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Challenges Faced by Mothers Caring for Children with Leukaemia During COVID-19 Pandemic: A Qualitative Study

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Purpose: This study aimed to investigate the experiences of parents who care for children diagnosed with leukaemia. This paper is focused solely on reporting the interview findings from participating mothers regarding the challenges of caring for children with leukaemia in the context of the COVID-19.

Design and methods: The study took place in a Jordanian hospital where a descriptive qualitative design approach was applied on one oncology floor and an oncology clinic. Semi-structured interviews were conducted with mothers of children aged 1–12 with acute lymphoblastic leukaemia (ALL). Inductive thematic analysis approach was undertaken. Written consent was obtained from all participants.

Results: Fifteen interviews were conducted with fifteen mothers. Four major themes reflect the different challenges parents and children face during the COVID-19 pandemic: children refusing to wear masks, social isolation, family relationship and financial concerns.

Conclusions: The findings of the current study present important data for health care professionals to help them understand the challenges faced by parents and children with leukaemia, especially during the COVID-19 pandemic.

Practical implications: This study suggests activating emotional support teams in hospitals. These teams can actively help mothers express their concerns and worries which might otherwise foster self-blame, guilt and isolation.

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Introduction

Childhood cancer is a persistent worldwide health problem. Approximately 300,000 new cases are diagnosed each year (WHO, 2018). The most common category is leukaemia, with a five-year survival rate of 84 to 90% (Tai et al., 2017; WHO, 2018). Children with cancer in low- and middle-income countries are four times more likely to die than children in high-income countries (WHO, 2018). In Jordan, cancer is responsible for approximately 14.6% of deaths from non-communicable diseases (WHO, 2018). In 2015, the crude incidence rate for all cancers in the pediatric age range was 89.2 per million (99.4 and 78.5 per million for boys and girls, respectively) (Jordan Cancer Registry, 2015). The most prevalent types of cancer in Jordan are leukaemia, lymphoma and brain tumours (Jordan Cancer Registry, 2015).

Anxiety, depression, and post-traumatic stress are examples of parents’ detrimental psychosocial results when their children have cancer (Ljungman et al., 2014; Sulkers et al., 2015; Sultan et al., 2016; Vrijmoet-Wiersma et al., 2008). Furthermore, health, environmental, financial and emotional pressures confront parents when their children have leukaemia (Saadah et al., 2014). One instance is how financial problems result from the need to cover medical costs for treatment, restrictions on working away from home and difficulties committing to full-time employment, due to parents being principal care providers (Saadah et al., 2014). Meanwhile, deleterious impacts on care providers’ emotional state and a greater risk of depression have been linked to limited social assistance and family earnings, reduced overall health status of care providers, their greater anxiety and more time spent on day-to-day care for their children, thus exacerbating the pressure on them (Wang et al., 2017).

The development of parental careers can also be undermined when their child develops cancer. According to research, the standard of living of fathers to a lesser extent than they do mothers (Rensen et al., 2019). Wiener and Battles’ research that investigated how the parental relationship was influenced by having a child with cancer identified that of the 192 parent participants, a negative effect...
on the spousal relationship was reported by 40% of individuals, with 3% having ended their relationship and 3.6% thinking about doing so. Nevertheless, a more robust marital relationship was noted by approximately 26% of respondents (Wiener et al., 2017). The spousal relationship was found to be placed under the greatest pressure during their child’s deterioration and spells in hospital (Wiener et al., 2017). The confirmation of cancer and need for treatment causing stress, a sense of being unappreciated, the difficulty of communicating and spending time together at such points, as well as the sense of emotional detachment of one’s partner, are the likely causes.

Children with cancer face several challenges during the COVID-19 pandemic (Seth, 2020). These include increased risk of death either from cancer or serious complications due to immunocompromised immunity (Hsu & Wang, 2020; Lewis, 2020). Patients who receive anti-cancer therapy have a higher risk of developing infective complications than healthy people because of immunosuppression (Ruggiero et al., 2020). Moreover, several procedures, such as chemotherapy, might be delayed as a result of COVID-19 infections overwhelming hospital facilities (Ding et al., 2020). Further concerns for patients with compromised immunity include a lack of Personal Protective Equipment for medical personnel (Seth, 2020), limited blood supplies, and ICU beds’ unavailability.

