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Lived Experiences of Support Among Parents of Children With Acute Lymphoblastic Leukemia During the COVID-19 Pandemic

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Abstract

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by

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MSW, Eastern Washington University, 1994

BBA/BS, University of Portland, 1990

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Human Services

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Abstract

Receiving a cancer diagnosis for one's child is a traumatic experience for any parent. Acute lymphoblastic leukemia (ALL) is the most prevalent form of leukemia in children. Treatment-related issues can negatively affect quality of life and cause long-term emotional, social, and financial stress for the parents. The world faced the COVID-19 pandemic in 2020. While professional support was available for the parents caring for their children undergoing ALL treatment during the pandemic, how these parents experienced support, including through social media, was unknown. Investigating parents' lived experiences of support, including social media support, during COVID-19 pandemic, was the focus of this generic qualitative study. The key research question was: How do parents of children diagnosed with ALL and receiving treatment describe their experiences of support, including online support through social media, during the COVID-19 pandemic? Lazarus and Folkman's transactional theory of stress and coping was the theoretical framework. Findings through thematic analysis from 10 semi-structured interviews of mothers with children undergoing ALL treatment during the COVID-19 pandemic resulted in four themes: unusual events leading to diagnosis, support system, online support/social media, and adjustments as a result of COVID-19. Study findings established the need for greater understanding of support for all parents caring for their children in ALL treatment. Implications for social change include better-informed support by the medical community for parents of children diagnosed with ALL undergoing treatments during the COVID-19 pandemic.

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Dedication

I dedicate this study to my late father, Gopal Seth, who always said I could achieve anything, and to my son, Gabriel. You are my hero. You have inspired me to pursue this study. I have learned so much from you. I love you to the moon and back.

Acknowledgments

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Chapter 1: Introduction

Cancer is the third leading cause of death among children in the United States (Advisory Board, 2018). Acute lymphoblastic leukemia (ALL), a cancer that affects the white blood cells, is the most prevalent form of leukemia diagnosed in children (den Hoed et al., 2015; Huang et al., 2018; Leibring & Andérzen-Carlsson, 2019; Liu et al., 2018; Williams & McCarthy, 2015), accounting for 28% of childhood cancers (American Cancer Society, 2020a; Siegel et al., 2017).

Pediatric cancer diagnosis and treatment can be highly stressful and can cause significant emotional upheaval (Granek et al., 2012; Kim et al., 2017). Parents may exhibit anxiety, depression, and stress along with experience grief and fear of the unknown (Cornelio et al., 2014; Malpert et al., 2015). Also common are stressors such as added medical expenses leading to financial challenges, social stigma, and loss of support from their established social systems (Cusinato et al., 2017; Dunn et al., 2012). These symptoms and stressors, if unattended and unaddressed, can result in clinically elevated levels of posttraumatic stress symptoms (PTSS; Dunn et al., 2012) and posttraumatic stress disorder (PTSD; Dunn et al., 2012; Graziano et al., 2016; Kearney et al., 2015). Following diagnosis, children receive medical attention, including treatment and hospitalization, requiring adjusting to the “new normal” for these children and their parents (Cheung & Krull, 2015; Kearney et al., 2015). During this challenging phase in life, parents may need emotional support to deal with their children’s challenges.

Medical and psychosocial support are standard practice in pediatric oncology (Kearney et al., 2015). However, the support received at diagnosis and during treatment typically lessens as parents adapt to changes over time and ends when treatment is complete (Cusinato et al., 2017; Picci et al., 2015). Social networking and social support are becoming common ways for people to reach out to others when coping with illness (Gage-Bouchard et al., 2017; Gün & Şenol, 2019). Many cancer patients and their caregivers use social media to obtain information and support (Gage-Bouchard et al., 2018; Gün & Şenol, 2019).

In addition to the traumatic and stressful experience of having a child diagnosed with ALL, parents of these children faced a new stressor in 2020: COVID-19. In December 2019, coronavirus 2019 (COVID-19) was initially identified and reported in Wuhan, China (Liang & Yang, 2020). COVID-19 resulted from the coronavirus SARS-CoV-2 and causes severe respiratory issues in humans (Hrusak et al., 2020). On March 11, 2020, COVID-19 was identified as a global pandemic, and the Centers for Disease Control (CDC) and the World Health Organization (WHO) joined to help countries address the pandemic (CDC, 2022). COVID-19 initially affected older adults, especially people with comorbidities such as diabetes, hypertension, obesity, and preexisting respiratory issues (Hrusak et al., 2020). However, Ramella et al. (2020) also identified challenges in treating cancer patients.

Parents of children with ALL now also faced stressors caused by COVID-19, including possible contagion during ALL treatment (Ramella et al., 2020). Adding pandemic-related concerns to what these parents already must deal with, including diagnosis, treatment, caring for the ill child, caring for other children, coping with work and household responsibilities, can increase parents' stress levels (Kawamura & Katz, 2014; Kim et al., 2017; Malpert et al., 2015). Research also showed that some parents of children with ALL are not confident with the information and support they receive from their children's medical teams (Davies et al., 2017). With access to social media, parents have places where they can vent, receive support, and obtain health-related information from other people in similar situations. Access to support through social media also allows parents to reach out when it is convenient for them.

At the time of this study, there was no research on parents' experiences of support, including support through social media, during COVID-19 while their children were receiving treatment for ALL. Although the children diagnosed with ALL in the present study did not have COVID-19, restrictions related to the pandemic, including treatment restrictions, affected them. Dealing with a child's illness is challenging enough for parents. Now parents also had to face the restrictions and challenges related to a pandemic. Although researchers have explored how parents feel when their child is diagnosed with and treated for ALL and have documented available support, I could not locate similar findings of support for parents during or after their children's ALL treatment during the COVID-19 pandemic. Parents' experiences of support, including social media support, during or after their children's ALL treatment at the time of the COVID-19 pandemic was the focus of this study.

Background of the Problem

Leukemia is the most common type of childhood cancer (den Hoed et al., 2015), and ALL is the most prevalent form of leukemia among children (den Hoed et al., 2015; Huang et al., 2018; Leibring & Andérzen-Carlsson, 2019; Liu et al., 2018; Williams & McCarthy, 2015). One in every 3 pediatric cancer diagnoses is leukemia, and 3 out of every 4 children diagnosed with leukemia are diagnosed with ALL (National Cancer Institute, 2020). ALL treatment consists of chemotherapy, radiation therapy, or a combination (Krull, Hockenberry, et al., 2013).

Parents typically experience a sense of shock when told about their child’s diagnosis and the upcoming planned road of treatment (Malpert et al., 2015). Psychological distress such as anxiety and depression are common in these parents (Cusinato et al., 2017; Pergert et al., 2016; van Oers et al., 2014). Social stressors, such as financial challenges and workplace issues caused by missing work when caring for their children, are also common (van Oers et al., 2014). Children diagnosed with ALL who are younger than 6 years of age have greater chances of developing neurological issues and long-term neurocognitive and psychological issues (Kalafatçılar et al., 2013). Not only do parents face the challenges of caring for these children during and after ALL treatment, but they also face a strong possibility that their children will need their support throughout their lifespan. The increased burden of caring for the ill child both during and after ALL treatment may cause additional stress and anxiety in the parents.

Support for the parents is essential when their children are diagnosed with ALL (Aburn & Gott, 2014) and throughout treatment. Support following diagnosis is treatment focused and normally ends when treatment is completed (Muskat et al., 2017). However, parents have expressed the need for emotional support after treatment is completed (Muskat et al., 2017).

Problem Statement

Life changes for parents when their children are diagnosed with cancer (Huang et al., 2018; Ward et al., 2014). The diagnosis causes distress in the parents, which may increase as they digest the information (Kim et al., 2017). With an ALL diagnosis, parents experience emotional, financial, and social stress, affecting their life on different levels (Cornelio et al., 2014; Cusinato et al., 2017). Although researchers such as Aburn and Gott (2014), Cornelio et al. (2014), and Cusinato et al. (2017) studied how parents feel when their child diagnosed with ALL and documented the support available to them, I did not find similar research on the parents’ experiences of seeking support during the COVID-19 pandemic. Nor could I find research suggesting that parents might have increased needs for support or might need different types of support, such as online, during the pandemic. Developing a better understanding of the parents’ experiences of support as they cope with their children’s illness during the COVID-19 pandemic may better inform the types of support available, the sources of support, and the kinds of support parents need and when they need it.

Purpose of the Study

The purpose of this generic qualitative study was to investigate the lived experiences of parents of children with ALL seeking support, including social media support, when their children were receiving treatment during the COVID-19 pandemic. These children and their parents must make significant adjustments to their lives because of ALL and had to make additional adjustments because of the COVID-19 pandemic. COVID-19 is a greater concern for individuals with cancer (Peng et al., 2020), and the chances of these children being affected by COVID-19 are also higher. Findings from this study resulted in nformed support for the parents so they may be better prepared to provide long-term care for their children and adjust to the new normal in the context of ALL and COVID-19.

Research Question

The research question that guided this study was: How do parents of children diagnosed with ALL and receiving treatment describe their experiences of support, including online support through social media, during the COVID-19 pandemic?

Theoretical Foundation

Lazarus and Folkman’s transactional theory of stress and coping emphasizes the perception of stress rather than the event that caused the situation itself and how to cope (Biggs et al., 2017) and was the theoretical foundation in the present study. According to Lazarus and Folkman (1987), there is a connection between a transaction (an event that leads to the stress), the individuals involved with the transaction, and how they cope with the emotions related to the transaction. To understand emotions better, reviewing the relationship between the person and the environment is essential (Lazarus & Folkman, 1987).

Other theories I considered for this study included trauma theory, cognitive-behavioral theory, psychoanalytic theory, and attachment theory. Trauma theory, specifically Herman’s model for addressing psychological trauma, posits that experiencing trauma affects how people respond to other events in their lives, both in the wake of the trauma experienced and the future (Herman, 1992). Although a child’s diagnosis and treatment for ALL can be traumatic for parents, the present study’s focus was on the parents’ experiences with support as they coped with this diagnosis and treatment during the pandemic. Cognitive-behavioral theory focuses on people’s emotional and behavioral responses to various life situations (Ringel & Brandell, 2012). Cognitive-behavioral therapy is used in trauma treatment, but my focus in this study was on how parents seek and receive support on Facebook. The psychoanalytic theory focuses on an event that occurs to people and connects it to hysteria or neuroses, focusing on addressing suppressed emotions (Ringel & Brandell, 2012). The present study’s focus was not on psychoanalyzing parents but instead on understanding their experiences as they coped with their children with ALL in the COVID-19 pandemic context. Attachment theory focuses on children’s need to attach and their responses to loss and separation (Ringel & Brandell, 2012). I did not use this theory because the present study’s focus was on the parents, not the children.

Nature of the Study

This study focused on parents' experiences of support, including support through on social media, when their children were diagnosed with ALL and received treatment in the context of the COVID-19 pandemic. As such, I identified generic qualitative methodology as the appropriate approach for conducting this study. Qualitative research is interpretive and descriptive (Merriam & Tisdell, 2016). This research approach values subjective information and the interpretation of people's experiences. It is an appropriate approach when the study focuses on developing a greater understanding of how people experience traumatic events such as the one that drove the present study.

Quantitative methodology was not appropriate for this study. My purpose was not to describe relationships between dependent and independent variables or to create numerical data and analyze it to find the answers to a research hypothesis as Bloomfield and Fisher (2019) detailed. A mixed methods approach was also not appropriate, as mixed methods research involves quantitative and qualitative methods (Bloomfield & Fisher, 2019). The present study's focus was qualitative. I explored the experiences of support, including social media support, among parents whose children diagnosed with ALL and were receiving treatment during the COVID-19 pandemic.

Qualitative research methods view research from different perspectives of people's own experiences (Rodriguez & Smith, 2018). Generic qualitative research focuses on participants' actual experiences, from their unique perspectives (Percy et al., 2015). When the data are collected, descriptions rise from the content of the information collected, and the participants’ words reflect their life experiences (Percy et al., 2015).

I used thematic analysis in this study. This approach is subject centered and useful for gathering information on specific experiences (Keshet et al., 2015). Themes developed through analyzing the information I gathered. Purposive sampling was used to identify the study participants. A specific population means a group of people who have something in common (Kahlke, 2014). For this study, the common characteristic was the parents of children diagnosed with ALL who sought support, including social media support, and coped with treatment issues and COVID-19 restrictions while their children received treatment.

Definition of Terms

Acute lymphoblastic leukemia (*ALL*): ALL is the most common form of cancer under age 15 years (Muskat et al., 2017) and is the most curable childhood cancer (Bava et al., 2017). In ALL, immature blood cells known as blasts are abnormal, so they cannot carry out normal functions. The abnormal blasts multiply rapidly, so regular blood stops developing (American Cancer Society, 2020b).

Chemotherapy: Chemotherapy involves chemical substances used to treat illnesses, specifically cancer. The substances can be in pill or liquid form or administered intravenously, into the muscle, or into the spinal canal (National Cancer Institute, 2020).

COVID-19: COVID-19 is the abbreviation assigned to the SARS-CoV-2 coronavirus, initially found among bats in late 2019 (CDC, 2022.) There are many different types of coronaviruses, and they typically cause upper respiratory infections. COVID-19 is a new virus not previously seen in humans.

Leukemia: Leukemia is the cancer of the blood and affects the body's ability to produce normal white blood cells. Among children, ALL and acute myelogenous leukemia (AML) are the two most common types of leukemia (American Cancer Society, 2020a).

