yous handled it and yous parented [child's name] so well*

through it", and I don't see that, I just see that I did what any parent would have to do when you're faced with an obviously unimaginable for your child". Kim (mother of a 17 year old girl) similarly noted the lack of time or space for reflection during treatment; *"I didn't have any time to kind of process what was going on. It was about getting to the next stage and trying to diggy it up"*.

As parents emerged from the intensity of treatment, many experienced a powerful shift in their priorities and worldview. As Peter (father of a 9 year old girl) reflected; *"the only thing that matters to me is what goes on inside the four walls of the house and that's both physically and mentally. I don't get too upset or stressed or worried about what else is going on, you know"*. Moreover, a number of parents reassessed their work-life balance, with some parents opting for a decreased workload and others changing careers altogether. For example, Andrew (father of a 12 year old girl) admitted, *"I would have been a workaholic so that changed me"*. Similarly, some parents who had once placed a very high value on their child's education and schooling reconsidered its importance. While it remained important for many parents, it no longer held the same weight as it once did, with parents focusing more on their child's well-being. As Kim (mother of a 17 year old girl) explained, *"I think maybe just the school one because like I've always been big on education, I always have been. Ahm just the value, I always saw a value in education in terms of future life. It's not the deciding factor so but yeah it's what they say, don't sweat the small stuff"*.

While the cancer journey is tough and emotionally draining, it also brings about new perspectives and outlooks on life post-treatment. For many, the trauma of their child's illness brought a renewed appreciation for the small, everyday moments that might once have gone unnoticed. Lauren (mother of an 8 year old girl) described how doing nothing now feels significant, saying; *"it's funny, if somebody says like "what did you do at the weekend?" I'll say "nothing" and, like, nothing is great. The fact that you can do nothing and be okay and still be healthy and be healthy enough to go into work every day and you know you just do appreciate the little things in life"*. She then went on to explain how this shift in perspective has shaped her approach to life post-treatment; *"quality, the fact that you're using that word quality, that's monumental. So for me I do quality now, I don't do quantity and I don't do anything else, so*

it's really grounded me and I prioritise ahm different things and I don't sweat the small stuff and we do lots of really ahm, you know we just do everything with more I don't know passion or zumph or love or care or whatever then we did before or maybe we're more aware and choose differently".

For some parents, the cancer experience served as an uninvited reminder of the fragility of life and the suddenness with which circumstances can change. As Rebecca (mother of an 8 year old boy) noted; *"I feel like, you kind of lose a bit of your own innocence, you know? And you know [it] reminds you of mortality, your own mortality, everyone's mortality"*. This heightened awareness often came with a renewed sense of what truly mattered. As Andrew (father of a 12 year old girl) shared; *"you know, what is the priority in life? It's family. It took that to sort of bring it home to me"*.

Ultimately, the cancer journey, while deeply challenging, led to significant personal growth. Many parents reflected with a renewed sense of awe by the fact they survived the most challenging time of their lives, making it through what they thought wasn't possible. As Lauren (mother of an 8 year old girl) reflected; *"you just cope, you cope, you have to cope cause you've no other way so you do".* The adversity brought about profound emotional insight and, for some, reinforced the importance of perseverance in the face of uncertainty. As Nicole (mother of a 9 year old boy) explained; *"don't give up hope, you know just keep the head on the shoulders and plough on everyday"*. This enduring mindset, for many parents, gradually revealed reserves of strength they hadn't recognised in themselves.

5.12.4.2 Empowered by Adversity, Driven to Advocate

This sub-theme captures how many parents, shaped by their experience of navigating the complexities of their child's treatment, emerged not only stronger but become advocates for change, awareness and support for others. For many, their experience did not conclude with the end of treatment, rather, it evolved into a deeper commitment to help others, raise awareness, and help influence change. For some, sharing their story became a way to give back and offer hope, as well as to make others feel less alone. As Lauren (mother of an 8 year old girl) shared; *"I advocate for the Cancer Fund for Children, the Daisy Lodge people because I obviously want to give back as well and they were very good to us and I've no*

problem sharing our story or talking about it. Ahm same as you like, this, you know if somebody can learn something from our experience that's great".

Many parents recognised the critical role of research and resources in childhood cancer, with many using their personal experiences as platforms for larger conversations around cancer care and needs. For example, Lauren (mother of an 8 year old girl) explained that her advocacy efforts included giving talks on the importance of blood donation; *"I give talks on blood donation and like people need to talk way more openly about that as well. We need way more people advocating for it, it's so important for cancer patients to have blood over a certain length [of] time"*.

Moreover, many parents became deeply involved in raising awareness of childhood cancer through fundraising, lobbying for more funding for childhood cancer research, working alongside organisations, and pushing for improvements in patient care and support services. For some, what had once felt like a time of helplessness evolved into purposeful action. Ryan (father of a 13 year old boy) shared his experience of organising a fundraising event; *"so, last year, we did a fundraiser for the four charities just to give something back. There was a lot of focus there for [child's name] to draw from that, that you know, he's a survivor giving back to those who are coming behind us. So we did a day in one of the local shopping centres and then we did a charity night and we raised 34,000*". For many, part of their self-discovery involved recognising that their experience could bring comfort and hope to others facing similar challenges. As Lauren (mother of an 8 year old girl) explained; *"if my story could help or if I could you know be of any sort of guidance or any bit of… and really you just probably need somebody to listen who understands"*. Through adversity, many parents discovered not only their inner strength and resilience, but also a voice and a meaningful way to support others facing similar challenges.

5.13 Discussion of Parents Findings

This study offers a deeper, more nuanced understanding of what life feels like for parents after their child's successful treatment for leukaemia. While previous research has recognised the emotional toll of caregiving and the anxiety that can persist beyond treatment (Davies & O'Connor, 2023; Inhestern et al.,

2020; Ljungman et al., 2014), this study captures the enduring psychological complexity that parents navigate long after treatment ends. The findings reveal that relief and gratitude are often accompanied by unresolved fear, emotional liminality, and a persistent sense of being suspended between a traumatic past and an uncertain future. What is novel about this study is its nuanced articulation of how parents inhabit this in-between space of post-treatment liminality, extending conceptualisations of liminality in cancer survivorship described by Willig and Wirth (2019), who highlight how terminally ill cancer patients experience a simultaneous state of connection and disconnection with their existence. In the present study, parents of childhood leukaemia survivors occupy a similarly liminal space, not as patients themselves, but as caregivers characterised by persistent vigilance, emotional tension and ongoing negotiation between hope for the future and the lingering trauma of the past. Crucially, these findings move beyond describing individual experiences to reveal both structural gaps in formal post-treatment care and relational gaps in the availability or consistency of social support. They offer a more layered understanding of recovery by highlighting how it is experienced emotionally and relationally by parents, not just how it is defined and measured in clinical terms. The following sections explore each theme in depth, highlighting the lived realities behind these emotional and psychosocial dynamics.

5.13.1 The Past Tugs, the Future Pulls

While the stress of managing a child's illness during treatment is acute and immediate, this study highlights that the post-treatment phase brings a more ambiguous form of psychological distress. Parents are no longer managing a crisis but rather navigating a prolonged period of uncertainty and unpredictability. This distinction highlights that the end of treatment does not mark an end to parental psychological hardship but rather signals a transition to a complex emotional landscape that requires ongoing recognition and support.

Crucially, the findings challenge the often implicit assumption that the end of treatment marks a psychological resolution (Bruce, 2006; Davies & O'Connor, 2023; Lee et al., 2024; Ljungman et al., 2014; McKenzie & Curle, 2011; Meeske et al., 2007; Peikert et al., 2020; Tutelman et al., 2022;

Wakefield et al., 2011). Instead, this phase initiates a complex and emotionally ambivalent terrain in which many parents remain suspended between past trauma and future hope. Even when medical evidence suggests a low probability of relapse, many parents struggle to fully trust that their child is 'safe' and, as described by one parent, find themselves "jumping to conclusions," further highlighting the enduring nature of fear (Davies & O'Connor, 2023; Long & Marsland, 2011). This persistent state of apprehension aligns with the concept of 'anticipatory anxiety' (Goodwin et al., 2023; Jacobsen et al., 1993; Lown et al., 2015), whereby distress is driven not by present danger but by the fear of future monitoring of their child's health, heightened reactivity to minor symptoms, and difficulty emotionally disengaging from the structured routines of treatment. These patterns underscore how, for many parents, survivorship entails not the absence of fear but the ongoing management of it.

This study extends prior research by highlighting how fear in the post-treatment phase is not static but dynamically reactivated by environmental cues such as health scares or reminders of hospital, echoing Herman's (1992) work on how trauma resurfaces through environmental triggers. Herman (1992) described how traumatic memories can be reactivated by environmental cues even years after the initial trauma and can trigger intense emotional reactions that seem disproportionate to the present context. Similarly, parents in this study described moments when a minor symptom or a child's fleeting illness reignited fears of relapse, underscoring the enduring emotional imprint of the cancer experience. As Janoff-Bulman (1992) observed, trauma disrupts an individual's fundamental assumptions of the world, leaving parents caught in a state of persistent fear and uncertainty despite rational evidence to the contrary. In this context, the post-treatment phase is not simply a return to normalcy but a space of psychological fragmentation, where the past remains close and fear can resurface unexpectedly.

Importantly, this fear coexists with a profound sense of relief. Many parents described feeling an overwhelming sense of relief once treatment was complete. This echoes previous research describing the end of treatment as an emotional turning point, where parents begin to regain a sense of normalcy after months or years of medical intervention and hospital visits (Mckenzie & Curle., 2012). Parents also expressed their overwhelming sense of gratitude and relief for their child's recovery, expressing

appreciation for their child's medical team and the resilience they exhibited as a family throughout treatment. This sense of gratitude that parents feel towards their medical team and support system mirrors previous research emphasising the critical role of strong social support in helping families cope both during and after cancer treatment (Ruiz-Rodríguez et al., 2022; Yoon et al., 2018; Zhang et al., 2020).

However, this sense of relief was often shadowed by apprehension about the future. The transition from highly structured, medically supervised routines to a life without constant oversight can leave parents feeling vulnerable and unprepared for the uncertainties that lie ahead (Davies & O'Connor, 2023; Slater, 2020; Wakefield et al., 2011; Walker et al., 2020). Parents described this shift not as a return to 'normal', but as a new psychological landscape that requires constant adaptation. Parents must rebuild routines and identities in a world that no longer feels predictable. There is no clear roadmap, and emotional recovery often trails far behind physical recovery (McKenzie & Curle, 2012; Davies & O'Connor, 2023).

One of this study's most distinctive contributions is its articulation of the post-treatment phase as a state of emotional liminality. Parents described no longer feeling in active crisis, nor being fully recovered. This sense of liminality reflects the idea of 'ambiguous loss' (Boss, 2010; 2021), where grief and uncertainty persist in the absence of clear closure. Several parents spoke of feeling tethered to the trauma of their child's illness while also sensing pressure to resume ordinary life. Moreover, some expressed grief for lost time, altered futures, or a perceived loss of innocence, while others experienced guilt for moving forward or for feeling unable to return to a previous version of life.

By reframing the end of treatment not as a clear psychological endpoint but as a prolonged and nonlinear adaptive process, this study offers a more nuanced understanding of parental survivorship. While these insights resonate with prior research (e.g., Davies & O'Connor, 2023; Long & Marsland, 2011; Ljungman et al., 2014), this study extends our understanding by conceptualising the post-treatment period as a dynamic psychological terrain shaped by the co-activation of past trauma and future anticipation. This dual temporality where grief, gratitude, hope, and fear coexist, has received limited attention in survivorship literature. In this context, social support and personal resilience are not simply

protective factors but enabling mechanisms that help parents navigate this liminal space. While some begin to rebuild their lives, they do so while carrying the imprint of their child's past illness, an invisible residue that shapes their worldview long after the last hospital visit. The findings suggest that understanding parental survivorship requires moving beyond dichotomous narratives of recovery and instead embracing its complexity, fluidity, and emotional ambiguity.

5.13.2 Cast Adrift, Yet Anchored

The end of treatment does not mark a clear point of closure for parents but rather initiates a period of psychological and relational reconfiguration. Existing literature has long acknowledged the reduction of formal support after treatment ends, with parents describing this shift as a cliff-edge moment (Davies & O'Connor, 2023; Wakefield et al., 2011). In the current study, this imagery of sudden abandonment was echoed but also extended, what emerged was not simply a drop-off in support, but an acute contrast between the visible end of treatment and the persistence of emotional, informational, and psychological needs. Despite knowing their child was officially in remission, parents in this study felt adrift in the vast expanse of the unknown. Parents' expressions of being "thrown into the great unknown" highlighted this suspended state, where one is no longer in crisis, but far from resolution.

The absence of structured aftercare leaves many parents feeling psychologically suspended, no longer in crisis, yet far from restored. While their child may be in remission, the emotional terrain remains unstable. Echoing Wakefield and colleagues (2011), many parents described this period as one of abandonment, where fears persist but professional engagement diminishes. Within this ambiguity, a heightened sense of vigilance takes root. Parents find themselves in a state of persistent hypervigilance, constantly monitoring their child for potential signs of relapse and interpreting minor symptoms as cause for concern (Barrett et al., 2020; Sisk et al., 2019). This study expands on this understanding by highlighting that this hypervigilance extends beyond just physical health, spilling into emotional and developmental monitoring, whereby parents are hypervigilant of any hint of emotional distress or social difficulty their child might experience, further adding to the complexity of the post-treatment experience.

Compounding this vigilance, parents in this study described moments where trauma resurfaced unexpectedly through interactions with their child. As children matured and began to make sense of their illness, they asked increasingly complex questions about procedures, terminology, or why they became sick. In responding to these questions parents reported being drawn back into emotionally charged memories they believed had been resolved. Several spoke of struggling to respond without re-experiencing distress, suggesting that trauma was not only internally reactivated but socially reawakened through their child's meaning-making processes. This dynamic of trauma reactivation through child-parent dialogue is underexplored in existing literature, which tends to position trauma as internally held rather than socially reawakened (Bruce, 2006; Long & Marsland, 2011; Murphy et al., 2021). This study's emphasis on this intersubjective reprocessing of trauma offers a novel lens for understanding how emotional healing is complicated by the developmental trajectories of survivors themselves.

Yet even amidst these currents of instability, many parents found themselves anchored by the support systems around them who provide both practical and emotional support. Consistent with previous research (Cohen & Wills, 1985; Conrad & Altmaier, 2009; Conway Keller et al., 2020; Gise & Cohen, 2022; Klassen et al., 2011; Tremolada et al., 2016; Wakefield et al., 2011), this study affirms that social support plays a pivotal role in buffering distress and enabling adaptation. Relationships with fellow cancer parents were particularly valued, providing a shared language and mutual empathy unavailable elsewhere. These connections offered a stabilising force, creating pockets of understanding in an otherwise isolating landscape. This echoes but also extends previous research that peer support among parents of childhood cancer survivors can serve as a unique source of validation and relational grounding (Björk et al., 2011; Davies & O'Connor, 2023; Ljungman et al., 2016).

However, not all relationships were strengthened or survived. In this study, some parents described how longstanding friendships faded over time, often due to others' discomfort, emotional withdrawal, or a perceived pressure to 'move on' once treatment ended. Similar patterns have been observed in previous research, where friendships have been shown to erode under the strain of emotional exhaustion, social discomfort, or unrealistic expectations of recovery and normalcy (Long & Marsland,

2011; Wakefield et al., 2011). This complex interplay between strengthened and weakened relationships underscores the importance of holistic survivorship care that proactively facilitates peer support networks, while also helping families prepare for the potential reshaping of their social networks.

Perhaps most strikingly, this study foregrounds how parents often face systemic barriers in accessing the very support they need. Parents in this study described a stark absence of signposting and guidance following treatment, despite the persistence of emotional and practical need. Many recounted feeling unsure where to turn for psychosocial or mental health support once medical care had ended, with several highlighting the lack of structured follow-up or clear referral pathways. These findings mirror previous research documenting similar discontinuities in post-treatment care (Conway Keller et al., 2020; Davies & O'Connor, 2023; Muskat et al., 2017; Wakefield et al., 2011). In addition, some parents described how structural inequities, such as prohibitive costs for private therapy and extensive wait times for public services further limited access to support, reflecting broader systemic issues identified in recent work (Delemere et al., 2023). For some, this gap resulted in prolonged distress and a sense of being adrift, while for others it catalysed a determined search for resources, networks, and alternative forms of support. Despite limited formal infrastructure, many families displayed remarkable persistence, bridging the gap through advocacy, research, and informal networks. Their determination to secure the resources they need reflects their resilience and perseverance in the face of adversity. However, while this resilience is admirable, it should not be mistaken for adequacy. The burden placed on parents to construct their own post-treatment anchors reveals a critical shortcoming in healthcare systems that often fail to extend meaningful psychosocial support beyond the treatment phase. This study supports emerging calls for a reorientation of survivorship care that moves beyond reactive, individualised models and instead prioritises proactive, equitable, and developmentally responsive systems of support (McLoone et al., 2025; Vetsch et al., 2017). In the absence of such structural reform, parents remain at risk of being cast adrift, left to navigate enduring complexities with insufficient guidance in a system still lagging behind their long-term needs.

5.13.3 "Finding the Play Button" Again

While the return to normalcy and the struggles associated with such are well documented in the literature (Conway Keller et al., 2020; McKenzie & Curle, 2012; Walker et al., 2020), the current study presents new insights that expand on existing understandings. *"Finding the play button"* again is not simply about reestablishing routines, it is about emotional recovery, identity reconstruction, and navigating the guilt and complexity that linger after the treatment ends. This period is marked not by closure but by ongoing psychological labour and adjustment. Consistent with previous studies (Parker et al., 2023; Petersen et al., 2022; Slater, 2020; West et al., 2015; Woodgate, 2006), parents frequently referred to the idea of a 'new normal'. Yet rather than a one-time adjustment, this study shows that the new normal is fluid and continually redefined in relation to the evolving needs of the child, the residual emotional impacts of treatment, and the shifting identities of parents themselves.

A key finding of this study is the identification of a profound liminal space experienced by parents in the post-treatment phase, a space between who they were and who they are now. This liminality captures the significant reworking of parental identity as they navigate the disorienting shift from being full-time caregivers to resuming the role of 'ordinary' parents. In line with Willig and Wirth's (2019) conceptualisation of liminality in cancer survivorship, where individuals occupy a simultaneous state of disconnection and potential for meaning-making, parents in the present study inhabit a similar space. While existing research often focuses on parental anxiety, post-traumatic stress, and coping strategies (Cheng et al., 2022; Greenzang et al., 2021; Wurz et al., 2022), this study highlights how recovery also involves an internal recalibration of selfhood, marked by grief for a version of themselves and their family that can no longer be reclaimed. This emotional complexity reveals that recovery is not just about healing from what happened, but adapting to a changed identity.

This reconstruction of identity and family life is further complicated by the ongoing nature of medical demands. In line with previous research (Carlsson et al., 2019; Kızılocak & Okcu, 2019; Landier et al., 2015; Larsen et al., 2022; Stein et al., 2008; Al-Mahayri et al., 2021), the current findings show that late and long-term effects, such as fatigue, body issues, developmental delays, neuropathy and other side-

effects create a sense of extended vigilance. The transition out of active treatment is not a simple return to life as it was before, but rather a process of adapting to an ever-evolving reality shaped by the lasting effects of childhood cancer and its treatment (Parker et al., 2023). Without coordinated, ongoing support, the end of treatment can paradoxically mark the beginning of a new, under-supported phase of distress.

Financial strain adds another layer to this extended burden. Consistent with past research (Mader et al., 2016; Roser et al., 2019; Santacroce et al., 2018), this study reveals how parents encounter unexpected, often sustained, financial pressures due to medication, therapies, and specialist services, many of which fall outside public funding. These costs are not simply logistical inconveniences, they represent a structural gap in survivorship services and the need for more comprehensive financial support that extends beyond the completion of treatment. Despite these ongoing challenges and in line with previous research, this study found that many parents exhibited notable resilience, and in some cases, post-traumatic growth (Barrett et al., 2020; Howard Sharp et al., 2023). Many expressed deep pride in their resilience and their ability to endure adversity. Although the process of recovery can be long and challenging, many parents found hope and strength in the opportunities that the future held. This sense of hope is essential for parents as it gives them a sense of purpose and momentum to keep moving forward despite the ongoing difficulties.

The resumption of everyday routines, such as returning to work, school, physical activity, and social life emerged as another critical component of the post-treatment phase. While the resumption of these routines is often viewed as a marker of recovery, the findings here suggest a more ambivalent reality. For many parents, returning to work brought a renewed sense of identity and normalcy but also introduced new tensions around productivity, flexibility, and caregiving responsibilities. Similarly, children's return to school was often experienced as both a milestone and a source of anxiety, with parents concerned about their child's stamina, emotional readiness, and potential social exclusion. This ambivalence points to the importance of flexible return-to-life support mechanisms that recognise the uneven terrain of post-treatment adjustment.

Reintegrating into social life and prioritising personal well-being were also identified as essential yet emotionally complex tasks. In line with previous studies (Carlsson et al., 2019; Whalan et al., 2024), many parents neglected their own physical and emotional well-being during their child's treatment to focus all of their attention on their child's care. However, as the immediate effects of the treatment subsided, many parents began to reclaim time for self-care, physical exercise, and socialising. These efforts played a central role in emotional recovery and improved quality of life (Björk et al., 2011; Nielsen et al., 2024; Schwartz-Attias et al., 2024). Yet for some, re-engaging socially was fraught with ambivalence, as parents felt emotionally out of sync with their peers, making the prospect of socialising again overwhelming for some. While social support has been widely recognised as protective against stress (Cohen & Wills, 1985; Melguizo-Garín et al., 2019), this study highlights that rebuilding social connections post-treatment is not always straightforward, as parents often had to navigate mismatched expectations, negotiate how much of their ongoing fears to disclose, and reconcile a sense of personal change with relationships that had remained largely the same.

An additional and significant complexity in recovery arises from the experience of guilt, encompassing both survivor guilt and sibling-related guilt. Although survivor guilt has been explored among childhood cancer survivors themselves (Cantrell & Conte, 2009; Molinaro & Fletcher, 2020), this study extends the concept to parents. Many expressed a quiet but persistent guilt for their child's survival in comparison to others who were less fortunate. This was compounded by guilt toward siblings whose needs were often deprioritised during treatment. For many parents, this guilt persisted long after treatment ended, functioning not as a momentary feeling but an enduring psychological undercurrent. These findings speak to cultural ideals around good parenting (Sevón, 2005) and their collision with the often unavoidable compromises of caregiving during crises. Guilt, in this sense, becomes not a transient emotion but a residual condition of survivorship.

5.13.4 Self-Discovery through Adversity

A powerful thread running through parents' narratives was the profound personal growth and transformation that parents often experienced following their child's treatment. Central to this process is a deep period of reflection and existential meaning-making, which often emerges only once the immediacy of treatment subsides. A recent systematic review by Halldorsdottir and colleagues (2022), synthesising findings from sixteen studies on post-traumatic growth among family members of childhood cancer survivors, found that nearly all participants reported some form of positive psychological change, such as strengthened relationships, personal growth, or a redefined outlook on life. Consistent with these findings, this study provides a detailed account of how such changes unfold, not simply as a byproduct of survival, but as a result of active reflection, existential meaning-making and reprioritisation.

One of the most striking insights was that many parents did not recognise their own resilience until after treatment ended. During treatment, their primary focus was on immediate survival, leaving little time for self-reflection or emotional processing. It was only in retrospect, sometimes months or even years later, that parents began to acknowledge the extent of what they had endured and how it had changed them. This temporal dimension of post-traumatic growth is supported by previous research (Carlsson et al., 2019; Davies & O'Connor, 2023; Ljungman et al., 2016) which suggests individuals undergo a profound shift in perspective following their child's successful treatment. Despite its challenges, adversity appeared to serve as a catalyst for personal reflection, existential meaning-making, and a more purposeful approach to life. For many, this reorientation led to a significant re-evaluation of what mattered most. Rather than striving for pre-illness aspirations, such as career advancement or academic performance, parents placed greater emphasis on health, family time, and psychological well-being.

In some cases, this resulted in practical life changes, including reducing work hours, changing careers or renegotiating daily routines to create more time for their children and themselves. While such accounts align with existing research (e.g., Davies & O'Connor, 2023; Kelada et al., 2020; Ljungman et al., 2016; Okada et al., 2023), this study adds crucial depth by foregrounding the constraints that shaped

these decisions. Not all families had the freedom to live in accordance with their new values. Financial strain, rigid employment conditions, and the enduring demands of caregiving often prevented parents from acting on their redefined priorities. This study therefore underscores the need to better understand how socioeconomic factors shape the possibilities and limits of post-treatment transformation (Mader et al., 2016; Roser et al., 2019; Santacroce et al., 2018).

In addition to this shift in priorities, the study also highlighted parents' heightened appreciation for life's simplest pleasures and awareness of life's fragility. Consistent with previous research (Davies & O'Connor, 2023; Ljungman et al., 2016) many parents reflected on their newfound appreciation for everyday, simple moments that previously may have been taken for granted, such as enjoying good health and being able to spend time together as a family. Parents spoke of being more present, less concerned with the future, and more focused on the here and now. The recognition that life can change abruptly fostered a more deliberate approach to living, marked by intention and attentiveness.