Difficulties also surround hospital consultation due to numerous institutions acting as management centres for the pandemic (Seth, 2020). This makes it problematic for scheduling outpatient consultations. Additionally, the inherent suppression of immunity children suffer from cancer treatment, combined with frequent visits to health care facilities, increases their susceptibility to coronavirus (Hsu & Wang, 2020). There is also a treatment delay because of social distancing (Cinar et al., 2020) and a shortage of blood supplies (Yadav & Pal, 2020).

Several strategies are recommended to enhance the management of COVID-19 (Bouffet et al., 2020). For example, official advice is to stay at home, maintain social distancing, frequently wash and sanitise hands with antiseptic solutions and avoid touching the eyes, nose and mouth wherever possible. Couples parenting a child with leukaemia must consider taking the required steps to protect their children from increased stress and anxiety levels.

Limited information exists on the prevalence of COVID 19 in children with cancer (Choi et al., 2020). Additionally, the impact this virus may have on the pediatric population and the management of children with cancer remains unclear and poorly documented (Baruchel et al., 2020; Bouffet et al., 2020). However, information related to the challenges facing parents in such a situation is vital. Exploring mothers’ experiences and challenges of caring for children with leukaemia can offer nurses and health professionals the relevant culturally sensitive knowledge for providing appropriate support and care (Abum & Gott, 2014). Therefore, this study’s purpose was to investigate the experiences of parents who care for children diagnosed with leukaemia. This paper is focused solely on reporting the interview findings from participating mothers regarding the challenges of caring for children with leukaemia in the context of the COVID-19.

Methods

Study design

A descriptive qualitative design approach was adopted in this study. Qualitative descriptive studies have been used to provide a comprehensive summary of events using the everyday terminology employed in those contexts (Sandelowski, 2000). We used this method as it has been identified as appropriate for research questions focused on understanding the who, what and where of events or experiences and to gain insights into poorly understood phenomenon (Kim et al., 2017). In the current study, utilizing a descriptive qualitative design approach provided detailed insights into parental experiences caring for children with leukaemia during the COVID-19 pandemic.

Study setting

This study was conducted in a children’s hospital in Amman. This hospital contains a specialized children’s cancer department which receives a variety of cases from across Jordan.

Sampling strategy

This research adopted purposeful sampling. Given the limited number of children being admitted to hospital during the COVID-19 pandemic, their recruitment for the study was based on their presence in hospital having been specifically admitted to the aforementioned departments where the research was being conducted. Family carers were considered eligible if they had a child aged 1–12 years old diagnosed with leukaemia and attending care in the study hospital’s Pediatric Oncology Clinic (POC) or pediatric oncology department. Family carers were considered ineligible if health care professionals thought the child too sick and distressed; the family carers have communication barriers.

Access and recruitment

A research assistant visited the child oncology units to familiarize themselves with the setting, provide information about the study to the nursing and medical administrative team and determine interest in the study. The head nurses identified the eligible parents; they were then approached by the research assistant to discuss the research and answer any questions. All parents were given documents inviting them to join the study and providing further information about it. They had approximately 72 h to think about whether or not they were willing to join the study. Seventeen mothers were approached for their participation, although of these, two mothers refused to participate. One of the mothers who declined participation had provided her consent one day after she was asked, although she later declined having discussed participation with her husband and family. The other carer had some family visitors at the time of being approached by the nurse, which may have placed her under a degree of social pressure.

Methods of data collection

Open-ended, semi-structured interviews promoted the conversation flow and explored specific contexts (Coad et al., 2015). Initial interview questions based on the literature but as new insights and ideas emerged, questions were refined (Table 1). The interviews were conducted by one of the co-authors (AK). They lasted between 30 and 60 min. All interviews were audio-recorded using digital recorder machine, which enabled the researcher to concentrate on listening to the interviewees rather than being distracted by detailed note-taking. However, a few written field notes were taken, especially for the non-verbal communication that occurred. At the end of each interview, the researcher summarised what was covered with the interviewees for

| Table 1 | Interview guide questions. |
|---------|---------------------------|
| Question |                          |
| 1. Could you describe to me what the differences in terms of caring for your child are? What about the COVID-19 situation? Tell me more, please. |
| 2. Could you describe how you tried to protect your child in this situation? |
| 3. What are the challenges you face in caring for your child, especially during the corona time? Explain how this affects the life of your family |
| 4. How you try to cope with these challenges? Explain more, please |
| 5. What are the facilitators that helped you to care for your child? |
| 6. Do you have any support system that helped you to cope well in this crisis? |
| 7. What is the effect of corona on your care plan for your child at home or the hospital? Clarify more, please. |
verification and strengthened the rigour. The interviews were held individually with the participants in an empty lecture hall in the hospital. The interviewees were given sufficient time to answer the questions, with no time pressure or coercion. The data collection concluded once the 15 interviews had arrived at the point of information saturation; this arises when no new information or insights can be derived from the data.