Neurocognitive impairment: Neurocognitive impairment means that parts of the brain are not operating effectively (Cheung & Krull, 2015; Hu et al., 2017). Neurocognitive impairment occurs in 40% of ALL survivors (Bava et al., 2017; Krull, Brinkman, et al., 2013).

Support: For the present study, support was defined as assistance provided by professionally trained individuals or nonprofessionals who provide emotional/social support (Kalliath et al., 2015) as well as support through social media. Trained professionals can be a person or people trained in health care or mental health care. For this study, health care professionals included physicians, nurses, and certified nurse aides. Mental health professionals included social workers, psychologists, and psychiatrists.

Assumptions

Assumptions for this study included the following. I first assumed that I could obtain a sufficient sample size by recruiting through Facebook. I assumed that the parents would be forthcoming and truthful about their children's health information, their own experiences, and their feelings following ALL treatment during the COVID-19 pandemic.

Finally, I assumed that generic qualitative methodology was appropriate for this study. These assumptions were necessary for the context of this study. Without them, it would not have been possible to gather the necessary information to address the identified problem.

Scope and Delimitations

In this study, I focused on parents' experiences of support, including support on social media, after their children were diagnosed with ALL and received treatment during COVID-19. I chose to focus on the parents' experiences with ALL diagnosis and treatment during COVID-19 as COVID-19 was a continuing global crisis at the time of this study but was too recent to have received previous researcher focus. Although Auburn and Gott (2014), Cornelio et al. (2014), and Cusinato et al. (2017) studied how parents felt when their children were diagnosed with ALL and documented the support available to these parents, I did not find similar research on the parents' experiences of support when the children were diagnosed with ALL and were receiving treatment during the COVID-19 pandemic.

The criteria for selecting parents was that their children were diagnosed with ALL and receiving treatment during the COVID-19 pandemic. The parents were single, married, or divorced. They were biological or adoptive parents. Since recruitment was through social media, the parents needed to have internet access. Transferability of study findings were aided by providing thick descriptions of the participants' experiences, which may be helpful for parents of children living with illnesses other than ALL.

Limitations

This study had several limitations. First, generic qualitative methods, qualitative analysis, and interpretation are less defined and established than other research approaches (Kahlke, 2014). Describing the participants' lived experiences limited the study to the participants' experiences. This is personal and subjective information instead of analyzing numbers and statistics to develop an objective perspective, as is the case when conducting quantitative research (Bloomfield & Fisher, 2019).

Second, the study sample size was 10 parents of children living with ALL and receiving treatment during the COVID-19 pandemic. This sample size aligns with standard sample sizes for qualitative studies (Benedetti et al., 2013). Benedetti et al. (2013) stated that qualitative studies should have between three and 10 participants but can also have samples in the 100s. Participants were found through purposive sampling by posting a flyer to a closed group on Facebook for parents with children who were diagnosed with ALL. Relying solely on recruiting participants on Facebook excluded information from parents who were not active on Facebook. As such, this sampling approach excluded these parents' perspectives, which might differ from parents who use social media.

For studies to be dependable, researchers must minimize biases. My son is a childhood ALL survivor who developed chemotherapy-induced depression and attention-deficit hyperactivity disorder leading to concentration challenges. My experiences as a parent of an ALL survivor were a potential study limitation as they could have led to bias in data analysis. I minimized any biases by using approaches standard in a qualitative inquiry such as journaling, bracketing, and establishing an audit trail, as suggested by Snelgrove (2014). These approaches are discussed in Chapter 3.

This study focused on the experiences of parents of children diagnosed with ALL and treated during the COVID-19 pandemic. This limited the study generalizability of the difficulties these parents have confronted as lived experiences. The parents in this study reached out to others, mostly on Facebook, for support in coping with their children's diagnoses during a worldwide pandemic. This experience is limited to this time as another pandemic has not affected the world similarly to COVID-19 (CDC, 2020a).

Significance of the Study

Current literature on children diagnosed with ALL primarily addresses cure rates treatment options, and how the illness and the treatment processes affect the children and their families. Available literature states that childhood ALL survivors can develop side effects and details how these may affect their physical abilities, social skills, functioning in school, emotional stability, and quality of life. However, there is little information on the parents' experiences of support as they cope with treatment, side effects, and day-to-day activities during the COVID-19 pandemic. There is limited guidance on navigating the issues when parents face new challenges, determining the resources available and how to access resources. There is some information on community resources, including support available from schools (Zannini et al., 2014). Findings from the present study may help to address these gaps and provide a better understanding the parents' experiences of coping with their children’s treatment, side effects, and day-to-day activities in general and specifically in the context of a worldwide pandemic. The findings may also help to inform health care and community-based resources for these parents, leading to positive social change.

One of the positive social changes is sharing knowledge with medical professionals about the parents’ experiences during and after ALL treatment in the context of a worldwide pandemic. Medical professionals may better understand the parents and provide support to the parents during their visit in person or via telehealth. The challenges parents face with a child’s illness, juggling work, and family responsibilities can be a burden. Awareness of what parents face and where they reach out to support may help medical teams better understand what the parents face.

Medical appointments are more frequent while children receive ALL treatment. Medical appointments during the COVID-19 pandemic may be via telehealth to reduce direct contact. An increase in telehealth use will help the parents maintain contact with the medical team to keep up with their child’s needs, both while receiving treatment and after treatment. When treatment is completed, the frequency of visits to the medical office decreases. This means the medical team has fewer interactions with the parents, leading to less knowledge on how the parents are doing as they deal with life changes after treatment, specifically during the pandemic. During treatment, appointments may be in person to continue with blood work and monitor medical conditions to continue with treatment.

Another social change is to empower parents as they receive support on Facebook from other parents who have similar experiences. After dealing with their child's diagnosis and treatment for ALL, parents cope with emotional, financial, and social changes. Making parents' needs evident will help medical professionals better support the parents, which will benefit the parents and their children. This information will also benefit schools as they look at what the parents have dealt with their child's illness and treatment to better equip them in the school environment.

Summary of Chapter 1

Parents' lives change forever when their children are diagnosed with cancer (Huang et al., 2018; Ward et al., 2014). The diagnosis causes distress in the parents, which may increase as they digest the information (Kim et al., 2017). Parents also often experience emotional, financial, and social stress, which can affect their life on different levels (Cornelio et al., 2014; Cusinato et al., 2017). They may face additional challenges if their children develop neurocognitive impairments resulting from ALL treatment (Bava et al., 2016, 2017). These challenges can be compounded by unprecedented and unforeseen events such as the COVID-19 pandemic.

Investigating the support parents receive resulted in findings that can help other parents in similar situations better meet their children's needs and lead to greater use of newer approaches, such as social media, to help parents cope with the psychological and social stressors that are often associated with being caregivers of children with special needs.

In this chapter, I discussed the problem addressed in the present study. I also presented the study purpose, the research question that drove this study, and the study methodology. Definitions of terms and study scope, limitations, assumptions, delimitations, and significance were detailed. In Chapter 2, I review the literature that informed this study.

Chapter 2: Literature Review

Acute lymphoblastic leukemia (ALL) is the most prevalent form of leukemia among children (den Hoed et al., 2015; Huang et al., 2018; Leibring & Andérzen-Carlsson, 2019; Liu et al., 2018; Williams & McCarthy, 2015). Issues begin at the time of diagnosis with ALL and continue during treatment (Cornelio et al., 2014; Kim et al., 2017). Emotional, financial, and social stress are common in the parents of these children, which can lead to depression, anxiety, and posttraumatic stress. Parents can experience further distress if their children develop neurocognitive impairments, which are a common side effect of treatment (Balsamo et al., 2016). Parental challenges intensified in the context of having a sick child during a worldwide pandemic such as COVID-19. This raised questions about the type of support parents can receive during a time when social distancing and other measures enacted to stop the virus's spread resulted in a world where isolation was common and support seemed difficult to find (Amaniera, 2021).

The purpose of this generic qualitative study was to achieve a fuller understanding how parents received support, including support through social media, as they coped with their children who were diagnosed with ALL and received treatment in the context of the COVID-19 pandemic. Some parents of children with ALL use Facebook as a support system to cope with their stress (Gage-Bouchard et al., 2017). Data from interviews conducted with parents of children with ALL were analyzed to answer the study question.

I begin Chapter 2 with a discussion of the literature search strategy, followed by a review of the transactional theory of stress and coping as this study's theoretical framework. This review leads to synthesis and analysis of studies on ALL, diagnosis and treatment, and side effects. I then review research on challenges facing parents of children diagnosed with ALL, social media, and the COVID-19 pandemic. A summary of the findings concludes the chapter.

Literature Search Strategy

I searched various databases in Walden University's online library for literature to inform this study. The subjects selected for the search were counseling, health sciences, human services, psychology, and social work. The databases searched for peer-reviewed articles were EBSCOhost, Education Source, Health & Psychosocial Instruments, Medline with Full Text, PsychINFO, SocINDEX, and Social Work Abstracts. The search terms were *childhood* and *acute lymphoblastic leukemia*. Other terms used with childhood and acute lymphoblastic leukemia included *leukemia*, *parents*, *COVID-19, depression with childhood leukemia*, *medical advice*, *on-line support*, *support groups for parents with ALL*, and *social media*. To compose the literature review, I chose peer-reviewed articles published from 2012 to 2020. Reviewing the selected articles and their references suggested other possible terms for additional literature searches. As I checked the references of articles published after 2012, the themes noted were *coping*, *posttraumatic stress*, *stress*, *social media*, and *COVID-19*. I searched for articles reflecting these themes as well.

Much of the extant literature dated to before 2012; fewer studies were available after 2012. Statistical information from articles published after 2013 were included to reflect the most current statistics possible. In addition to articles published after 2013, I conducted internet searches to obtain current information on COVID-19 and treatment information for ALL. The later articles and statistical information continued to show gaps in the literature on these parents' experiences of receiving social media support, specifically on Facebook, and specifically during a worldwide pandemic. These gaps are apparent in the following review of the literature. I preface this review with a discussion of the study's theoretical foundation.

Theoretical Foundation

The transactional theory of stress and coping, which explains how people cope with their emotions during stressful situations/transactions in life (Lazarus & Folkman, 1987), was the present study's theoretical foundation. Lazarus and Folkman began their research in the mid-1960s, with Lazarus initially addressing transactions, relationships, processes, and emotions as a system (Lazarus & Folkman, 1987). Lazarus's concept of stress begins with a better understanding of appraisal and coping, reflecting a focus on emotions rather than stressful situations (Lazarus & Folkman, 1987). Folkman revised Lazarus's original theory to encompass positive and negative emotions during stressful situations and life processes (Biggs et al., 2017).

When people experience stress in life, they learn to cope by managing their emotions and addressing the stress itself (Biggs et al., 2017). As the transactional theory of stress and coping emphasizes the perception of the stressful event instead of the event itself, the focus is also on responding to the event (Biggs et al., 2017). Specific to the present study, this theory helped me better understand the parents' experiences, including when they first hear the diagnosis of ALL and when their children receive treatment. This theory also helped understand the parents' experiences when facing additional stressors caused by a worldwide pandemic. I next discuss key elements of the transactional theory of stress and coping.

Transaction and Relationship

Transaction and relationship are two interdependent system variables introduced by Lazarus and Folkman (1987). It is vital to understand both people and their environments to understand relationships (Lazarus & Folkman, 1987). This knowledge is necessary for understanding what people's personal experiences are in life-threatening situations. According to Lazarus and Folkman, transaction and relationship are interchangeable, although transaction focuses on the interplay of variables and relationships emphasizing unity.

Process

Process is another interdependent system variable introduced by Lazarus and Folkman (1987). They explained process as what changes over time and situations. Stress and coping are both processes; stress presents challenges that people wish to change; coping is an act that actually took place or is currently occurring and occurs over time (Lazarus & Folkman, 1987). Specific to the present study, process related to parents' experiences of support when their children were diagnosed with ALL and received treatment in the context of the COVID-19 pandemic. The parents dealt with stress. In these situations, as Biggs et al. (2017) noted, coping strategies must be initiated.

Emotions

Emotions depend on environmental and personal variables and processes (Lazarus & Folkman, 1987). Environment variables include outside demands, constraints, and resources, including coping methods that are either problem focused or emotion focused (Lazarus & Folkman, 1987). Personal variables include goals, beliefs, mediating processes (including primary and secondary appraisals), emotional outcomes after encounters, and long-term outcomes that result in how people will function after the event. Both cognitive appraisal and coping, discussed next, factor into how people address challenging situations (stressors).

Cognitive Appraisal

Lazarus and Folkman (1987) defined cognitive appraisal as how people interpret the stimuli surrounding them and determine how the stimuli affect their wellbeing. These interpretations ultimately influence people’s perceptions of the stress present in various situations. There are two types of cognitive appraisal: primary and secondary (Lazarus & Folkman, 1987). Primary appraisal occurs when people determine whether events are stressful and relevant to them (Biggs et al., 2017; Lazarus & Folkman, 1987). They may determine that an event is irrelevant, in which they have no vested interest in the situation; benign positive, meaning that they perceive a situation as positive and not as a threat to well-being, and stressful, meaning they perceive negative effects and possible threats to well-being. Secondary appraisal encompasses determining actions to cope with stressful events (Biggs et al., 2017; Lazarus & Folkman, 1987). Secondary appraisal provides the perspective that not all stressors are harmful (Oh, 2017). Secondary appraisal is supplemental to primary appraisal because what is harmful or beneficial depends on the control individuals must overcome challenging situations (Lazarus & Folkman, 1987).