Beyond personal transformation, many parents described how their experience motivated them to advocate for change and support other families facing similar struggles. Through their first-hand experience, they are uniquely equipped to identify systemic shortcomings and areas in need of improvement. While previous research has identified advocacy as a form of meaning-making and empowerment (e.g., Gage-Bouchard et al., 2017; Sisk et al., 2021), this study expands on those findings by showing how advocacy also becomes a tool for parents to re-establish control, purpose and existential meaning in a post-treatment landscape where they often feel powerless. Parents used their lived expertise to identify gaps in care, support other families, and raise awareness through campaigns and community action. In doing so, they transformed deeply personal hardship into social contribution, an act that not only benefited others but helped many parents rebuild their own sense of self and efficacy.

5.14 Strengths and Limitations of the Qualitative Strand for Parents

Several strengths characterised the qualitative strand of this mixed-methods study. Foremost, the findings offer a valuable contribution to our understanding of parents' experiences during the post-treatment

period and the transition to life after childhood leukaemia. In particular, the qualitative phase sheds light on their lived experiences of social support, resilience and quality of life, areas that are crucial yet often underexplored. By capturing these subjective perspectives, the study offers a nuanced account of parents' post-treatment realities, which will be further integrated with the quantitative findings in the following chapter.

Despite these strengths, some limitations also exist. Firstly, the majority of parent participants in this phase were mothers, which may limit the transferability of these findings to fathers of childhood leukaemia survivors. Fathers may experience and respond to their child's illness in different ways, and their perspectives remain underrepresented in the current analysis. This pattern is consistent with broader trends in paediatric psycho-oncology research, where fathers are frequently underrepresented (Davison et al., 2017). Several factors contribute to this, including recruitment strategies that rely on mothers as primary caregivers, fathers' lower availability due to work responsibilities, and gendered norms around help-seeking and participation in psychosocial research (Davies & O'Connor, 2023; Davison et al., 2017). Future research would benefit from more targeted strategies to engage and retain fathers, ensuring that their perspectives are fully incorporated into understandings of family adjustment after childhood cancer.

Second, the cultural homogeneity of the participating parents may constrain the applicability of findings to more diverse populations. With the exception of one parent of Chinese origin/descent, all other parents were of Irish or British origin/descent. This limits the transferability of the findings to more diverse populations, where cultural norms and beliefs may influence how parents experience illness, access support, and make meaning of survivorship. Future research would benefit from greater inclusion of a broader range of ethnic and cultural backgrounds.

5.15 Conclusions of the Qualitative Strand

Overall, this qualitative strand of the mixed-methods enquiry provides a nuanced understanding of the post-treatment experiences of childhood leukaemia survivors and their parents, highlighting the complexity and ongoing negotiation inherent in life after treatment. The post-treatment phase is shown to

be a dynamic process in which children and parents continually adapt to changes in identity, relationships and daily life, rather than returning to a pre-illness ‘normal’. For children, developmental stage shapes the ways they process memories, reconstruct their sense of self, engage socially, and utilise available supports, with older children often negotiating more complex identity challenges and social reintegration than younger children. For parents, recovery involves inhabiting a liminal space marked by persistent emotional tension, ongoing vigilance, and the simultaneous experience of relief, fear and grief, as they reconcile the lasting impacts of their child’s illness with the desire to resume everyday life. Together, these findings underscore that social support and resilience are intertwined mechanisms central to sustaining quality of life, enabling both children and parents to navigate ongoing emotional and practical challenges, find continuity in disrupted routines, and cultivate purpose, growth, and a renewed sense of agency in the post-treatment phase. Supporting children and their parents in the post-treatment phase is therefore crucial for long-term well-being, highlighting the need for ongoing, holistic and developmentally sensitive care that addresses both emotional and practical needs.

Chapter 6: Integrative Discussion

6.0 Introduction

This chapter will present a detailed discussion of the integration of the quantitative and qualitative findings of the present study. This chapter will start by outlining how the qualitative and quantitative findings were integrated. Next, the integration of the child and parent findings across both the quantitative and qualitative strands of the study will be detailed. Finally, the main findings of the mixed-methods study will be critically discussed.

6.1 Integrating the Qualitative and Quantitative Findings

The aim of this mixed-methods integration was to combine quantitative and qualitative findings to develop a more comprehensive and nuanced understanding of the post-treatment experiences relating to social support, resilience and quality of life among childhood leukaemia survivors and their parents, one that could not be achieved by either strand alone. As previously outlined in chapter 3 (section 3.4.1), the triangulation protocol was utilised to integrate the quantitative and qualitative findings for children and parents. In line with the processes outlined by O'Cathain and colleagues (2010) and Farmer and colleagues (2006), findings across both the quantitative and qualitative strands of the study were considered in terms of convergence (agreement across methods), complementarity (enrichment from different perspectives), dissonance (contradictions), and silence (constructs appearing in only one data source). More recent advances in mixed-methods research also informed the analytic approach, including the use of joint displays as a means of aligning quantitative patterns with qualitative narratives (Creswell & Plano Clark, 2018; McCrudden et al., 2021) and structured integration techniques such as the Pillar Integration Process (Johnson et al., 2019) which emphasise the generation of new insights at the intersection of data sources. Taken together, this approach ensured that the integration extended beyond the identification of similarity or difference to highlight the distinctive contributions that emerge only through the combination of qualitative and quantitative evidence.

6.1.1 Convergence

Several findings demonstrated convergence, where quantitative and qualitative data reflected consistent patterns in post-treatment experiences. First, across children and parents, social support consistently emerged as a foundational factor underpinning resilience and quality of life, with developmental stage shaping how support was experienced and enacted. Second, for parents, both strands of data highlighted that perceived social support is limited or uneven after treatment, reflected in reduced contact with healthcare providers and fragmented social networks. Finally, across both children and parents, moderate-to-high resilience was evident in questionnaire scores and mirrored in narrative interviews, underscoring resilience as a central feature of post-treatment adjustment. Table 6.1 presents the convergence between quantitative and qualitative findings for children and parents.

Table 6.1: *Convergence Between Quantitative and Qualitative Findings*

Area of Convergence	Quantitative Finding	Qualitative Finding	Key Insight
Social support as a key factor associated with resilience and quality of life.	**Children:** Higher social support was linked to greater resilience and quality of life. Developmental stage influenced these associations: in younger children, higher social support was linked to both physical and psychosocial aspects of quality of life, whereas in older children, resilience was primarily associated with psychosocial quality of life. (See section 4.9.4). **Parents:** Higher social support positively correlated with resilience and mental well-being. (See section 4.10.4).	**Children:** Younger children relied primarily on parental reassurance to reintegrate into school and daily life, while older children emphasised the importance of peers and trusted adults to manage persistent challenges and rebuild routines (See sections 5.9.2 and 5.9.4). **Parents:** Parents described emotional availability, encouragement, and understanding from partners, extended family, and close friends as critical for coping and adjustment (See section 5.12.2.4).	Social support is a core mechanism underpinning resilience and quality of life across both children and parents. Developmental stage shapes how support manifests in children, while parents rely on broader social networks to sustain coping.
Perceived reduction in available support post treatment.	**Parents:** Perceived support decreased as time since diagnosis and end of treatment increased. (See section 4.10.3).	**Parents:** Parents reported fragmentation of structured support and reduced contact with healthcare providers (See section 5.12.2.2).	Perceived social support is limited or uneven after treatment, reflected in parents' experiences of reduced contact and fragmented networks, highlighting a critical post-treatment vulnerability and the need for sustained, structured follow-up care and social support mechanisms.
Resilience despite the disruption of cancer treatment.	**Children:** Moderate-to-high resilience scores, indicating effective coping and adaptive functioning. (See section 4.9.2).	**Children:** Accounts of returning to school, engaging socially, and adapting to residual anxieties or physical limitations (See sections	Resilience emerges as a dynamic, lived process in both children and parents. It highlights adaptive coping strategies that enable reintegration and

Area of Convergence	Quantitative Finding	Qualitative Finding	Key Insight
	Parents: Moderate-to-high overall resilience scores, indicating effective coping and adaptive functioning. (See section 4.10.2).	5.9.2 and 5.9.4). **Parents:** Parents described sustaining routines, managing medical follow-ups, and supporting their child emotionally while navigating their own fears and uncertainties (See section 5.12.3.1).	ongoing adjustment post-treatment. Reinforces that resilience should be viewed as contextually shaped, not only a numerical score.

Across both children and parents, social support consistently emerged as a key factor associated with resilience and quality of life. For children, quantitative findings indicated that social support was linked to greater resilience and higher quality of life, with differences in response depending on developmental stage. Among younger children, higher parental support was associated with improvements across both physical and psychosocial domains of quality of life, a pattern echoed in their qualitative narratives of needing reassurance, protection and assistance from parents when reintegrating into school and everyday life. Among older children, quantitative data suggested that resilience was more strongly tied to psychosocial quality of life than to physical well-being. Qualitative accounts clarified this pattern, highlighting that support from peers and trusted adults was especially critical for managing emotional adjustment and rebuilding social connections.

Similarly, for parents, the quantitative data showed that higher social support was positively correlated with resilience and mental well-being. This statistical association was mirrored in interview accounts, where parents described how emotional availability, encouragement, and understanding from partners, extended family, or close friends provided the psychological scaffolding that enabled them to cope and adjust. Taken together, the convergence across both strands underscores the robustness of the link between social support, resilience and quality of life for children and parents alike, while also highlighting that developmental stage shapes the way support is experienced and enacted within the child group.

Another area of convergence was the experience of support in relation to the post-treatment period. Although the study was cross-sectional, quantitative findings indicated that parents further from the end of treatment tended to report lower perceived support on the MSPSS (Zimet et al., 1988) compared with those closer to treatment completion. This pattern was echoed in qualitative narratives, where parents described feeling that support from healthcare providers, hospital services, or formal follow-up programs was less accessible or consistent after treatment ended. Parents described navigating fragmented systems and reduced contact with professional supports, leaving some feeling isolated at a critical juncture in their post-treatment adjustment. These accounts highlight that support structures are

temporally sensitive and context-dependent, underscoring the importance of ongoing, structured follow-up care and sustained social support mechanisms.

Finally, a clear area of convergence lay in the moderate-to-high resilience observed across both younger and older children, as well as parents. Quantitative data indicated generally positive resilience scores for younger children, older children, and parents, suggesting that, despite the stress and disruption of the cancer experience, most children and parents maintained effective coping and adaptive functioning. This statistical finding was mirrored in qualitative narratives, where both children and parents described strategies and experiences that exemplified this resilience. Parents spoke of sustaining daily routines, managing ongoing medical follow-ups and finding ways to support their child emotionally, all while navigating their own fears and uncertainties. Children's narratives similarly reinforced the quantitative findings, with accounts of returning to school, engaging in social activities and re-establishing a sense of normalcy, demonstrating adaptive coping even when residual anxieties or physical limitations often persisted. Together, the quantitative and qualitative data converge by demonstrating that resilience is a central feature of post-treatment recovery for both children and parents, enabling reintegration and ongoing adjustment post-treatment.

6.1.2 Complementarity

Several findings demonstrated complementarity, with quantitative and qualitative data examining related domains but offering different perspectives or emphasising distinct aspects of the experiences. First, across children and parents, higher physical than psychological health was evident in questionnaires, with interviews showing how emotional recovery was more complex and prolonged. Second, for children, the role of developmental stage in shaping social support and psychosocial quality of life were reflected in survey scores and further explained through narratives of reassurance, disrupted friendships or vivid treatment memories. Finally, for parents, strong overall support in quantitative data was nuanced and contextualised by qualitative accounts that revealed variability in its quality and sustainability. Table 6.2 presents the complementarity of quantitative and qualitative findings for children and parents.

Table 6.2: *Complementarity Between Quantitative and Qualitative Findings*

Area of Complementarity	Quantitative Finding	Qualitative Finding	Key Insight
Variation between physical and psychological health post-treatment.	**Children:** Both younger and older children reported higher physical than psychosocial health post-treatment; social and emotional functioning consistently lower than physical functioning. (See section 4.9.2). **Parents:** Better physical than mental health in quality of life measures, indicating that emotional well-being was more compromised than physical functioning. (See section 4.10.2).	**Children:** Physical recovery generally achieved but emotional recovery was more complex. Older children experienced lingering anxieties, disrupted friendships, and heightened sensitivity to social and environmental cues such as peer acceptance and school reintegration (See sections 5.9.2 and 5.9.4). **Parents:** Persistent worry, hypervigilance, and emotional strain, highlighting the enduring emotional toll despite adequate physical functioning (See section 5.12.1.1).	Physical recovery generally occurs more quickly than emotional recovery for both children and parents. This demonstrates that post-treatment care cannot focus solely on physical health; psychosocial well-being is a persistent challenge requiring targeted, developmentally informed support for both children and their caregivers.
Perceptions of social support across developmental stages/parental social support.	**Children:** Younger children reported greater overall social support than older children across all sources and rated these sources as more important. (See section 4.9.2). **Parents:** Generally perceived strong social support. (See section 4.10.2).	**Children:** Younger children benefited from reassurance and structured assistance facilitating reintegration; older children faced disrupted friendships, heightened sensitivity to being perceived as different and more complex social challenges (See sections 5.9.2 and 5.9.4). **Parents:** Experiences were variable; some relationships deepened, others faded or became unpredictable (See section 5.12.2.4).	Social support functions differently across developmental stages and for parents. While quantitative scores may suggest broad support, qualitative narratives reveal variability in both quality and impact. This underscores the importance of assessing both perceived and received support, and tailoring interventions to developmental stage and family context.

Area of Complementarity	Quantitative Finding	Qualitative Finding	Key Insight
Perceptions of illness and psychosocial health across developmental stages.	**Children:** Younger children reported greater psychosocial quality of life scores than older children. (See section 4.9.2)	**Children:** Older children retained vivid, emotionally intense treatment memories contributing to anxiety and disrupted peer relationships; younger children had more fragmented or absent memories with fewer emotional difficulties (See section 5.9.1).	Developmental stage and memory intensity influence psychosocial recovery; older children's vivid recollections prolong emotional adjustment, while younger children's fragmented memories may protect against ongoing distress. This highlights the need for age-sensitive psychosocial support that addresses memory-related anxiety in older children.

Complementarity was evident in the variation between physical and psychological health post-treatment. Quantitative data indicated that both younger and older children reported higher physical than psychosocial health on the PedsQL (Varni et al., 2001), with social and emotional functioning consistently lower than physical functioning. Similarly, parents reported higher physical than mental health on the SF-36 (Ware & Sherbourne, 1992), indicating that emotional well-being was more compromised than physical functioning post-treatment. Qualitative narratives deepened this picture by showing how emotional recovery was more complex and prolonged, even when physical functioning had been restored. Children, particularly older children, described lingering anxieties, disrupted peer connections, and heightened sensitivity to being perceived as different, with emotional recovery often contingent on social and environmental cues such as peer acceptance and school dynamics. Parents, meanwhile, spoke of ongoing vigilance, fear of relapse and the emotional burden of managing uncertainty. Taken together, these findings illustrate how physical recovery may progress more visibly and consistently, while emotional recovery unfolds in less linear ways, highly responsive to relational and contextual factors. This insight underscores the need for psychosocial follow-up that extends beyond physical recovery and addresses the enduring emotional challenges faced by both children and parents.

Complementarity was also evident in perceptions of social support, highlighting developmental differences among children and nuanced parental experiences. For children, quantitative findings using the CASSS (Malecki et al., 2000) showed that younger children perceived greater overall support than older children across all sources and rated these sources as more important. Qualitative narratives added depth, revealing the mechanisms and variability behind this pattern. Younger children benefited from reassurance and structured assistance from family, peers and school, which facilitated smoother reintegration into daily routines. Older children, in contrast, described more complex social challenges, including disrupted friendships and heightened sensitivity to being perceived as different, which influenced how they accessed and relied on support. These insights contextualise the quantitative patterns, showing that while children of all ages receive support post-treatment, the ways in which it is experienced, interpreted, and utilised differ according to developmental stage. This points to the

importance of tailoring interventions to the child's developmental stage, recognising that support is not experienced uniformly but negotiated in age-dependent ways.

Among parents, experiences of support were similarly complex. Quantitative data using the MSPSS (Zimet et al., 1988) indicated generally strong levels of perceived social support, suggesting that parents were well supported overall across family, friends, and significant others. Qualitative narratives added depth to this picture, revealing variability in how support was experienced and enacted. Some parents experienced deepened relationships, especially with their partners or close friends, while others recounted fading connections or unpredictable support from unexpected sources. These narratives expanded upon numerical trends, highlighting the emotional labour involved in seeking, negotiating and sustaining support, and demonstrating the relational complexity behind the quantitative scores. Together, the quantitative and qualitative findings provide a richer understanding of parental social support, showing that strong overall support may coexist with varied, sometimes challenging, lived experiences.

Finally, complementarity emerged in relation to children's perceptions of their illness and their psychosocial health across developmental stages. Quantitative findings using the PedsQL (Varni et al., 2001) indicated that younger children reported higher scores than older children in the psychosocial health domain, which includes emotional, social and school functioning. Within this domain, social functioning was rated highest, followed by emotional functioning and school functioning, with younger children consistently reporting slightly higher scores than older children across all subdomains. Qualitative narratives provided depth to this pattern, revealing that older children often retained vivid and emotionally intense recollections of treatment, which contributed to ongoing anxieties, disrupted peer relationships, and heightened sensitivity to difference. In contrast, younger children described experiences that were more fragmented or partially absent, with fewer reported emotional difficulties and smoother adjustment. These findings indicate that differences in psychosocial outcomes are not only a matter of recovery itself but also reflect developmental differences in how children perceived, interpreted and emotionally processed their illness and treatment experiences.

6.1.3 Dissonance

Several findings demonstrated dissonance, where quantitative and qualitative data appeared to tell contrasting stories about post-treatment experiences. Firstly, for older children, high resilience and physical health scores contrasted with narratives of fatigue, anxiety and fears of relapse. For parents, resilience scores were lower for those further from the end of their child's treatment, which contrasted with qualitative narratives describing growth and transformation. Separately, quantitative measures of physical health overlooked parents' accounts of support as restorative and enabling. Table 6.3 presents the dissonance between quantitative and qualitative findings for children and parents.

Table 6.3: *Dissonance Between Quantitative and Qualitative Findings*

Area of Dissonance	Quantitative Finding	Qualitative Finding	Key Insight
High resilience scores versus ongoing emotional struggles.	**Children:** Moderate-to-high resilience scores across both younger and older children. (See section 4.9.2).	**Children:** Many older children described persistent fears of relapse, anxiety, disrupted peer relationships, identity struggles, difficulty achieving 'normalcy' (See sections 5.9.2 and 5.9.3).	Older children may display strong resilience while still experiencing ongoing emotional challenges, highlighting resilience as a dynamic, multidimensional process. Quantitative scores alone may mask the complexity of their lived adjustment post-treatment.
Reported strong physical health versus hidden ongoing physical challenges.	**Children:** High physical health scores across both younger and older children. (See section 4.9.2).	**Children:** Many older children reported fatigue, chronic pain, vulnerability to minor illness, ongoing management of physical limitations (See section 5.9.2).	Among older children, strong quantitative ratings of physical health may mask hidden, fluctuating, or less visible physical challenges. This suggests that recovery trajectories are more complex than survey scores imply and points to the need for follow-up care that attends to subtler, ongoing physical burdens.
Parents further from the end of their child's treatment had lower resilience scores, contrasting with qualitative accounts of personal growth.	**Parents:** Resilience scores were significantly negatively correlated with months since their child's end of treatment. (See section 4.10.3).	**Parents:** Narratives of ongoing personal growth, transformation, and renewed appreciation for life (See section 5.12.4.1).	While resilience scores declined among parents further from treatment completion, qualitative accounts revealed ongoing personal growth. This dissonance may reflect group-level decline alongside transformation for a subset of parents, underscoring resilience as multidimensional and not fully captured by quantitative

Area of Dissonance	Quantitative Finding	Qualitative Finding	Key Insight
			scores alone.
Lack of measurable association between social support and physical health versus narrative reports of restorative effects of emotional support.	**Parents:** No significant association between social support and physical health. (See section 4.10.4)	**Parents:** Emotional support described as revitalising, enabling return to daily activities, exercise, and sense of normalcy (See section 5.12.3.1 and 5.12.2.3).	Although no statistical link was found, parents described emotional support as revitalising and restorative. This suggests that the benefits of social support may manifest in more subtle, subjective, or indirect ways not captured by physical health measures, highlighting the limits of relying solely on quantitative data.

Among older children, dissonance emerged between moderate-to-high quantitative resilience scores on the RS25 (Wagnild & Young, 1993) and qualitative narratives of ongoing emotional struggle. Interviews revealed that many older children continued to experience persistent fears of relapse, anxiety about social reintegration, and challenges with identity and normalcy. These emotional and psychosocial difficulties were often intertwined with their perceptions of difference from peers and concerns about being treated differently. Taken together, these findings indicate that children may display strong resilience while still experiencing ongoing emotional challenges. Quantitative scores alone may therefore mask the complexity of children's lived adjustment post-treatment, capturing evidence of coping and adaptation without fully reflecting the internal emotional labour and relational contexts that shape recovery.

Dissonance was also observed between high quantitative physical health scores and qualitative narratives of ongoing physical challenges amongst older children. Quantitative data suggested that both younger and older children experienced relatively high levels of physical health on the PedsQL (Varni et al., 2001), implying a broadly positive trajectory of recovery and suggesting that children are generally able to resume daily activities without significant impairment. However, the qualitative narratives, particularly from older children, described persistent physical vulnerabilities that were largely invisible in the questionnaire data, including chronic fatigue that fluctuated day-to-day, lingering pain in muscles and joints, and heightened sensitivity to minor illnesses such as colds or infections. These experiences were often intertwined with ongoing anxiety about physical well-being and fear of relapse, creating a layered interplay between physical symptoms and emotional states. These accounts indicate that while children may function adequately day-to-day, underlying physical vulnerabilities and the effort required to maintain 'normal' activity levels may not be fully captured by standardised measures.

Among parents, a clear dissonance emerged when examining resilience in relation to the number of months elapsed since their child's end of treatment. Quantitative data indicated a significant negative association between the number of months since the end of treatment and parents' resilience scores on the RS25 (Wagnild & Young, 1993), suggesting that resilience decreased the further parents were from the

treatment period. This trend may capture the waning of immediate post-treatment support, the accumulation of everyday stressors, and the enduring uncertainty about long-term health outcomes. In contrast, qualitative narratives conveyed experiences of personal growth, transformation and evolving inner strength. Many parents spoke of developing a renewed appreciation for life, re-evaluating priorities, strengthening relationships and cultivating resilience in ways that were deeply reflective and existential. While resilience appears to diminish on average at the group level, some parents, both within and potentially beyond those interviewed, experience resilience as a deepening and transformative process. This suggests that resilience is multidimensional, not fully captured by quantitative scores alone, and warrants further investigation to better understand the subgroup of parents for whom resilience is sustained or strengthened over time.

Among parents, a notable dissonance emerged regarding the relationship between social support and physical health. Quantitative data indicated no significant association between perceived social support and physical health. In contrast, qualitative narratives highlighted that emotional support was experienced as revitalising and restorative, helping them regain energy, re-engage with daily activities, return to work, participate in exercise and reclaim a sense of normalcy in life after their child's treatment. These accounts suggest that aspects of support meaningful to physical functioning may not be fully reflected in the measured scores, highlighting the value of exploring lived experience alongside questionnaire data.

6.1.4 Silences

Several silences emerged in this study, representing aspects of post-treatment experience emphasised in qualitative narratives but not captured by quantitative measures. These included existential transformation, referring to shifts in life perspective, personal meaning, or identity following the cancer experience, the nuances of peer-based or parent-to-parent support, and the hidden emotional burdens of survivorship. While instruments captured broad domains of social support, resilience and quality of life, they were not designed to reflect these more nuanced or deeply personal experiences. These silences do

not imply that quantitative measures lack value but rather indicate areas where numerical assessments may provide a partial view of experience. They suggest that some aspects of post-treatment life are more difficult to quantify or operationalise, highlighting the complementary role of qualitative inquiry in revealing dimensions of experience that are less easily captured through standardised metrics. These insights also indicate directions for future research, where refined quantitative tools or integrated mixed-methods approaches could provide a more comprehensive understanding of survivorship. Table 6.4 presents the silences identified between quantitative and qualitative findings.

Table 6.4: *Silences Between Quantitative and Qualitative Findings*

Area of Silence	Quantitative Finding	Qualitative Finding	Key Insight
Identity & existential meaning-making.	Quantitative measures captured broad domains such as social support, resilience and quality of life, but aspects such as identity reconstruction and existential reflections were not captured, whereas qualitative methods allowed these dimensions of post-treatment experience to be explored.	**Children:** Older children described shifts in self-concept, increased maturity, life appreciation, and future orientation after treatment (See section 5.9.3). **Parents:** Parents described transformation in caregiver identity, altered worldview, and deepened sense of purpose (See sections 5.12.4.1 and 5.12.4.2).	Identity and existential reflections represent essential dimensions of the post-treatment experience that were not captured by the quantitative measures in this study, highlighting how qualitative inquiry can reveal deeper, lived aspects of survivorship.
Cancer-specific peer networks and parent-to-parent connections.	Social support scales assessed broad categories (e.g., family, friends, significant others) but not cancer-specific peer contexts.	**Children:** For older children cancer-specific peer groups (e.g., CanTeen Ireland) provided understanding, identity validation, and emotional safety (See section 5.9.4). **Parents:** Informal parent-to-parent connections offered practical advice, emotional validation, and mutual understanding (See section 5.12.2.3 and 5.12.2.4).	Standardised measures captured general support but did not reflect the specific, context-sensitive forms of support identified qualitatively. This highlights the importance of considering the source, function and meaning of support in post-treatment adjustment, and suggests a need for future research to assess these nuanced dimensions.
Emotional burden of child illness-related questions post-treatment.	**Parents:** Quantitative measure assessed emotional quality of life generally but did not capture the specific cognitive/emotional labour of responding to a child's post-treatment questions about illness or	**Parents:** Parents reported anxiety, uncertainty, and emotional conflict when responding to their child's questions about illness and risk (See section 5.12.2.1).	This silence identifies a unique post-treatment stressor that is often invisible in quantitative metrics. It highlights the need for research and interventions addressing parental emotional labour in supporting

Area of Silence	Quantitative Finding	Qualitative Finding	Key Insight
	risk.		children's understanding and coping.
Survivor and sibling related guilt.	**Parents:** Not captured in quantitative measures.	**Parents:** Lingering survivor guilt and guilt over the impact on siblings (See section 5.12.3.2).	Standard measures often overlook moral and relational challenges post-treatment. Recognising this gap points to the importance of including items on survivor and sibling-related guilt in future psychosocial research.