Data analysis

In accordance with the extant research (Van Nes et al., 2010), the language that the data was collected in was retained for the analysis. No analytical issues would arise from assessing information in a language that was not the native language of the researchers, namely Arabic. This research’s inductive thematic analysis approach is explained stage-by-stage as follows. Firstly, the researchers became acquainted with the collected data, reading through it a number of times each. The initial codes were indicated and suggested in notes made by the principal researcher (MA) as part of this phase. Secondly, the initial codes were produced. Open coding was pursued at the outset of the analytical stage, which refers to how MA undertook coding of any data aspect that could potentially be insightful (Merriam & Tisdell, 2015). This research also adopted analytic coding, through which meaning is meticulously appraised, and some explication is offered, rather than simply description (Richard, 2015). The co-researchers (AK and FT) appraised and provided recommendations on the coding framework that was sent to them. The third stage occurred following the completion of the coding, involving identifying possible themes and categories from the varied codes, a process that MA undertook. Themes were developed from the codes by MA with the assistance of visual depictions in the form of thematic maps, which facilitated identifying the varied levels of codes and themes’ interrelationships. Certain amendments were made to the established theme and code relationships during several meetings with the co-authors, AK and FT. The fourth stage was the themes’ definition and naming. The data was easily comprehensible to the reader; MA sought to develop succinct and pithy themes (Braun & Clarke, 2006). To explore and verify the final themes once developed, MA presented the research group (AK and FT) with the thematic structure.

Ethical considerations

Ethical approval for this study was obtained from the Institutional Review Board of the Jordanian Royal Medical Service/Queen Rania Al Abdullah Hospital for Children (3/2020). Participation was voluntary. The information sheets and informed consent con

Study rigour

The study’s rigour was attained in several ways. For example, the findings’ credibility was enhanced using a peer debriefing technique (Lincoln & Guba, 1985). The Principal investigator (MA) distributed examples of the interview transcripts to the co-investigator (FT) and (AK) for their input. Furthermore, MA sent a coded interview to the co-researchers to gain their opinion on the coding process and decisions. Additionally, MA provides NVivo report samples to the other researchers to understand how she developed the categories and themes from the preliminary codes. A further approach attempted to achieve credibility was summarising the main points discussed during the interviews with the participants directly following the interview’s conclusion. Moreover, we sought to enhance the findings’ transferability by providing examples of the raw data, for instance, direct quotes from the participants, so that alternative interpretations could be considered (Dawson, 2009; Stake, 1995). The dependability was ensured by verifying the data analysis process with the co-investigators, ending them samples of the data analysis reports (extracted from NVivo) to evaluate the analysis process and it is quality.

Findings

Participants’ characteristics

Fifteen family carers, all of them mothers, participated (Table 2). They came from different cities in Jordan including Amman, Jerash, Ajlun and the Jordan Valley. The mothers are married and live with their families. The majority of mothers had a primary or secondary school level education, with two educated to diploma level. Four mothers had acquired undergraduate degrees. In terms of employment, two had jobs, two were carers, and 11 were housewives. All the children were diagnosed with acute lymphocytic leukaemia (ALL).

Themes

Four major themes reflect the different challenges parents and children face during the COVID-19 pandemic: children refusing to wear masks, social isolation, family relationship and financial concerns.

Refusing to wear masks

Several mothers (60%) reported that their children refused to wear personal protective equipment, especially face masks, designed to protect them from COVID-19. The mothers reported different reasons for their children’s refusal to wear masks. For instance, mother (1) said their children felt sensitive wearing face masks while their friends and peers did not:

No, no, even hygiene, she refuses to put she says why me to put I say to her, Mum, from the corona from the corona … see people see how people talk about it … I usually help her to wear mask from outside the home until we arrive my father-in-law’s home … but when we arrive at my father-in-law’s home, she usually says I feel tired … remove it … she does not accept … (M1).

Other mothers (27%) reported face masks left their children feeling uncomfortable or irritable:

She consists crying to remove them … she refuses to wear them … I just sterilize her hands (M15).

Another mother (11) mentioned that she works hard to protect her child from contacting people. However, her child was unhappy wearing the face mask:

Mother: My kids go outside to play with their neighbours … but my daughter does not go to play with them … I usually tell them … do not contact her … clean your hands …AK. What about her … does she wear the mask? Mother: Yes, I wear her but not always … it disturbs her … she does not like it … no not always (M11).