Coping

Lazarus and Folkman described coping as the conscious and unconscious efforts people make to solve problems and reduce stress (Butler, 1993). There are two coping models: the animal model and the ego psychology model (Lazarus & Folkman, 1987). In the animal model, coping reflects behavioral responses affected by the environment. There is no thought process on how situations are managed. The ego psychology model emphasizes the thinking process (known as the ego process) needed to make decisions and adapt to one’s environment (Lazarus & Folkman, 1987). Coping methods such as denial and intellectualization are considered neurotic. In contrast, realistic and flexible coping strategies use humor and healthy coping with stressful situations (Lazarus & Folkman, 1987).

Lazarus and Folkman (1987) explained that coping is reflected in challenging situations in which people learn to deal with harm or threat. These efforts lead to an emotional response, which can be positive or negative. Coping was especially relevant to the present study given the study focus on analyzing the experiences of support among parents having children diagnosed with ALL and being treated during the COVID-19 pandemic.

Rationale for Theory Choice

Researchers often use the transactional theory of stress and coping to study how people cope with their emotions during stressful times (Jones & Lynn, 2018). Jones and Lynn (2018) used this theory in their study on the stressors of parents whose children were in intensive care units. Through analyzing posts to 20 blogs, Jones and Lynn identified 156 codes reflecting stressors, emotion-focused coping, problem-focused coping, and other noncategorized codes illustrating the parents' experiences. They further found that the stressors reflected the parents waiting for news, sometimes feeling information were not shared fast enough, and at times it was information overload.

Using the transactional theory of stress and coping, Jones and Lynn (2018) found that even when parents accepted the reality and focused on the next steps, their response changed from coping to stress as soon as there was a change in their children's health. Jones and Lynn's study is relevant to the present study as I gathered information from social media, similarly to their study approach. Jones and Lynn's study also supported using the transactional theory of stress and coping in the present study.

Oh (2017) used Folkman and Lazarus's stress-coping model to guide an investigation on the relationship between communication from health professionals and psychological distress among cancer patients' caregivers. Oh found that when negative communication exists between the health professionals and the caregivers, their psychological distress increases. Caregivers' trust levels toward the health care professionals indicated the coping resources used, such as self-efficacy, to reduce psychological distress (Oh, 2017).

Oh (2017) showed that individuals adapt to stressful situations differently. This study's findings supported the focus in the present study on investigating the lived experiences of seeking and receiving support, including using social media, among parents of children diagnosed with ALL and receiving treatment during the COVID-19 pandemic.

Knowing what ALL is and how it is treated provides an essential frame to the present investigation. I discuss ALL in the next section to provide this frame. Included in this discussion is detail on what ALL is, how it is treated, and cure rates.

Childhood Acute Lymphoblastic Leukemia

Leukemia is the cancer of the bone marrow and the blood and accounts for 28% of childhood cancers (American Cancer Society, 2020a). ALL is one of the most common types of childhood leukemia and is fatal if not treated (Bartram et al., 2012). Children did not survive ALL in the past; when they were diagnosed, they went to the hospital to confirm the diagnosis and were then sent home to die (Aburn & Gott, 2014). ALL is now a very treatable disease, with cure rates in the 90% range (Balsamo et al., 2016; Hunger & Mullighan, 2015; Vetsch et al., 2018). This range reflects children who survived childhood ALL for more than 5 years after treatment, who are considered long-term survivors (Bava et al., 2016, 2017).

Treatment options for children diagnosed with ALL focus on chemotherapy administered in three phases: induction, consolidation (also known as intensification, including the stage of interim maintenance and delayed intensification), and maintenance (American Cancer Society, 2020a). Reaching remission is the goal during the first phase (American Cancer Society, 2020a). Ninety-five percent of children diagnosed with ALL enter remission after 1 month of induction (American Cancer Society, 2020c). The first month is one of the most intense stages during the treatment process, with frequent visits to the oncologist's office and multiple hospitalizations. Hospitalizations due to infections and other complications can develop during induction (American Cancer Society, 2020b). Some high-risk patients, such as those who develop T-cell ALL, may receive radiation to the brain. However, more intense chemotherapy is administered first (American Cancer Society, 2020c).

The next phase is consolidation/intensification. It starts when leukemia is in remission, which typically lasts a few months. The length of time depends on how long it takes the child to reach remission. This phase consists of chemotherapy and radiation, if needed (American Cancer Society, 2020c). Chemotherapy may be more intense during this phase. There may be another intense chemotherapy during consolidation known as delayed intensification. Parents of children diagnosed with ALL who are in high-risk groups may also be advised to pursue bone marrow transplants (American Cancer Society, 2020c).

After induction and consolidation and the leukemia is in remission, maintenance can begin. This is the last treatment phase (American Cancer Society, 2020b). This treatment phase include daily and weekly medications given as pills. Steroids are used every 4 to 8 weeks with medication given intravenously (American Cancer Society, 2020b). Other medications are used depending on the type of ALL and the risk standards, including medications given as intrathecal therapy (American Cancer Society, 2020b).

For children who develop T-cell ALL and relapse, oncologists will consider bone marrow transplant as an option. Children receive radiation when they have an extramedullary relapse (leukemia cells found in one part of the body such as cerebrospinal fluid or testicles, but not detected in the bone marrow; American Cancer Society, 2020c). During any part of the treatment phases, depending on blood counts, the children receive red blood, plasma, and platelet transfusions as needed in addition to receiving chemotherapy treatment (American Cancer Society, 2020c). Other tests and treatment that can occur in children diagnosed with ALL is a bone marrow transplant, an option when the children do not respond to chemotherapy shortly after beginning treatment after diagnosis (American Cancer Society, 2020c).

It takes 2–3 years to complete chemotherapy for ALL. Types and dosages of chemotherapy depend on the child’s classified risk groups. The classification depends on the risk group and prognostic factors (American Cancer Society, 2020c). Prognostic factors are the factors that affect the child's prognosis after diagnosis and include the following:

- Diagnosis age. Children ages 1–9 years have a better cure rate; children older than age 10 years are considered at higher risk.
- Initial white blood cell count. When diagnosed, children with white blood cell counts of more than 50,000 cells per cubic millimeter will be placed in a higher risk category and need more intensive treatment.
- ALL subtype.
- Gender. Girls have a higher cure rate than boys, and treatment for girls is shorter than for boys.
- The number of chromosomes in the leukemia cells. Children are more likely to be cured if they have more than 50 chromosomes, called hyperdiploidy (normal human cells have 46 chromosomes). Children with fewer than 44 chromosomes, known as hypodiploidy, have lower cure rates.
- Chromosome change, or translocation. Children with leukemia cells who have translocation between chromosomes 12 and 21 have a higher cure rate, whereas translocation between chromosomes 9 and 22 requires additional medication such as imatinib (Gleevec). Children with a translocation between chromosomes 4 and 11 have a low survival rate.
- Initial treatment response. Children who go into remission within 1–2 weeks of beginning chemotherapy treatment have a better prognosis than those who

do not go into remission after this timeframe (American Cancer Society, 2020d).

Parents today have expectations of long-term treatment and care. However, the road to remission can present significant challenges for these parents. I discuss some of these challenges and the resulting concerns next.

Challenges Facing Parents of Children Diagnosed With Cancer

Cancer diagnosis and treatment can negatively affect an entire family's quality of life and well-being (Cusinato et al., 2017; de Arruda-Colli, 2018; Lakkis et al., 2016; Wakefield et al., 2015). When a child is diagnosed with ALL, what was previously considered normal life is interrupted. Research has shown that parents of children with cancer, including ALL as it is the most common childhood cancer, face psychological, sociological, and socioeconomic challenges and need psychological and social and socioeconomic support. I discuss findings from these studies in the following section.

Psychological Challenges

Stress

Stress is a key issue in parents of children diagnosed with and being treated for cancer and is the focus of numerous studies on this population. Stress levels between genders can differ; Picci et al. (2015) found that mothers felt more emotionally burdened and experienced more stress about their children's illnesses compared to fathers. However, mothers and fathers both developed symptoms after their children were diagnosed, including depression, insomnia, and sleep disturbances (Picci et al., 2015). In a matched-group comparison study, Cusinato et al. (2017) used attachment theory to study parent–child relationships prior to children becoming ill and how it impacted the family during diagnosis and treatment. They noted that parents typically experience a sense of distress when their children are diagnosed with cancer, and the stress increased during treatment. They also found that stress could cause neuroendocrine dysfunctions resulting in physical issues such as headaches, weight changes, and loss of sleep and memory. However, the parents adjusted better to the changes caused by the child's illness when they had social support and relationships such as marital and family ties, and were able to communicate with others during one of the most challenging times in their lives (Cusinato et al., 2017).

Lakkis et al. (2016), who studied parents of children diagnosed with cancer in Lebanon, found that overwhelming stress impacted their quality of life and led to psychological distress. The intensity of the treatment options and the duration of treatment affected the parents' quality of life, including their physical and emotional well-being, resulting in challenges in caring for their ill children and their other children (Lakkis et al., 2016). Lack of social support, specifically from family and relatives, also added to their stress. Other family members who were experiencing financial burdens worked long hours and were not available to help the parents (Lakkis et al., 2016).

Based on their findings, Lakkis et al. (2016) recommended expanding programs for teaching coping strategies. Coping mechanisms, including dealing with new issues from the child's diagnosis, receiving information on new resources, and dealing with health care systems, helped to relieve stress in these parents. Lakkis et al. also recommended screening for psychological distress to identify parents at risk for developing disruptive stress levels.

Posttraumatic Stress Disorder

Findings from several studies showed that PTSD can develop in parents and children from the trauma experienced during cancer diagnosis and treatment. Cusinato et al. (2017) noted that a form of posttraumatic stress can develop in parents who had challenges adjusting to the child's diagnosis and the side effects of the child's illness. Hovén et al. (2016 also found that PTSD can develop in these parents and that hyperarousal and avoidance were mediators between reexperiencing the traumatic events and depression. Salloum et al. (2015) found that PTSD can result in both parents and children after they experience a traumatic event, including cancer. They may struggle with long-term and short-term emotional issues, academic issues, low social support, substance abuse, neuropsychological changes, suicide, and depression (Salloum et al., 2015). Although the parents' reactions are rooted in the child's illness, another contributing factor to their stress is their ability to fulfill their parenting roles (Salloum et al., 2015). When stress levels increase, children can exhibit behaviors such as temper tantrums, irritability, and angry outbursts (Salloum et al., 2015). These actions contributed to the parents' stress in Salloum et al.

Malpert et al. (2015) specifically studied emotional stress in parents of long-term ALL survivors. They found that 3.9% of the parents in their study showed signs of PTSD, resulting from emotional stress experienced during their children's illnesses. Malpert et al. further found that 43.7% of mothers and 35.3% of fathers experienced moderate to severe PTSS.

Anxiety and Depression

Anxiety and depression in parents of children who are ill can cause feelings of sense of uncertainty (Aburn & Gott, 2014). Aburn and Gott (2014) found that parents of children diagnosed with ALL had concerns about the future and loss in life. Adding to concerns about the of life's unpredictability, parents do not always understand the information presented to them about their children's diagnoses and treatment (Aburn & Gott, 2014).

Avoine-Blondin et al. (2018) focused on the quality of life for children with advanced cancer receiving palliative care. They found that parents need information about their children's illnesses delivered to them in ways they can understand and concluded that improving communications from the professional medical team helped parents understand the process with their children. Aburn and Gott (2014) had a similar finding in determining that professionals should share information in layman's terms about what is going on with children diagnosed with ALL and determine how much information the parents will handle at a time. Aburn and Gott discussed the importance of determining how much information parents can handle, which can depend on the parents' feelings at the time of diagnosis and during ALL treatment (Aburn & Gott, 2014). At the time of diagnosis, parents typically have questions including overall treatment safety, possible infection risks, and caring for their children at home, all reflecting the need for further education and resources (Aburn & Gott).

Further establishing the importance of support for the parents, Aburn and Gott (2014) discussed how to empower parents, how to provide education and information about the illness, and how to help parents deal with the medical challenges through the emotional roller coaster that treatment oftentimes presents. Because of information and emotional overload, parents can have difficulty processing medical data, so professionals may need to repeat information at different times and in other ways (Aburn & Gott, 2014). Parents are not always familiar with medical terminology and with what is going on with their children. As such, they may not know what questions to ask the medical team (Aburn & Gott, 2014).

Anxiety and depression can also result in parents feeling isolated and guilty. Kim et al. (2017) found that Korean mothers of children with cancer felt isolated and guilty and had a sense of uncertainty. These mothers felt isolated because taking care of their children separated them from the rest of the world. They felt guilty for wanting to take a break from caretaking, especially when it was problematic or too challenging (Kim et al., 2017). Kim et al. also found that these mothers enjoyed spending time with other mothers whose children were sick, especially with the same illness, and stressed the importance of family time. While isolation led to caregiver stress, spending time with other mothers alleviated feelings of distress (Kim et al., 2017). Kim et al.’s findings align with Cusinato et al. (2017), who also noted the importance of social support for parents in managing feelings associated with the ALL diagnosis.