One of the most salient silences related to identity and existential meaning-making. Both older children and parents articulated powerful narratives of identity loss, reconstruction, and meaning-making in the aftermath of treatment. Older children described shifts in self-concept, maturity, life appreciation and future orientation. Similarly, parents described transformations in their caregiver identities, with many expressing a deepened sense of purpose and an altered worldview shaped by their child's illness. None of the quantitative instruments used in this study measured these processes. This is not a gap in coverage within the chosen measures, but rather a domain that requires different methodological approaches. The silence therefore underscores the distinctive contribution of qualitative inquiry in capturing existential and identity-based aspects of survivorship that cannot be meaningfully reduced to standardised items.

Another important silence concerned peer-based support groups and informal forms of support. Social support was assessed in children using the CASSS (Malecki et al., 2000) and in parents using the MSPSS (Zimet et al., 1988). However, these measures focused on broad categories such as family, friends, and significant others, without differentiating support received through cancer-specific peer groups or parent-to-parent connections. In contrast, qualitative narratives highlighted these forms of support as uniquely meaningful. For older children, survivor peer groups such as CanTeen Ireland provided rare spaces of understanding, identity validation and belonging. For parents, informal connections with other parents of childhood leukaemia survivors were described as among the most valuable sources of advice, reassurance and mutual recognition. The absence of items capturing these particular contexts represents a silence not of unmeasured social support, but of the context-dependent forms of connection that standardised tools may miss.

Further silences were evident in the nuanced burdens parents described when responding to their child's illness-related questions post-treatment. Although aspects of emotional well-being were assessed through quality of life and resilience measures, these instruments did not capture the specific and emotionally taxing experience of navigating their child's queries, deciding what to disclose and managing their own distress while offering reassurance. By combining quantitative measures with qualitative

narratives, this study highlights these hidden layers of post-treatment burden, illustrating how integrated methods can provide a more comprehensive understanding of parental experiences. These findings underscore the importance of exploring these specific challenges in future research to better support parents in the post-treatment phase.

Finally, guilt emerged as a deeply felt but unmeasured experience among parents. Survivorship guilt in relation to other families and guilt toward siblings due to the unequal attention necessitated by treatment, were both described as enduring tensions. While quantitative measures captured general well-being and support, they did not include items addressing these ethically and relationally complex dimensions of parental experience. This silence points to an area where lived experiences extend beyond the reach of existing standardised tools.

Together, these silences reveal that while quantitative measures successfully captured broad constructs of social support, resilience and quality of life, they were less able to reflect profound shifts in perspective, identity and meaning-making, the specificity of cancer-related peer support, or the hidden emotional and ethical burdens described by parents. Addressing these silences in future research, whether through the development of more nuanced quantitative measures or the continued integration of qualitative inquiry, will be critical for a fuller understanding of life after childhood leukaemia.

6.1.5 Summary of the Integrated Analysis

Integrating the findings from both the qualitative and quantitative phases of this mixed-methods study has been essential in developing a deeper, more nuanced understanding of the post-treatment experiences of childhood leukaemia survivors and their parents. The triangulation of findings enabled the identification of convergence, complementarity, dissonance and silences across the datasets, each offering distinct but interrelated insights.

Areas of convergence reinforced and corroborated to the findings, confirming the central role of social support and resilience in post-treatment adjustment for both children and parents. Complementarities extended these insights, with quantitative patterns, such as variations in quality of life

and resilience by developmental stage, being contextualised and enriched by qualitative narratives of recovery trajectories, identity reconstruction, and evolving support needs.

Dissonances highlighted differences between datasets, reflecting the complexity of survivorship and offering deeper insights. While quantitative scores often suggested stability in psychosocial outcomes, qualitative narratives revealed hidden struggles including enduring fears of relapse, emotional exhaustion and liminality in the transition from patient to survivor. Finally, silences drew attention to experiences not captured by quantitative measures but prominent in qualitative accounts, including identity reconstruction and existential meaning-making, cancer-related peer support, the emotional burden of responding to children's questions, and enduring survivor and sibling-related guilt. These findings highlight the need to consider multiple methods to fully understand the nuanced and ethically significant dimensions of life after childhood leukaemia.

6.2 Discussion of the Integrated Findings

The preceding section presented the integrated quantitative and qualitative findings, highlighting patterns of convergence, complementarity, dissonance and silences across children and parents. In the following discussion, these findings are brought together to explore the deeper insights they offer about post-treatment experiences of childhood leukaemia survivors and their parents. The aim is to move beyond describing patterns to understanding what these integrated findings reveal about post-treatment adaptation. To begin, the rationale for using a mixed-methods approach and the overarching aim of the study will be revisited, providing a foundation for the subsequent critical discussion.

6.2.1 Study Rationale and Aim

Life after childhood leukaemia can be profoundly challenging for both survivors and their parents. Even after successful treatment, children and parents often face lingering physical, psychological, and social effects that shape daily life and long-term adjustment (Davies & O'Connor, 2023; Keller et al., 2024; Hendriks et al., 2021; Muskat et al., 2017). Survivors may contend with late effects, fear of relapse, and

psychosocial adjustment difficulties, while parents frequently navigate ongoing anxiety, hypervigilance, and shifts in family and social dynamics (Larsen et al., 2022; Lundgren et al., 2025; Mckenzie & Curle, 2012; Muskat et al., 2017; Tremolada et al., 2017). While the literature is quite expansive relating to the impacts of cancer while on active treatment and in long-term survivorship (typically 5+ years post-treatment), less is known about the lived experiences of survivors and their parents during the post-treatment period, particularly in terms of how these experiences interact with social support, resilience, and quality of life (Keller et al., 2024; Wilford et al., 2019).

Despite increased survival rates, the psychosocial dimensions of post-treatment survivorship remain underexplored, particularly when considering the perspectives of both children and parents. Social support, resilience and quality of life are key factors in post-treatment adjustment, yet existing research has largely focused either solely on child or parent experiences, quantitative or qualitative measures, or isolated constructs (Marbot et al., 2025). Understanding how children and parents experience and negotiate these psychosocial factors is critical, as they influence coping, adaptation and overall family well-being.

This study addressed these gaps by adopting a mixed-methods design, integrating quantitative indicators with qualitative narratives to capture both measurable outcomes and the lived experience of post-treatment life. By examining social support, resilience and quality of life across children and parents, the study revealed shared and divergent patterns in how these constructs are experienced and interrelated post-treatment. Key findings included the gap between physical and emotional recovery, developmental influences, variability in social support, links between support, resilience and quality of life, and the roles of cancer-specific networks, identity work, survivor and sibling related guilt, and ongoing personal growth. These insights foreground the complexity of post-treatment survivorship and provide a foundation for understanding how families navigate hidden burdens and reconstruct a sense of normalcy and purpose after treatment.

6.2.2 The Hidden Labour of Negotiating Support and Normalcy

The convergence across social support, resilience and quality of life findings demonstrated that post-treatment survivorship for childhood leukaemia survivors and their parents is not a linear trajectory of recovery. Rather, resilience and well-being emerged as dynamic, actively negotiated processes, with both children and parents relying on social support not simply as a resource but as a foundation for strategies such as rebuilding routines, re-engaging in school or work, and sustaining family harmony. Complementing this convergence, qualitative narratives revealed the hidden labour underlying these outcomes, showing that resilience depends on the strategic management of social and familial resources rather than merely the availability of support. Previous research has documented links between social support, resilience and quality of life in childhood cancer survivorship (Kazak et al., 2010; Tremolada et al., 2017; McDonnell et al., 2021) and highlighted adolescents' challenges around peer disclosure (Ingersgaard et al., 2021; Inhestern et al., 2020; Yi & Lee, 2024), but these studies often treat support as a static resource rather than a negotiated, ongoing process that must be continually managed, whether through parents actively rebuilding sources of support once hospital contact diminished, or children managing how and when to disclose their cancer experience to peers to preserve a sense of normalcy and belonging.

The integrated findings also revealed that recovery unfolded unevenly across temporal and developmental dimensions. For both parents and children physical recovery occurred more rapidly than emotional recovery, creating a temporal disjunction between the visible end of treatment and the ongoing psychosocial challenges experienced by many children and parents. For parents, this gap was often experienced as persistent worry and careful monitoring of their child, despite confirmation from their medical team that treatment had concluded successfully. While for children this gap sometimes surfaced as lingering anxiety or a sense of being different from peers, despite all outward markers of normalcy. This pattern highlights that psychosocial well-being cannot be assumed to follow physical recovery and requires sustained, developmentally informed support. Developmental stage and memory intensity further shaped how children managed this post-treatment negotiation. Younger children, whose treatment

memories were often fragmented, tended to reintegrate into everyday life more easily, treating illness as one event among many. In contrast, older children, whose memories were more vivid and whose cognitive capacities allowed for greater reflection, engaged more actively with issues of identity, peer belonging and meaning. These age-related patterns echo established developmental theories (Erikson, 1982; Piaget, 1971; Vygotsky, 1978), suggesting that as adolescents' cognitive and social capacities expand, so too does their awareness of difference and vulnerability, influencing how they process and integrate post-treatment experiences. Memory intensity therefore functioned as both a developmental and emotional mechanism, where coherence of memory facilitated reflective meaning-making but also sustained emotional burden. These insights help explain why psychosocial recovery and resilience were more effortful for older children, requiring greater social and cognitive labour to sustain a sense of normalcy.

For children, quality of life and resilience in post-treatment life were closely tied to managing peer relationships and maintaining a sense of normalcy. Convergence across quantitative and qualitative data confirmed that children's resilience and quality of life were closely linked to social support, with older children relying on peers and trusted adults for emotional support and coping, while younger children drew more heavily on parental support. Although quantitative scores suggested generally adequate resilience and quality of life, qualitative accounts revealed the subtle, sustained effort underlying these outcomes. Older children often engaged in selective non-disclosure of their cancer history to peers, a strategy that appeared to protect autonomy, peer acceptance and continuity of identity, while also supporting emotional well-being and social integration. Previous research has highlighted that young survivors face multiple barriers to disclosure, including fears of discrimination, exclusion, internalized shame, self-stigma and psychological distress (Honda et al., 2024). Complementarity in the integrated findings highlighted how qualitative narratives explained and extended the quantitative patterns, showing that selective engagement and non-disclosure functioned as active resilience strategies, rather than mere avoidance, aligning with previous literature on the centrality of peer belonging during adolescence (Fladeboe et al., 2021; Ingersgaard et al., 2021; Kent et al., 2012). Children appeared to monitor peer

responses, adjust social visibility and manage disclosure based on context, illustrating that these deliberate strategies not only sustain resilience but also support emotional well-being and social integration.

Alternative explanations are also possible. For example, among older children, selective engagement and non-disclosure could be interpreted as avoidance, fear of rejection, anxiety-driven withdrawal or a response to social stigma rather than adaptive resilience. Some children may have limited disclosure out of concern about peer judgment or anticipation of negative social evaluation, suggesting a protective but potentially socially isolating behaviour. However, the integrated findings suggest that these behaviours were often contextually strategic, representing deliberate management of disclosure, peer responses and social visibility in ways that maintained autonomy, peer relationships and a sense of normalcy. These patterns extend previous research on social challenges in adolescent survivorship by showing that what might appear as withdrawal can, in fact, be an adaptive strategy (Jones et al., 2020; Savaş et al., 2025).

Critically, these behaviours reveal a dynamic tension between the protective and constraining aspects of selective engagement. Regulating visibility could safeguard identity, peer acceptance and autonomy by allowing children to control how much of their cancer history was known and thereby avoid stigma, pity or exclusion, yet this regulation also requires ongoing cognitive and emotional effort as children anticipate peer reactions and monitor social contexts. While resilience has previously been conceptualised as a relational and co-constructed process embedded in everyday social negotiation (Hill et al., 2024; Sisto et al., 2019), the integrated findings demonstrate the hidden labour required to sustain it post-treatment, showing resilience as an ongoing practice of vigilance, adjustment and identity management. This highlights that children's well-being was maintained not solely through tangible support but through subtle relational strategies and the preservation of perceived normalcy.

For parents, the negotiation of support was shaped by the withdrawal of structured clinical scaffolding after treatment completion. Quantitatively, resilience scores were lower among parents who were further from the end of treatment, suggesting that sustaining resilience and well-being becomes

more challenging as structured clinical support diminishes. Qualitative narratives contextualised this trend, revealing the experience of a 'support cliff' when structured clinical interactions ended. Convergence across quantitative and qualitative strands confirmed that parental support and resilience are closely linked, while complementarity highlighted how qualitative accounts added nuance, showing the variability, relational labour and emotional effort parents invested to maintain well-being despite the reduction of formal supports. During treatment, healthcare teams provided regular guidance, reassurance and emotional scaffolding. Qualitative narratives indicated that the withdrawal of structured clinical support post-treatment left parents with fewer external scaffolds, contributing to feelings of isolation and uncertainty, consistent with findings reported in previous research (Davies & O'Connor, 2023; Larsen et al., 2024; Muskat et al., 2017).

Furthermore, a particularly important pattern of dissonance emerged in the parental data. Quantitatively, resilience scores were lower among parents whose children were further from the end of treatment, contrasting with qualitative narratives describing personal growth, adaptation and relational strengthening. This apparent contradiction suggests that resilience may shift in form rather than simply diminish over time. Qualitative accounts indicated that as parents moved further from treatment, resilience became less about immediate coping and more about sustained emotional regulation, relational problem-solving, proactive planning and adaptive meaning-making, dimensions that are not fully captured by standardised measures. Lower scores may also reflect genuine increases in caregiving burden or fatigue, measurement limitations, or both. Importantly, these findings offer a nuanced interpretation of parental resilience, highlighting the strategies that may enable continued adaptation despite the reduction of formal support.

Taken together, the integrated findings collectively show that post-treatment adaptation for childhood leukaemia survivors and their parents is not a straightforward outcome of support availability. Rather, they reflect a complex, relational process in which well-being is actively constructed through ongoing negotiation. The process is relational because outcomes depend on interactions with peers, family members, and broader social networks, with well-being emerging in the context of these

relationships rather than in isolation. It is negotiated because both children and parents actively manage support, disclosure, routines and responsibilities. These developmental and temporal findings further emphasise that the negotiation of support and normalcy unfolds unevenly, with older children and parents carrying greater emotional labour over time, while younger children recover more rapidly but may lack the reflective capacity to make sense of their experiences. Children selectively engage with peers and modulate social visibility to protect autonomy and maintain normalcy, while parents coordinate resources, uphold routines, and adjust to the withdrawal of structured medical support. These findings advance our understanding of survivorship by showing that well-being after childhood leukaemia appears closely linked to how children and parents navigate social, familial, and medical environments. Participants' narratives illustrate that managing peer interactions, coordinating family routines, and adjusting to changes in formal support involve active, relational processes that support resilience and quality of life. By integrating qualitative and quantitative insights, this study provides a richer, leukaemia-specific understanding of how social support, resilience and quality of life are dynamically interrelated across children and parents.

6.2.3 Symbolic and Identity-Affirming Dimensions of Peer and Parent Support

As identified in the silences of the integrated findings, standardised measures of social support captured broad categories such as family and general peers but overlooked cancer-specific peer and parent networks that qualitative narratives revealed to be uniquely meaningful. Children's social support was assessed using the CASSS (Malecki et al., 2000), and parents' support using the MSPSS (Zimet et al., 1988). Although these instruments captured family and general peer support, they did not reflect cancer-specific peer networks or parent-to-parent connections, which qualitative narratives highlighted as uniquely meaningful. These relationships offered far more than companionship, they provided mutual understanding, shared language, and validation of experiences that could not be easily articulated to those outside the survivorship community. For children, survivor groups such as CanTeen Ireland provided spaces of understanding, identity validation and belonging that general peer networks could not offer. For

parents, informal connections with other parents of childhood leukaemia survivors offered advice, reassurance and mutual recognition grounded in shared experience. These examples show that standardised measures, while robust for general support, did not reflect these uniquely relational forms of support such as emotional reciprocity, mutual recognition and sense of community that arise from shared experiences of illness. This silence points not only to the value of peer-based support but also to the need for instruments capable of capturing these unique relational dimensions. While no established condition-specific measures currently exist for the post-treatment phase, the qualitative findings provide essential insight into these uniquely meaningful forms of support, highlighting the need for research and clinical approaches that integrate generic measures with newly developed, condition specific measures when assessing social support, resilience and quality of life to fully understand and foster these outcomes.

Previous research has documented the value of cancer-specific peer support for children, showing that participation in peer-group interventions and camps can reduce emotional distress, enhance coping skills and strengthen psychosocial well-being (Geertz et al., 2023; Kelada et al., 2020; Neville et al., 2019; O'Connell et al., 2024). For parents, studies have emphasised that connections with other parents provide crucial emotional support, practical guidance and a sense of community during and after a child's treatment (Nielsen et al., 2024; Wilford et al., 2020). These findings align with the qualitative accounts in the current study, confirming the value of peer networks in post-treatment adaptation, though this was more evident among older children. Younger children tended to emphasise parents as their primary source of support, whereas older children highlighted cancer-specific peers as vital for belonging and identity validation. What this study adds is a more nuanced understanding of these networks within childhood leukaemia survivorship, highlighting that they operate differently from general friendships or family support. They provide symbolic recognition, identity validation and belonging that are rooted in the shared experience of survivorship. Although the quantitative measures captured frequency and importance for children and frequency for parents, these dimensions did not fully reflect the symbolic and identity-affirming qualities described in qualitative accounts. This highlights a broader gap in

measurement and underscores the need for instruments that can explicitly assess cancer-specific symbolic and identity-affirming forms of support alongside conventional indicators.

Several explanations may account for this silence. First, the instruments used were not designed to differentiate between general and illness-specific peer connections. Older children consistently emphasised that survivor peers served a qualitatively different role even when general 'classmate' and 'close friend' support were captured by the CASSS (Malecki et al., 2000). Parents similarly described connections with other parents as distinct from family or friend support in the MSPSS (Zimet et al., 1988). Second, while standardised measures such as the CASSS (Malecki et al., 2000) and MSPSS (Zimet et al., 1988) capture aspects of availability, frequency and perceived importance of support, cancer-specific peer and parent networks are valued for symbolic and identity-affirming functions that go beyond these dimensions. For example, older children described feeling uniquely understood and connected when interacting with other leukaemia survivors, an experience that conveyed shared identity and belonging even in the absence of frequent contact. Similarly, parents spoke of emotional reassurance and validation gained simply from knowing that other parents had navigated the same challenges, which offered a form of support not easily quantified by frequency or general availability. Third, these networks often gain importance after treatment ends when medical support recedes and social reintegration challenges intensifies, meaning fixed-time-point assessments may fail to capture their peak relevance. Fourth, access to peer groups is not uniform and differences in availability may have contributed to the absence of such support in quantitative data. Connections to cancer-specific peer networks often occur through informal pathways, such as word-of-mouth from other families, previous engagement with support organisations (e.g., Childhood Cancer Ireland, CanTeen Ireland), or existing social networks. Families who are less aware of these resources, or face social, cultural, or logistical barriers may have reduced access or visibility to these supports. Consequently, some children and parents may never engage with cancer-specific peer networks.

These explanations have several implications. Conceptually, while previous research across cancer survivorship has recognised that illness-specific peer connections represent a distinct and highly

valued form of relational support, offering shared understanding, belonging, and normalisation beyond what general friendships can provide (Ingersgaard et al., 2021; Kent et al., 2013; Soejima et al., 2015), the current study extends this understanding in two important ways. First, it highlights that such peer-to-peer connection is also critical for parents, whose access to other parents of childhood leukaemia survivors provided emotional reassurance and experiential knowledge often unavailable in their usual networks. Second, it shows that illness-specific peer support differs across childhood and adolescence, with younger children primarily drawing on parents and family as key sources of connection, while older children place increasing importance on peers for belonging, identity reconstruction and confidence in navigating life beyond treatment.

Methodologically, they highlight the limitations of many existing instruments and demonstrate the value of mixed-methods for detecting silences in measurement. Practically, recognising the unique value of these networks underscores the need for structured referral pathways to survivor groups and parent networks, and for evaluation frameworks that capture identity-related outcomes rather than perceived adequacy or frequency of support. The findings also highlight how support negotiation extends beyond managing disclosure or mobilising resources. Children's engagement in peer networks represents an active strategy to secure belonging and affirmation, while parents' connections with other parents functioned as a deliberate approach to access experiential knowledge and reassurance. The study advances understanding of survivorship resilience by showing that resilience involves not only accessing support but also engaging with cancer-specific peer and parent networks that provide affirmation, belonging, and shared understanding. The unique meaning and identity-affirming qualities of these networks are not fully captured by standardised instruments, yet they are critical for post-treatment adaptation.

Taken together, this discussion highlights a nuanced insight of the study that standardised approaches to social support may not fully capture the symbolic and identity-affirming roles of cancer-specific peer and parent networks. By making visible the unmeasured yet vital role of cancer-specific peer and parent networks, it reframes how support is understood in the context of survivorship. Rather than a

backdrop of general family and peer ties, support emerges as a dynamic, negotiated and identity-affirming resource that is inseparable from the shared experience of children and parents who have navigated cancer diagnosis, treatment, and survivorship. This insight challenges existing conceptualisations of social support, highlights the limitations of current measures and sets a clear agenda for future research, measurement and intervention to capture the full relational ecology of survivorship and to recognise the spaces of belonging and recognition that support children and parents in maintaining and enhancing quality of life after treatment.

6.2.4 The Hidden Emotional and Ethical Labour of Parents After Treatment

An additional important silence emerging from the integrated findings concerned the hidden emotional and ethical burdens experienced by parents in the post-treatment period, particularly the pervasive experience of survivor guilt. Parents described guilt in multiple dimensions, including in relation to other families whose children experienced relapse or death, reflecting moral tension and feelings of undeserved fortune, and toward siblings who received less attention due to the demands of caring for the child who had undergone treatment. While previous research has documented stress, anxiety and caregiving burden after childhood cancer (Chaghazardi et al., 2022; Cheng et al., 2022; Greenzang et al., 2016; Vetsch et al., 2018; Wurz et al., 2022), and examined parental guilt in paediatric cancer populations more broadly (Carlsson et al., 2019; Jin et al., 2025; Kestler-Peleg et al., 2025), few studies have focused specifically on childhood leukaemia or fully captured how guilt is relationally embedded and actively navigated in everyday parenting. The findings of this mixed-methods study extend current knowledge by showing that survivor guilt is not just an internalised feeling but an ongoing, ethically charged effort that parents navigate in ways that draw on and sustain their resilience, shape engagement with support networks, and influence post-treatment quality of life.

Survivor guilt may influence a range of everyday parenting decisions, including how attention is allocated between siblings, how much emotional energy is invested in future planning, and how routine parenting tasks are managed. In this sense, survivor guilt can be understood as a form of continuous

cognitive and emotional labour that remains largely invisible to standardised measures yet profoundly shapes how parents manage family responsibilities, sustain well-being, and draw on their resilience after treatment. The hidden labour of parental guilt can be understood in multiple ways. On one hand, guilt may act as a relational mechanism, prompting vigilance and sustained attentiveness to family needs. In this sense, it may support adaptive parenting by reinforcing careful management of children's health, emotional well-being and social reintegration, aligning with resilience as a dynamic, contextually embedded process (Brewer et al., 2019). On the other hand, guilt may also be a source of psychological strain, contributing to ongoing worry, fatigue and emotional ambivalence. Parents described balancing gratitude and relief with awareness of other families' losses and striving for fairness toward siblings while meeting the demanding needs of the child who survived leukaemia.

The leukaemia-specific context may further intensify parental experiences of guilt and moral tension. Compared with many other paediatric cancers, leukaemia involves longer treatment trajectories, extended periods of hospitalisation and a persistent risk of relapse (Rheingold et al., 2024; Smitherman et al., 2016; Sørensen et al., 2019). These factors may make parenting after treatment especially stressful. Parents may find it hard to stop worrying about their child's health and seeing that other children have worse outcomes can increase feelings of guilt or a sense of undeserved fortune. This provides a leukaemia-specific lens that is often absent in previous research, which tends to treat parental guilt generically across childhood cancers without considering differences in treatment intensity or illness trajectory (Carlsson et al., 2019; Jin et al., 2025; Kestler-Peleg et al., 2025).