Social isolation

All mothers participating in the study exhibited a tendency towards social isolation. This isolation started before the corona outbreak due to caring for their ill children, although it became more pronounced after the pandemic struck. The majority of mothers (65%) reported that they closed themselves off and focused their attention on their children.
Table 2

| Interviewee No. | No. of interviews | Settings | Child’s occupation | Child’s age | Child’s gender | Mother’s education | Mother’s age | Time since diagnosis | Mother’s occupation | Mother’s age | Diagnosis | Mother # |
|-----------------|-------------------|----------|--------------------|-------------|---------------|-------------------|--------------|---------------------|-------------------|--------------|------------|---------|
| 1               | 1                 | Bed side | Housewife          | 10 yrs.     | F             | 35 yrs. Tawjihi   | 6 M          | 3 yrs.               | Tawjihi           | 37 yrs.      | ALL        | 1       |
| 2               | 1                 | Bed side | Housewife          | 9 yrs.      | M             | Secondary school  | 4 yrs.       | 3 yrs.               | Housewife         | 37 yrs.      | 2 ALL      | 2       |
| 3               | 1                 | Bed side | Housewife          | 26 M.       | F             | Diploma           | 15 M.        | 2 yrs.               | Housewife         | 29 yrs.      | ALL 5 yrs. | 3       |
| 4               | 1                 | Bed side | Housewife          | 18 M.       | M             | Tawjihi           | 2 M          | 2 yrs.               | Housewife         | 27 yrs.      | ALL 2 yrs. | 4       |
| 5               | 1                 | Bed side | Housewife          | 17 M.       | F             | 8th grade         | 2 M          | 2 yrs.               | Housewife         | 42 yrs.      | ALL 2 yrs. | 5       |
| 6               | 1                 | Bed side | Housewife          | 5.5 yrs.    | M             | BSC               | 1 M          | 1 M                  | Housewife         | 28 yrs.      | ALL 1 M.   | 6       |
| 7               | 1                 | Bed side | Teacher (left)     | 11.5 yrs.   | F             | Primary school    | 2.5 yrs.     | 5 yrs.               | Employee          | 50 yrs.      | ALL 2.5 yrs. | 7       |
| 8               | 1                 | Bed side | Employee           | 12 yrs.     | M             | BSC               | 2 yrs.       | 3 yrs.               | Employee          | 42 yrs.      | ALL 2 yrs. | 8       |
| 9               | 1                 | Bed side | Housewife          | 10 yrs.     | F             | Secondary school  | 3 yrs.       | 3 yrs.               | Housewife         | 44 yrs.      | ALL 3 yrs. | 9       |
| 10              | 1                 | Bed side | Housewife          | 6 yrs.      | M             | BSC               | 3 yrs.       | 3 yrs.               | Housewife         | 30 yrs.      | ALL 3 yrs. | 10      |
| 11              | 1                 | Bed side | Housewife          | 21 M.       | F             | Tawjihi           | 1 yr.        | 6 yrs.               | Housewife         | 32 yrs.      | ALL 1 yr. | 11      |
| 12              | 1                 | Bed side | Accountant         | 2.5 yrs.    | F             | BSC               | 1 M          | 7 yrs.               | Accountant        | 37 yrs.      | ALL 1 M. | 12      |
| 13              | 1                 | Bed side | Housewife          | 15 M.       | M             | 8th grade         | 3 M          | 8 yrs.               | Housewife         | 36 yrs.      | ALL 3 M. | 13      |
| 14              | 1                 | Bed side | Housewife          | 3 yrs.      | F             | 10th grade        | 2 yrs.       | 2 yrs.               | Housewife         | 22 yrs.      | ALL 2 yrs. | 14      |
| 15              | 1                 | Bed side | Employee (left)    | 5 yrs.      | F             | Diploma           | 5 yrs.       | 5 yrs.               | Employee (left)   | 35 yrs.      | ALL 5 yrs. | 15      |

* In Jordanian culture, housewife indicates that the woman is not working but she stays at home for childrearing of children

Some children suffered due to being alone while others preferred isolation. For some, being alone is an unnatural situation, but here it was unavoidable because of, for example, the social stigma connected with the disease. Mothers 1 and 9 have children who were shamed because of their conditions. Mother 9 was blamed for the illness of her child by her husband’s relatives. Child 9 preferred to be isolated because other children laughed at her baldness. The relatives of mother 9’s husband blamed her for the child’s illness, while mother 1 decided to distance herself after her sister-in-law’s children told her daughter her baldness was caused by chemotherapy:

Mother: Their way ... their way [of communication] ... I do not know how ... all of them know ... for example, the sons of my brother-in-law ... they always tell her ... why are you bald [the mother is crying] ... AK: How do you overcome this thing? Mother: I avoid getting outside home ... I do not go and return ... AK: What about her ... what was her response? Mother: She always says ... Mum, look how this speaks with me ... I brought her a wig ... its price is 50 JD ... but she did not like it ... Mum, I do not like it ... it disturbs me ... she said that I felt the head cap is better than the wig ... the son of my cousin removed the cap and she seems bald ... I avoid getting out because of that (M1).

Another mother (10) imposed isolation upon her child during the pandemic, although before corona, she permitted him to play with his friends:

AK: Do you permit your child to play with other children? Mother: Before corona, yes ... but after corona, no AK: How about your social relationship? Mother: I do not go neither return ... the benefit of my child is more important (M10).

Mother 8 noticed a significant change in her child and wanted him to return to school and have contact with other children:

First of all, to be cured ... then the education I will compensate for him ... and to return and mix up with people as he became isolated ... his mixing up with people around him significantly decreased ... (M8).

Mother 12 reported that, because of her work and childcare responsibilities, she does not have any social relationships:

AK: How do you describe your relationship with your neighbours? Mother: I do not have any social relationships, just relatives and work ... as I have a family with many needs and tasks (M12).

However, mother 6 considered it neither possible nor practical to isolate her 5.5-year-old child. Instead, she accompanies him wherever he goes:

AK: What are the precautions you took for his condition ... in home ... outside ... everything? Mother: Well ... now at home he plays with his father and his brother ... most of the time in front of my eyes ... I have fear that his brother to hit him or to take him outside the home ... I never permit him to go out except when I go with him ... around me ... Mum, I do not like it ... it disturbs me ... she always tells me ... and I prevent anybody from touching him ... he plays from a distance (M6).

The family relationship

Children’s illnesses put significant pressure on families. Several issues contribute to this stress, such as mothers’ insistence on accompanying their children during treatment and, from another perspective, the children insisting their mothers stay with them:

AK: Do you mind if somebody helps you in terms of staying with her at the hospital? Mother: No ... I want only myself to be with her ... (M11).

Several mothers (20%) felt responsible for childcare, although this had negative ramifications for their families. In some instances, mothers left jobs to look after their children, while others left the children with their families to care for them:

Mother: I left everything ... my work ... I told my boss in the work ... I sent my kids to my family ... my husband is at home ... I left everything and stayed with her ... with the medical care ... my opportunity is to stay with her ... my cognition is with her ... my Mum shared me in rearing of my kids ... so they are with honest hand ... so my aim of being with her is to relief her suffering (M12).

The majority of mothers (70%) revealed they treated their ill children differently due to the youngsters’ sensitivity and irritability. However, treating the children in a special manner left their other children feeling ignored:
AK: So, your daughter (X) … do you treat her in a unique manner?  
Mother: I take care of X more … but I treat X in the same manner as I treat them … but how can I tell you … I sleep near her at night but my other daughter tells me why you sleep near her, Mum, and something like this … I tell her because she is sick … she is sick … she has fever … fever … I am scared for her … my life changed … unlike if she is not sick … changed (M1).

The financial burden

Mothers 6, 9 and 15, because of COVID-19, suffered from a significant lack of financial resources which hindered opportunities to treat their children's conditions:

In the beginning, I was going and back using public buses … Right now, I need to use a taxi with corona … expensive, very expensive … you know, transportation is difficult during corona (M9).

Mother 15 postponed her future ambitions and plans, such as working and establishing her own home, to care for her child:

I had a job but I left it … I want to work in communication … we had a home … we built it but we did not complete it … because of the many financial commitments related to the disease … we are still in a rented house (M15).

Moreover, mother 6 encountered financial concerns when attempting to find treatment for her child. Meanwhile, mothers from rural areas, especially those from a low socioeconomic background, faced even greater economic hardships. For instance, transportation costs became more difficult during the pandemic, increasing the financial burden:

Honestly … the debts increase over us … my husband took a loan … and this is increased our suffering … there was a charity which gave us 150 JD … today we spent 60 JD … because my husband is coming and returning to hospital … I bring food with me to the hospital (M6).