Sociological Stressors

As reflected in the present study's focus, having support from others, including support from social media, can help to diminish feelings of isolation and loneliness, two key sociological stressors. Parents in Cornelio et al. (2016) spoke of challenges with professionals because parents felt they could not trust professionals' information. When parents are not able to trust professionals involved in their children's treatment, they want to turn to others. However, some parents may keep their relatives at a distance because of the fear of medical complications (Cornelio et al., 2016). When the parents isolate themselves from people who are closest to them, such as their extended families, they can become increasingly lonely and isolated. When people feel lonely, connecting with the outside world is crucial.

Parents deal with many issues when their children with ALL are being treated, which can be a highly stressful time for the entire family (Muskat et al., 2017). Using qualitative interpretative description methodology, Muskat et al. (2017) interviewed 17 parents whose children had been treated for ALL and found that the parents felt both relief over treatment being complete and apprehension about the future. Muskat et al. recommended continuing support for parents after treatment completion, especially given changes in relationships with their health care teams and to help them return to life following treatment.

Pergert et al. (2016) researched how foreign-born parents try to deal with their children's cancer diagnoses and the disruptions these diagnoses can cause. Study findings showed that these parents accessed resources in their home countries to deal with stressors, including lack of sleep, anxiety, depression, financial challenges, challenges in caring for the ill child and other children, and dealing with health care professionals as they were not familiar with the resources where they were now living (Pergert et al., 2016). The parents worked at staying strong and in control during difficult times, known as reassuring thinking (Pergert et al. 2016). Pergert et al. found that parents sought support more from families and from close friends, wherever they may be. They also sought spiritual support and support from other parents experiencing similar challenges, especially when the prognosis was poor. Study findings emphasized the parents' needs for support other than from professionals.

Socioeconomic Stressors

Socioeconomic aspects such as low income levels and loss of work when dealing with ill children can also cause parenting stress. Kunin-Batson et al. (2014) found that family stress, including parental stress, was higher in low-income households. Parents with low socioeconomic status need social support to deal with depression (Kingston, 2013). Socioeconomic issues discussed in Kingston (2013) included housing and finances leading to increased depression. Lower economic households have more challenges accessing resources for better physical well-being, emotional and social health, and increase in stresses (Kunin-Batson et al., 2014).

The burden of managing finances was addressed by Tsimicalis et al. (2020). Parents deal with financial challenges after cancer diagnoses and use strategies to manage expenses to reduce living expenses and reduce unnecessary cancer costs. Parents in Tsimicalis et al. used other resources such as tapping into their savings, leveraging their benefits and assets, and attempting to increase their wages as well as requesting assistance from other support systems. The study results showed that parents increased their family debt by using existing credit, negotiating credit loads, forgoing paying bills, relying on savings, increasing work hours, and relying on other support systems (Tsimicalis et al.).

All these issues underscore the need for support. With all the issues that parents face and feel, they are not always able to talk to their medical teams about their feelings and experiences during treatment. They may also be reluctant to reach out to friends and family for various reasons. As such, some parents reach out for support through social media. Jones and Lynn (2018) and Gün and Şenol (2019) both identified the need for parents to seek and receive support through social media to gain information and support from others with similar experiences. I next discuss social media as a support mechanism for parents of children diagnosed with ALL.

Social Media as a Support Mechanism

In addition to professional support and social support from families and friends, parents of children diagnosed with ALL are turning to social media for help (Gage-Bouchard et al., 2017, 2018). Specific cancer-related issues discussed on social media include treatment protocols, information on side effects and late effects, medication issues and how to take medication, and caregiving challenges, among others (Gage-Bouchard et al., 2017, 2018). Social media access has changed how people search for information as the internet became the place to obtain information, including health-related services (Gage & Bouchard et al., 2017, 2018). People can feel supported when they communicate online about issues such as medical information, resources, and emotional support with others who are dealing with similar concerns (Gage-Bouchard et al., 2017, 2018; Gün & Şenol, 2019). Sharing personal experiences on social media can also increase access to a broader and more diverse network of resources (Gage & Bouchard et al., 2017, 2018).

Social networking sites such as Facebook, Twitter, and YouTube are the most commonly used sites (Gage-Bouchard et al., 2017; Gün & Şenol, 2020). Facebook is the most common social networking site used (Gage-Bouchard et al., 2018; Huestis et al., 2020). Gage-Bouchard et al. (2018) identified other often-used sites as YouTube, Twitter, CaringBridge, and PatientsLikeMe.

In a 2017 study, Gage-Bouchard et al. analyzed the content from 12 months of data gathered from 18 publicly accessible Facebook pages hosted by parents of children diagnosed with ALL. They found that the parents exchanged information on highly specialized health-related information, including details on health services and their use, recognizing symptoms, treatment protocols and compliance, medical procedures, and medication use and compliance. Parents also provided emotional support tailored to other parents' needs that reflected empathy, encouragement, and hope (Gage-Bouchard et al., 2017). This support improved parents' knowledge of the disease and expanded their support networks and how social support is essential for parents to cope with the illnesses and health-related information (Gage-Bouchard et al., 2017).

In 2018, Gage-Bouchard et al. studied online communities on Facebook related to health support, specifically childhood cancer, to determine how social support in these communities helped families of children diagnosed with cancer. In this study, parents identified the importance of exchanging information with other parents in similar situations such as talking about diagnoses, navigating the health care system after diagnosis, how to advocate for their ill children, and how to access resources (Gage & Bouchard et al., 2018). In addition to exchanging information, the parents also used Facebook for emotional support and noted that doing so benefited their peer networking experiences, improved psychosocial and clinical outcomes of the children and parents, and helped build a peer-to-peer support for parents (Gage & Bouchard et al., 2018).

Gün and Şenol (2019) studied parents in Turkey who had access to two online communities where they could communicate with each other. This study showed that parents felt emotionally supported by other parents and received information from the professional team (Gün & Şenol, 2019). Parents using online communities gained information from others as well as emotional support (Gün & Şenol, 2019).

Some social networking sites allow parents to blog about their own experiences (Jones & Lynn, 2018). Jones and Lynn (2018) analyzed blogs written by parents of children in hospital intensive care units to identify how they were coping with their situations. During their children's hospital stays, the parents initially shared information on their emotions. Their coping strategies then moved to a more problem-based form of coping during the hospital stays (Jones & Lynn). These findings illustrate the importance of supporting parents emotionally and with information that will help parents cope during challenging times.

Huestis et al. (2020) also identified social media, specifically Facebook, as a resource for obtaining information on medical conditions and questions parents may have about posthospitalization and aftercare at home. In addition to aftercare, Huestis et al. discussed parents sharing personal stories caring for their children with tracheostomies and noted that using Facebook groups helped familiarize the parents with practices to care for the child at home and provided them emotional support. While Huestis et al.'s focus was on parents of children with tracheostomies, their findings are transferable to parents of children in other situations and are similar to the results of Gage-Bouchard et al. (2018) and Gün and Şenol (2019).

Not having internet access limits sources of medical information. This can cause challenges, as Davies et al. (2017) identified parents' lack of trust with medical teams because the parents felt they were not receiving accurate information. However, although the internet and social media offer access to more news, Gage-Bouchard et al. (2018) found that 67% of cancer information they analyzed was medically/scientifically inaccurate. This means that not all medical information found on the internet is reliable.

Reliability became an even more important concern when parents of children diagnosed with ALL faced a new challenge, the COVID-19 pandemic, discussed next.

COVID-19 and Its Impact on Parents of Children Diagnosed With ALL

The COVID-19 pandemic put a new spin on life for parents who were already dealing with their children's ALL diagnoses. SARS-CoV-2, commonly called COVID-19, was initially detected in China in December 2019 (Liang & Yang, 2020) and quickly spread worldwide (Vrdoljak et al., 2020). By March 2020, the World Health Organization reported that the virus had affected 163 countries and increased to 200,000 cases (Hrusak et al., 2020). As of December 22, 2021, there were 275,233,892 confirmed cases of COVID-19 and 5,364,996 deaths worldwide. In the United States, there were 50,565,638 cases and 798,942 deaths (WHO, n.d.).

The CDC (2020d) presented guidelines on preventing the spread of COVID-19 that included keeping distances from people who may be infected and showing coughing and sneezing symptoms. Other preventative methods include washing hands frequently for at least 20 s after activities like touching one's face, handling animals, and before handling food; avoiding close contact with people; keeping nose and mouth covered with a mask or cloth face cover; protecting one's mouth and nose when coughing or sneezing; cleaning and disinfecting frequently; and monitoring health frequently (CDC, 2020b).

Paying attention to individuals living with cancer during the pandemic is essential for illness prevention. Liang and Yang (2020) conducted an early analysis of data from cancer patients in China and found that older cancer patients were more affected and that men were more at risk. However, these findings do not suggest that parents of children with cancer can ignore the possibility of their children contracting COVID-19. Instead, COVID-19 concerns underscore the necessity for parents of children with ALL to pay attention and continue to follow their children's treatment regimens.

Diagnosis and treatment delays due to the pandemic are key concerns in emerging research. Vrdoljak et al. (2020) discussed how COVID-19 can affect cancer patient mortality due to delays in diagnosis and treatment. Examples presented were for people diagnosed with early signs of breast cancer needing biopsy procedures in Central and Eastern Europe, where the study was conducted. Ramella et al. (2020) stated that medical professionals in low and middle-income countries must continue treatment protocols so the cancer treatment does not lose its priority in the face of the ongoing pandemic. Hrusak et al. (2020) came to a similar conclusion in their study of children diagnosed with leukemia and receiving treatment after COVID-19 was discovered. These researchers also urged medical professionals to not allow COVID-19 to interfere with leukemia treatment and urged continuing research.

Further research will result in findings that will raise awareness of the issues and concerns that parents of children diagnosed and receiving ALL treatment face. While the findings in the studies discussed in this chapter focused on adults and children, what was not found in these studies identified the need to conduct further research on the types of support parents receive, particularly during the COVID-19 pandemic.

Summary and Conclusion

The literature reviewed in this chapter revealed a gap in the knowledge regarding parents’ support experiences when their children are diagnosed with ALL, particularly during the COVID-19 pandemic. Although researchers have studied ALL, its treatment, the trauma experienced by children and their parents when diagnosed and treated, and, to a limited extent their experiences during the pandemic, no researchers had focused on parents’ experiences with support, including support through social media, during the pandemic at the time of this writing. The literature review showed that parents were overwhelmed with the ALL diagnosis, treatment, juggling family and work responsibilities, financial issues, and the need to care for their ill children. Issues related to the ongoing COVID-19 added another layer of concern.

In Chapter 3, I discuss the research methodology used to conduct this study. Included are details on the research design and rationale, my role as the researcher, sampling approaches, and participant criteria and recruitment. I also discuss data gathering and analysis methods and how I addressed issues of trustworthiness.

Chapter 3: Research Method

The purpose of this generic qualitative study was to investigate the lived experiences of support, including online support through social media, among parents of children diagnosed with ALL and receiving treatment during the COVID-19 pandemic. In Chapter 3, I discuss the research design and rationale, my role as the researcher, the study methodology, participant selection approach, and the criteria for study participation. I also describe participant recruitment, data gathering, and the data analysis approach. I conclude with a discussion on issues of trustworthiness, including credibility, transferability, dependability, confirmability, and ethical procedures. The chapter ends with a summary.

Research Design and Rationale

The research question for this study was: How do parents of children diagnosed with ALL and receiving treatment describe their experiences of support, including online support through social media, during the COVID-19 pandemic? The phenomenon of interest was the parents' lived experiences receiving support through Facebook as they cope with the child diagnosed with ALL and receiving treatment during a worldwide pandemic. The events studied were people's lives. The parents' experiences were the essence of their lived experience or the phenomenon, as van Manen (2014) stated.

Generic qualitative methodology was used in this study. This method is appropriate when no other methodologies will yield the intended results (Kahlke, 2014). Although all qualitative research methods reflect different approaches to investigating people’s experiences (Rodriguez & Smith, 2018), the generic qualitative approach does not have a formal methodological framework and is not guided by a specific set of philosophical discussions as in other qualitative methods (Kahlke, 2014). It can instead blend established philosophies to create new methods (Kahlke, 2014).

Generic qualitative methodology focuses on exploring opinions, attitudes, and beliefs of people involved in various circumstances (Percy et al., 2015) and is useful for discovering and understanding people’s experiences and perspectives (Auta et al., 2017), which was the intent in the present study. Generic qualitative methodology is a descriptive qualitative approach and provides interpretive descriptions (Kahlke, 2014). The focus is on how people interpret their experiences, how they create their worlds, and the meaning they give to the experiences (Kahlke, 2014). Data collection is inductive and typically reflects codes using language in the data gathered.

Other qualitative methodologies include narrative, phenomenology, ethnography, and grounded theory. Narrative methodology is used to describe participants’ perspectives and to understand their experiences but does not make meaning from the affected individuals’ actual words (Haydon et al., 2017). I planned to use the participants’ actual words to describe their experiences of receiving support after their children’s ALL diagnoses and while they were being treated during the COVID-19 pandemic, so narrative methodology was not an appropriate approach. Phenomenology focuses on the experience and meaning of a phenomenon (van Manen, 2014). This method was not used as the focus of this study was not on the phenomenon, the experience, or on making meaning of the experience but to instead gain better understanding of the parents' experience with using social media. The goal was to use their words to gain a better understanding of their experiences.