The hidden labour of survivor guilt also intersected with post-treatment communication, shaping how parents engaged with family and support networks, drew on resilience, and experienced quality of life. Some parents described the difficulty of responding to their child's questions about their illness, making decisions about what to disclose and how to frame information, as well as negotiating fairness between siblings while continuing to monitor the health of the survivor. While previous research has examined parental communication in the context of childhood cancer, showing that parents often struggle with when and how to share information with their child (Badarau et al., 2015; Coyne et al., 2016; Son et

al., 2019), these studies have largely focused on the active treatment phase, leaving the post-treatment period relatively underexplored. The findings of this mixed-methods study suggest that after treatment completion, disclosure practices are not isolated communication challenges but are closely intertwined with survivor guilt, moral reasoning and emotional regulation. Parents' experiences indicate that emotional and ethical considerations, such as balancing attention between siblings and protecting their child, may shape decisions about what and how to communicate, and that survivor guilt could be one factor influencing these processes. By focusing on the post-treatment phase, these interpretations suggest that such emotional and moral work may continue to influence family dynamics and adaptation long after active treatment, offering a nuanced perspective that has been largely absent in previous research.

Taken together, these findings highlight an under-recognised domain of survivorship, namely the hidden, relational and ethically complex labour of parents, particularly mediated through survivor guilt. Conceptually, this study advances understanding of post-treatment parental resilience as an active process, shaped by ongoing ethical and emotional decision-making, and co-constructed through interactions with family and support networks. Methodologically, it underscores the limitations of standardised instruments in capturing the nuances of morally and relationally embedded experiences, reinforcing the value of qualitative and mixed-methods approaches in post-treatment research. Practically, these insights suggest that interventions should move beyond general psychosocial support to explicitly address ethical decision-making, sibling balancing, and the management of survivor guilt. By situating these findings within and against existing literature, the study advances understanding of the lived reality of post-treatment adaptation in childhood leukaemia, highlighting what has been overlooked and why it matters.

6.2.5 Unseen Dimensions of Identity and Existential Meaning-Making After Treatment

Another critical silence emerged regarding identity reconstruction and existential meaning-making. Standardised measures do not capture identity reconstruction and existential meaning-making, even though our qualitative findings demonstrate that these processes are central to post-treatment resilience,

social support and quality of life in childhood leukaemia survivorship. Previous qualitative studies of childhood cancer survivors have pointed to identity disruption, meaning-making and life reappraisal as important dimensions of childhood cancer survivorship (Berkman et al., 2022; Halldorsdottir et al., 2022; Tremolada et al., 2016; Zhang et al., 2023), but this mixed-methods study moves beyond such broad claims by offering a leukaemia-specific perspective, showing how identity reconstruction and meaning-making uniquely shape resilience, social connectedness, and quality of life. Quantitative scores suggested moderate-to-high resilience, social support and quality of life, which alone might indicate steady adaptation. Yet, qualitative narratives revealed a far more nuanced, fluctuating experience, with children and parents describing shifts in self-concept, family priorities and interpretations of life. These processes are inherently personal, context-dependent and temporally dynamic. While they were not captured by the quantitative measures used in this study, they emerged as important dimensions of post-treatment experience that warrant further exploration in future research.

Developmental stage emerged as a key mechanism shaping identity reconstruction and existential meaning-making after treatment. Consistent with previous research (Belpame et al., 2019; Dinç et al., 2024; Larsen et al., 2022; Tremolada et al., 2016), younger children generally integrated their illness experience in concrete ways, treating it as one event among many rather than a defining feature, while older children navigated more complex tensions between autonomy, peer belonging and survivor identity, sometimes resisting illness-centred labels. Parents' identity work reflected caregiving responsibilities, family dynamics and shifting life priorities. What this study adds is nuance and specificity in the context of childhood leukaemia, showing how identity reconstruction and existential reflection operate as dynamic mechanisms shaping resilience, social connectedness, and quality of life in ways that are temporally and developmentally contingent. Standardised measures of resilience, social support or quality of life are not designed to assess identity reconstruction or existential meaning-making. Integration of qualitative narratives, however, reveals how peer comparison, autonomy and family negotiation shape these processes, highlighting dimensions of post-treatment adaptation that are not captured by numeric assessment.

Timing and context further shape identity and meaning-making. Consistent with research on post-treatment adjustment (Björk et al., 2011; Davies & O'Connor, 2023; Slater, 2020), both older children and parents described intensified reflection during transitions from intensive treatment back to everyday life, when the immediate crisis had passed but new uncertainties emerged. This study adds specificity by showing how transitional periods, from intensive treatment to everyday life, can act as critical windows for identity work and existential reflection, which in turn influence children's and parents' resilience, engagement with support networks and perceived quality of life. For both older children and parents, these moments of introspection were described as important to their recovery and sense of moving forward. However, such reflections are unlikely to be captured by standardised assessments of resilience or quality of life. Furthermore, relational scaffolds, including survivor groups and parent-to-parent networks, complement these individual processes. As previously mentioned, such connections often provided affirmation, narrative scaffolding and mutual recognition. For some children, engagement in peer groups provided spaces to explore survivor identity, while some parents benefited from mutual recognition and experiential advice from other parents. Yet, these supports did not replace the highly individual, reflective processes occurring internally or within families, underscoring the unique, qualitative nature of identity and existential work.

Taken together, these integrated findings suggest that post-treatment identity and meaning-making are multi-layered, dynamic and context-dependent processes. Integration highlights multiple explanations for the observed patterns, showing that existential reflection can simultaneously support resilience and provoke distress, developmental stage shapes the form of identity work, timing and life transitions influence the salience of meaning-making, and relational scaffolds provide both opportunity and constraint. These insights extend existing knowledge by explaining how and why adaptation unfolds unevenly and by revealing mechanisms that single-method studies are unlikely to detect. By integrating children's and parents' perspectives it highlights the relational and situational processes that contribute to resilience, shape experiences of social support and influence quality of life, offering a richly detailed, leukaemia-specific understanding of post-treatment life.

6.3 Conclusion of the Integrative Analysis

In summary, the integration of both phases of this mixed-methods study demonstrates that social support, resilience and quality of life are central to the post-treatment experiences of childhood leukaemia survivors and their parents. The integrative analysis revealed several key findings. Physical recovery typically preceded emotional recovery for both children and parents. Social support functioned differently across developmental stages and family contexts, and both developmental stage and memory intensity influenced psychosocial adjustment. Resilience and quality of life were closely linked to social support, yet standardised measures often masked underlying emotional and relational challenges, particularly among older children and parents. Cancer-specific peer and parent networks, identity reconstruction, survivor and sibling-related guilt, and ongoing personal growth emerged as important but underexplored aspects of post-treatment life. By integrating quantitative and qualitative perspectives, this study offers a detailed, leukaemia-specific understanding of post-treatment life and the interrelationship between social support, resilience and quality of life as experienced by both children and parents. The final conclusions and implications of the current study will be presented in the next chapter.

Chapter 7: Conclusions

7.0 Introduction

In this concluding chapter of the thesis, the original contribution the present study makes will be considered, the strengths and limitations of the mixed-method study will be examined, and the implications of the findings will be outlined with regards to practice implications, future research implications and policy implications. Finally, concluding remarks will synthesise insights into the post-treatment experiences of childhood leukaemia survivors and their parents, focusing on social support, resilience, and quality of life.

7.1 The Original Contribution of the Present Study

This study makes an original contribution by advancing understanding of post-treatment survivorship following childhood leukaemia. Through the integration of quantitative and qualitative findings, and by incorporating both child and parent perspectives, this study provides new insights into how families navigate life after treatment. To the author's knowledge, no previous mixed-methods research has examined survivor and parent experiences alongside each other, nor explored the relationship between social support, resilience and quality of life in the context of childhood leukaemia. The core contributions this thesis makes in the domains of theoretical knowledge, empirical evidence, method, research context (i.e., the setting in which the research was undertaken), and knowledge of practice (i.e., how the findings may be utilised in applied settings) are outlined in Table 7.1 below. More specifically, the contributions are distinguished in terms of whether they support previous research or literature, develop and/or expand on existing research, or represent new and original contributions to empirical knowledge and clinical practice.

In terms of theoretical knowledge, the current study provides support for and extends a number of established theories and frameworks. Developmental theories (Ainsworth, 1989; Erikson, 1982; Piaget, 1971; Vygotsky, 1978) were collectively reinforced by age-related differences in memory coherence, stress appraisal and support-seeking, but extended by showing that the end of treatment can heighten

stage-specific tensions around autonomy, identity, and belonging, and that memory and meaning-making are actively co-constructed within children's social worlds. Similarly, the study offers a theoretical refinement to social, ecological and family systems perspectives (Bronfenbrenner, 1979; Bowen, 1978), highlighting the relational interplay between parent and child resilience, and showing that family-level adaptation is shaped by ongoing negotiations of identity, moral responsibility and the reconstruction of normalcy. The findings also extend labelling theory (Becker, 1963) by demonstrating that illness identities imposed during treatment do not simply persist passively but are actively resisted, renegotiated or redefined in survivorship.

Most notably, the study advances the social support buffering model (Cohen & Wills, 1985), showing that its assumptions require adaptation to account for developmental stage at the time of the stressor. For younger children, treatment completion was not always perceived as stressful, meaning that coping resources were not activated as the model predicts. For older children, social support was not merely received but actively managed, for example through selective disclosure, functioning both as a buffer and as a tool for identity work. The findings also highlight the unique buffering role of parents, whose support actively shapes children's stress appraisal and coping capacity, suggesting the need to expand the model to include parental scaffolding as a key mechanism. In addition, the findings provide empirical support for resilience frameworks (Davydov et al., 2010; Luthar et al., 2000; Masten, 2001, 2014), illustrating resilience as a dynamic, relational process rather than a fixed trait. For both children and parents, resilience was co-constructed through interactions, memories and meaning-making, reflecting both adaptive functioning and post-traumatic growth (Tedeschi & Calhoun, 2004; Seiler & Jenewein, 2019; Vanderveren et al., 2020). These findings therefore reinforce and contextualise existing understandings of resilience by showing how they take shape within the developmental and relational dynamics of life after childhood leukaemia. The findings also highlight gaps in broader theoretical models of adjustment to chronic illness. Existing frameworks, such as Lazarus and Folkman's stress and coping model (1984), Leventhal's common-sense model (2016), Livneh's stage model (2022), and Dekker's general model (2024), provide valuable insight into cognitive, emotional, behavioural, and physiological

responses to illness, but they do not fully capture the developmental, relational, and identity-related processes observed in this study. Adjustment is not always linear or predictable, and coping resources are mobilised differently across developmental stages, influenced by parental scaffolding and social context. To the author's knowledge, this study is among the first in childhood leukaemia survivorship to draw on diverse theoretical perspectives to interpret post-treatment experiences, showing how these frameworks may be refined to better capture developmental, relational and identity-related processes.

This study makes a significant contribution by providing empirical evidence on the post-treatment experiences of childhood leukaemia survivors and their parents, focusing on the relationships between social support, resilience and quality of life. Prior to this research, few studies have examined these psychosocial factors in the context of childhood leukaemia post-treatment, and even fewer captured the perspectives of both children and parents simultaneously. By adopting a mixed-methods design, this research addresses these gaps, offering a holistic understanding of life after childhood leukaemia that goes beyond medical outcomes to consider the nuanced ways in which psychosocial recovery unfolds during the post-treatment phase. Key findings of this thesis that contribute unique knowledge to the field of childhood leukaemia survivorship include the identification of cancer-specific peer networks and parent-to-parent connections as distinct, identity-affirming forms of support, which operated beyond the scope of standardised measures to offer a sense of belonging and mutual understanding for both children and parents. The study also highlighted how children's developmental stage shapes the function and meaning of memories, identity work and social support, with younger children relying on parental scaffolding and routines, and older children selectively engaging with peers and networks to navigate post-treatment identity and social reintegration. For parents, emotional experiences such as survivor guilt were revealed to be sustained, relational forms of labour, influencing ongoing decision-making, disclosure, and engagement with supports. Together, these findings demonstrate that social support is an active mechanism through which resilience is fostered and quality of life is sustained, highlighting the importance of recognising and supporting the nuanced, context-dependent ways children and their parents experience psychosocial well-being, even when such processes cannot be fully captured by standard

instruments. Interventions should therefore be tailored for children and parents individually, supporting meaningful peer and parent networks, addressing ongoing emotional challenges, and fostering resilience, identity reconstruction and quality of life post-treatment.

Regarding the methodological approach employed, this study makes a notable contribution to knowledge surrounding mixed-methods research in the field of childhood cancer survivorship. It also supports research seeking to include the voice of the child, which is particularly valuable in childhood cancer survivorship, as children's perspectives reveal how they actively navigate post-treatment challenges, manage peer and family relationships, and engage in identity reconstruction, processes that parent-proxy reports may not fully capture (Eiser & Morse, 2001; Klassen et al., 2006; Sherifali & Pinelli, 2007). Furthermore, the research promotes the gathering of dual perspectives within survivorship studies. By capturing both childhood leukaemia survivor and parent perspectives, key information has been identified regarding the differing challenges, coping strategies and relational dynamics experienced by both following treatment. A distinct methodological contribution of this study lies in the concurrent integration of quantitative measures assessing social support, resilience and quality of life with qualitative interviews capturing lived experiences of survivors and parents. This integration enabled the study to identify where measurable outcomes converged with, complemented, or diverged from participants' subjective experiences, as well as silences that standardised instruments did not detect. For example, while quantitative scores indicated generally moderate-to-high resilience, qualitative narratives revealed fluctuating emotional vulnerabilities, identity reconstruction, and the importance of peer and parent networks. By applying this integration framework specifically to the post-treatment context, the study provides new empirical insights into the nuanced dynamics of social support, resilience and quality of life for children and their parents, demonstrating the value of mixed-methods designs for generating a richer, more contextually grounded understanding of psychosocial outcomes after childhood leukaemia treatment.

Finally, considering the contextual and practical contributions of this research, the present study is the first to examine the post-treatment experiences of childhood leukaemia survivors and their parents

using a mixed-methods design. Furthermore, this research is the first to investigate how survivors and parents experience and navigate social support, resilience and quality of life specifically during the transition to life beyond treatment. This research is of particular importance given the evolving landscape of survivorship care for children and adolescents who have completed cancer treatment. Across national and international paediatric oncology agendas, there is increasing recognition of the need for structured psychosocial support that extends beyond medical treatment. The National Model of Care for Psycho-Oncology Services for Children, Adolescents and Young Adults (CAYA) with Cancer and their Families provides a framework for delivering integrated, developmentally informed, and family-centred psychosocial care (Greally et al., 2023). By capturing the perspectives of both survivors and their parents, this study offers a deeper understanding of the lived experiences and challenges faced during the post-treatment phase. For example, the identification of cancer-specific peer networks and parent-to-parent connections highlights the importance of fostering structured opportunities for peer support and parental networking. Findings around children's developmental differences in memory, identity work, and engagement with social supports highlight the need for age-appropriate interventions that support children's independence while promoting social reintegration. For parents, persistent emotional labour, including survivor guilt and vigilance, points to the necessity of targeted support to address ongoing psychological burden and facilitate coping. These nuanced insights can support healthcare professionals, support organisations and policymakers in refining and implementing psychosocial care strategies that are sensitive to developmental stage, family dynamics and long-term quality of life in line with the CAYA model. The implications of the current research study are considered in greater detail in section 7.3.

Table 7.1: *Original Contribution of the Present Study*

Domain	Supported	Developed	New
Theoretical Knowledge	*Provides theoretical support for:* - Developmental theories (Ainsworth, 1989; Erikson, 1982; Piaget, 1971; Vygotsky, 1978). - Social, ecological & family systems theories (Bronfenbrenner, 1979; Bowen, 1978). - Social support buffering model (Cohen & Wills, 1985). - Resilience frameworks (Davydov et al., 2010; Luthar et al., 2000; Masten, 2001, 2014). - Adjustment to chronic illness models (Lazarus & Folkman, 1984; Leventhal, 2016; Livneh, 2022; Dekker, 2024).	*Develops further knowledge relating to:* - Developmental theories (Ainsworth, 1989; Erikson, 1982; Piaget, 1971; Vygotsky, 1978). - Social, ecological & family systems theories (Bronfenbrenner, 1979; Bowen, 1978). - Social support buffering model (Cohen & Wills, 1985). - Resilience frameworks (Davydov et al., 2010; Luthar et al., 2000; Masten, 2001, 2014). - Adjustment to chronic illness models (Lazarus & Folkman, 1984; Leventhal, 2016; Livneh, 2022; Dekker, 2024).	*Creates new empirical evidence relating to:* - First integrated application of the social support buffering model (Cohen & Wills, 1985) in childhood leukaemia survivorship, highlighting parental scaffolding as a key mechanism through which social support mitigates post-treatment stress.
Empirical Evidence	*Supports existing empirical evidence relating to:* - Social support is central to psychosocial outcomes for children and parents. - Resilience influences quality	*Develops upon empirical evidence by:* - Examines the interplay of memories, identity and social relationships in shaping children's post-treatment	*Creates new empirical evidence relating to:* - Relationship between, and factors related to social support, resilience and quality of life among

Domain	Supported	Developed	New
	of life. - Emotional vulnerability, including fear of relapse and guilt, shapes experiences of resilience, social support and quality of life post-treatment.	experiences. - Highlights how children's age and developmental stage influence recovery trajectories and psychosocial adjustment. - Demonstrates the dual nature of post-treatment support, encompassing both enduring and fading sources of connection. - Explores nuanced mechanisms through which social support shapes resilience and quality of life.	childhood leukaemia survivors and their parents. - Self-reported levels of social support, resilience and quality of life among children and parents. - Post-treatment experiences of childhood leukaemia survivors and their parents, with a particular focus on social support, resilience and quality of life. - Provides a holistic, mixed-methods understanding of post-treatment psychosocial recovery beyond medical outcomes.
Methodological Approaches	*Supports methodological approaches employing:* - The use of mixed-methods in healthcare research. - The use of a convergent parallel design in healthcare research.	*Further develops methodological approaches by:* - Directly accessing the voice of the child to elucidate their lived experiences from their perspectives rather than parent proxy reports. - Gathering dual perspectives (child and parent).	*Contributes new methodological approaches via:* - Integrates quantitative measures of social support, resilience and quality of life with qualitative interviews to reveal convergence, divergence, and context-dependent silences in post-treatment experiences of children and parents, providing nuanced insights

Domain	Supported	Developed	New
			into psychosocial recovery.
Research Context	*Supports research in the following contexts:* - Research investigating the relationship between, and factors related to social support, resilience and quality of life among childhood leukaemia survivors and their parents. - Research investigating the post-treatment experiences of childhood leukaemia survivors and their parents.	*Further develops research in the following contexts:* - Expands on limited research by providing a leukaemia-specific perspective on post-treatment experiences, integrating both child and parent voices, and linking social support, resilience, and quality of life in ways not previously examined.	*Unique context of the present research:* - Represents the first study, both nationally and internationally to explore the post-treatment experiences and relationship between social support, resilience and quality of life amongst childhood leukaemia survivors and their parents.
Practical Implications	*Supports practical implications for:* - The need for targeted post-treatment care and survivorship programmes for all childhood leukaemia survivors and their parents.	*Further develops practical implications for:* - The role of healthcare professionals, support organisations and policymakers in recognising the importance of psychosocial support and structured post-treatment care.	*Unique practical implications:* - Provides unique, evidence-based recommendations for tailoring psychosocial interventions during the post-treatment transition, with a focus on enhancing social support networks, fostering resilience, and promoting quality of life, informed directly by the lived experiences of survivors and parents. - Provides empirical support

Domain	Supported	Developed	New	
				for the CAYA Model of Care (Greally et al., 2023) in the context of post-treatment childhood leukaemia, illustrating how targeted interventions around social support, resilience, and quality of life can address the unique needs of survivors and their parents.

7.2 Study Implications

In this section, the implications of the findings of the present study will be highlighted with regard to implications for practice, future research and policy.

7.2.1 Practice Implications

The practice implications of the present study have particular relevance to healthcare professionals and cancer support organisations, both within Ireland and internationally. A number of key recommendations for practice can be made:

- Currently, there is no formal, nationwide psycho-oncology or survivorship service for children and adolescents in Ireland, meaning that structured psychosocial support post-treatment is limited and inconsistently available. The post-treatment phase remains a vulnerable period for both survivors and their parents, yet it is often characterised by reduced formal support. There is a clear and pressing need to improve survivorship care by extending psychosocial support well beyond the end of medical treatment. Ongoing psychosocial care is not yet consistently embedded as a standard component of survivorship planning for childhood cancer, either nationally or internationally, highlighting a critical gap in support during the post-treatment phase.
- Developmentally sensitive support is critical, as the needs of younger children differ markedly from those of adolescents. Interventions must account for age-related differences in memory, communication, autonomy and emotional processing. For example, younger children may require play-based or creative approaches, while older children and adolescents may benefit more from peer-led or identity-focused support. In the current Irish context, child services in CHI Crumlin provide care for children up to age 16, after which survivors transition to adult services. This shift can create gaps in developmentally appropriate psychosocial care, particularly for adolescents navigating complex identity and peer relationships. The new children's hospital currently under development in Dublin plans to include a dedicated transitional service for 16-20 year olds, aiming to bridge the gap between paediatric and adult services. Tailored interventions during this

phase should focus on supporting identity development, peer connections and autonomy, ensuring that adolescents continue to receive psychosocial support during this critical post-treatment period.

- Healthcare professionals should be aware of the hidden emotional burdens parents carry well into the post-treatment phase. These burdens may be recognised through psychosocial assessment, validated screening tools for parental distress, or structured conversations that help identify emerging emotional challenges. Such burdens include managing lingering trauma, responding to difficult questions from children, maintaining family stability, and supporting siblings who may feel overlooked. Structured interventions such as trauma-informed parent counselling, psychoeducation, and peer support may help mitigate this emotional load and foster long-term resilience and quality of life.
- Children's memories of their illness experience, whether vivid or fragmented, can have a lasting impact on their psychological adjustment and identity development. Healthcare professionals should be attentive to how children recall their treatment and consider interventions such as memory work, which involves structured reflection activities to help children process their experiences, and therapeutic storytelling which uses narrative or creative techniques to help children make sense of their journey (Akard et al., 2015; Cho & Akard, 2024; Jones et al., 2021).
- The value of peer-specific cancer support organisations (e.g., CanTeen Ireland) was strongly evident, particularly for older children. These groups provide unique spaces for survivors and parents to share experiences, reconstruct identity and develop a sense of belonging that is often lacking in mainstream services. To address this gap, healthcare professionals should actively signpost families to peer support networks, and services should consider integrating structured opportunities for peer connection within post-treatment care pathways.

7.2.2 Research Implications

The present study offers several important directions for future research, particularly in advancing a more nuanced and holistic understanding of the post-treatment experiences of childhood leukaemia survivors and their families. Building on these findings, several key directions for future research are proposed:

- Future research should explore the dissociation between physical recovery and ongoing psychosocial challenges, as this study found that while children and parents generally regain physical health relatively quickly after treatment, emotional and relational recovery often persists for longer. Developmental stage and memory intensity were identified as key factors shaping these experiences, with older children's vivid recollections prolonging emotional processing, while younger children's fragmented memories may buffer against distress. Investigating these factors could guide developmentally sensitive interventions aimed at addressing ongoing emotional challenges and promoting psychosocial well-being throughout the post-treatment phase.
- Future research should delve deeper into the relational and existential dimensions of survivorship, including how identity, meaning-making and interpersonal relationships evolve in the aftermath of treatment. To capture these complex, dynamic processes, studies could employ longitudinal or mixed-methods designs, allowing for in-depth exploration of survivors' and parents' experiences over time.
- Longitudinal research is required to capture how social support, resilience and quality of life evolve and fluctuate over time. Such designs would help identify critical turning points in recovery and better inform the timing and nature of interventions. Longitudinal studies could also reveal how developmental stage, family dynamics and life transitions influence these processes, providing a more nuanced understanding of the interplay between social resources, coping capacity and well-being. This evidence could directly inform the timing, content and tailoring of interventions, ensuring that support is delivered when it is most impactful and matched to the changing needs of children and parents across the post-treatment period.

- Existing quantitative instruments often fall short in capturing the complex realities of survivorship for both childhood leukaemia survivors and their parents, particularly aspects tied to the stories they tell about their experiences, such as how children remember treatment and reconstruct their identity, and how parents reflect on caregiving, family dynamics and support networks. While the quantitative instruments employed in this study captured broad dimensions of social support, resilience and quality of life, they did not fully reflect the personal significance, context or meaning behind these experiences. This gap partly reflects the a priori focus of the present study, which targeted social support, resilience and quality of life, rather than the broader narrative or existential aspects of survivorship. Addressing this limitation in future research would allow for a more comprehensive understanding of the complex, multifaceted realities of post-treatment recovery. Applying these insights to both child and parent focused measures would enable researchers to better capture the psychological, emotional and social subtleties of survivorship and link quantitative trends with lived experience.
- Although siblings and broader family dynamics were not the primary focus of this study, qualitative data suggests their relevance. Future research should include siblings and the wider family network, including extended caregivers such as grandparents, aunts, uncles, or other significant family members involved in the child's care. Survivor guilt, parental guilt, and shifting family roles are all important areas for further exploration. Research that centres siblings or includes whole-family perspectives could uncover hidden impacts and unmet needs that often remain invisible in survivor-focused studies.
- The replicability and generalisability of the findings of the present study should be assessed in studies with larger and more diverse sample sizes. Doing so will help clarify the broader applicability of the findings and may reveal additional variations based on demographic, clinical or contextual factors.
- Fathers, children with neurodiversity or mental health needs, and families from minority or marginalised backgrounds remain underrepresented in survivorship research. Future studies

should adopt more inclusive recruitment strategies and flexible methodologies to ensure that a wider range of voices and experiences are captured. This may involve the use of alternative communication methods, creative participatory approaches or culturally responsive frameworks.