Discussion

The current study investigated the experiences of mothers caring for children with leukaemia. The findings demonstrate that mothers of children with leukaemia faced several challenges and stressors that affected their abilities to cope with their difficult situations.

The current study's findings demonstrate that numerous children (60%) refused to wear personal protection devices, especially the face mask. Although the pandemic prompted strict regulations, such as the isolation of COVID-19-negative children to help advance their treatment (Baruchel et al., 2020), the children resisted wearing masks for several reasons, citing discomfort, restriction of movement and feeling different from their peers. For instance, mothers described their children as suffering from mood disturbances, irritability and nerves. This finding supports the conclusion of previous research (Pound et al., 2012; Williams & McCarthy, 2015), which showed that parents reported their children becoming “moody, emotional, aggressive and clingy”. This could be one of the corticosteroids’ effects on their children's behaviours (Williams & McCarthy, 2015). This research has expanded the current comprehension of the impact on children’s discomfort and social isolation stemming from the interventions taken to mitigate COVID-19’s spread.

The current study also found that caring for a child with leukaemia affected familial relationships. Mothers and children's long stays in the hospital affected the marital bond and other siblings' care. All mothers in the current study discourage their husbands from visiting their children in the hospital because of COVID-19 fears. The fear of exposure and social distancing strategies create anxiety and negatively impact the social support system (Klein et al., 2020), exaggerating the mothers' and children’s isolation. These findings substantiate previous studies (West et al., 2015), which found that caregivers of leukemia patients require longer stays in hospital than other caregivers and need to manage the complications resulting from highly toxic treatment (Pailler et al., 2016). The current study has extended these findings, identifying an original insight: the epidemic has increased and exacerbated the gap between family members. This diminished the direct contact between the father and the affected child, thus compounding the social distancing greater extent than previously.

The current study found that COVID-19 placed an extra financial burden on parents. For instance, aside from the medical cost, families spent significant amounts of money on travel and lodging during their children's treatments. These findings match other studies (Gemmill et al., 2011; Hagiwara et al., 2018; West et al., 2015; Wiese & Daver, 2018). The mothers in the current study prioritize caring for their children with leukaemia. Some left their jobs to care for their children, as shown in additional research (Naidoo et al., 2016; Neu et al., 2014).

Changing family, work and financial circumstances may lead to negative consequences including housing instability, interpersonal violence and child abuse (Centers for Disease Control and Prevention, 2020). This is congruent with other studies (Othman et al., 2011; Saadah et al., 2014). For instance, caregiving parents can experience financial difficulties due to an inability to work full-time or outside the home, medical bills and treatment expenses (Saadah et al., 2014).

Moreover, the current study demonstrates that mothers from rural areas, especially those with low socioeconomic background, faced greater financial distress in line with the findings of previous studies (Deniz & Inci, 2015; Lynagh et al., 2018). The current study's findings also established that parents suffered from a double economic crisis as a consequence of the COVID-19 pandemic, with the resulting crises linked to transportation scarcity and costs during the pandemic period. This is particularly true for those individuals living far from the hospital where the research was conducted.

This study has a key strength. The nature of the qualitative interviews increases the depth of understanding about the effect of the coronavirus pandemic. Having no information about corona’s psychosocial impact on carers of children with leukaemia motivates the need to acquire a thorough understanding of the pandemic. This will increase people’s knowledge base and increase the understanding of parents' burdens in such situations. This is the first study which sheds light on the effect of the COVID-19 pandemic on vulnerable immunosuppressive children with leukaemia.

Practice implications

The findings of the current study present important data for health care professionals to understand the contextual factors of caregiving can help nurses and health professionals provide support for caregivers. The study's current findings demonstrate that mothers can lack a support network, especially during the COVID-19 pandemic, making it challenging to face multiple challenges as they care for their children. Therefore, any holistic approach to the care of children with leukaemia or other types of cancer should include family caregivers' systematic support (Ferrell et al., 2017; Kearney et al., 2015).

Moreover, this study recommends activating emotional support teams in hospitals. These teams can actively help mothers express their concerns and worries which might otherwise foster feelings of self-blame, guilt and isolation (Naidoo et al., 2016). Additionally, frequent meetings involving other family members, especially fathers, can provide them with information to avoid misunderstandings, improve family cohesion, and increase familial support. Moreover, these discussions can reinforce fathers' role in supporting mothers and protecting the integrity of the family (Wiener et al., 2017). Finally, assessing mothers' coping mechanisms can help teams initiate strategies to assist them in adapting to their role of caring for children with...
cancer (Cypress, 2016; He et al., 2016), especially during a stressful life event such as the COVID-19 pandemic.