Ethnography describes a particular culture and focuses on cultural implications (van Manen, 2014). Reeves et al. (2013) stated that ethnography is used to look at data gathered in more than one way (through observations, interviews, and documentary data) instead of looking at the data collected and understanding the meaning of participants experiences. I did not use ethnography as a method for this study as there were no documentary data to review and no observations were conducted. I conducted interviews with participants over the phone to gather information only, which did not meet the criteria for ethnography.

Grounded theory methodology focuses on life meanings, autobiographic information, and theorizing meaning, with the result being the creation of a new theory (van Manen, 2014). I analyzed the data collected from interviewing parents by using their words and looked for the implications of their experiences. My plan was not to develop new theories as this time but instead to develop a deeper understanding of parents' experiences during the pandemic and using social media as coping with their situation. As such, I did not consider grounded theory as a research method.

In this study, I reviewed the parents' lived experiences by organizing their words into themes and examining patterns of their shared experiences. I used the participants' actual words to provide an in-depth conceptual description of the parents' experiences to understand the phenomenon. As such, generic qualitative methodology was the best fit for this study.

Role of the Researcher

I was the sole researcher in this study, and my role was as an observer–participant. Researchers can be insiders if they live and work in the participant's social context but may not always be familiar with the participant experiences (Finefter-Rosenbluh, 2017). I am familiar with ALL treatment but was not familiar with what it would be like to take care of a child receiving ALL treatment during the COVID-19 pandemic. I did not know any of the participants personally.

In the present study, I was initially a member of a closed group on Facebook, which made me an insider as I gathered information from participants in the closed group. According to IRB requirements, the name of the closed Facebook group was kept confidential. I was able to join this closed group because I am the mother of an ALL survivor. When I joined the group, questions were asked on why I wished to join. My response was to be a support for other parents who are going through ALL treatments with their child and wished to be a support. The group administration accepted me into the group, allowing me to be an insider. Being an insider, I acted as a member of the group and an observer. I was also an outsider as I explored unfamiliar environments and learned characteristics. My son no longer receives ALL treatment. He completed his treatment in 2010; as such, there is more than a 10-year distance between the treatment and the day-to-day medical challenges. Although I am acquainted with other parents who experienced similar situations, social media was not available when my son and I went through his illness. The COVID-19 pandemic is a new phenomenon.

I was able to relate to the parents, but not emotionally tangled with their issues, and focus on the task of being the researcher for this study. I kept my awareness of my own biases, beliefs, and experiences as a survivor's mother (Finefter-Rosenbluh, 2017).

It was essential for me to separate from the study participants while I conducted the interviews because my own experiences could have been a barrier. To manage my own biases, beliefs, and experiences of ALL survivor's mother, I kept a journal to reflect on my thoughts and feelings about each interview conducted, as suggested by Finefter-Rosenbluh (2017). I continued to be aware of my own biases throughout data analysis by keeping the journal and reviewing and discussing the data collected with my dissertation committee members.

Methodology

Participant Selection Logic

I used purposive sampling to identify participants for this study. I based participant selection on the criteria of being parents of children who were diagnosed with ALL and receiving treatment during COVID-19. Participant eligibility was established through their membership in a Facebook group for parents of children with ALL. There were 10 study participants. The specific population for this study was parents of children with ALL during COVID-19 pandemic restrictions while their children continued to receive ALL treatments. A specific population means group of people with something in common (Kahlke, 2014). I selected 10 participants as the sample size as this size aligned with guidance on standard sample sizes for qualitative studies being between three and 10 participants (Benedetti et al., 2013). I did consider sample size as it relates to saturation, which Hennink et al. (2019) explained as being the point where data collection becomes redundant.

Instrumentation

The instrument used in this study was an interview protocol that I developed. The protocol consisted of questions and prompts and reflected key issues and themes identified in the literature review and analysis. See Appendix A for this protocol. The interview questions were developed through the literature review on the importance of getting background information on the parents' experience with ALL diagnosis. It was important to find out about their support system again basing from the literature review on the challenges they faced, the support they already had before seeking social media, and how social media became a support for them.

Procedures for Recruitment, Participation, and Data Collection

I recruited participants through Facebook. Initially, I reached out to the administrative members for one of the closed Facebook groups specifically for parents with children with ALL. I sent a message via messenger and waited for a response from the administrative team before I proceeded. I explained the study and sent a copy of the flyer (see Appendix B) I wished to post on their website. When they approved to post the flyer, I posted it. The flyer contained a brief explanation of the study and contained my contact information (name, email address, and phone number) so potential participants could contact me directly. I posted the flyer three times before 10 people responded.

The potential participants contacted me by email, phone, or text message, and I followed up with phone calls to each one. During the phone calls, I explained the study and assured the potential participants of confidentiality. I also advised them that I would send them a consent form and that I could not interview them until they reviewed and returned these forms.

After communicating with the parents, I obtained their email addresses and sent out the consent forms. I gave the parents the option to either mail or email the consent forms back when reviewed and decide to consent. All 10 sent the consent forms back and indicated their consent to participate. All participants in this study were volunteers and understood the voluntary nature of the study.

The consent form contained details on the study purpose and the measures I would take to maintain confidentiality. Participants were advised that they could stop the interview process at any time and could determine how much or how little they wanted to share. They were informed that they would not be asked to do anything they were not comfortable doing. Participants were given the option to meet more than one time if we ran out of time for the first interview. All participants completed the interviews in one meeting time.

I offered the participants their choice of phone or Facetime interviews. All participants chose to talk on the phone. I set up an appointment with each of the participants to talk on the phone. I used a private location when conducting the interviews to avoid any interruptions that could affect the data collection process. I conducted all the interviews between June 1, 2021, and July 28, 2021. All participants were interviewed once.

Interviews were conducted until I reached a point of saturation, a guiding point in qualitative research and analysis (Hennink et al., 2019). Saturation is the point where the data collected becomes repetitive (Hennink et al., 2019). The data collection events varied with each of the participants, as was expected, but there were enough similarities between them to establish saturation.

I audio recorded the interviews and took notes. The notes were saved to a Word document, separated by dates. The audio recordings were saved to a USB drive. Only I could access the data.

Data Analysis Plan

I categorized and coded the information according to the rising themes from the data obtained. I used thematic analysis, following Crowe et al.'s (2015) guidance, to identify key themes from coding. I hand coded all of the data and did not use software for coding or analysis. More detail on data analysis is in Chapter 4.

Issues of Trustworthiness

Credibility

Establishing study credibility/internal validity assures that the study makes sense and is of value (Miles et al., 2014). Maxwell (2013) stated that validity does not apply directly with qualitative studies as there is no test of proving things wrong. As such, I focused solely on establishing credibility. Specific steps included using more than one data source (participant interviews and notes I took during the interviews), which reflected methods triangulation.

Transferability

Transferability (external validity) refers to the extent to which study results can be generalized or transferred to other situations or settings (Miles et al., 2014). In qualitative research, transferability is primarily established by describing the study context in detail, also described as providing rich, thick detail, and by clearly stating the study's central assumptions (Korstjens & Moser, 2018). I followed both of these steps in this study.

Dependability

Miles et al. (2014) described study dependability as establishing the findings as consistent and reliable. Examples of areas to review in ensuring dependability include the research question or questions and whether the findings truly reflect the raw data collected. Having my dissertation committee review this study helped to establish the information collected as dependable, as suggested by Miles et al. (2014).

Confirmability

Confirmability, the last element in establishing trustworthiness in qualitative studies, reflects steps taken to ensure that the findings are a true reflection of the participants' views and words and not a reflection of the researcher's (Miles et al., 2014).

In the present study, I kept a journal of my thoughts and reactions to the data collected to minimize any bias or personal views that may arise during this process.

Ethical Procedures

Walden University's institutional review board (IRB) granted approval to conduct this study. While conducting this study, I maintained privacy, transparency, and confidentiality, reflecting guidance in Gupta (2017). All participant data were deidentified to protect their privacy and confidentiality. I am the only one who can access the data collected. All paper-based data were maintained in my personal office at home, in a secured desk drawer. All other data collected are on my personal computer and saved in a USB drive separate from the computer. All data and files related to the study will follow all procedures directed by the dissertation committee and the IRB. Specifically, data will be kept for 5 years in a locked drawer. After 5 years, paper-based data will be destroyed using a shredder. Digital data will be deleted from my computer, and the USB drive will be destroyed.

Summary

I began this chapter with a discussion of the rationale for using generic qualitative methodology as this study's research method. Following this were sections on my role as the researcher, participant selection, the study instrument, data collection and data analysis. I also detailed discussed issues of trustworthiness in this chapter, including steps taken to establish study credibility, transferability, dependability, and confirmability. The last section focused on ethical procedures. I present the results from analyzing the data in Chapter 4.

Chapter 4: Results

The purpose of this qualitative generic study was to investigate the lived experiences of support among parents of children diagnosed with ALL and receiving treatment during the COVID-19 pandemic. The research question was: How do parents of children diagnosed with ALL and receiving treatment describe their experiences of support, including online support through social media, during the COVID-19 pandemic? In this chapter, I present the data collected from the 10 interviews conducted from mothers of children going through ALL treatment. I also detail the study setting, demographics, data collection, data analysis, evidence of trustworthiness, and the results of the research question.

Study Setting

The study setting was virtual. Eight of the 10 participants were in the United States; one was in Europe, and one was in Asia. I found all participants through a Facebook support group for parents with children diagnosed with ALL and currently going through treatment. There were no organizational or personal influences at the time of the study that would have influenced interpretation of the study results.

Demographics

All participants met the criteria to participate in this study. All participants were mothers. I interviewed 10 mothers of children diagnosed with ALL either before or during the COVID-19 pandemic and currently undergoing treatment for ALL. Nine of the 10 completed the interviews.

All participants were assigned numbers to protect their identity. The numbers used are in both Chapters 4 and 5 when identifying the participants. As shown in Table 1, most of the participants live in the United States. Of note, the children of seven of the 10 participants were diagnosed with ALL during the COVID-19 pandemic.

Table 1

Participant Demographics

Participant	Location (all United States unless otherwise indicated)	No. of children	Diagnosed before or during COVID-19	Completed interview?
1	West Coast	1	Before	Yes
2	East Coast	2	During	Yes
3	West Coast	1	During	Yes
4	West Coast	2	During	Yes
5	East Coast	2	Before	Yes
6	West Coast	1	Before	Yes
7	East Coast	1	During	Yes
8	Midwest	2	During	Yes
9	Europe	4	During	Yes
10	Asia	1	During	No/partial

Data Collection

All interviews were conducted between June 1, 2021, and July 28, 2021, after receiving approval from Walden University’s IRB (#05-05-21-033897). I posted a flyer on a Facebook group that is closed to anyone other than parents of children with ALL. I received consents from 10 participants for the study. I completed nine interviews in full. I started the 10th interview, but the participant was not able to complete the interview as her child woke up, after which she stated she was not able to continue with the interview. There was no response when I reached out to this participant via text. I tried to connect by texting four different times, and she did not respond. My last text stated that if she wished to reach out to me, she knew where to reach me. I thanked her for her participation up to that point, and that I looked forward to hearing from her soon.

All interviews were conducted by phone in my home office. I audio recorded the data and took notes. There were no variations to the data collection method detailed in Chapter 3. I followed the interview process described in Chapter 3 (see Appendix A for the questions asked). I asked probing questions when I wanted to know more about the participant’s situation. The interview sessions varied from 45 to 110 min. The only unusual circumstance was not being able to complete the 10th interview.

Data Analysis

All interviews were audio recorded and saved to a secure, password-protected device. I started analyzing the data as I completed each interview. After each interview was completed, I transcribed the interview and typed it out. As I conducted each of the interviews, I took detailed handwritten notes in addition to recording each of the interviews. After taking handwritten notes for each of the interviews, I typed out each of the handwritten notes for each of the interviews to start the analysis of the data collected. Qualitative research focuses on interpreting phenomena to make sense of people’s experiences and the meanings attached to them (Crowe et al., 2015). Thematic analysis is used to identify the components in the data and form them into coherent descriptions of people’s experiences (Crowe et al., 2015). I listened to the interviews repeatedly to make sure I transcribed them correctly. During transcribing, I also listened to their voices, and the tone of their voices spoke volumes.

I began data analysis by rereading all of the interview transcriptions and my notes. Immersing myself into the data I collected by rereading the information multiple times helped me to become familiar with the information gathered from each of the participants. I then went through the transcriptions and my notes to identify patterns and themes and noted them in the participants’ comments with a highlighter when they arose. Kahlke (2014) explained the importance of making meaning from the experiences and that using open codes and themes is important with thematic analysis. I also noted key passages in the participants’ comments and organized them for later use in presenting the study findings.

Evidence of Trustworthiness

Credibility

Study credibility assures that the study makes sense and is of value (Miles et al., 2014). I made no adjustments to the steps I detailed in Chapter 3 to establish study credibility. I used more than one data source: interviews and my written notes.

Transferability

Transferability (external validity) refers to the extent to which study results can be generalized or transferred to other situations or settings (Miles et al., 2014). I made no adjustments to the steps I detailed in Chapter 3 to establish transferability. As shown throughout this study, I described the study context in detail. As shown in Chapters 4 and 5, I provided rich, thick detail of the findings. I also clearly stated the study's central assumptions in Chapter 1. Information collected through interviewing parents of children with ALL can be transferred to others in similar situations such as parents of children with cancer or other acute illnesses during the pandemic.