- Finally, future research should move beyond descriptive accounts and begin evaluating the effectiveness of psychosocial interventions that address the specific needs highlighted by survivors and parents in this study. Implementation science frameworks could support the integration of evidence-based practices into survivorship care, such as peer-led programmes for survivors and parents, family-focused interventions including sibling support, trauma-informed counselling to address fear of relapse and guilt, and resilience-building workshops. Evaluating these approaches in real-world settings would help ensure that psychosocial care meaningfully addresses the needs identified in this study.

7.2.3 Policy Implications

At a policy level, based on the findings of the present study, the following is recommended:

- The National Model of Care for Psycho-Oncology Services for Children, Adolescents and Young Adults (CAYA) with Cancer and their Families in Ireland, developed by the HSE's National Cancer Control Programme and Children's Health Ireland (Greally et al., 2023), provides a comprehensive framework for delivering developmentally appropriate psychological care across the cancer continuum. The current study reinforces the relevance of this model by demonstrating the importance of developmentally sensitive support (e.g., different needs of younger children vs. adolescents), highlighting the enduring emotional vulnerability of both survivors and parents, and showing the interdependence of family members' well-being. These findings align closely with the model's emphasis on integrated, developmentally informed, and family-centred psycho-oncology services. Policymakers must ensure that this model is not only adopted but fully resourced and embedded into survivorship planning in all CAYA cancer care settings.

- Survivorship support must extend beyond the end of treatment and be tailored to the developmental needs of different age groups. As this study showed, post-treatment recovery varies significantly between younger and older children, with differences in emotional, social and cognitive needs. Policies should reflect this diversity by requiring survivorship plans that are age-appropriate, flexible and developmentally tailored to key transitional phases such as returning to school or re-engagement with peer life.
- Parents face enduring psychosocial challenges, including lingering trauma, fear of relapse and complex family dynamics. National policy should ensure that parents are recognised as co-survivors and provided with structured psychosocial support such as trauma-informed counselling, parent-specific peer support opportunities, and guidance on managing post-treatment transitions within the family system.
- Peer-specific cancer support organisations, such as CanTeen Ireland, were identified in this study as essential sources of identity reconstruction and belonging, particularly for adolescents. While this finding has immediate relevance for the Irish context, where sustained investment and formal integration of such organisations into survivorship pathways is needed, it also has broader international relevance. Policy development should recognise the unique value of these groups and secure sustainable funding. Alternative or complementary models of peer connection, such as hospital-based groups, school reintegration programmes or digital platforms could extend the reach of peer support and guarantee equitable access across geographic and socio-economic contexts.

7.3 Researcher Reflections

Reflecting on this study from my perspective as a survivor of childhood leukaemia has been both personally insightful and deeply meaningful. My lived experience offered an acute awareness of the challenges that can arise once treatment ends, including the sudden withdrawal of structured support and the uncertainty surrounding recovery. While my positionality informed the focus on social support,

resilience and quality of life, conducting the study brought new perspectives that extended beyond my personal experience. Engaging with the accounts of children and parents revealed how social relationships can both sustain and strain recovery, how resilience is not a stable trait but an ongoing process shaped by developmental stage and context, and how quality of life depends on far more than physical health alone. These insights deepened my appreciation of the dynamic interplay between emotional, developmental and social factors that influence how survivors and parents experience life beyond treatment. I recognise that my personal lens has enriched my interpretation of the findings but also required careful attention to maintain analytic rigor. Being an expert-by-experience allowed me to sensitively interpret the emotional and relational nuances in the data, while remaining open to perspectives that differed from my own. This reflection reinforces the value of integrating lived experience into research, not only to inform study design and interpretation, but also to shape practical recommendations that are grounded in the realities of post-treatment life. Ultimately, this study has reinforced my understanding that psychosocial recovery extends well beyond physical health, and that meaningful support requires attentiveness to developmental stage, emotional needs and the broader social context. My reflections as a researcher highlight the potential for lived experience to inform both research and practice, ensuring that interventions and policies are attuned to the realities of children and their parents' navigating life after childhood leukaemia.

7.4 Strengths and Limitations of the Present Thesis

To the best of the author's knowledge, this is the first mixed-methods study to explore the lived experiences and interrelationships between social support, resilience and quality of life among childhood leukaemia survivors and their parents in the post-treatment phase. This alone constitutes a key strength, as the integration of quantitative and qualitative findings offers a multidimensional understanding of a complex and often overlooked period in paediatric oncology care. For example, quantitative measures suggested moderate-to-high levels of resilience and social support for parents, yet qualitative narratives revealed ongoing emotional vulnerability, identity reconstruction, and existential meaning-making,

highlighting areas of dissonance that would have been invisible using quantitative scores alone. Similarly, patterns of convergence and complementarity across methods illustrated how developmental stage and family dynamics shape post-treatment experiences, providing a nuanced, leukaemia-specific understanding of how social support, resilience and quality of life interact. By capturing both measurable trends and lived experiences, the study offers a multidimensional perspective on post-treatment recovery, demonstrating the value of mixed-methods integration in uncovering complex psychosocial processes.

Another key strength of the present study lies in the inclusion of children's voices, a critical contribution given the historical predominance of parent-proxy perspectives in paediatric health research (Eiser & Morse, 2001; Fisher et al., 2021; Inhestern et al., 2020; Klassen et al., 2006; Sherifali & Pinelli, 2007). By engaging directly with children, this study challenges normative assumptions about children's communicative capacities and affirms their role as active participants in the research process. Developmental stage influenced the type and depth of responses, with younger children providing more concrete, concise accounts and older children offering more detailed reflections. This highlights both the value of including children's perspectives and the importance of exploring methods that can capture the richness of experiences across different developmental stages, such as creative or play-based techniques for younger children. Including both child and parent perspectives enabled a more nuanced and layered understanding of the distinct yet interconnected experiences of post-treatment recovery. Finally, the findings underscore the importance of integrating the voices of both children and parents in the development of healthcare policies and survivorship care models. In doing so, this research contributes to more inclusive, developmentally sensitive and family-centered approaches to post-treatment support for childhood leukaemia.

Despite the strengths of the current study, limitations also existed. First, the inclusion of younger children, while a key strength, also introduced developmental constraints on the richness of data. Younger children provided more concrete and concise accounts, which may have limited insight into the nuanced, reflective aspects of their post-treatment experiences. Second, parent perspectives predominated in the dataset. While the study deliberately sought both child and parent viewpoints, the greater representation

of parents may have influenced the relative weight of parent experiences in the integrated analysis. Third, the cross-sectional design of the study presents an inherent limitation. By capturing experiences at a single time point, it was not possible to examine how social support, resilience and quality of life may fluctuate over time or how trajectories of recovery evolve. Furthermore, the study's design precluded the determination of causal relationships, instead only correlational associations between key variables could be identified. Longitudinal research is needed to explore the directionality and stability of these associations and to understand how children's and parents' experiences shift throughout survivorship. Finally, the sample excluded children and parents of children with significant neurodiversity or mental health needs. This decision was made to minimise confounding influences, as such conditions can present their own distinct and unique challenges that could obscure the primary focus of the study. From an equality, diversity, and inclusion perspective, this exclusion highlights that the experiences of under-served or marginalised populations are not represented. However, this exclusion limits the generalisability of the findings, as the sample cannot be considered fully representative of all childhood leukaemia survivors and their families. Future research should aim to inclusively capture the perspectives of children with diverse neurodevelopmental and mental health profiles. Doing so will require thoughtful consideration of accessible and appropriate data collection methods, such as adapted questionnaires, interpretation support or alternative qualitative approaches (e.g., arts-based methods) to ensure the meaningful participation of these often-overlooked groups. Additionally, fathers were underrepresented across both phases of the study. As a result, the findings predominantly reflect maternal perspectives, potentially limiting insight into gender-specific experiences. The lack of fathers' voices in paediatric research is well-documented (Davison et al., 2017), therefore future studies should make targeted efforts to recruit and engage fathers to address this persistent gap.

7.5 Conclusion

This study provides the first mixed-methods investigation into the post-treatment experiences of childhood leukaemia survivors and their parents, with a particular focus on understanding how social

support, resilience and quality of life interact during the transition to life beyond treatment. It makes a unique contribution to the literature by offering a deeper understanding of how these key psychosocial factors are experienced and interrelated by both survivors and their parents during the post-treatment phase. By integrating quantitative measures with qualitative interviews, the study identified where measurable outcomes converged with lived experience, where they offered complementary insights, where discrepancies arose, and where important aspects, such as the unique value of cancer-specific peer networks or sustained emotional burdens were not captured by standard instruments. This approach provided new empirical insights into the dynamic interplay between social support, resilience and quality of life, demonstrating how social support actively scaffolds resilience and sustains quality of life, while developmental stage and memory intensity shape the meaning and impact of post-treatment experiences. The findings indicate that both survivors and parents benefit from ongoing psychosocial support, developmentally sensitive interventions, and access to peer-specific support networks, which together promote resilience and long-term quality of life. Conversely, reduced formal support, unaddressed emotional burdens and the lack of structured survivorship services may contribute to poorer psychosocial outcomes. Key enablers of post-treatment adjustment include recognition of developmental needs, provision of tailored psychosocial support for both survivors and parents, and access to peer-specific support networks. These findings have important implications for healthcare professionals, support organisations and policymakers, highlighting the importance of embedding developmentally informed, family-centred psychosocial care into survivorship practices to optimise psychosocial outcomes and support children and their parents in navigating life after childhood leukaemia.

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Appendices

Appendix A: Quality Appraisal for the Systematic Review

Criteria - quantitative studies	Bikmazer et al., 2020	Conrad & Altamaier, 2009	D'Urso et al., 2018	Ekim & Ocakci, 2015	Gilliam et al., 2012	Gilliam et al., 2013	Greszta, 2006	Liu et al., 2020	Soejima et al., 2015	Wright et al., 2013
1. Clearly stated aims	Y	Y	Y	Y	Y	Y	Y	P	Y	Y
2. Participant eligibility and recruitment strategy clearly documented	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Main features of population/design described	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4. Non-responders (and non-participants) described	P	P	Y	Y	N	Y	N	N	N	Y
5. Presence of a control group	Y	N	N	N	N	N	Y	N	N	Y
6. Main limitations identified and acceptable	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
7. Sample size justified	N	N	N	N	N	N	N	N	N	Y
8. No evidence of selective reporting of results	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
9. Statistical methods described	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
10. Statistical methods appropriate	Y	Y	Y	Y	Y	Y	P	Y	Y	Y

11. Measures relevant, validated and described adequately	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
12. Results discussed adequately	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Total Score	**21**	**19**	**20**	**20**	**18**	**20**	**17**	**17**	**18**	**24**

Score Key: Y (Yes) = Score of 2; P (Partial) = Score of 1; N (No) = Score of 0; DK (Don't know) = Score of 0

Scoring: 17-24= good quality; 9-16= acceptable quality; 0-8= low quality

Appendix B: Recruitment Materials (Quantitative Strand)
Appendix B1. Cover Letter

Thank you for expressing interest in our study exploring the end of treatment experiences for childhood leukaemia survivors and their parents. Included you will find a parent/guardian pack and a child pack with the following documents in each: plain language statement/information leaflet, consent/assent form, questionnaire and resources/supports.

If you/your child are interested in participating in this study we kindly ask you to do the following:

1) Read the plain language statement/information leaflet.
2) Complete the consent/assent form if you wish to participate in the study.
3) Complete the questionnaire booklet.
4) Place the consent/assent forms in one of the stamped envelopes and the questionnaire booklets in the other stamped envelope (i.e., separate envelopes to ensure identifying personal data will not be collected with questionnaire answers).
5) Return both pre-paid envelopes by post.

If you prefer, you can complete the study online using the following link:
https://dcupsychology.fra1.qualtrics.com/jfe/form/SV_dbgr1Y7cfoMBD0y

If you have any questions, please contact me by email at avril.deegan23@mail.dcu.ie
Once again, we would like to extend our gratitude for your assistance and support - without your input, this research would not be possible.

Kind regards,
Avril Deegan

Parent/Guardian Plain Language Statement/Information Leaflet

Name of Study: A Longitudinal, Mixed Methods Study Investigating Resilience, Social Support and Quality of Life Amongst Childhood Leukaemia Survivors and their Parents.

Site	**CHI at Crumlin**
Principal Investigator(s) and Co-Investigator(s)	**Ms. Avril Deegan - avril.deegan23@mail.dcu.ie** **Dr. Chiara Besani - chiara.besani@childrenshealthireland.ie** **Prof. Owen Smith - owensmith62@me.com** **Dr. Simon Dunne - simon.dunne@dcu.ie** **Prof. Pamela Gallagher - pamela.gallagher@dcu.ie** **Prof. Veronica Lambert - veronica.lambert@dcu.ie**
Study Organiser/ Sponsor	**Irish Research Council Enterprise Partnership Scholarship in partnership with Breakthrough Cancer**
Data Controllers	**Dublin City University**

My name is Avril, and I am a student at Dublin City University. I am a leukaemia survivor having been diagnosed with leukaemia at 5 years old. Now, I am doing research to explore the end of treatment experiences for children and their parents. This research is being conducted by principal investigator Dr. Chiara Besani and her research team at CHI at Crumlin. You are now being invited to take part in this research study.

Before you decide whether or not you wish to take part, please read this information sheet carefully. Don't feel rushed or under pressure to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with your family, friends or GP.

Why is this study being conducted?

We are interested in learning about you and your child's experiences of the end of treatment phase so we can improve future care and treatment. This study will have a specific focus on social support (the support we receive from others), resilience (our ability to cope) and quality of life (our general state of well-being).

Who is conducting this study?

This study is being conducted by postgraduate research student, Ms. Avril Deegan, principal investigator Dr. Chiara Besani, Prof. Owen Smith, Dr. Simon Dunne, Prof. Pamela Gallagher and Prof. Veronica Lambert from the School of Psychology and School of Nursing, Psychotherapy and Community Health at Dublin City University (DCU) and CHI at Crumlin. This study is funded by the Irish Research Council (IRC) in partnership with Breakthrough Cancer Research. The study has received ethical approval from the CHI research ethics committee.

Why have I been invited to take part in this research?

You and your child have been invited to take part in this research as your child has successfully completed treatment for leukaemia within the past 5 years and is aged under 18 years old. As a parent/guardian you have been invited to take part in this study.

If I give consent to take part what will we be asked to do?

Participation in this study is completely voluntary. Completing the consent form indicates that you wish to participate in the study. If you do not agree to any question on the consent form, other than the question asking about future contact or interview participation, your data will not be included for analysis. If you consent to take part, you will be asked to complete a questionnaire about your experiences of social support, resilience and quality of life, either online or in paper form. The questionnaire should take approximately 30 minutes to complete. Further to this if your child completed treatment within the past 6 months, you and your child would be invited for follow up in 6 and 12 months allowing us to track the relationship over time. If you do not consent to be contacted again, or do not complete the questionnaire today, we will not send you the questionnaire at any future time points. If you do consent to be contacted for the next phase, we will send you some reminder information about the study, a new consent form and the same questionnaire again. Each time you are sent the questionnaire, you will be asked again whether you would like to continue on with the study or not – you can stop participating at any time! You will also be asked whether you agree to be contacted for interviews at a later date. Once again you are free to answer yes or no to this question. You can consent to take part in the questionnaire aspect of the study and decline to be contacted for an interview if you wish.

Your child will also receive a plain language statement/information leaflet about completing a questionnaire and possible interview about their experiences of social support, resilience and quality of life at the end of treatment. Please be aware that you are under no obligation to share this information with your child, however doing so implies that you consent for your child to participate. The child plain language statement/information leaflet will be a simple, easier to read version. If you wish for your child to participate, we would encourage you to discuss the leaflet with your child. If you give consent for your child to take part, we will remind them that this does not mean they have to take part, just that if they want to take part, you have confirmed that it is OK for them to do so. If you complete the questionnaire in hard copy form, we would ask you to kindly return the questionnaire using the enclosed stamped addressed envelope.

What if my child and I decide we do not want to take part?

That is totally fine, there is no obligation to take part in this study. It is entirely voluntary. I understand that not everyone will have the time to take part in this study. Each time you are sent the questionnaire, you will be asked again whether you would like to continue on with the study or not – you can stop participating at any time! If you choose not to take part in the study, this will in no way affect your

child's future medical care or legal rights being affected. Moreover, if only you want to participate in this study and your child does not, or vice versa, that is perfectly fine, we will allow for that.

What happens if me or my child change our minds?

While completing the questionnaire, you may decide to stop participating in the study at any time without your child's current or future medical care or legal rights being affected. If you wish, you can ask for your data stored to be destroyed. If you request this and it is possible to identify your data, we will destroy all data that are still in our possession. We will no longer use or share your data for research from this point onwards.

Are there any benefits to taking part in this research?

While there may be no immediate benefits to you and your child from taking part in the study, the researchers hope that studies such as these will inform future research and policy on how best to support survivors and their parents on their journey of survivorship. The IRC and Breakthrough Cancer Research who are funding the project will receive annual reports and the findings from the study may be published in academic journals.

Are there any risks or downsides to taking part?

There should be no risks involved in taking part, however if you feel it might help to talk to somebody about any of the issues that came up, we can put you in touch with someone (e.g., your local GP and/or Dr. Chiara Besani and her team at CHI) who can advise you on next steps.

Why do you ask for our names and email address?

We ask you for your name and email address for two reasons. Firstly, if you are eligible and agree to be contacted for the follow-up phases of the study, we ask you for your email address so that we can easily send you the questionnaire. We will also match your name and email address to a unique code – you can see this code on your consent form and questionnaire booklet. This code will be attached to your questionnaire, allowing us to track data over time without having any identifying information, such as your name, attached to your answers.

What will happen to my personal data?

All the information you and your child provide will be de-identified (i.e., no one will be able to tell what you specifically answered). Personal data will be processed only as is necessary to achieve the objective

of the research and will not be processed in a way that damage or distress will be caused to the participant. In rare circumstances (e.g., where a disclosure may occur), the researchers may be obliged to divulge confidential information regarding participants in this study in line with legal obligations.

For those eligible for the follow up aspects of this study, participant data must be identifiable to the researcher at each stage. As described above, this will be done by giving each participant a unique ID code (it will be on the consent form and questionnaire). We will also ask for your name and email address in the consent form, and this will be matched with your code. You will be given two envelopes and will be asked to return your consent form and questionnaire in separate, sealed envelopes. This means your email address will not be stored with your answers. You can return the envelopes to the researcher directly if you wish to complete the questionnaire now, or you can take the questionnaire with you and return it via post (stamped and addressed envelopes are available on request!). Coding the data means it can be de-identified after it is collected and in any of the results we report. As a result, no participant will be identifiable in any of the results or analysis. Data will be processed and protected in compliance with GDPR guidelines at all times and will be used solely for research purposes.

Who will have access and use of personal data collected?

Only the research team will have access to personal data and these will be treated in the strictest of confidence at all times.

How will my data be kept secure?

All consent forms and hard copy questionnaires will be kept in a locked cabinet in the researcher's (Ms. A Deegan's) office in the School of Psychology, DCU. Electronic copies of the questionnaires will be kept on an encrypted, password protected laptop on the DCU Google Drive in the School of Psychology, DCU. Names and email addresses will be included in a password-protected file in which it will be matched with your unique ID code, and accessible to the researcher only. Your ID code and questionnaire data will also be inputted in a separate, password-protected file on the DCU Google Drive, which only the researcher can access.

What will happen to my data?

Data will be retained for a period of 5 years or until the results are published. Findings will be used for statistical purposes and may also be used in scientific publications, reports or presentations. Training in data protection law and practice has been provided to those involved in carrying out the research.

Is there anything else I need to know?

If you would like to talk informally with us about any questions or queries you may have about this research, please contact me by email at avril.deegan23@mail.dcu.ie. Additionally, you can contact my supervisor at simon.dunne@dcu.ie

If you have any concerns or questions, you can contact:

- Principal Investigator: Dr. Chiara Besani - chiara.besani@childrenshealthireland.ie
- Data Protection Officer CHI: dpo@olchc.ie

Website: https://www.olchc.ie/About-Us/Privacy-Statement-GDPR/

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland.

Email: dpo@dataprotection.ie

Thank you for reading this information leaflet. Feel free to take all of the time you need to make your decision about whether you would like to participate. If you are happy to participate there is a document called a consent form that we would like you to sign.

Appendix B3. Child 8-12 Years Plain Language Statement/Information Leaflet

Plain Language Statement/Information Leaflet (8-12 years)

My name is Avril, and I am a student at Dublin City University. Like you, I am a leukaemia survivor! I was diagnosed with leukaemia when I was 5 years old and spent many days in hospital just like you. Now, I am doing a project on what it is like to have leukaemia and its treatment.

What will I do in the project?

I would like you to fill out a survey about what it is like to have survived leukaemia. I will ask you questions about how people help you, how strong you feel and what life is like for you now. Your parent/guardian will also fill out a similar survey to you. If you completed treatment within the past 6 months, you and your parent/guardian will be invited for follow-up at 6- and 12-months so that we can track your experience over time. I will also ask if you are ok with me asking to have a little chat with you about your experiences at a later date.

How long will this all take?

Not too long, probably about 30 minutes but you can take your time and you can take as many breaks as you want to or stop whenever you want to.

Why do we want this information?

I want to know more about being a survivor so I can help more children like me and you!

What will happen to my answers?

I will be writing a big essay about what you and other children tell me, but don't worry I won't write your name in the essay. There are no right or wrong answers so don't worry!

What should I do if I do not want to take part?

That is fine, I won't mind at all.

If you have any questions, just ask your parent/guardian if you can contact me - I am very happy to answer any questions you may have!

My email address is avril.deegan23@mail.dcu.ie

Appendix B4. Child 13-17 Years Plain Language Statement/Information Leaflet

Plain Language Statement/Information Leaflet (13-17 years)

My name is Avril, and I am a student at Dublin City University. Like you, I am a leukaemia survivor! I was diagnosed with leukaemia when I was 5 years old and spent many days in hospital just like you. Now, I am doing a project on what it is like to have leukaemia and its treatment.

What will I do in the project?

I would like you to fill out a questionnaire about what it is like to have survived leukaemia. I will ask you questions about how supported you feel, how resilient or strong you feel and how life is for you now. Your parent/guardian will also fill out a similar questionnaire to you. If you completed treatment within the past 6 months, you and your parent/guardian will be invited for follow up in 6- and 12-months so that we can track your experience over time. You will also be asked whether you agree to be contacted for an interview at a later date.

How long will this all take?

Probably about 30 minutes but you can take your time and you can take as many breaks as you want to. If you completed treatment within the past 6 months, I will give you the exact same questionnaire to complete again in 6 and 12 months. When you are filling out the questionnaire, it is fine if you decide you want to stop at any stage and you do not want to take part anymore. Whether you want to take part or not is completely up to you.

Why do we want this information?

I want to gain a better overall understanding of what life is like for survivors at the end of treatment so I can help more leukaemia survivors like me and you in the future.

What will happen to my answers?

You will not be writing your name anywhere on the questionnaire so no one will know what you have answered. Your answers will be locked up safely so that no one else can see them. I will be writing a long essay about what you and the other children tell me but don't worry I will not mention your name in the essay. There are no right or wrong answers, I am just really interested in finding out more about the experiences of leukaemia survivors at the end of treatment.

What should I do if I do not want to take part?

That is fine, I won't mind at all.

If you have any questions you want to ask, please let me know. I would be very happy to answer any questions you have!

My email address is avril.deegan23@mail.dcu.ie

Thank you for reading this information leaflet. If you do decide to take part in this study, you will be given a copy of this leaflet to keep and will be asked to sign a form. Your parent(s) will also be told about the study. They will also be asked to sign a consent form to show that they are happy for you to be part of this research project.

Appendix B5. Parent/Guardian Consent Form

Parent/Guardian Consent Form

Study Title: A Longitudinal, Mixed Methods Study Investigating Resilience, Social Support and Quality of Life Amongst Childhood Leukaemia Survivors and their Parents.

We are doing this study to try and find out more about you and your child's experiences of the end of treatment phase. In particular, we are interested in you and your child's perceptions of resilience, social support and quality of life.

The Irish Research Council (IRC) in partnership with Breakthrough Cancer Research are funding this study being carried out by principal investigator Dr. Chiara Besani (CHI) and researchers Ms. Avril Deegan, Prof. Owen Smith (CHI), Dr. Simon Dunne, Prof. Pamela Gallagher and Prof. Veronica Lambert from the School of Psychology and School of Nursing, Psychotherapy and Community Health at Dublin City University (DCU).

If you would like further information on any aspect of the study, please contact the study team directly using the details provided.

Contact Details: Avril Deegan - avril.deegan23@mail.dcu.ie

Participants name(s) (please list here your name and the full name of your child who you consent to participate):

Parent Name: _____

Child Name: _____

Please tick yes/no next to each statement	Yes	No
I am the parent/guardian of a child under 18 years who has successfully completed treatment for any type of leukaemia within the past 5 years.		
I confirm that I have read and understood the Plain Language Statement/Participant Information Leaflet for this research study and any questions have been answered satisfactorily.		
I understand that participation in the study is voluntary and that we are free to withdraw at any time without my child's current or future medical care or legal rights being affected.		
I am aware that the information that I provide to the researcher can only be protected within the limitations of the law, i.e., it is possible for data to be subject to subpoena, freedom of information request or mandated reporting by some professions.		
I understand that the research data collected as part of this study will be used for statistical purposes and may also be used in scientific publications. I understand that me or my child will not be identifiable in those reports or publications.		