Limitations

This study also has its limitations. Since mothers form the focus of this study, data may be incomplete due to limited input from fathers due to restrictions caused by the virus. This study recommends involving health professionals, such as doctors and nurses, as study participants to obtain all perspectives and find solutions to decrease the risk of these challenges. Although the study findings cannot be generalized, the participants’ experiences and insights appear transferable to other families in similar situations. Finally, since this study focused only on mothers of children with ALL, future research should focus on different types of childhood cancer to acquire a deeper understanding of mothers’ caring experiences.

Conclusion

The findings of the current study can help health care providers understand the challenges faced by a mother of a child with leukaemia, especially during the COVID-19 pandemic. Children with leukaemia are at double risk from dying from cancer itself or the infection. Mothers adopt different strategies to protect their children from the virus, although they also face several challenges that disrupt their ability to provide the most substantial possible care. This study’s uniqueness stems from it being the first one to explore the challenges of parents caring for children with leukaemia during the COVID-19 pandemic. More studies are required to quantify these challenges and to develop solutions that relieve the stress and suffering of those children and their families.

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Contributors

MA drafted the manuscript and contributed to the study protocol, data collection, data analysis, and interpretation. FT and AK contributed to the study protocol, data collection, data analysis, and interpretation. All authors have discussed the results and contributed to the final manuscript.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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References