Dependability

Miles et al. (2014) described study dependability as establishing the findings as consistent and reliable. I made no adjustments to the steps I detailed in Chapter 3 to establish dependability. I asked the same interview questions to all the participants in the same order. The raw data collected through all the interview questions were analyzed and used in compiling the themes for this study. I kept a journal during the time I conducted the interviews with each participant and maintained a journal during data analysis.

Confirmability

Confirmability, the last element in establishing trustworthiness in qualitative studies, reflects steps taken to ensure that the findings are a true reflection of the participants' views and words and not a reflection of the researcher's (Miles et al., 2014). I made no adjustments to the steps I detailed in Chapter 3 to establish confirmability. I maintained a journal, which helped me process my thoughts and feelings both before and after each interview. I kept reminding myself that this was not my story but was instead that of the participants as the goal was to explore their experiences

Results

Four themes emerged from the data collected and analyzed from the participant interviews: unusual events leading to diagnosis, support system, online support/social media, and adjustments because of COVID-19. Table 2 shows the alignment between the themes and the interview questions. Table 3 shows themes identified from the interviews.

Table 2

Interview Questions and Emergence of Themes

Question #	Question	Theme
1	Tell me about when your child was diagnosed with ALL.	1
2	Tell me about your family members. Who helped you during this time? Describe your support system. (Probing question: How about support on line?)	2, 3
3	Where were you when you first heard about COVID-19? Any news about it being a pandemic?	4
4	Was your child receiving treatment when you heard about the pandemic/where in the treatment process was your child?	4
5	What was your schedule like?	4
6	What changes did you have to make to adjust since the pandemic?	4
7	How was online support for you? (Probing question: Where and what do you post on social media?)	3, 3
8	How old was your child?	4
9	Was your child in school?	4

Table 3

Themes Identified From Data Collected

Theme	Meaning	Examples
Unusual events leading to diagnosis	All participants noted unusual events other than fever prompting them to take their child to the hospital, which then led to more tests to reach diagnosis.	Participant 1's daughter had a nose bleed that would not stop for hours. Participant 3's daughter developed a rash on her legs. The medical team did not think much of it as she had a bruise from tripping and falling previously. Participant 4 said that her daughter is a complainer so when she said her feet hurt, she told her to take ibuprofen, when she checked on her at 2 a.m., her daughter was sleeping. When she woke up and said her feet still hurt, Participant 4 took her daughter to the hospital.
Support system	All participants had a solid support system at home and/or close to home.	Participant 2 identified her parents being her biggest support. Participant 3 identified her support as being her daughter, her child's father, and her parents. Her own mother and sisters were supportive but could not be there due to COVID-19 and her mother works in urgent care. Participant 8 said that she and her husband went through their child's treatment together. She identified her husband's mother as a big support as her husband is an ALL survivor himself, so his mother understood exactly what they were going through.

Theme	Meaning	Examples
Online support/social media	Most participants reached out and found the support group online through social media and shared/posted about their initial diagnosis with acute lymphoblastic leukemia (ALL). As time passed, instead of sharing challenges, they posted encouraging information for other parents to read.	Participant 1's child was in the hospital the first time she started looking on Facebook for a parent leukemia support group. She noted a lot of confusion and a lot of posts about COVID-19. Participant 5 stated that the social worker at the hospital told her about support on line when her child was first admitted. Participant 5 went on social media looking for answers for questions and to see if others had similar experiences to hers. Participant 4 said she found online support way later. She said she posted on social media by responding to other people's posts, especially if she had something okay to say, but she mostly observed.
Adjustments to COVID-19	Participants revealed that COVID-19 caused issues such as only 1 parent allowed in the hospital. A positive was that other children were home from school so children with ALL did not feel as isolated from their friends as other children were home doing virtual school until the time came to return to school in person.	Participant 2 recalled that when her daughter was first diagnosed, they allowed both parents into the hospital. After Covid hit, the parents took turns in the parking lot. Participants 4 shared that when her child was diagnosed, COVID-19 was already present, schools were closed, and masks were already mandated. She explained that some things were helpful during COVID-19 as she was able to work from home, which would not have happened in other times.

Theme 1: Unusual Events Leading to Diagnosis

Theme 1 relates to the first interview question, which focused on the events leading up to the children being diagnosed with ALL. All 10 participants talked about unusual events that prompted them to contact their pediatricians or to go to the emergency room. Two mothers said their children had high fevers but only one, Participant 10, contacted the pediatrician immediately. She was advised to just observe her daughter. As previously noted, this is the only comment from Participant 10; her child woke up and she then ended the interview.

Participant 8 also identified her child as having a fever, but she did not immediately consult the pediatrician as they thought it was simply a symptom of being sick. However, the fever never went away.

> She never seemed to kick it, so we thought it was an additional cold. But then in mid-May, she was lethargic for 3 weeks and then she started groaning, holding her stomach, and then she threw up and lost consciousness. We called the hospital and they diagnosed her.

Participant 8's comments showed that she handled things on her own, that she saw her child's symptoms as not being out of the ordinary, and that she thought she could handle them. However, as time went by, she saw that the symptoms were not going away, and as other symptoms came up, she sought medical help.

Participant 1's child did not have a high fever but did have nosebleeds that would go on for hours, so she made an appointment with a pediatrician. The appointment snowballed into being admitted to the hospital.

> Because the nosebleed would not stop, urgent care put a damper on it, but my husband took her temperature. It wasn't high so we kept her from school and

> made an appointment to see the pediatrician that day at 5p.m. We were told she may be anemic, so they took her blood level, like her hemoglobin, I can't remember the name of it, where they poke your finger and I just remember the look on the nurse when she did it. They sent us to the ER to get a full blood workup, and we came home.

About 20 minutes after Participant 1 and her family got home, the pediatrician called and said they had to go to the emergency room right away: "They are expecting you."

Two of the mothers said their children were complainers, and both mothers wished they listened to their children sooner. Participant 4 said,

> She is a complainer in general, so I told her to take ibuprofen for pain [her feet hurt] and let me know. I went to sleep. I checked on her at 2 a.m., and she was asleep, and in the morning, I asked how her legs where, and she said not good. For some reason I decided to take her to [hospital name redacted] instead of her pediatrician's office. When we got there, at first they thought she had a back injury and they did blood work. [It] came back, then oncology came in and we were admitted from that point on, so it was a snowball effect from that point.

Participant 5 talked about regretting that she did not listen to her son more closely prior to his diagnosis.

> He is a very healthy ninth grader, and when he started complaining about headaches, I did not pay attention. I regret that so much. [I said], "Okay, you gotta go to school even if you have a headache. You need to go to school, take Tylenol

> and that is it." But the headache . . . he would complain like twice a week following that, he would complain that "I am tired, Mom," but I was thinking this boy does not want to go to school because he was a little bit lazy, and he is 15 years old. I work full time, so I said "No, no, no, you have to go to school, that is it."

Participant 5's son continued complaining of being tired, so she made an appointment with the pediatrician. However, prior to the appointment, she came home and noticed that her son was pale and running a low fever. Her son being pale was "the thing that really scared me . . . I know something was wrong." She added that she never thought her son could have ALL.

Participant 2 talked about her child being sick with absence seizures and childhood epilepsy. Having abnormal blood work brought things to the forefront, but not immediately. When they saw a doctor, they were initially told that it was not leukemia. However, within a couple of days, her daughter started having digestive issues, so she had her blood tested for food-related intolerances. While they were waiting for the results, Participant 2 noticed that her daughter, who is a swimmer, was not performing as usual.

> The swim coach and I were watching her swim, and we were saying she was not kicking right, she had a really slow kick and looked lazy. Previously she had a rhythmic kick, not fast, but meticulous, and it was not the same.

Participant 2 remembered the pediatrician calling and saying they wanted to do more blood work because the test did not look right. “They were going to reorder blood work and they wanted us to go to the local hospital lab to get processed faster, I said sure, and I took her.” The blood work came back in about 5 hours. Later, the pediatrician told Participant 2 to pack her daughter’s bags and head to the hospital. There, “We spoke to the hematology/oncology group and her blood work does not look right and she has some abnormal blast-like cells. I went okay, I know just enough medical stuff to make me dangerous.” At that point, the oncologists were not sure if it was leukemia, “So they went ahead with the bone marrow biopsy, which is when they confirmed she had leukemia.”

Participant 3 talked about a family member (her mother) being in the medical field, which is how she discovered that her daughter had ALL. Her mother looked at her daughter and told her to get blood work done immediately. “I asked my mom what she thought, and my mom said, ‘You don’t want me to say it, I think she has leukemia.’” Participant 3 did not take her daughter to the hospital immediately as it was 4 hours from where she lived, and she wanted to return to where she lived before seeking medical attention.

Participant 9 is also a medical professional but did not diagnose leukemia in her daughter because she was acting like a mother, not a medical professional, when her daughter was feeling ill. She explained that due to COVID-19 and the lockdown, her daughter was sent to two different hospitals over a 3-week period before physicians determined she had leukemia, and she was transferred to another hospital to begin treatment. It then took another 7 hours for an ambulance to transport her.

In review, the first theme reflected what happened to these parents and their children that led to the children being diagnosed with ALL. Until diagnosis, the children all experienced different symptoms, leading the parents to seeking medical attention and sometimes being sent home before further tests were conducted that led to the diagnosis. The participants’ comments reflected their concerns and worries about the unknown during this time until they heard the diagnosis of ALL.

Theme 2: Support System

Theme 2 relates to the second interview question, which focused on exploring the participants’ support systems and the people who helped them. Participants 2, 3 5, 7, and 8 said their parents were their support system. Participant 1 said that her primary support was her husband, her work friends and school family. She held off telling her mother for a bit because “she is highly anxious and tends to make things about her. After time, she was supportive.” Participant 1 further shared that her dentist and her dental hygienist were sources of support as the dental hygienist’s son was recently diagnosed with ALL and goes to the same hospital.

Participant 6 talked about how helpful her friends from her child’s daycare were as well as individuals at her husband’s workplace, who told him to take whatever time he needed. Participant 4 said that her support system was her husband and her friend, who stayed with them. Participant 5 talked about her parents, sister, and daughter being huge supports. Her words reflect the passion and the appreciation she had for her daughter.

> My daughter was 17 years old and she became a wolf! She was my support, beside my mom, dad, and sister, she was my real support. She was making medical decisions with me, next to me, when the doctors were explaining medical procedures I could not understand. Not because of my English but I was devastated I could not assimilate what was going on.

Participant 9 talked about how much her 17-year-old twin sons were a great help taking care of their younger sister who was 8 years old while the parents were going back and forth to the hospital.

> They were only allowing one parent at the hospital. So when my husband came we would trade, I would go home and vice versa, basically. It was just us and our 17-year-olds . . . They are a great help with their younger sister and they kept an eye out on their younger sister. They were amazing.

Most participants identified having help from immediate family. Participant 8 specifically talked about her mother-in-law being very helpful in taking care of their younger daughter as well. She added that her mother-in-law understood because her (Participant 8’s) husband is an ALL survivor: “She understands exactly what we are going through.”

This theme focused on the support systems that participants had during the time of diagnosis and during treatment. I determined that all the participants had support systems. Whether the support was provided by family members or friends, they were people the participants were comfortable leaving their other children with while they were taking care of their ill children.

Theme 3: Online Support/Social Media

The theme of online support/social media evolved when I asked the question about the participants going on social media for support. All the participants found the closed support group for parents of children with ALL, which is where I made contact with them. Participants 1, 2, 4, 5, 7, and 9 said they found support online about children with ALL during the first hospitalization after diagnosis.

Participant 1 talked about posting on the day of diagnosis and remembered that "People reached out and answered. In the beginning you have so many questions and you are looking into trying to find answers and looking for people to tell you that it is going to be okay." Participant 2 said she initially reached out to Leukemia Lymphoma Society as she was part of a bike team before her child's illness, and her social worker told her about the support group on Facebook. She recalled,

> I Googled or searched on Facebook because I felt I needed it, I don't Google but I really appreciated it during Covid. I needed a place to talk to other parents, I needed to hear from other moms and dads, other people who are going through this and others that understand.

Participant 5 said that the social worker at the hospital told her about online support groups and that joining them might help her to not feel alone.

> So, I started looking in Facebook groups for ALL. My son was 15, so we looked, and I saw moms like me with family and kids in that age range. Moms would tell me about different groups online, talking about a mom in Texas or Utah, and sharing how their children were doing. How wonderful it was, then Covid hit.

Participant 7 said she does not use social media as a rule but did go on Facebook. She recalled,

> I wanted to figure out some way to connect with people. My first thought was to look in my area, but I did not get very far, so I found the group on Facebook. I have not used it very much. I am sure there is so much more out there but I'm just not there yet.

Participant 9 also talked about going online during the first 3 weeks her child was in the hospital.

> The hospital talked about the Facebook page. When I first saw it, there were a lot of horror stories, bad stories, and I said I could not do this, so I stayed away for a few weeks. Through the hospital's official web page, there is one specifically for parents. I got to the UK ALL one and then the American ALL and the moms from port placement, moms who were feeling isolated.

Participant 3 found the support group for parents with ALL after she talked to someone her mother knew. She recalled,

> I was involved in a group with a friend online and she told me about the Facebook support group. That has been a support through everything. There was another

> family member I knew, a nurse practitioner that worked with my mother. Her grandchild had ALL and [I] got in touch with that family through Facebook. So you are connecting with not just the group; we got connected with others through Facebook and texting.