Future Use of Information (choose one option as appropriate)	Yes	No
I consent to be contacted in the future, via the below email, to re-send the questionnaire aspect of this research project, with the possibility that I may be invited for follow-up. If so, please provide your email address: _____		
I consent to be contacted in the future, via the email address I provided, to send information about the interview phase of this research project, with the possibility that I may be invited to take part in an interview.		

***NB** if you do not agree to any of the above questions, other than the questions relating to future contact and interview participation, your data will not be included in the study. You are free to complete the questionnaire if you wish. If you do not wish to complete the questionnaire, please return it to the researcher. Thank you for your time!

☐ I give consent for my child as named above to take part in this research.

☐ I give consent for my own participation in this research.

_____ _____ _____

Parent/legal guardian's name **Date** **Signature**

Appendix B6. Child 8-12 Years Assent Form

Child Assent Form (8-12 years)

Study Title: A Longitudinal, Mixed Methods Study Investigating Resilience, Social Support and Quality of Life Amongst Childhood Leukaemia Survivors and their Parents.

Contact details: Avril Deegan - avril.deegan23@mail.dcu.ie

Please tick yes/no next to each statement	Yes	No
I am 8-12 years old.		
I have successfully completed treatment for any type of leukaemia within the past 5 years.		
This study and this form have been explained to me.		
My questions have been answered in a way I understand.		
I know that there is no risk for me to take part in the study and my information will be safe.		
I understand that it is OK to stop taking part at any time.		
I understand that I may be contacted in the future to complete another questionnaire.		
I understand that I may be contacted for a follow up chat/interview.		
I am happy to take part in this research project.		

I am happy to take part in this research project.

_____ _____

Child's signature **Date**

_____ _____ _____

Parent/Legal guardian's name (In BLOCK LETTERS) **Date** **Signature**

STATEMENT OF INVESTIGATORS RESPONSIBILITY

I have explained the nature, purpose, procedures, benefits, risks, and alternatives to this research study. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed assent.

_____ _____ _____

Doctor/Researcher's name **Date** **Signature**

Appendix B7. Child 13-17 Years Assent Form

Child Assent Form (13-17 years)

Study Title: A Longitudinal, Mixed Methods Study Investigating Resilience, Social Support and Quality of Life Amongst Childhood Leukaemia Survivors and their Parents.

Contact details: Avril Deegan - avril.deegan23@mail.dcu.ie

Please tick yes/no next to each statement	Yes	No
I am 13-17 years old.		
I have successfully completed treatment for any type of leukaemia within the past 5 years.		
This study and this form have been explained to me.		
My questions have been answered in a way I understand.		
I understand that taking part in this study involves collecting and using information about me which may be published in a research journal.		
I understand that any of my information used in publications or presentations will by completely anonymised, so no one will ever be able to know that it is about me.		
I understand that it is OK to stop taking part at any time.		
I understand that I may be contacted in the future to complete another questionnaire.		
I understand that I may be contacted for a follow up chat/interview.		

I am happy to take part in this research project.		

I am happy to take part in this research project.

_____ _____

Child's signature **Date**

_____ _____ _____

Parent/Legal guardian's name **Date** **Signature**
(In BLOCK LETTERS)

STATEMENT OF INVESTIGATORS RESPONSIBILITY

I have explained the nature, purpose, procedures, benefits, risks, and alternatives to this research study. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed assent.

_____ _____ _____

Doctor/Researcher's name **Date** **Signature**

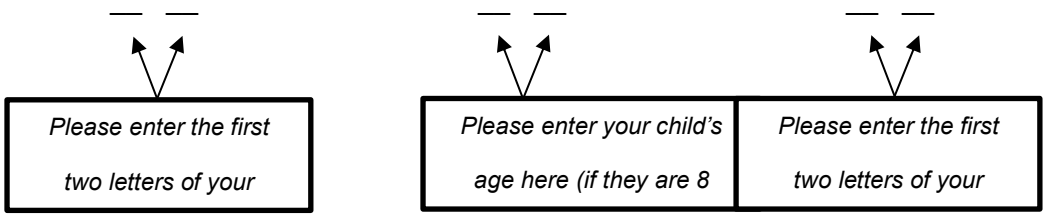
Appendix B8. Parent/Guardian Questionnaire

Parent/Guardian Questionnaire

To be completed by one parent, if both parents would like to complete the questionnaire an additional paper copy can be requested from Avril, and she will send one to you by post.

If you have any questions, you can contact Avril
avril.deegan23@mail.dcu.ie

In order to help us to link you and your child's answers, please list the following letters/numbers:



For example, if your child's name was Susan Smith and she was 8 years old, you would enter:

S U 0 8 S M

Section A
About You

Please answer all of the questions by ticking the boxes that apply to you or by writing in the spaces provided.

1. What is your age in years?

_____years

2. What is your gender?

☐ Male
☐ Female
☐ Prefer not to say
☐ Other (please state) _____

3. Please specify your ethnicity.

White:

☐ Irish
☐ Irish Traveller
☐ Roma
☐ Any other White background

Black or Black Irish:

☐ African
☐ Any other Black background

Asian or Asian Irish:

☐ Chinese
☐ Indian/Pakistani/Bangladeshi
☐ Any other Asian background

Other, including mixed group/background:

☐ Arabic
☐ Mixed (please specify) _____
☐ Other (please specify) _____

4. What age is your child?

_____years

5. What is your child's gender?

☐ Male
☐ Female

☐ Prefer not to say
☐ Other (please state) _____

6. Which of the following best describes your relationship to the child?

☐ Parent
☐ Legal guardian

7. What is the highest level of education you have completed?

☐ Less than Junior Certificate
☐ Junior Certificate
☐ Leaving Certificate
☐ Higher Certificate
☐ Ordinary Bachelor's Degree
☐ Honours Bachelor's Degree
☐ Higher Diploma
☐ Master's Degree
☐ Doctoral Degree
☐ Other (please specify) _____

8. What is your current working status?

☐ Employed
☐ Unemployed
☐ Student
☐ Retired
☐ Other (please state) _____

9. What is your current marital status?

☐ Single
☐ Married
☐ Divorced
☐ Separated
☐ Widowed
☐ Unmarried partner/living as a couple

10. What county are you and your child currently living in? (e.g., Dublin, Cork)

_____

11. What type of Leukaemia was your child diagnosed with?

☐ Acute lymphoblastic leukaemia (ALL)

☐ Acute myeloid leukaemia (AML)
☐ Chronic myelogenous leukaemia (CML)

12. What type of treatment has your child received? (tick all relevant options)

☐ Chemotherapy
☐ Radiotherapy
☐ Surgery
☐ Targeted therapy
☐ Immunotherapy
☐ Bone marrow or stem cell transplant
☐ Chimeric antigen receptor (CAR)-T cell therapy
☐ Other (please state) _____

13. What age was your child when diagnosed?

_____years

14. How many months have passed since your child's diagnosis?

_____months

15. What age was your child when their treatment ended?

_____years

16. How many months have passed since your child ended treatment?

_____months

17. Did your child's cancer ever relapse?

☐ Yes
☐ No

End of Section A

Section B
Social Support

In this section you will be asked questions in relation to your perceived social support.

Please tick the box most relevant to you (one box for each question).

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1. There is a special person who is around when I am in need.							
2. There is a special person whom I can share my joys and sorrows.							
3. My family really tries to help me.							
4. I get the emotional help and support I need from my family.							
5. I have a special person who is a real source of comfort to me.							
6. My friends really try to help me.							
7. I can count on my friends when things go wrong.							
8. I can talk about my problems with my family.							
9. I have friends with whom I can share my joys and sorrows.							
10. There is a special person in my life who cares about my feelings.							
11. My family is willing to help me make decisions.							
12. I can talk about my problems with my friends.							

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End of Section B

Section C
Resilience

In this section, we would like you to tick the box most relevant to you (one box for each question).

	Strongly Disagree	Disagree	Somewhat Disagree	Neither Agree or Disagree	Somewhat Agree	Agree	Strongly Agree
1. When I make plans I follow through with them.							
2. I usually manage one way or another.							
3. I am able to depend on myself more than anyone else.							
4. Keeping interested in things is important to me.							
5. I can be on my own if I have to.							
6. I feel proud that I have accomplished things in life.							
7. I usually take things in my stride.							
8. I am friends with myself.							

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	Strongly Disagree	Disagree	Somewhat Disagree	Neither Agree or Disagree	Somewhat Agree	Agree	Strongly Agree
9. I feel that I can handle many things at a time.							
10. I am determined.							
11. I seldom wonder what the point of it all is.							
12. I take things one day at a time.							
13. I can get through difficult times because I've experienced difficulty before.							
14. I have self-discipline.							
15. I keep interested in things.							
16. I can usually find something to laugh about.							
17. My belief in myself gets me through hard times.							

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	Strongly Disagree	Disagree	Somewhat Disagree	Neither Agree or Disagree	Somewhat Agree	Agree	Strongly Agree
18. In an emergency, I'm somebody people generally can rely on.							
19. I can usually look at a situation in a number of ways.							
20. Sometimes I make myself do things whether I want to or not.							
21. My life has meaning.							
22. I do not dwell on things that I can't do anything about.							
23. When I am in a difficult situation, I can usually find my way out of it.							
24. I have enough energy to do what I have to do.							
25. It's okay if there are people who don't like me.							

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End of Section C

Section D
Quality of Life

In this section you will be asked questions in relation to your quality of life.
Please circle/tick the box most relevant to you (one box for each question).

1. In general, would you say your health is:				
Poor	Fair	Good	Very Good	Excellent
2. Compared to one year ago, how would you rate your health in general now?				
Much worse than one year ago	Somewhat worse than one year ago	About the same as one year ago	Somewhat better than one year ago	Much better than one year ago

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?			
	No, not limited at all	**Yes, limited a little**	**Yes, limited a lot**
3. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.			
4. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing.			
5. Lifting or carrying groceries.			
6. Climbing several flights of stairs.			
7. Climbing one flight of stairs.			
8. Bending, kneeling or stooping.			
9. Walking more than a mile.			
10. Walking several blocks.			
11. Walking one block.			
12. Bathing or dressing yourself.			

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During the past 4 weeks, have you had any of the following problems with your work or other daily activities as a result of your physical health?		
	Yes	**No**
13. Cut down the amount of time you spent on work or other activities.		
14. Accomplished less than you would like.		
15. Were limited in the kind of work or other activities.		
16. Had difficulty performing the work or other activities (e.g., it took extra effort).		

During the past 4 weeks, have you had any of the following problems with your work or other daily activities as a result of any emotional problems (such as feeling depressed or anxious)?		
	Yes	**No**
17. Cut down on the amount of time you spent on work or other activities.		
18. Accomplished less than you would like.		
19. Didn't do work or other activities as carefully as usual.		

20. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?				
Not at all	Slightly	Moderately	Quite a bit	Extremely

21. How much bodily pain have you had during the past 4 weeks?					
None	Very Mild	Mild	Moderate	Severe	Very Severe

22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?				
None at all	A little bit	Moderately	Quite a bit	Extremely

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These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling. **How much of the time during the past 4 weeks….**						
	None of the time	**A little bit of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All of the time**
23. Did you feel full of pep?						
24. Have you been a very nervous person?						
25. Have you felt so down in the dumps that nothing could cheer you up?						
26. Have you felt calm and peaceful?						
27. Did you have a lot of energy?						
28. Have you felt downhearted and blue?						
29. Did you feel worn out?						
30. Have you been a happy person?						
31. Did you feel tired?						

32. During the <u>past 4 weeks</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting friends, relatives etc.)?				
None of the time	Little of the time	Some of the time	Most of the time	All of the time

How true or false is each of the following statements for you?					
	Definitely false	**Mostly false**	**Don't know**	**Mostly true**	**Definitely true**
33. I seem to get sick a little easier than other people.					
34. I am as healthy as anybody I know.					
35. I expect my health to get worse.					
36. My health is excellent.					

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END OF QUESTIONNAIRE

Please check that you have answered all of the questions in the questionnaire.

Thank you for filling out the questionnaire. We have included a resource sheet in your survey pack which has the details of useful services you might like to contact if you need some help.

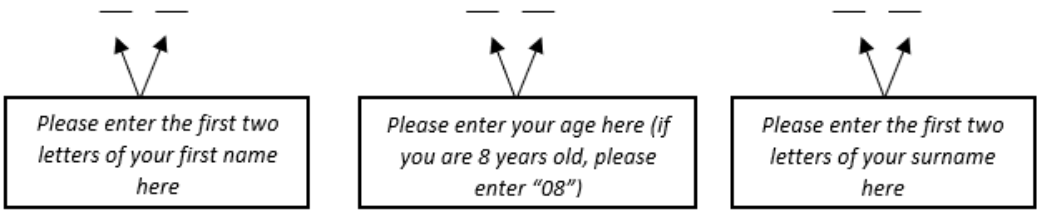
Please return the completed questionnaire to the research team in the stamped addressed envelope we have included in your survey pack.

Appendix B9. Child 8-12 Years Questionnaire

Child Questionnaire
8-12 years

If you have any questions, you can contact Avril
avril.deegan23@mail.dcu.ie

In order to help us to link you and your parent's answers, please list the following letters/numbers:



For example, if your name was Susan Smith and you were 8 years old, you would enter:

S U 0 8 S M

Section A
About You

Please answer all of the questions by ticking the boxes that apply to you or by writing in the spaces provided.

1. What is your age?

_____years

2. What is your gender?

☐ Male
☐ Female
☐ Prefer not to say
☐ Other (please state) _____

3. Please specify your ethnicity.

White:

☐ Irish
☐ Irish Traveller
☐ Roma
☐ Any other White background

Black or Black Irish:

☐ African
☐ Any other Black background

Asian or Asian Irish:

☐ Chinese
☐ Indian/Pakistani/Bangladeshi
☐ Any other Asian background

Other, including mixed group/background:

☐ Arabic
☐ Mixed (please specify) _____
☐ Other (please specify) _____

4. What county are you living in? (e.g., Dublin, Cork)

_____

5. What type of leukaemia did you have?

☐ Acute lymphoblastic leukaemia (ALL)
☐ Acute myeloid leukaemia (AML)
☐ Chronic myelogenous leukaemia (CML)
☐ I don't know

6. What type of treatment have you received? (tick all relevant options)

☐ Chemotherapy
☐ Radiotherapy
☐ Surgery
☐ Targeted therapy
☐ Immunotherapy
☐ Bone marrow or stem cell transplant
☐ Chimeric antigen receptor (CAR)-T cell therapy
☐ Other (please state) _____
☐ I don't know

7. What age were you when you were diagnosed?

_____years

8. How many months have passed since you were diagnosed?

_____months

9. What age were you when your treatment ended?

_____years

10. How many months have passed since your treatment ended?

_____months

11. Did your cancer ever come back?

☐ Yes
☐ No

End of Section A

Section B
Social Support

On the next two pages, you will be asked to respond to sentences about some form of support or help that you might get from either a parent, a teacher, a classmate, or a close friend. Read each sentence carefully and respond to them honestly. There are no right or wrong answers.

For each sentence you are asked to provide two responses. First, rate how often you receive the support described and then rate how important the support is to you. Below is an example. Please read it carefully before starting your own ratings.

Sample Item:

My Teacher(s)…	How often?						Important?		
	Never	Almost Never	Some of the Time	Most of the Time	Almost Always	Always	Not Important	Important	Very Important
1…my teacher(s) helps me solve problems.	1	2	(3)	4	5	6	1	2	(3)

In this example, the student describes her 'teacher helps me solve problems' as something that happens 'some of the time' and that is 'very important' to her.

Please ask for help if you have a question or don't understand something. Do not skip any sentences. Please turn to the next page and answer the questions. Thank you!

My Parent(s)…	How often?						Important?		
	Never	Almost Never	Some of the Time	Most of the Time	Almost Always	Always	Not Important	Important	Very Important
1…show they are proud of me.	1	2	3	4	5	6	1	2	3
2…understand me.	1	2	3	4	5	6	1	2	3
3…listen to me when I need to talk.	1	2	3	4	5	6	1	2	3
4…make suggestions when I don't know what to do.	1	2	3	4	5	6	1	2	3
5…give me good advice.	1	2	3	4	5	6	1	2	3
6…help me solve problems by giving me information.	1	2	3	4	5	6	1	2	3
7…tell me I did a good job when I do something well.	1	2	3	4	5	6	1	2	3
8…nicely tell me when I make mistakes.	1	2	3	4	5	6	1	2	3
9…reward me when I've done something well.	1	2	3	4	5	6	1	2	3
10…help me practice my activities.	1	2	3	4	5	6	1	2	3
11…take time to help me decide things.	1	2	3	4	5	6	1	2	3
12…get me many of the things I need.	1	2	3	4	5	6	1	2	3

My Teacher(s)…	Never	Almost Never	Some of the Time	Most of the Time	Almost Always	Always	Not Important	Important	Very Important
1…cares about me.	1	2	3	4	5	6	1	2	3
2…treats me fairly.	1	2	3	4	5	6	1	2	3
3…makes it ok to ask questions.	1	2	3	4	5	6	1	2	3
4…explains things that I don't understand.	1	2	3	4	5	6	1	2	3
5…shows me how to do things.	1	2	3	4	5	6	1	2	3
6…helps me solve problems by giving me information.	1	2	3	4	5	6	1	2	3
7…tells me I did a good job when I've done something well.	1	2	3	4	5	6	1	2	3
8…nicely tells me when I make mistakes.	1	2	3	4	5	6	1	2	3
9…tells me how well I do on tasks.	1	2	3	4	5	6	1	2	3
10…makes sure I have what I need for school.	1	2	3	4	5	6	1	2	3
11…takes time to help me learn to do something well.	1	2	3	4	5	6	1	2	3
12…spends time with me when I need help.	1	2	3	4	5	6	1	2	3

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My Classmates…	How often?						Important?		
	Never	Almost Never	Some of the Time	Most of the Time	Almost Always	Always	Not Important	Important	Very Important
1…treat me nicely.	1	2	3	4	5	6	1	2	3
2…like most of my ideas and opinions.	1	2	3	4	5	6	1	2	3
3…pay attention to me.	1	2	3	4	5	6	1	2	3
4…give me ideas when I don't know what to do.	1	2	3	4	5	6	1	2	3
5…give me information so I can learn new things.	1	2	3	4	5	6	1	2	3
6…give me good advice.	1	2	3	4	5	6	1	2	3
7…tell me I did a good job when I've done something well.	1	2	3	4	5	6	1	2	3
8… nicely tell me when I make mistakes.	1	2	3	4	5	6	1	2	3
9…notice when I have worked hard.	1	2	3	4	5	6	1	2	3
10…ask me to join activities.	1	2	3	4	5	6	1	2	3
11…spend time doing things with me.	1	2	3	4	5	6	1	2	3
12…help me with projects in class.	1	2	3	4	5	6	1	2	3

My Close Friend…	Never	Almost Never	Some of the Time	Most of the Time	Almost Always	Always	Not Important	Important	Very Important
1…understands my feelings.	1	2	3	4	5	6	1	2	3
2…sticks up for me if others are treating me badly.	1	2	3	4	5	6	1	2	3
3…spends time with me when I'm lonely.	1	2	3	4	5	6	1	2	3
4…gives me ideas when I don't know what to do.	1	2	3	4	5	6	1	2	3
5…gives me good advice.	1	2	3	4	5	6	1	2	3
6…explains things that I don't understand.	1	2	3	4	5	6	1	2	3
7…tells me he or she likes what I do.	1	2	3	4	5	6	1	2	3
8…nicely tells me when I make mistakes.	1	2	3	4	5	6	1	2	3
9…nicely tells me the truth about how I do on things.	1	2	3	4	5	6	1	2	3
10…helps me when I need it.	1	2	3	4	5	6	1	2	3
11…shares his or her things with me.	1	2	3	4	5	6	1	2	3
12…takes time to help me solve my problems.	1	2	3	4	5	6	1	2	3

End of Section B

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Section C
Resilience

In this section, we would like you to tick the response that gives the best answer for you.

	Not at all like me	Not much like me	Somewhat like me	A lot like me
1. I finish what I begin				
2. When I get upset, I know how to calm down				
3. I like to think about all the things I want to do				
4. I don't like to give up, even when something is hard to do				
5. I like to practice hard to get good at what I'm doing				
6. I am excited to learn new things				
7. I am happy with myself				
8. When I do something, I want to do it well				
9. I like to find something to laugh or smile about everyday				
10. I think I am ok just the way I am right now				

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End of Section C

Section D
Quality of Life

In this section, please tell us how much of a problem each one has been for you during the past ONE month by selecting the best answer for you.

*In the past **ONE month**, how much of a **problem** has this been for you…*

ABOUT MY HEALTH AND ACTIVITIES ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard for me to walk more than 100 meters					
2. It is hard for me to run					
3. It is hard for me to do sports activity or exercise					
4. It is hard for me to lift heavy things					
5. It is hard for me to have a bath or shower by myself					
6. It is hard for me to do chores around the house					
7. I have aches or pains					
8. I have low energy					

ABOUT MY FEELINGS ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I feel afraid or scared					
2. I feel sad or down					
3. I feel angry					
4. I have trouble going to sleep and/or sleeping					
5. I worry about what will happen to me					

HOW I GET ALONG WITH OTHERS ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I have trouble getting along with other kids					
2. Other kids do not want to be my friend					
3. Other kids tease me					
4. I cannot do things that other kids my age can do					
5. It is hard to keep up when I play with other kids					

ABOUT SCHOOL ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard to pay attention in class					
2. I forget things					
3. I have trouble keeping up with my schoolwork					
4. I miss school because of not feeling well					
5. I miss school to go to the doctor or hospital					

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End of Section D

END OF QUESTIONNAIRE

Please check that you have answered all of the questions in the questionnaire.

Thank you for filling out the questionnaire. We have included a resource sheet in your survey pack which has the details of useful services you might like to contact if you need some help.

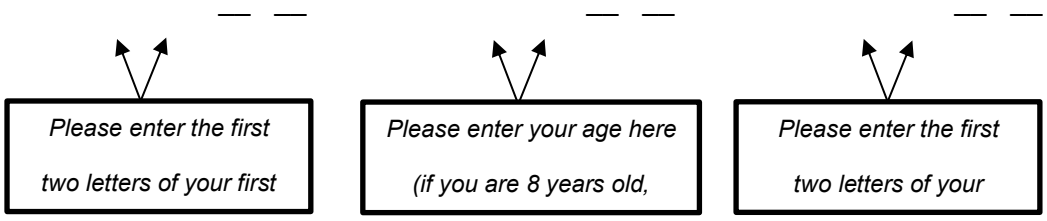
Please return the completed questionnaire to the research team in the stamped addressed envelope we have included in your survey pack.

Appendix B10. Child 13-17 Years Questionnaire

Child Questionnaire 13-17 years

If you have any questions, you can contact Avril
avril.deegan23@mail.dcu.ie

In order to help us to link you and your parent's answers, please list the following letters/numbers:



For example, if your name was Susan Smith and you were 8 years old, you would enter:

S U 0 8 S M

Section A
About You

Please answer all of the questions by ticking the boxes that apply to you or by writing in the spaces provided.

1. What is your age?

_____years

3. What is your gender?

☐ Male
☐ Female
☐ Prefer not to say
☐ Other (please state) _____

4. Please specify your ethnicity.

White:

☐ Irish
☐ Irish Traveller
☐ Roma
☐ Any other White background

Black or Black Irish:

☐ African
☐ Any other Black background

Asian or Asian Irish:

☐ Chinese
☐ Indian/Pakistani/Bangladeshi
☐ Any other Asian background

Other, including mixed group/background:

☐ Arabic
☐ Mixed (please specify) _____
☐ Other (please specify) _____

5. What county are you living in? (e.g., Dublin, Cork)

_____

5. What type of leukaemia did you have?

☐ Acute lymphoblastic leukaemia (ALL)
☐ Acute myeloid leukaemia (AML)
☐ Chronic myelogenous leukaemia (CML)

☐ I don’t know

6. What type of treatment have you received? (tick all relevant options)

☐ Chemotherapy
☐ Radiotherapy
☐ Surgery
☐ Targeted therapy
☐ Immunotherapy
☐ Bone marrow or stem cell transplant
☐ Chimeric antigen receptor (CAR)-T cell therapy
☐ Other (please state) _____
☐ I don’t know

7. What age were you when you were diagnosed?

_____years

8. How many months have passed since you were diagnosed?

_____months

9. What age were you when your treatment ended?

_____years

10. How many months have passed since your treatment ended?

_____months

11. Did your cancer ever come back?

☐ Yes
☐ No

End of Section A

Section B
Social Support

On the next two pages, you will be asked to respond to sentences about some form of support or help that you might get from either a parent, a teacher, a classmate, or a close friend. Read each sentence carefully and respond to them honestly. There are no right or wrong answers.

For each sentence you are asked to provide two responses. First, rate how often you receive the support described and then rate how important the support is to you. Below is an example. Please read it carefully before starting your own ratings.

Sample Item:

My Teacher(s)…	How often?						Important?		
	Never	Almost Never	Some of the Time	Most of the Time	Almost Always	Always	Not Important	Important	Very Important
1…my teacher(s) helps me solve problems.	1	2	(3)	4	5	6	1	2	(3)

In this example, the student describes her 'teacher helps me solve problems' as something that happens 'some of the time' and that is 'very important' to her.

Please ask for help if you have a question or don't understand something. Do not skip any sentences. Please turn to the next page and answer the questions. Thank you!