Aburn, G., & Gott, M. (2014). Education given to parents of children newly diagnosed with acute lymphoblastic leukaemia: The parent’s perspective. Pediatric Nursing, 40(5), 243–248 256 https://pubmed.ncbi.nlm.nih.gov/25929116/
Baruchel, A., Bertrand, Y., Boisvert, N., Breton, B., Ducassou, S., Ganderer, V., ... Committee, S. L. (2020). COVID-19 and acute lymphoblastic leukaemias of children and adolescents: First recommendations of the leukaemia committee of the French society for the fight against cancers and leukaemias in children and adolescents (SFCLE). Bulletin du Cancer, 107(6), 629–622https://doi.org/10.1016/j.bulcan.2020.04.003.
Bouffet, E., Chalimene, J., Sullivan, M., Blondi, A., Rodriguez-Galindo, C., & Pritchard-Jones, K. (2020). Early advice on managing children with cancer during the COVID-19 pandemic and a call for sharing experiences. Pediatric Blood & Cancer, 67(7), Article e28327https://doi.org/10.1002/pbc.28327.
Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101https://doi.org/10.1191/1478088706qp063oa.
Centers for Disease Control and Prevention (2020). Coronavirus disease. Stress and coping Retrieved 10 May from https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/managing-stress-anxiety.html.
Choi, S. H., Kim, H. W., Kang, J. M., Kim, D. H., & Cho, E. Y. (2020). Epidemiology and clinical characteristics of coronavirus disease 2019 in children. Clinical and Experimental Pediatrics, 63(4), 135–137https://doi.org/10.3345/cep.2020.00353.
Cinar, P., Kuhal, T., Freidell, A., Mishra, A., Shulman, L., Bachman, J., ... Liu, C. (2020). Safety at the time of the COVID-19 pandemic: How to keep our oncology patients and healthcare workers safe. Journal of the National Comprehensive Cancer Network, 18(6), 683–694https://doi.org/10.1016/j.jnccn.2020.02.022.
Coad, J., Gibson, F., Horstman, M., Milnes, L., Randall, D., & Carter, B. (2015). Be my guest! Challenges and practical solutions of undertaking interviews with children in the home setting. Journal of Child Health Care, 19(4), 432–443https://doi.org/10.1177/1743539014547419.
Cypress, B. S. (2016). Understanding uncertainty among critically ill patients in the intensive care unit using Michels’ theory of uncertainty of illness. Dimensions of Critical Care Nursing, 35(1), 42–49https://doi.org/10.1097/DCC.0000000000000152.
Dawson, J. (2009). Thick description. In A. J. Mills, G. Durepos, & E. Wiebe (Eds.), Encyclopedia of case study research. Sage Publicationshttps://digitalcommons.fairfield.edu/communications-books/8.
Degen, H., & Inci, F. (2015). The burden of care and quality of life of caregivers of leukemia and lymphoma patients following peripheric stem cell transplantation. Journal of Psychosocial Oncology, 33(3), 250–262https://doi.org/10.1080/07347323.2015.1019960.
Ding, Y. Y., Ramakrishna, S., Long, A. H., Phillips, C. A., Montiel-Esparza, R., Diorio, C. J., ... Baruchel, A., Bertrand, Y., Boissel, N., Brethon, B., Ducassou, S., Gandemer, V., ... Committee, S. L. (2020). Delays in cancer diagnoses and high mortality in children during the COVID-19 pandemic. Pediatric Blood & Cancer, 67(9), 1–1https://doi.org/10.1002/pbc.28427.
Ferreri, B. R., Ternel, J. S., Temin, S., Alexi, E. R., Balboni, T. A., Basch, E. M., ... Smith, T. J. (2017). Integration of palliative oncology into standard oncology care: American society of clinical oncology clinical practice guideline update. Journal of Clinical Oncology, 35 (1), 96–112https://doi.org/10.1200/JCO.2016.70.1474.
Gemmill, R., Cooke, L., Williams, A. C., & Grant, M. (2011). Informal caregivers of hematopoietic transplant patients: A review and recommendations for interventions and research. Cancer Nursing, 34(6), E13–E21https://doi.org/10.1097/NON.0b013e31820a592d.
Hagawara, M., Sharma, A., Chung, K. C., & Defea, T. E. (2018). Healthcare utilization and costs in patients with newly diagnosed acute myeloid leukaemia. Journal of Medical Economics, 21(11), 1119–1130https://doi.org/10.3182/2018.1513847.
He, S., You, L.-M., Zheng, J., & Bi, Y.-L. (2016). Uncertainty and personal growth through positive coping strategies among Chinese parents of children with acute leukemia. Cancer Nursing, 39(3), 205–212https://doi.org/10.1097/NON.0b013e31833473e9.
Hsu, S. H., & Wang, S. Y. (2020). Trends in provision of palliative radiotherapy and chemotherapy among hospices in the United States, 2011–2018. JAMA Oncology, 6(7), 1106–1108https://doi.org/10.1001/jamaoncol.2020.0923.
Jordan Cancer Registry (2015). Statistic summary. Jordan cancer registry, cancer incidence in Jordan - 2014, non-communicable diseases directorate-MOHhttp://www.moh.gov.jo/Echosubvis/3/SystemAssets/43605f25-4f45-4446-b6de-1e3f5c5a04bf.pdf.
Kearney, J. A., Saley, C. G., & Muriel, A. C. (2015). Standards of psychosocial care for parents of children with cancer: A survey of Australian and New Zealand haematology oncology society members. Pediatric Nursing, 67, 5-6https://doi.org/10.1097/ONC.0b013e3182576832.
Kim, H., Sefcik, J. S., & Bradway, C. (2017). Characteristics of qualitative descriptive studies: A systematic review. Research in Nursing & Health, 40(1), 23–42https://doi.org/10.1002/nur.21768.
Klein, J. D., Koletzko, B., El-Shabrawi, M. H., Hadjipanayis, A., Thacker, N., & Bhutta, Z. (2020). Promoting and supporting children’s health and healthcare during COVID-19 - International paediatric association position statement. Archives of Disease in Childhood, 105(7), 620–624https://doi.org/10.1136/archdischild-2020-315707.
Lewis, M. A. (2020). Between scylla and charybdis - Oncologic decision making in the time of covid-19. The New England Journal of Medicine, 382(24), 2285–2287https://doi.org/10.1056/NEJMp2006588.
Lincoln, Y., & Guba, E. (1985). Naturalistic inquiry. SAGEhttps://us.sagepub.com/en-us/nam/naturalistic-inquiry.book842.
Ljungman, L., Cernwall, M., Gronqvist, H., Ljotsson, B., Ljungman, G., & von Essen, L. (2014). Long-term positive and negative psychological late effects for parents of childhood cancer survivors: A systematic review. Pediatr Blood Cancer, 67(9), Article e22409https://doi.org/10.1002/pbc.22409.
Lynagh, M. C., Williamson, A., Bradstock, K., Campbell, S., Carey, M., Paul, C., ... Bhutta, Z. (2014). Exploring sleep-wake experiences of mothers of children with ALL. Journal of Pediatric Nursing, 29(5), 410–42https://doi.org/10.1016/j.pedn.2014.01.002.
Othman, A., Mohamed, N., Hussin, Z. A., & Blundell, S. (2011). Psychological distress and associated factors in parents of children with cancer. International Journal of Social Science and Humanity, 37–42https://doi.org/10.7763/jissi.2011.v1.7.