Participant 6 moved to another state to be closer to her family but still felt isolated as her support system was in another part of the country. She received advice to seek other support: “I was told to look for support groups online, so that is when I went to Facebook and found our ALL group.”

The mothers found social media as support, especially the specific ALL group on Facebook. I then asked about continuing to use social media for support. Participant 1 talked about the confusion during COVID-19. She explained,

> I am not sure about support online, but there was a lot of confusion, a lot of posts about Covid. One kid in treatment was on the news and he tested positive. Where there were multiple questions and responses about Covid, the Facebook group administration closed all the comments and provided an explanation on the group post that they were not going to keep the posts up to avoid any confusion to the group members that may not be accurate medical information.

One of the mothers were interested in being a support for other parents who were going through the same thing. Participant 2 used social media to be helpful. She talked about social media as a place to contribute and where she can be helpful.

> Or, if there is something I am worried about, or I just need to say something, such as the things I need to vent. I feel like when she [her daughter being treated] had toxicity, I posted more, I read through and contributed as someone posted about IM [interim maintenance] or DI [delayed intensification].

Participant 4 talked about being helpful to others by responding to other people's posts.

> Depending on what people post, I comment on people's posts if I have something okay to say about it. Mostly, I observe, I found it to be helpful. In a social media group or on Facebook, I mostly respond to people's questions . . . I think I posted to someone's post about anxiety, about I will never be the same, and now 7 months into it, everyone is back to their lives but we are still in crisis mode as we are in active treatments, so it is really hard. My son's in baseball, and I look at things with a different lens, and it's hard for me to see everyone doing their own thing.

All of the participants were very grateful for the information available on social media. Participant 8's comments reflected this gratitude: "Social media is a wonderful resource. I will use when I need it, and I am okay just have the access to it, knowing that the information and the support being there is good." However, some participants noted hesitancy in using social media. Participant 6 hesitated about posting information on Facebook due to her husband's position in the military. She said,

> I have become more private with our lives, especially when my husband was gone for 6 months on his appointment, it was more important to keep my mouth shut on social media to keep my husband safe and to keep us safe than to express my thoughts and feelings and potentially put anyone at risk.

Other participants were looking for answers for their children's symptoms and experiences. Participant 3 talked about using social media to learn more about her child's medical needs and to express her concerns during Covid. She said,

> I think I posted about constipation, and I posted about [my] going back to school as I'm a stay-at-home mom. Putting her in school was the thought before Covid; now that is not going to happen with everything shutting down, and she got sick so I'm like really not going back to work, and thinking about going back to school. So I posted on there, is it crazy for me to go back to school when my daughter is going through this? A lot of people were very supportive.

Participant 3 added,

> I post a lot of social media and my partner does not. I usually don't post personal, not in depth, so having a group be private where I can post things and have it be private [is important.] What I did was create my own group for my close friends and family where I can feel comfortable posting things so they can post on what is going on with my daughter.

Participants 5 and 7 also went on line to look for answers to some of the medical challenges their children were facing. Participant 5 explained how people showed concern initially but then faded.

> I was looking for more people who had the same reaction with chemo, and I did not find anyone, so the doctor did tell me that it is not common but it does happen. I went to social media asking questions like "Did this happen to your son or daughter?" All I got was no, but this and that but not what my son had.
>
> I was all over social media because I wanted to know answers. Talking to people all over the place, you are hoping to hear that someone will know or have experiences, so you have something in common. The hard part this time was there was no one.

Participant 6 talked about her hesitance to use social media.

> I remember posting about [my daughter's] first diagnosis anniversary. That was a big one. The first time I posted about when she was diagnosed and that was the social media acknowledgement of her diagnosis. There were a lot of people who were shocked because of ignorance and people saying she will have treatment and then she is going to be fine out of ignorance. That is not quite how treatment works, but it is okay, not that it is not what happens, it is life changing and the new normal is not the same normal as other kids.

Participant 5 added that she was very shy about posting.

> I do not post a lot about cancer in general, nothing specific about my son or his pain, and he does not have a page, I do general posting like September is Blood Cancer Awareness Month, there are 1.4 million blood cancer survivors in the U.S. and in general.

Participant 7 went on Facebook to look for answers for her son's medical experiences with ALL. She recalled that she searched online during the induction phase for information on his medicine, the food he was eating during induction, and whether he should take his medicine with his meals. She checked Facebook daily for information on her son's ANC (absolute neutrophil count) and shared her family's experiences there too. She also asked questions about what might be coming up and what could they expect in the future.

> I searched out on line support, during induction being 4, we were trying to take his medicine with food with what he was eating during induction and what we were cooking. as it was insane how much he ate, but our concern was his phosphorus level. On social media, we were checking and sharing daily on ANC to come up and would ask what can we expect.

Participant 9 talked about the importance of talking to others, especially during hospitalization.

> It was helpful to use social media to communicate with others and talking about when you were at the hospital or when you get hospitalization and support from one another. I used Facebook and ALL websites for treatments on a regular basis.

> I initially talked about my daughter’s diagnosis and at that point, my world was turned upside down, [so] I asked about showing pictures of their children . . . They were doing amazing . . . It was nice to see people in different stages and especially knowing that they are doing well now.

All of the mothers had their reasons for connecting with others on social media, either to receive support or to ask questions about the different medical experiences and challenges they faced, or to be a resource for other parents going through similar challenges. They all felt the need to connect with other parents of children going through ALL.

In summary, the participants talked about their experiences with seeking support online even with the support systems they had at home. They had questions that they wanted to ask and felt they would find answers on social media. The participants reached out to social media for support and information, but their spouses and significant others did not. The participants talked about posting questions when their children were initially diagnosed but that over time, they did not post questions. Instead, they posted encouraging messaging and answered others’ questions.

Theme 4: Adjustments With COVID-19

In addition to the devastation from the diagnosis of ALL, the study participants faced additional challenges because of the COVID-19 pandemic. Feeling isolated was common, even when at the hospital with the medical team and other families. Participant

9 said that at the hospital, everything was closed, and there was no way of getting together with others to share what they were going through.

> We were all so isolated . . . you only see people in passing and [are] not able to stop and talk because you are not allowed to. It may take a couple weeks to notice what is going on when normally it won’t take that long as we should be able to communicate with others.

Participant 2 talked about needing a place for parents to talk to other parents who understand during the pandemic: “I don’t need Google to tell me things. I just need to hear from other moms and dads, and other people who are going through this and others that understand.” Participant 6 talked about wanting to help others because she did not want others to feel alone: “If what I went through will help someone else, that is wonderful because we cannot do it alone and from my point of view if you care enough to ask then you care enough to hear the answer.” Participant 6 explained how isolated she felt after she moved to Washington as they started treatments in New Mexico. She talked about how it took time to get better and the only friend she found, they could not play with as the mother of the child did not believe in immunizations and her daughter did not have an immune system due to treatments.

In addition to adjusting to feeling isolated and feeling the need to talk to other parents during the pandemic, all the participants shared about other ways in which they had to adjust to their child’s ALL treatment. Participant 1 said,

> The hospital started saying only one parent can stay in March or April, so we started taking turns, and when my husband was there the hospital said that they had changed the policy overnight and told my husband that we had to meet downstairs, and they changed the policy of how many people can be in the room and clinic, only allowing one parent. We realized that the hospital was changing their policies because of Covid.

Participant 9's family experienced similar policy changes, necessitating the same tag-team approach with her husband: "When my husband came we would trade, I would go home and vice versa." Participant 6 also talked about changes at the hospital necessitated by the pandemic's spread.

> We get a call saying the policy has changed and only one parent can come to the clinic. What???? And this is like overnight they changed. So we had to quickly readjust and talk with our daughter to see who she wanted to have with her. We had a feeling what she would say " Mommy," but we were not going to take that power of deciding away from her. She said Mommy, so off we go. That was the start of our Covid journey

Participant 2 also recalled adjustments they had to make for hospital stays and appointments.

> When she [her daughter] was diagnosed, they let both parents be there at the hospital/appointments, especially coming and going. When Covid first hit, parents were switching in the parking lot, which changed so they could be in the building

> but only one parent can spend the night and only one parent could go to appointments.

She also discussed her relief when the restrictions started lifting.

> It was nice as I would carry a lot of anxiety going into the appointments, so it was nice that he [her husband] could be there with me. We could walk outside to get coffee . . . He is better at distracting, and I am the comfort and cuddly . . . It was wonderful when we could divide.

Participant 5 talked about being told to stay home and to come to the hospital only every 2 weeks. She recalled that the physicians did not know what was really going on at that time and said,

> The worst part of Covid was that doctors did not know. The beautiful team would tell me you have to stay home, just like that, and we will figure out about treatments, but we still don’t know if [treatment would be] at the clinic, home, hospital. I said, “What are you talking about? He needs his treatment and we know what treatment means, it means life” [she was tearful].
>
> His treatments never stopped, we went to the hospital every 2 weeks during Covid. We did everything every 2 weeks, chemo, blood work . . . and in the pandemic in New York, had family or friends drive me to the hospital, did not take public transport, I was so scared, so I would put two masks on him, protective shields and gloves, gown, it was a crazy thing. The rule was he does not touch anything, we wore gloves, I push the door open, I will touch so that he

> will walk behind me and not touch anything, we were afraid for Covid because we did not know.

Participant 7 talked about isolation from family as a challenge during the pandemic as they were not able to have people over to their house. She explained,

> We have people who wanted to come visit, they visited through the window, so if it was cold outside, we were visiting through the front window and if it was nice outside, we would sit out together. Our church did a big parade when he came home, and people would stop by during the weeks and months to visit outside as gathering at the church stopped too.

Participant 9 shared frustration for things opening up as COVID-19 numbers went down. She said that

> It is harder now because we are opening up because it would be easier if things were closed [isolated] because everyone will be in the same situation ,all wearing masks and no exceptions. What is nice is because with Covid, my daughter understands the importance of wearing a mask; she is used to doing the precautions, so Covid-wise, we are good.

Some participants identified being happy about having to make these adjustments. Participant 7 talked about not missing out on things during the pandemic.

> We missed out on things, but we really did not miss out on a lot because there was not a lot of things going on because of Covid. The church did outside drive-through service and they would put it on Facebook. We still use that. Preschool

> was already virtual and it got cancelled.Our kids program at the church was not going on, so we were not really missing out too much. Selfishly, Covid-19 was a good and bad thing because in a way, our son was missing things because he was sick, but he really was not because others were missing things because of Covid.

Participant 8 talked about the kids keeping their masks on when they went back to school and that this adjustment was a good thing: “Going back to school was for more the mental health for all of us.”

The participants also discussed what school was like for their children during the pandemic. Participant 1 talked about how it was nice that her child did miss a lot of school and other extracurricular activities just because she was sick and that everyone was missing out during the pandemic. She said,

> It was a good thing that everything was shut down, we did not have to deal with everyone going to school, everyone going to gymnastics, everything was closed. Emotionally it was good. Emotionally, Covid was not a stress, everything was shut down, everyone was home except when we had doctor’s appointments, and she [her daughter] did not have to miss school because everything was shut down.

Other participants talked about their children wanting to go back to school. Participant 2’s daughter wanted to go back to school and start swimming again. She was diagnosed in October 2021. School had been virtual, but her brother went back to school in person. She was able to return to swimming but she has to have own lane due to social distancing requirements.

Other participants expressed hope that their children would be able to start school on time. Participant 7's son was 4 years old, and her family's goal was that he would go to kindergarten in person beginning in the fall. Participant 3 said her daughter was 3 years old and was not in school, "But we are hoping maybe parttime preschool in the fall, still playing with the idea definitely something to talk about and see what the doctors will say." Participant 6 said that her daughter was in kindergarten when she was diagnosed. She called the school's director and decided to pull her out of day care. Since then, her daughter has attended kindergarten online, in a hybrid classroom, and then in person.

> When they did the hybrid our doctor gave us the green light, absolutely go for it. In March/April, they brought all the kids back to school and the doctor said to get her in school, get her socializing. She loved going to school and we had the arrangement with the nurse on what to do, what the next steps were, what we needed to do. All was planned out and she did not need it, she never even went to the nurse's office.

Another adjustment was attending school at home. Participants 4 and 5 both talked about school sending teachers home. Participant 4 talked about a teacher from the district assigned to her daughter for school at home. The teacher coordinated work needed to do to keep up with schoolwork.

Participant 5 talked about the challenges with schooling for her son, specifically how changes in how her son was instructed because of Covid resulted in his feeling like he was not learning anything.

> School was tough . . . He was diagnosed in September. The first month we were in the hospital, he did nothing about school, then after that the school sent private teachers . . . they came to the house every day. Then Covid hit, so the teachers went home, and my son was in school from home. Then in June 2020, the school said he passed everything, but my son would say "I did not learn anything." I said, "Miho, it's okay, right now, this is not priority." Now September 2020, we start everything online, students, teachers, everything. Then he would say to me "I am not learning anything," so I just told him to do what he could.
>
> At the end of the second year, Participant 5 and her son talked with her son's counselors and told them that he felt he did not know anything. The counselor said it was not anyone's fault, including the teacher's. Her son also asked if he could repeat the grade but was told he could not as he had passed everything.

Summary

The research question that was the focus of this study was: How do parents of children diagnosed with ALL and receiving treatment describe their experiences of support, including online support through social media, during the COVID-19 pandemic? All of the participants shared their challenges from the time of diagnosis and their adjustments with COVID-19 pandemic. Analysis of the data from the participant interviews showed that most participants searched for online support almost immediately. However, they did not continue to post about the challenges they were facing for various reasons, including privacy and wanting to be a support for others after the initial diagnosis period and asking all of the questions they had. They remembered how nervous and scared they were initially. They also wanted to support others with encouraging words.