My Parent(s)…	How often?						Important?		
	Never	Almost Never	Some of the Time	Most of the Time	Almost Always	Always	Not Important	Important	Very Important
1…show they are proud of me.	1	2	3	4	5	6	1	2	3
2…understand me.	1	2	3	4	5	6	1	2	3
3…listen to me when I need to talk.	1	2	3	4	5	6	1	2	3
4…make suggestions when I don't know what to do.	1	2	3	4	5	6	1	2	3
5…give me good advice.	1	2	3	4	5	6	1	2	3
6…help me solve problems by giving me information.	1	2	3	4	5	6	1	2	3
7…tell me I did a good job when I do something well.	1	2	3	4	5	6	1	2	3
8…nicely tell me when I make mistakes.	1	2	3	4	5	6	1	2	3
9…reward me when I've done something well.	1	2	3	4	5	6	1	2	3
10…help me practice my activities.	1	2	3	4	5	6	1	2	3
11…take time to help me decide things.	1	2	3	4	5	6	1	2	3
12…get me many of the things I need.	1	2	3	4	5	6	1	2	3

My Teacher(s)…	Never	Almost Never	Some of the Time	Most of the Time	Almost Always	Always	Not Important	Important	Very Important
1…cares about me.	1	2	3	4	5	6	1	2	3
2…treats me fairly.	1	2	3	4	5	6	1	2	3
3…makes it ok to ask questions.	1	2	3	4	5	6	1	2	3
4…explains things that I don't understand.	1	2	3	4	5	6	1	2	3
5…shows me how to do things.	1	2	3	4	5	6	1	2	3
6…helps me solve problems by giving me information.	1	2	3	4	5	6	1	2	3
7…tells me I did a good job when I've done something well.	1	2	3	4	5	6	1	2	3
8…nicely tells me when I make mistakes.	1	2	3	4	5	6	1	2	3
9…tells me how well I do on tasks.	1	2	3	4	5	6	1	2	3
10…makes sure I have what I need for school.	1	2	3	4	5	6	1	2	3
11…takes time to help me learn to do something well.	1	2	3	4	5	6	1	2	3
12…spends time with me when I need help.	1	2	3	4	5	6	1	2	3

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	How often?	Important?

My Classmates…	Never	Almost Never	Some of the Time	Most of the Time	Almost Always	Always		Not Important	Important	Very Important
1…treat me nicely.	1	2	3	4	5	6		1	2	3
2…like most of my ideas and opinions.	1	2	3	4	5	6		1	2	3
3…pay attention to me.	1	2	3	4	5	6		1	2	3
4…give me ideas when I don't know what to do.	1	2	3	4	5	6		1	2	3
5…give me information so I can learn new things.	1	2	3	4	5	6		1	2	3
6…give me good advice.	1	2	3	4	5	6		1	2	3
7…tell me I did a good job when I've done something well.	1	2	3	4	5	6		1	2	3
8… nicely tell me when I make mistakes.	1	2	3	4	5	6		1	2	3
9…notice when I have worked hard.	1	2	3	4	5	6		1	2	3
10…ask me to join activities.	1	2	3	4	5	6		1	2	3
11…spend time doing things with me.	1	2	3	4	5	6		1	2	3
12…help me with projects in class.	1	2	3	4	5	6		1	2	3
My Close Friend…	**Never**	**Almost Never**	**Some of the Time**	**Most of the Time**	**Almost Always**	**Always**		**Not Important**	**Important**	**Very Important**
1…understands my feelings.	1	2	3	4	5	6		1	2	3
2…sticks up for me if others are treating me badly.	1	2	3	4	5	6		1	2	3
3…spends time with me when I'm lonely.	1	2	3	4	5	6		1	2	3
4…gives me ideas when I don't know what to do.	1	2	3	4	5	6		1	2	3
5…gives me good advice.	1	2	3	4	5	6		1	2	3
6…explains things that I don't understand.	1	2	3	4	5	6		1	2	3
7…tells me he or she likes what I do.	1	2	3	4	5	6		1	2	3
8…nicely tells me when I make mistakes.	1	2	3	4	5	6		1	2	3
9…nicely tells me the truth about how I do on things.	1	2	3	4	5	6		1	2	3
10…helps me when I need it.	1	2	3	4	5	6		1	2	3
11…shares his or her things with me.	1	2	3	4	5	6		1	2	3
12…takes time to help me solve my problems.	1	2	3	4	5	6		1	2	3

End of Section B

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Section C
Resilience

In this section, we would like you to tick the box most relevant to you (one box for each question).

	Strongly Disagree	Disagree	Somewhat Disagree	Neither Agree or Disagree	Somewhat Agree	Agree	Strongly Agree
1. When I make plans I follow through with them.							
2. I usually manage one way or another.							
3. I am able to depend on myself more than anyone else.							
4. Keeping interested in things is important to me.							
5. I can be on my own if I have to.							
6. I feel proud that I have accomplished things in life.							
7. I usually take things in my stride.							
8. I am friends with myself.							

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	Strongly Disagree	Disagree	Somewhat Disagree	Neither Agree or Disagree	Somewhat Agree	Agree	Strongly Agree
9. I feel that I can handle many things at a time.							
10. I am determined.							
11. I seldom wonder what the point of it all is.							
12. I take things one day at a time.							
13. I can get through difficult times because I've experienced difficulty before.							
14. I have self-discipline.							
15. I keep interested in things.							
16. I can usually find something to laugh about.							
17. My belief in myself gets me through hard times.							

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	Strongly Disagree	Disagree	Somewhat Disagree	Neither Agree or Disagree	Somewhat Agree	Agree	Strongly Agree
18. In an emergency, I'm somebody people generally can rely on.							
19. I can usually look at a situation in a number of ways.							
20. Sometimes I make myself do things whether I want to or not.							
21. My life has meaning.							
22. I do not dwell on things that I can't do anything about.							
23. When I am in a difficult situation, I can usually find my way out of it.							
24. I have enough energy to do what I have to do.							
25. It's okay if there are people who don't like me.							

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End of Section C

Section D
Quality of Life

In this section, please tell us how much of a problem each one has been for you during the past ONE month by selecting the best answer for you.

*In the past **ONE month**, how much of a **problem** has this been for you…*

ABOUT MY HEALTH AND ACTIVITIES *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard for me to walk more than 100 meters					
2. It is hard for me to run					
3. It is hard for me to do sports activity or exercise					
4. It is hard for me to lift heavy things					
5. It is hard for me to have a bath or shower by myself					
6. It is hard for me to do chores around the house					
7. I have aches or pains					
8. I have low energy					

ABOUT MY FEELINGS *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I feel afraid or scared					
2. I feel sad or down					
3. I feel angry					
4. I have trouble going to sleep and/or sleeping					
5. It worry about what will happen to me					

HOW I GET ALONG WITH OTHERS *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I have trouble getting along with other teens					
2. Other teens do not want to be my friend					
3. Other teens tease me					
4. I cannot do things that other teens my age can do					
5. It is hard to keep up with my peers					

ABOUT SCHOOL *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard to pay attention in class					
2. I forget things					
3. I have trouble keeping up with my schoolwork					
4. I miss school because of not feeling well					
5. I miss school to go to the doctor or hospital					

End of Section D

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END OF QUESTIONNAIRE

Please check that you have answered all of the questions in the questionnaire.

Thank you for filling out the questionnaire. We have included a resource sheet in your survey pack which has the details of useful services you might like to contact if you need some help.

Please return the completed questionnaire to the research team in the stamped addressed envelope we have included in your survey pack.

Appendix C: Resources/Supports

Appendix C1. Parent/Guardian Resources/Supports

Parent/Guardian Resources/Supports

Many thanks again for participating in our research. Your time and contributions are really appreciated. If you wish to contact us or are interested in the findings of the study, please feel free to contact Avril by e-mail: avril.deegan23@mail.dcu.ie

In case any of the questions have adversely affected you in any way, please feel free to ring the following helplines or consult the following websites.

Parent-line
www.parentline.ie
Tel: 1890927277

Aware
www.aware.ie
Tel: 1890 303302

We have asked your child to talk to you in case any of the questions made him/her feel upset in any way. Additionally, below is a list of child-friendly resources that you can refer your child to if he/she needs any further support.

Irish Cancer Society
www.cancer.ie
supportline@irishcancer.ie
Tel: 1800 200 700

Childhood Cancer Ireland
www.childhoodcancer.ie
info@childhoodcancer.ie
Tel: +353 1 554 5655

Reach Out
www.reachout.com

Jigsaw
www.jigsaw.ie

Appendix C2. Child Resources/Supports

Child Resources/Supports

Thank you so much for taking part in our project!
We really appreciate you filling in our questionnaire. If you want to contact us or to find out more about the study, please feel free to contact us by email, if you have your parents' permission:
avril.deegan23@mail.dcu.ie

In case any of the questions made you feel upset in any way, please talk to your parents or feel free to ring the following helplines or look at the following websites with your parents' permission.

Irish Cancer Society
www.cancer.ie
supportline@irishcancer.ie
Tel: 1800 200 700

Childhood Cancer Ireland
www.childhoodcancer.ie
info@childhoodcancer.ie
Tel: +353 1 554 5655

Reach Out
www.reachout.com

Jigsaw
www.jigsaw.ie

Appendix D: Recruitment Advertisements

Appendix D1. Poster

Childhood Leukaemia Survivorship Study

My name is Avril Deegan, and I am a leukaemia survivor and researcher at DCU. The aim of my study is to explore the **end of treatment** experience for survivors and parents/guardians, particularly surrounding social support, resilience and quality of life so that future care can be improved. **Children and parents/guardians** are asked to take part in a survey/interview about their experiences.

GET INVOLVED!

Children must

- Be under 18 years of age.
- Survived leukaemia within the past 5 years.

Parents/guardians must

- Have a child aged under 18 years who has survived leukaemia within the past 5 years.

Parents/guardians must agree that their child can take part.

If you are interested in knowing more or you think you would like to participate, please contact me by email at avril.deegan23@mail.dcu.ie

Your participation is entirely voluntary!

Appendix D2. Email Message

Dear X,

My name is Avril Deegan and I am a PhD student in DCU and I am conducting a piece of research to better understand the relationship between social support, resilience and quality of life among children with leukaemia and their parents/guardians following treatment by examining how this relationship develops and changes over time from the perspective of both the child and the parent. As a leukaemia survivor I believe supporting families during the transition to survivorship is vital and this research will help inform such support.

This research is being funded by the Irish Research Council in partnership with Breakthrough Cancer Research. I am emailing you today in the hope that you would be able to share and circulate this information with your potentially relevant contacts.

I would like to involve children who have successfully completed treatment for any type of leukaemia within the past 5 years who are aged under 18, as well as parents/guardians of such children to complete a questionnaire regarding their end-of-treatment experience of social support, resilience and quality of life. Those participants who completed treatment within the past 6 months, would be invited for follow-up questionnaires at 6 and 12 months post treatment, allowing us tFo track this relationship over the most difficult period of survivorship. Qualitative interviews with parents/guardians and children will further elucidate their experiences of the post-treatment phase. The results of this research will help inform future research and policy on how best to support survivors and their parents on their journey of survivorship.

If you are happy for your members to receive information about this study, please forward the attached email and link. Your help is greatly appreciated!

Kind Regards,
Avril Deegan

'Dear X,

You are invited to participate in a PhD research project that is being conducted by myself, Avril Deegan. The aim of my research is to examine the end of treatment experiences of social support, resilience and

quality of life for childhood leukaemia survivors and their parents/guardians. As a leukaemia survivor I believe supporting families during the transition to survivorship is vital and this research will help inform such support.

Therefore, I am looking for children who have successfully completed treatment for any type of leukaemia within the past 5 years who are aged under 18, as well as parents/guardians of such children to complete a questionnaire regarding their end-of-treatment experience of social support, resilience and quality of life. Those participants who completed treatment within the past 6 months, would be invited for follow-up questionnaires at 6 and 12 months post treatment, allowing us to track this relationship over the most difficult period of survivorship. Qualitative interviews with parents/guardians and children will further elucidate their experiences of the post-treatment phase. The results of this research will help inform future research and policy on how best to support survivors and their parents on their journey of survivorship.

Please find attached a plain language statement/information leaflet which will provide additional information about the study. Below is a link to the questionnaire, should you wish to participate. If you would prefer to complete the questionnaire using paper and pen, please contact me via email (avril.deegan23@mail.dcu.ie) and I would be happy to arrange. Your time and insight would be greatly appreciated! Thank you in advance.

Kind Regards,
Avril Deegan'

*NOTE: 'X' will be replaced with the contact person's name

Appendix D3. Social Media

As part of my PhD, I want to examine the end of treatment experiences of social support, resilience and quality of life among childhood leukaemia survivors and their parents/guardians. It is hoped that this will help to inform future research and policy on how best to support survivors and their parents on their journey of survivorship.

I am looking for children who have successfully completed treatment for any type of leukaemia within the past 5 years who are aged under 18, as well as parents/guardians of such children to take part in a questionnaire.

For more information click the link below or contact me!

This research is being conducted in DCU School of Psychology with the support of the Irish Research Council and Breakthrough Cancer Research.

Appendix E: Ethical Approval

Appendix E1. CHI Ethical Approval

Children's Health Ireland

CHI Research Ethics Office
Email: ethics.committee2@olchc.ie
Tel: 01-409 6307 / 6243

Avril Deegan
School of Psychology
Dublin City University
Dublin 9

16th May 2023

REC REF: **REC-261-23**

A Longitudinal, Mixed Methods Study Investigating Resilience, Social Support and Quality of Life Amongst Childhood Leukaemia Survivors and their Parents
Principal Investigator: Dr Chiara Besani
Co-investigators: Prof Owen Smith, Dr Simon Dunne, Prof Pamela Gallagher, Prof Veronica Lambert, Avril Deegan

Dear Avril,

Further to your email correspondence dated 5th April 2023, I can confirm that the submitted updated application form and associated documents have successfully addressed all of the minor issues raised by the CHI Research Ethics Committee.

This project is **APPROVED** with the expectation that it is conducted as stated in the reviewed application. An annual report for this project should be submitted to the CHI Research Ethics Office on or before the anniversary of this approval.

I wish you every success with this study and the completion of your PhD, should you require any assistance in the future please do not hesitate to contact me.

Yours sincerely,

Dr Eugene Dempsey
CHI Research Ethics Officer

Cc: Dr Chiara Besani, CHI at Crumlin; Dr Simon Dunne, DCU; Prof Veronica Lambert, DCU; Prof Pamela Gallagher, DCU

CRA Registered Charity Number (RCN): 20202295 **Revenue Charitable Status CHY:** 22235
Board Members: Prof James Browne (Chairman), Mr Con Cronin, Ms Mary Cryan, Mr Liam Dowdall, Prof Martin Elliott, Ms Catherine Guy, Dr Anne Kilgallen, Dr Gavin Lavery, Ms Brigid McManus, Mr Turlough O'Sullivan, Mr Sean Sheehan

Appendix E2. DCU Ethical Approval

Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

Ms Avril Deegan
School of Psychology

6th November 2023

REC Reference: **DCUREC/2023/091 (Full Committee Review)**

Proposal Title: **A Longitudinal, Mixed Methods Study Investigating Resilience, Social Support and Quality of Life Amongst Childhood Leukaemia Survivors and their Parents**

Applicant(s): **Ms Avril Deegan, Dr Simon Dunne, Prof Pamela Gallagher, Dr Chiara Besani, Prof Owen Smith**

Dear Colleague(s),

Thank you for your application to DCU Research Ethics Committee (REC). Further to its review by the committee and resting on the assumption of information accuracy and completeness, DCU REC is pleased to issue ethical approval for this research project. Please include reference to this approval in all materials used to recruit research participants.

Researchers are responsible for ensuring that the research project to which this ethical approval refers is carried out as specifically described in the application form. Should modifications to the research project be required at a later stage, researchers must submit a research amendment application form to REC for approval, prior to the implementation of modifications.

Please note that it is the responsibility of the PI to ensure that any other DCU compliance requirements relevant to the research project, such as those related to data protection, insurance, health and safety, or legal issues, are fully met in advance of initiating the project.

As part of DCU REC's ongoing monitoring process, a research progress report may be required. DCU REC will request this report from the PI as appropriate.

DCU REC wishes you every success in your research.

Yours sincerely,

Dr. Melrona Kirrane
Chairperson
DCU Research Ethics Committee

DCU
Research & Innovation

Taighde & Nuálaíocht Tacaíocht
Ollscoil Chathair Bhaile Átha Cliath,
Baile Átha Cliath, Éire

Research & Innovation Support
Dublin City University,
Dublin 9, Ireland

T +353 1 700 8000
F +353 1 700 8002
E research@dcu.ie
www.dcu.ie

Note: Please retain this approval letter for future publication purposes. Research students should include this letter as a thesis appendix.

Appendix F: Recruitment Materials (Qualitative Strand)

Appendix F1. Recruitment Email

Dear
I hope you are keeping well. I am contacting you today as you are a participant in the on-going questionnaire phase of our research project, which aims to examine your experiences of the end of treatment phase, specifically your experiences of social support (support from family, friends etc.), resilience (inner strength) and quality of life (happiness).

As a leukaemia survivor I am aware of the difficulties families face during the transition to survivorship and that no two families' experiences are the same. With this in mind, we are now beginning the complementary phase of the project, which involves interviewing you to further examine these experiences.

We are contacting you as you indicated that you might be interested in taking part in such an interview. The interviews will be conducted by myself, Avril Deegan, and they can take place at CHI, DCU, in a location chosen by you, via Zoom or over the telephone – whatever would be most comfortable for you! Interviews are expected to last around 45 minutes and will be recorded using an audio recording device – no video will be recorded. Below you will see a link to a plain language statement/information leaflet which outlines all the details about what participation would involve, as well as consent/assent forms.

If you would like to take part in an interview, please respond to this email confirming your interest by completing the two forms in the links below. We will then be in touch to arrange a date and time that is most convenient for you! If you have any queries about the study or what is involved, please don't hesitate to email.

Information Leaflet/Consent Form: [Link]
Interview Scheduling Form: [Link]

Thank you once again for your participation in this research project to-date; your time and insight are hugely appreciated!

Kind regards,
Avril Deegan

Appendix F2. Interview Scheduling Form

We are delighted to hear that you're interested in taking part in an interview! As outlined in the Plain Language Statement/Information Leaflet attached to the email, interviews can take place in CHI Crumlin or remotely via video conference (e.g., Zoom) – whatever would be most comfortable for you! Alternatively, if a face-to-face or video interview cannot be arranged, we can conduct the interview over the phone. Interviews are expected to last no more than one hour. Please indicate which interview format you would prefer in the section below – you can select all the options you would be comfortable with:

I would like to schedule an interview at (please select all options that you would be comfortable with – we will be in touch again to arrange the specific location and date!):

☐ CHI Crumlin

☐ My home
- Please provide your address

☐ A neutral venue of my choice
- Please provide the name and address of this venue

☐ Via Zoom
- Please confirm your email address

☐ There is no convenient location for me to meet for an interview, I would only like to participate over the telephone.
- Please provide your phone number

In order to schedule the date and time of the interview, I would like to be contacted via:

☐ The email address provided above.

☐ Telephone – Please provide your phone number.

Remember: information gathered here (e.g., your address or phone number) is for interview scheduling purposes only and will not be stored as part of the research output.

Appendix F3. Parent/Guardian Plain Language Statement/Information Leaflet

Parent/Guardian Plain Language Statement/Information Leaflet

Name of Study: A Longitudinal, Mixed Methods Study Investigating Resilience, Social Support and Quality of Life Amongst Childhood Leukaemia Survivors and their Parents.

Site	**CHI at Crumlin**
Principal Investigator(s) and Co-Investigator(s)	**Ms. Avril Deegan - avril.deegan23@mail.dcu.ie** **Dr. Chiara Besani - chiara.besani@childrenshealthireland.ie** **Prof. Owen Smith - owensmith62@me.com** **Dr. Simon Dunne - simon.dunne@dcu.ie** **Prof. Pamela Gallagher - pamela.gallagher@dcu.ie** **Prof. Veronica Lambert - veronica.lambert@dcu.ie**
Study Organiser/ Sponsor	**Irish Research Council Enterprise Partnership Scholarship in partnership with Breakthrough Cancer**
Data Controllers	**Dublin City University**

My name is Avril, and I am a student in the School of Psychology at Dublin City University. I am a leukaemia survivor having been diagnosed with leukaemia at 5 years old. Now, I am doing research to explore the end of treatment experiences for children and their parents. This research is being conducted by principal investigator Dr. Chiara Besani and her research team at CHI at Crumlin. You are now being invited to take part in this research study.

Before you decide whether or not you wish to take part, please read this information sheet carefully. Don't feel rushed or under pressure to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with your family, friends or GP.

Why is this study being conducted?

We are interested in learning about you and your child's experiences of the end of treatment phase so we can improve future care and treatment. This study will have a specific focus on social support (the support we receive from others), resilience (our ability to cope) and quality of life.

Who is conducting this study?

This research is being conducted as part of a postgraduate (PhD) degree by Ms. Avril Deegan, along with principal investigator Dr. Chiara Besani, Prof. Owen Smith, Dr. Simon Dunne, Prof. Pamela Gallagher and Prof. Veronica Lambert from the School of Psychology and School of Nursing, Psychotherapy and Community Health at Dublin City University (DCU). This study is funded by the Irish Research Council in partnership with Breakthrough Cancer Research. The study has received ethical approval from the research committees in CHI and DCU.

Why have I been invited to take part in this research?

You are a participant in the questionnaire phase of the project, where you consented to take part in an interview about your experiences of the end of treatment phase. We are contacting you as we are now beginning the interview phase of the project.

If I give consent to take part what will we be asked to do?

Participation in this study is completely voluntary. Participation in this phase involves taking part in a one-to-one interview with Ms. Avril Deegan.

Consent to participation: If you would like to participate in the interview, please click through to the consent form by clicking the link included in this email. This form is used to ensure that you are fully informed on what is required if you participate in this project. If you would like to ask the researchers any questions before deciding to participate, please don't hesitate to contact us using the information provided.

Scheduling the interview: We aim to ensure participants are as comfortable as possible throughout this process, and you can choose to take part in the interview onsite at CHI Crumlin, at DCU, at your home, or at a location that is convenient for you. If you would prefer a remote-interview, you can opt to take part via video-call on Zoom. If you would like to participate, please click the link in the email to begin the interview scheduling process! You will first be asked to confirm your email address and your interest in taking part. You will then be asked to select the interview format that is most comfortable and convenient for you; if you opt for a face-to-face interview off-site, you will be asked to provide an address where the interview might take place. If a face-to-face interview would not be convenient or comfortable for you, you can choose to do an interview over the telephone. In this case, you will be asked to provide your phone number. You can then opt to be contacted either by email or over the phone in order to schedule a date and time for the interview that is convenient for you! None of the information collected as part of the interview scheduling process will be included as part of the research data.

The interview process: At the beginning of the interview, you will be provided with additional copies of this plain language statement/information leaflet and the consent form, should you wish to review them again. If you're participating in the interview remotely, we will email these to you! We aim for the interview to be a relaxed conversation, where we can discuss your experiences of the end of treatment phase. The interviewer will specifically explore your experiences of social support, resilience and quality of life. The interview will be recorded on an electronic device, to ensure the researcher has an accurate record of the conversation. This recording will be an audio file only – there will be no video recording. The researcher will then transcribe the audio recording. It is important to note that you do not have to answer any question; you can ask the interviewer to move to a different question, to pause the interview, or to stop completely at any point, without needing to give any reason. The interviewer will always respect your requests and will not question you any further. Remember, participation is completely voluntary!

Your child will also receive a plain language statement/information leaflet about doing an interview about their experiences of the end of treatment. Please be aware that you are under no obligation to share this information with your child, however doing so implies that you consent for your child to participate. The child plain language statement/information leaflet will be a simple, easier to read version. If you wish for your child to participate, we would encourage you to discuss the leaflet with your child. If you give consent for your child to take part, we will remind them that this does not mean they have to take part, just that if they want to take part, you have confirmed that it is OK for them to do so. Your child will be given the option of having their parent/guardian with them at the time of interview or of being interviewed alone (if you do wish to be present during the interview please let us know in advance). This will allow your child to personally voice their views on what the end of treatment phase is like.

How long will the process take?

The interview should take around 45 minutes to complete depending on how much you wish to speak to us about.

What if my child and I decide we do not want to take part?

That is totally fine, there is no obligation to take part in this study. It is entirely voluntary. I understand that not everyone will have the time to take part in this study, and some families may not be interested. If you choose not to take part in the study, this will in no way affect your child's future medical care or legal rights being affected. Moreover, if only you want to participate and your child does not, or vice versa, that is perfectly fine, we will allow for that.

What happens if me or my child change our minds?

If you and/or your child agree to take part but later change your minds, all you have to do is let me know. You do not have to give a reason for withdrawing and withdrawing from the study will in no way affect your child's current or future medical care or legal rights being affected. If you wish, you can ask for your data stored to be destroyed. If you request this and it is possible to identify your data, we will destroy all data that are still in our possession. We will no longer use or share your data for research from this point onwards.

Are there any benefits to taking part in this research?

While there may be no immediate benefits to you and your child from taking part in the study, the researchers hope that studies such as these will inform future research and policy on how best to support survivors and their parents on their journey of survivorship. The Irish Research Council and Breakthrough Cancer Research who are funding the project will receive annual reports and the findings from the study may be published in academic journals.

Are there any risks or downsides to taking part?