All the participants were mothers and had support system at home. Nine were married or had a significant other, and either had other family members or friends to help them during treatment. Even with support at home, most of the participants initially reached out to social media for support when their children were diagnosed with ALL. Most of the mothers would access social media but not post about their own issues. They instead provided information that would be helpful for others and offered support for others going through challenges such as initial diagnosis or challenges at other junctions during the treatment process.

In Chapter 5, I interpret and discuss the findings. I also provide recommendations for practice and future research and detail the study limitations. The chapter ends with a summary and a discussion on implications for social change.

Chapter 5: Conclusion and Recommendations

The purpose of this generic qualitative study was to investigate the experiences of support, including online support through social media, of parents of children diagnosed with ALL and receiving treatment during the COVID-19 pandemic. ALL is the most prevalent form of leukemia among children (Huang et al., 2018; Leibring & Anderzen-Carlsson, 2019; National Cancer Institute, 2020). Parents do not wish to hear that their children are sick. Being told their children have cancer can lead to anxiety and depression (Cusinato et al., 2017; Pergert et al., 2016; van Oers et al., 2014). When a child is diagnosed with ALL, the parents' reactions can include shock, disbelief, and fear of the unknown (Cornelio et al., 2014; Malpert et al., 2015). Professional support is available for parents going through the challenges of having a sick child, but what was not known was how parents experienced support, including support through social media as they coped with and cared for their children with ALL during the COVID-19 pandemic.

A key finding in this generic qualitative study was that most parents sought support online when their child was first diagnosed with ALL and while in the hospital. They asked questions and wanted to know if there were others experiencing the same devastation they were going through. As they continued to look at the online support, they found it bothersome when others posted about concerns of their children such as relapse and complications that other children were experiencing as they were concerned about their own children experiencing the same things. What came from the participants was that most of them decided to post about general information on leukemia or post pictures of milestones such as reaching maintenance or knowing that they were approaching end of treatment.

In this chapter, I provide an interpretation of the findings presented in Chapter 4. Following this are discussions on study limitations and recommendations. I conclude with a section on social implications and a summary.

Interpretation of the Findings

I conducted this study to gain a better understanding of the parents' experiences with support, including online support, received during COVID-19 when their children were receiving treatment for ALL. The following interpretation of the study findings reflects the data collected from the interviews conducted with the participants, the research question, and the research presented and reviewed in Chapter 2.

The theoretical framework for this study was Lazarus and Folkman's (1987) transactional theory of stress and coping. This theory explains how people cope with their emotions during stressful times in life. It emphasizes the perception of the stressful event instead of the event itself (Biggs et al., 2017). If there is one key takeaway from the analysis of study findings, it is that having a child diagnosed with ALL and going through treatment is extremely stressful for all involved, including the parents.

ALL is the most prevalent form of leukemia among children, and more children are living beyond the illness. However, the fact that an ALL diagnosis is no longer a death sentence does not mitigate the issues parents deal with, including emotional, financial, and social stress leading to depression, anxiety, and posttraumatic stress.

Cornelio et al. (2014) explained that mothers shared feelings of isolation and loneliness leading to depression and the sense of emptiness. Lakkis et al. (2016) talked about feeling overwhelmed leading to lack of sleep, having anxiety, depression, financial challenges, and how to care for the other children when they are attending to their ill child.

During the interviews, the participants talked about the unusual events that occurred with their children and led to either going to the emergency room or calling their doctor's office, which resulted in ALL diagnoses. These events were stressful for the study participants as evidenced from their voices during the interviews when they expressed the stress and devastation they felt and experienced when their children were diagnosed. In a study on relationships between health care professionals and caregivers of cancer patients, Oh (2017) also found that certain aspects of the treatment process, including communication issues with the health care team, led to increased stress for the parents. Children diagnosed with ALL experience trauma caused by painful invasive procedures, frequent hospitalizations, separation from family and friends, and not being able to go to school or play in the playground with their friends (Dupuis et al., 2015; Leibring & Andérzen-Carlson, 2019). Although these researchers focused on children with cancer and their experiences, I related their findings to how the parents were doing when their children were diagnosed with ALL and how they handled treatment and hospitalizations.

The study participants very openly expressed their devastation and not knowing what steps to take next other than to follow what the medical team said. Most of the participants found emotional support on social media shortly after diagnosis. One participant talked about reaching out to social media after her family moved from one state to another as she lost the support she had from her friends when they moved even if she was moving to be closer to her family.

For the present study, the other factor to take into consideration was the COVID-19 pandemic, which added a layer of stress to the parents' experiences. Although the mothers talked about the initial devastation, some of the mothers talked about the changes and the adjustments they had to make because of COVID-19. Initially, only older cancer patients were affected with COVID-19 and mostly men (Liang & Yang, 2020), and children diagnosed with leukemia was not affected receiving treatment (Hrusak et al., 2020). Participants in the present study noted that their children were already doing school virtually after COVID-19, so when the ALL diagnosis came, their lives related to school did not change because they were already home. One of the changes was the requirement to wear a mask and only allowing one parent to be at the hospital with the ill child. One of the mothers shared her concern about her daughter going back to school in person as she had lost her hair and it had not grown back in yet. She stated that they were talking about creating a hat or a wig to help her daughter deal with being bald.

Although dealing with COVID-19 was a challenge as a pandemic worldwide, and the participants for this study shared how the pandemic affected them such as going to appointments at the clinic and hospitalizations, dealing with school was not a challenge as everyone was in school virtually. Some of the mothers found it a relief to be isolated and felt more stress when reopening began and children returned to school in person.

Limitations of the Study

The first study limitation is not able to generalize the study findings to larger populations due to the study methodology. Rodriguez and Smith (2018) described qualitative research as research reflecting people’s personal experiences and viewpoints. As such, the findings reflect these unique experiences, which may differ from those of others. The second limitation is that the information gathered was limited to the perspectives of mothers of children with ALL as they were the only study participants. The third limitation is that the information gathered in this study is limited to individuals who could access social media on the internet. There may be differences if I had interviewed individuals without this access. The fourth limitation is most of the participants were from the United States. As such, their viewpoints primarily reflect those of mothers in the United States. The last limitation is that all participants had family support. As such, what parents without support systems experience and feel is not represented in the study findings.

Recommendations

This study’s focus was on the experiences of mothers of children living with ALL and undergoing treatment during the COVID-19 pandemic. Considering the limitations previously discussed, I next make the following recommendations for future research. I then make recommendations for practice in the Implications section.

Mothers responded to my flyers and participated in this study. Malpert et al. (2015) found that more mothers experience PTSS than fathers. This represents a possible gap in understanding of the fathers’ involvement and experiences. Future research on fathers of children whose children are diagnosed with ALL may help to better understand their experiences. Conducting research with fathers and learning their global perspectives will present experiences of a specific population with something in common (see Kahlke, 2014).

Second, conducting further research on what the parents of children with ALL experience may help practitioners provide the support these parents need and encourage the parents to participate in online support specific to parents with children with ALL. The mothers in the present study believed that the people who understood them best were other parents of children with ALL. They voiced a lack of understanding from their medical teams. Medical teams gaining the trust of the parents of children with ALL will result in positive social change as the parents will feel more supported, especially during the COVID-19 pandemic.

Implications

The literature reviewed for this study reflected information on cancer, pediatric ALL, treatment options, and the stress parents of ALL patients experience. In the middle of the chaos of dealing with their children’s illness, parents experience anxiety, depression, and feeling uncertain about what is going on and about the future (Aburn & Gott, 2014). Parents caring for their ill children experience feeling isolated from the world (Kim et al., 2017). They may also feel guilty for wanting a break due to exhaustion from taking care of their ill children (Kim et al.). Some studies showed that mothers felt better when they spent time with others going through the same experience, emphasizing the importance of social support (Cusinato et al., 2017).

When children are diagnosed with ALL, some parents have support, and some do not. For many parents, regardless of existing support, social media can be extremely important in helping them cope with their children's illness (Gage-Bouchard et al., 2017). Gage-Bouchard et al. (2017) noted the importance of parents discussing whatever that is on their minds on social media that they are not able to discuss with friends or family members. When I talked with the mothers in the present study about their sense of isolation, their comments led to my identifying a gap in the knowledge about the COVID-19 pandemic and its impact on parents of children receiving ALL treatment. When the mothers talked about the isolation due to COVID-19, they recalled gravitating toward talking with other parents of children with ALL, leading them to searching for support on social media. Some of the participants talked about the confusion with what to believe with COVID-19, and depending on the types of questions asked on the website, the site's administrative team would discontinue the discussion online because they did not have the answers about COVID-19.

Lazarus and Folkman's transactional theory of stress and coping was this study's theoretical foundation. It emphasizes the perception of stress rather than the event that caused the situation and how to cope with the situation (Biggs et al., 2017). Parents' experiences and coping with their child’s illness, and now having to cope with COVID-19 is what the parents had to cope with. After finishing the nine interviews, it became evident that dealing with COVID-19 was tolerable in addition to how the initial ALL diagnosis and the treatment affected the parents and how they coped with the situation. Most of the mothers in the study reached out to social media during the first hospital stay. This leads to believing that parents needed the support from others experiencing similar situation. After conducting the study, it became evident that the participants knew a lot about ALL, but they felt the ability to reach out to other parents about the ALL illness was helpful for them to understand and be able to relate to the parents.

Findings from this study established the need of ongoing support for parents with children with ALL as being vital beyond diagnosis as questions continue to rise during treatment. Offering different ways of providing support is important, including in person, via telephone, and through social media. Interdisciplinary teams work with the parents and children diagnosed with ALL (Slabbert & Steenkamp, 2018). In addition to these teams, I recommend making a computer or laptop available to the parents of children diagnosed with ALL so they can access social media and connect with other parents through Facebook and other social media. This will give the parents options to either reach out to the interdisciplinary team for support or to reach out to other parents experiences similar experiences through Facebook/social media. This also gives professionals options as they are aware of mothers’ challenges but not always sure of which strategies to use to help (Gilson et al., 2018).

Because of the limitation of majority of the participants being from the United States, reaching out to organizations worldwide may provide global perspectives. Enhanced cultural awareness for the interdisciplinary team may facilitate better understanding of the parents' experiences.

Conclusion

Parents are understandably traumatized when their children are ill, and this is especially so when receiving a cancer diagnosis for one's child. In this study, I explored the lived experiences of parents of children who were diagnosed with ALL, a highly treatable form of childhood cancer but still a disrupter of quality of life. Interviews with the study participants underscored the importance of support during trying times. Analysis of the results showed that all participants had good support systems to help them navigate the difficulties ahead. Even with a good support system, relying on social media became important during the COVID-19 pandemic.

The value of support during trying times cannot be emphasized enough. My hope is that all parties involved in ALL treatment, and especially medical professionals and teams, use this study's findings to help them establish stronger and more supportive relationships with parents of children undergoing ALL treatment. I also hope that these results bring greater awareness of the importance of support, including online support, to the medical profession. As noted in this study, the medical team's key focus is on treating the sick child, and while team members provide support throughout the treatment process, it is largely limited to this focus. The parents' emotional needs are not typically a key point of consideration. I also hope that the medical profession recognizes the importance of continued support for the parents after treatment completion.

This study's findings underscore the importance of having multiple sources of emotional support. This includes online support for all parents. Having computers available at the clinics so that any parents can participate on social media can help these parents access support from other parents with same or similar experiences, which the study participants identified as a key reason why they used social media. Whether they choose to access social media or prefer to remain with more traditional sources, providing the support needed during traumatic times not only can help to address emotional, social, and financial stress in the parents while their children are being treated for ALL, it can benefit the parents and their children and help them prepare for the road ahead.

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Appendix A: Interview Guide

Date:________________________________

Location:______________________________

Name of Interviewee:_____________________

Interview Questions

RQ: How do parents of children diagnosed with ALL and receiving treatments seek and receive support through Facebook during COVID-19 pandemic?

Tell me about your family members.

1. Tell me about when your child was diagnosed with ALL/Cancer?
2. Who helped you during this time? Describe support system?

   Probing question: How about support on-line?

3. Where were you when you first heard about COVID-19? Any news about it being a pandemic?
4. Was your child receiving treatments when you heard about the pandemic/where in the treatment process was your child?
5. What was your schedule like?
6. What changes did you have to make to adjust since the pandemic?
7. How was on-line support for you?

Probing Question: Where and what do you post on social media?

8. How old is your child?

9. Were they in school?

Appendix B: Recruitment Flyer

I WANT TO HEAR YOUR JOURNEY

As a parent of a child with acute lymphoblastic leukemia (ALL), what is it like dealing with COVID-19, illness, and treatments?

Can I hear your story, journey, and experience? We can talk on the phone so I don't interrupt your busy day any more than necessary.

I am a doctoral student at Walden University, and I am doing this study is to better understand your experience as parents of children diagnosed with ALL and receiving treatments during the COVID-19 pandemic.

PLEASE CONTACT ME DIRECTLY and we can talk more.

I hope to hear from you soon.

Name: Laxmi Seth

Email address: [redacted]
Phone #: [redacted] **(texts or phone calls welcome)**

If I don't answer, PLEASE leave me a message with your name and a way to contact you