There should be no risks involved in taking part; however, if you feel it might help to talk to somebody about any of the issues that came up, we can advise you on next steps. During the interview the researcher will regularly check with you and/or child that you are ok to continue. You can skip any questions you don't want to answer, you can take a break, you can reschedule or withdraw completely at any time during the interview, and this will not lead to any problems for you. There is also a potential risk that a connection to your identity could be made. Great care will be taken to ensure the confidentiality of all data and the risk to participants of a breach of confidentiality is considered very low. Confidentiality of the information provided to the researcher(s) cannot always be guaranteed. Information can only be protected within the limitations of the law, i.e., it is possible for data to be subject to subpoena, freedom of information request or mandated reporting by some professions

How will my data be protected?

As the researcher must be in contact with you to schedule the interviews, participants will be identifiable to the researcher. However, both the recorded interview (audio only) and the transcribed data will be stored under a unique ID code, on an encrypted, password-protected laptop; your name or any other identifying information will not be included! Furthermore, the researcher will remove any details from the transcribed data-file that may make a participant identifiable. Questionnaires will also be labelled with your unique code. As a result, no participant will be identifiably in any of the results or analysis. In rare circumstances (e.g., where a disclosure may occur), the researchers may be obliged to divulge confidential information regarding participants in this study in line with legal obligations.

How will my data be kept secure?

Qualtrics, a cloud-based site will be used for the secure scheduling of interviews. If you would like the interview to take place over the phone, you will be asked to provide relevant contact information here. Only the researcher and the DCU Qualtrics administrator will have access to this data. Only the

researcher (Ms. A Deegan) and supervising researcher (Dr. S Dunne) will have access to the interview audio recordings and the transcribed data-files. All data will be stored under unique ID codes (no names will be used), on an encrypted, password-protected laptop. Once downloaded, the interview audio recording will be immediately deleted from the recording device. The data will be transcribed by the researcher, and at this stage, the data will be pseudo-anonymised, with any references to place, names, or individuals removed. The pen and paper questionnaires will be stored in a locked cabinet in DCU. The questionnaire data will be inputted into an encrypted, password-protected laptop, and will be labelled with the participants' unique ID codes. This data will be stored separately to consent forms, and no identifying information will be included. The supervising researchers and the examiners will have access to the anonymised data upon request, and this data may also be shared via online data sharing repositories. No individual participant would be identifiable in any of this data!

Is there anything else I need to know?

If you would like to talk informally with us about any questions or queries you may have about this research or if you would like a copy of the final study,, please contact me by email at avril.deegan23@mail.dcu.ie. Additionally, you can contact my supervisor at simon.dunne@dcu.ie

If you have any concerns or questions, you can contact:

- Principal Investigator: Dr. Chiara Besani - chiara.besani@childrenshealthireland.ie
- Data Protection Officer CHI: dpo@olchc.ie

Website: https://www.olchc.ie/About-Us/Privacy-Statement-GDPR/

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland.

Email: dpo@dataprotection.ie

If you are interested in participation, please click the link in the email view the consent form and to schedule your interview. Thank you!

Plain Language Statement/Information Leaflet (8-12 years)

My name is Avril, and I am a student in the School of Psychology at Dublin City University. Like you, I am a leukaemia survivor! I was diagnosed with leukaemia when I was 5 years old and spent many days in hospital just like you. Now, I am doing a project on what it is like to have leukaemia and its treatment.

What will I do in the project?
I would like you to have a quick chat with you about what it is like to have survived leukaemia. I will ask you questions about how people help you, how strong you feel and what life is like for you now. To make sure I don't forget anything important I will record our chat.

How long will this all take?
Not too long, probably about 1 hour max but you can take your time and you can take as many breaks as you want to or stop whenever you want to.

Can one of my parents stay with me while we chat?
Yes, of course they can.

Why do we want this information?
I want to know more about being a survivor so I can help more children like me and you!

What will happen to my answers?
I will be writing a big essay about what you and other children tell me, but don't worry I won't write your name in the essay. There are no right or wrong things to say so don't worry!

What should I do if I do not want to take part?
That is fine, I won't mind at all.

If you have any questions you want to ask before we start, you can ask your parents if you can contact me. I would be very happy to answer any questions you have!

My email address is avril.deegan23@mail.dcu.ie

Appendix F5. Child 13-17 Years Plain Language Statement/Information Leaflet

Plain Language Statement/Information Leaflet (13-17 years)

My name is Avril, and I am a student in the School of Psychology at Dublin City University. Like you, I am a leukaemia survivor! I was diagnosed with leukaemia when I was 5 years old and spent many days in hospital just like you. Now, I am doing a project on what it is like to have leukaemia and its treatment.

What will I do in the project?
I would like you to have a quick chat with you about what it is like to have survived leukaemia. I will ask you about how supported you feel, how resilient or strong you feel and how life is for you now. Your parent/guardian will also be asked similar questions. To make sure I don't forget anything important I will record our chat.

How long will this all take?
That depends on how much you say but around 45 mins. You can take your time and you can take as many breaks as you want to. It is fine if you decide you want to stop at any stage or you do not want to take part anymore. Whether you want to take part or not is completely up to you.

Can one of my parents stay with me while we chat?
Yes, of course they can.

Why do we want this information?
I want to gain a better overall understanding of what life is like for survivors at the end of treatment so I can help more leukaemia survivors like me and you in the future.

What will happen to my answers?
I will be writing a long essay about what you and other young people tell me, but don't worry, I won't mention your name in the essay! There are no right or wrong things to say. I'm just really interested in your story. Your answers will be locked away in a safe place so that no one else can see them.

What should I do if I do not want to take part?

That is fine, I won't mind at all.

If you have any questions you want to ask, please let me know. I would be very happy to answer any questions you have!

My email address is avril.deegan23@mail.dcu.ie

Thank you for reading this information leaflet. If you do decide to take part in this study, you will be given a copy of this leaflet to keep and will be asked to sign a form. Your parent will also be told about the study. They will also be asked to sign a consent form to show that they are happy for you to be part of this research project.

Appendix F6. Parent/Guardian Consent Form

Parent/Guardian Consent Form

Study Title: A Longitudinal, Mixed Methods Study Investigating Resilience, Social Support and Quality of Life Amongst Childhood Leukaemia Survivors and their Parents.

We are doing this study to try and find out more about you and your child's experiences of the end of treatment phase. In particular, we are interested in you and your child's perceptions of resilience, social support and quality of life.

The Irish Research Council (IRC) in partnership with Breakthrough Cancer Research are funding this study being carried out by principal investigator Dr. Chiara Besani (CHI) and researchers Ms. Avril Deegan, Prof. Owen Smith (CHI), Dr. Simon Dunne, Prof. Pamela Gallagher and Prof. Veronica Lambert from the School of Psychology and School of Nursing, Psychotherapy and Community Health at Dublin City University (DCU).

If you would like further information on any aspect of the study, please contact the study team directly using the details provided.

Contact Details: Avril Deegan - avril.deegan23@mail.dcu.ie

Participants name(s) (please list here your name and the full name of your child who you consent to participate):

Parent Name: _____

Child Name: _____

Please tick yes/no next to each statement	Yes	No
I am the parent/guardian of a child under 18 years who has successfully completed treatment for any type of leukaemia within the past 5 years.		
I confirm that I have read and understood the Plain Language Statement/Participant Information Leaflet for this research study and any questions have been answered satisfactorily.		
I understand that participation in the study is voluntary and that we are free to withdraw at any time without my child's current or future medical care or legal rights being affected.		
I understand that an audio-recording will be made of both mine and my child's interview. Transcript copies will be made available to participants upon request (i.e., for their own interview).		
I understand that the data collected as part of this study will be kept entirely confidential.		
I understand that the research data collected as part of this study will be used for statistical purposes and may also be used in scientific publications. I understand that me or my child will not be identifiable in those reports or publications.		

Future Use of Information (choose one option as appropriate)	Yes	No
I consent to be contacted in the future, via the below email, for possible further interviews. If so, please provide your email address: _____		

Thank you for your time!

_____ _____ _____

Parent/legal guardian's name **Date** **Signature**

STATEMENT OF INVESTIGATORS RESPONSIBILITY

I have explained the nature, purpose, procedures, benefits, risks, and alternatives to this research study. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

_____ _____ _____

Doctor/Researchers name **Date** **Signature**

Appendix F7. Child 8-12 Years Assent Form

Child Assent Form (8-12 years)

Study Title: A Longitudinal, Mixed Methods Study Investigating Resilience, Social Support and Quality of Life Amongst Childhood Leukaemia Survivors and their Parents.

Contact details: Avril Deegan - avril.deegan23@mail.dcu.ie

Please tick the box next to each statement if you understand and agree	Yes	No
I am 8-12 years of age.		
I have successfully completed treatment for any type of leukaemia within the past 5 years.		
This study and this form have been explained to me.		
My questions have been answered in a way I understand.		
I know that there is no risk for me to take part in the study and my information will be safe.		
I understand that it is OK to stop taking part at any time.		
I understand that Avril is going to talk to me about being a survivor and there are no right or wrong things to say.		
I am happy to take part in this research project.		

I am happy to take part in this research project.

_____ _____

Child's signature **Date**

_____ _____ _____

Parent/Legal guardian's name **Date** **Signature**

Appendix F8. Child 13-17 Years Assent Form

Child Assent Form (13-17 years)

Study Title: A Longitudinal, Mixed Methods Study Investigating Resilience, Social Support and Quality of Life Amongst Childhood Leukaemia Survivors and their Parents.

Contact details: Avril Deegan - avril.deegan23@mail.dcu.ie

Please tick yes/no next to each statement	Yes	No
I am 13-17 years of age.		
I have successfully completed treatment for any type of leukaemia within the past 5 years.		
This study and this form have been explained to me.		
My questions have been answered in a way I understand.		
I understand that taking part in this study involves collecting and using information about me which may be published in a research journal.		
I understand that any of my information used in publications or presentations will be completely anonymised, so no one will ever be able to know that it is about me.		
I understand that it is OK to stop taking part at any time.		
I understand that Avril is going to talk to me about being a survivor and there are no right or wrong things to say.		
I am happy to take part in this research project.		

I am happy to take part in this research project.

_____ _____

Child's signature **Date**

_____ _____ _____

Parent/Legal guardian's name (In BLOCK LETTERS) **Date** **Signature**

STATEMENT OF INVESTIGATORS RESPONSIBILITY

I have explained the nature, purpose, procedures, benefits, risks, and alternatives to this research study. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed assent.

_____ _____ _____

Doctor/Researcher's name **Date** **Signature**

Appendix F9. Parent/Guardian Interview Topic Guide

Central Topic	**Prompts**
Tell me about your experiences of….. Being a parent/guardian of a child who has survived leukaemia	Diagnosis? Treatment? End of treatment? Leaving hospital? Maintaining balance in home life? Other siblings? Spouse? Significant other?
Tell me about your experience of….. <u>Quality of Life</u> (general sense of well being/happiness/feeling well)	How would you describe your physical functioning/well-being? How would you describe your emotional functioning/well-being? How would you describe your social relations and activities? How would you describe your overall quality of life?
Tell me about your experience of….. <u>Social Support</u> (how valued, loved, cared for we feel by others)	Who, what, why, when, how, how often do you feel supported by others? (family, friends, partner, significant other, nurses, doctors, medical team, hospital, work etc.) Can you give me examples of when you felt supported by someone? Tell me about who makes you feel valued/loved/cared for? (emotional support) Tell me about who gives you the advice and information you need? (informational support) Tell me about who provides you with practical and/or material support (financial assistance/services/resources)? (instrumental support) Tell me about who you can share your worries and fears with? Seek affirmation? (appraisal support) How important is this support? Most beneficial? Do you feel more or less supported than before? How? What support needs do you have?

	How did the support you received impact your well-being/ability to cope?
Tell me about your experience of….. <u>Resilience</u> (ability to cope with change/stress, inner strength to adapt positively, ability to rebuild your life after cancer)	As a parent/guardian of a child who has had cancer and survived how do you position yourself in this world/find meaning in life? What has given you motivation and strength? Do you remember times that were particularly difficult for you? How did you manage and not get discouraged or give up? How has your perspective or outlook on life changed over the course of the cancer journey? How do you handle unpleasant feelings such as anger, sadness, fear etc.? How do you stay confident and keep going? Can you tell me about the positive aspects/experiences?

Appendix F10. Child Interview Topic Guide

Central Topic	**Prompts**
Tell me about your experiences of….. Having leukaemia	Diagnosis? (when you were told you had leukaemia) Treatment? (when you were in hospital/visiting nurses and doctors) End of treatment? (when you were told you didn't have to go to hospital anymore/no cancer anymore) Leaving hospital? (going back home after being in hospital)
Tell me about your experience of….. <u>Quality of Life</u> (happiness/feeling well)	Tell me about your day-to-day life activities How does your body feel? - feel sick, have pain or funny feelings in your body? What are some things that make you happy/sad/angry/afraid? Tell me about your friends & the kinds of fun things you like to do with them; e.g., play soccer, dance etc Tell me about school? What do you like best/least about school? Now compared to during treatment?
Tell me about your experience of….. <u>Social Support/Support you experience</u> (how valued, loved, cared for we feel by others)	Who, what, why, when, how, how often do you feel supported by others? (e.g., family, friends, teachers, classmates, nurses, doctors etc.) Can you give me examples of when you felt supported by someone? (cared for) Tell me about someone who you had the most support/interaction from? How? Why? Tell me about who makes you feel valued/loved/safe/happy/cared for? How? Why? (emotional support) Tell me about who gives you advice and information? How? Why? (informational support) Tell me about who helps you with things? How? Why? (instrumental support) Tell me about who you can share your worries and fears with? How? Why? (appraisal support) How important is this support? (or help)

	Do you feel more or less supported than before? How? (diagnosis, treatment, recovery) Would you like more support?
Tell me about your experience of….. <u>Resilience</u> (ability to cope with change/stress, inner strength)	How do you keep strong and motivated? How do you handle unpleasant feelings such as anger, sadness, pain etc.? How do you stay positive? When things are tough how do you stay strong? Can you give me examples? Think back to when you were on treatment versus now

Appendix G: Risk Protocol for In-Person Interviews

The measures outlined below will be taken to maximise the researchers safety when conducting interviews in an off-site location. These measures apply across all interview formats.

For all on-site interviews in DCU the postgraduate researcher will:

1. Inform the supervising researcher of the time and exact location (i.e. room number) of the interview at least one day in advance.
2. Send the supervising researcher an SMS text message before the interview commences.
3. Send the supervising researcher an SMS text message indicating that the interview has finished.
4. In addition, the researcher will also check-in and share her location with the DCU Security Team using the university SafeZone app before the interview commences. The check-in timer will be set for the duration of the interview, and the researcher will check-out when the interview has been completed. If the researcher does not check-out, the SafeZone app will alert DCU Security services, and a response team will check the location. Use of the SafeZone app is in-line with DCU Lone and Out of Hours Working Policy.

Offsite in the Interviewee's Home

The below measures have been identified in order to maximise researcher safety during interviews conducted at the interviewees home. For all interviews conducted at the interviewee's home, the researcher will:

1. Inform the supervising researcher of the time and location (exact address) of the interview, at least 1 day in advance.
2. Send an SMS message to the supervising researcher when she has arrived at the location for the scheduled interview.
3. Be vigilant for signs that the participant is in an unfit state to perform the interview before entering their home. In the event that the individual appears to be unfit for participation, the researcher will withdraw from the situation, indicate that they will be in touch at a later stage to re-arrange the interview.
4. Be mindful of any potential safety risks upon entering the participant's home. The researcher will also make note of the most accessible route of escape open to them. In the event that the researcher encounters a risk to their safety, they will extricate themselves from the premises via the exit route identified.
5. Send an SMS message to the supervising researcher when the interview has been completed. If supervising researcher does not received confirmation of the conclusion of the interview, they will attempt to contact the researcher directly via mobile phone and will follow-up on this as necessary.

4. In addition, the researcher will also check-in and share her location with the DCU Security Team using the university SafeZone app before the interview commences. The check-in timer will be set for the duration of the interview, and the researcher will check-out when the interview has been completed. If the researcher does not check-out, the SafeZone app will alert DCU Security services, and a response team will ring to ensure everything is ok. Use of the SafeZone app is in-line with DCU Lone and Out of Hours Working Policy.

Offsite in a Neutral Venue

The below measures have been identified in order to maximise researcher safety during interviews which are conducted in a neutral venue. For all offsite interviews, the researcher will:

1. Aim to ensure that the chosen location is appropriate for an interview. Locations should have low noise levels to minimise disruption to recording, and sufficient privacy to ensure the participant is comfortable speaking openly. Where possible (i.e. if the location is in the Dublin area), the researcher will visit the location in advance to assess its suitability.
2. Inform the supervising researcher of the time and location (exact address) of the interview, at least 1 day in advance.
3. Send an SMS message to the supervising researcher when she has arrived at the location for the scheduled interview.
4. Send an SMS message to the supervising researcher when the interview has been completed. If supervising researcher does not received confirmation of the conclusion of the interview, they will attempt to contact the researcher directly via mobile phone, and will follow-up on this as necessary.
5. In addition, the researcher will also check-in and share her location with the DCU Security Team using the university SafeZone app before the interview commences. The check-in timer will be set for the duration of the interview, and the researcher will check-out when the interview has been completed. If the researcher does not check-out, the SafeZone app will alert DCU Security services, and a response team will ring to ensure everything is ok. Use of the SafeZone app is in-line with DCU Lone and Out of Hours Working Policy.

Appendix H: Safety Protocols

Appendix H1. *Protocol if a participant becomes upset*

This is an exploratory study and deemed low risk, however, it is possible that a participant may become upset during the interview (especially where upsetting memories might emerge).

- Ms. A Deegan will discuss with the participant at the start of all interviews that they can stop the interview at any time for any reason, agree a sign or word, they can decide not to answer any question, they can take breaks, reschedule, withdraw completely and that they should notify the researcher if they feel upset.
- The researcher will be continuously alert and monitor for cues of upset throughout the interviews e.g. by monitoring visual cues and regularly check that all participants are comfortable with how the interview is progressing.
- Should a participant become upset, the interview will be stopped and it will be checked that the participant is okay. Any upset will be acknowledged and empathy provided as appropriate (within the scope of a researcher's role). Time will be allowed for the participant to deal with any upset, and participants will be reminded that they can withdraw, take a break, or reschedule.
- For child participants, the researcher will check if they would like to speak to a parent/guardian. Parents/guardians may be monitoring their child already by being in the same room or observing from another adjoining room, with a door open or through a glass door.
- Alternatively, with child participants, the parent/guardian can give the researcher their mobile number and in agreement with the child arrange that the researcher can contact them if any concerns arise during the interview.
- Children may also have their own mobile phone (if they wish to call their parents). On completion of the interview details of additional supports that participants can access then or later will be provided.

Appendix H2. Protocol if a child protection issue arises

It will be stressed at the start of the study to parents/guardians and children at the start of the interview that absolute confidentiality cannot be guaranteed if child protection issues arise. If a child discloses any information that suggests that they or anyone else is at risk (i.e. abusive behaviour), the researcher is obliged under the Children First: National Guidance for the Protection and Welfare of Children (Department of Children and Youth Affairs, 2017) to safeguard the welfare of the child, regardless of the effect this will have on the study.

In accordance with the Department of Children and Youth Affairs Children's First document (2017), the below protocol will be followed if any child disclosed issues
relating to safety:

1. "……[name of child], you've told me that ……... [e.g. someone is hurting you]. This is something that I can't keep private between us, I need to tell, so that someone can help you. It is good that you have told me though. I have to tell……[name of designated person in CHI at Crumlin/DCU] about this so that they can
arrange things, so that you can be helped."
2. The researcher will gently end the interview, ensuring that the child is not distressed or allowing them time to recover if they are distressed.
3. Depending on the nature of the disclosure, the researcher would make a judgement,
based on the best interests of the child, whether or not to inform the parent/s of this disclosure.
4. Agreed staff member at CHI at Crumlin/DCU would be informed of disclosure as soon as is possible (preferably immediately). Any concern of abuse etc. would be reported to the on-duty social worker of the appropriate health board.
5. Outside normal hours or if there was a serious threat to the child or other children the Gardaí would be informed immediately.
6. Information would be accurately recorded using templates from the National Guidelines for reporting such allegations.

Appendix H3. Protocol if a participant discloses suicidal ideations or there are concerns regarding mood and/or safety

This is an exploratory study and deemed low risk, however, it is possible that a participant discloses suicidal ideations or there are concerns regarding mood and/or safety.

It will be stressed to parents/guardians and children at the start of the interview that absolute confidentiality cannot be guaranteed if suicidal ideation or concern regarding mood and/or safety arise. If a child discloses any information that suggests that they or anyone else is at risk (i.e. suicidal ideation), the researcher is obliged under the Children First: National Guidance for the Protection and Welfare of Children (Department of Children and Youth Affairs, 2017) to safeguard the welfare of the child, regardless of the effect this will have on the study. The procedure as outlined above by the Department of Children and Youth Affairs Children's First document (2017) will be followed if a child arises suicidal ideations or there are concerns regarding mood and/or safety. The researcher will softly bring the interview to a close. This will be reported to Dr. Chiara Besani or a delegated member of the psycho-oncology team immediately. The child and child's parent/guardian will be informed of this. If the interview is being conducted online or via telephone, permission to contact GP will be sought from the parent/guardian.

Appendix I: Research Dissemination

Appendix I1: Publications

Deegan, A., Brennan, C., Gallagher, P., Lambert, V., & Dunne, S. (2023). Social support and childhood cancer survivors: A systematic review (2006–2022). *Psycho-Oncology.* https://doi.org/10.1002/pon.6128

Appendix I2: Conference Proceedings

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2025). *Exploring the relationship between social support, resilience and quality of life amongst childhood leukaemia survivors and their parents.* International Society of Paediatric Oncology (SIOP) Conference, Amsterdam, Netherlands, October 20th-23rd 2025 *(online publication)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2025). *Exploring the post-treatment experiences of parents of childhood leukaemia survivors: The role of social support, resilience, and quality of life.* International Society of Paediatric Oncology (SIOP) Conference, Amsterdam, Netherlands, October 20th-23rd 2025 *(online publication)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2025). *Exploring the post-treatment experiences of childhood leukaemia survivors: The role of social support, resilience, and quality of life.* 31st Annual PanCare Meeting, Jahorina, Bosnia and Herzegovina, September 17th-19th 2025 *(oral presentation)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2025). *Life after childhood leukaemia: Parents experiences of social support, resilience and quality of life.* European Health Psychology Society (EHPS) Conference, Groningen, Netherlands, August 26th-29th 2025 *(poster presentation)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2025). *Exploring the relationship between, and factors related to social support, resilience and quality of life amongst*

childhood leukaemia survivors and their parents. Childhood Cancer International (CCI) Europe Conference, Budapest, Hungary, May 14th-17th 2025 *(oral presentation)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2025). *Life after childhood leukaemia: Exploring the relationship between social support, resilience and quality of life amongst childhood leukaemia survivors and their parents.* Irish Psychosocial Oncology Network (IPSON) Conference, Dublin, Ireland, March 20th 2025 *(poster presentation)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2024). *Life after childhood leukaemia: Exploring the relationship between social support, resilience and quality of life amongst childhood leukaemia survivors and their parents.* St. James Hospital Multidisciplinary Meeting, Dublin, Ireland, November 1st 2024 *(oral presentation)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2024). *Protocol: A longitudinal, mixed methods study investigating resilience, social support and quality of life amongst childhood leukaemia survivors and their parents.* Irish Psychosocial Oncology Network (IPSON) Conference, Dublin, Ireland, March 13th 2024 *(poster presentation)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2024). *Life after childhood leukaemia: An investigation into the relationship between social support, resilience & quality of life amongst childhood leukaemia survivors.* Annual CAYAS (Childhood, Adolescent and Young Adult Cancers & Survivorship) Conference, Dublin, Ireland, October 11th 2024 *(poster presentation)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2023). *Protocol: A longitudinal, mixed methods study investigating resilience, social support and quality of life amongst childhood leukaemia survivors and their parents.* Summit Conference, Cork, Ireland, November 20th-21st 2023 *(poster presentation)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2023). *Protocol: A longitudinal, mixed methods study investigating resilience, social support and quality of life*

amongst childhood leukaemia survivors and their parents. The Psychological Society of Ireland Annual Conference, Athlone, Ireland, November 8th-10th 2023 *(poster presentation)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2023). *Life after childhood leukaemia.* Annual CAYAS (Childhood, Adolescent and Young Adult Cancers & Survivorship) Conference, Dublin, Ireland, September 11th 2023 *(poster presentation)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2023). *Protocol: A longitudinal, mixed methods study investigating resilience, social support and quality of life amongst childhood leukaemia survivors and their parents.* IPOS World Congress of Psycho-Oncology, Milan, Italy, August 31st-September 3rd 2023 *(poster presentation)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2023). *Social Support and Childhood Cancer Survivors: A Systematic Review (2006-2022).* IPOS World Congress of Psycho-Oncology, Milan, Italy, August 31st-September 3rd 2023 *(poster presentation)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2023). *Protocol: A longitudinal, mixed methods study investigating resilience, social support and quality of life amongst childhood leukaemia survivors and their parents.* Psychology, Health and Medicine Annual Conference, Limerick, Ireland, May 26th *(oral presentation)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2023). *Social Support and Childhood Cancer Survivors: A Systematic Review (2006-2022).* All-Ireland Student Psychology Congress, Dublin, Ireland, May 11th-12th 2023 *(oral presentation)*.

Deegan, A., Gallagher, P., Lambert, V., Besani, C., Smith, O. & Dunne S. (2023). *Social Support and Childhood Cancer Survivors: A Systematic Review (2006-2022).* Irish Association for Cancer Research Conference (IACR), Athlone, Ireland, February 22nd-24th 2023 *(poster presentation)*.