**Title**

COVID-19 and children with cancer: Parents’ experiences, anxieties, and support needs

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**Abbreviations**

|  |  |
| --- | --- |
| **Abbreviation** | **Full term/phrase** |
| ALL | Acute Lymphoblastic Leukemia |
| CNS | Central Nervous System |
| AML | Acute Myeloid Leukemia |
| PPE | Personal Protective Equipment |

**Abstract**

**Background**

Children with cancer were designated as clinically vulnerable if they were to contract SARS-CoV-2 due to immune suppression in the early phase of the covid-19 pandemic. Our aim was to explore experiences, information and support needs, and decision-making of parents with a child with cancer in response to this phase in the UK.

**Methods**

Parents of a child with cancer completed a survey, as the UK moved into a period of ‘lockdown’. An online survey was developed by the research team to capture parents’ experiences, information and support needs, and decision-making, using closed statements and open text boxes. Descriptive quantitative analyses and qualitative thematic content analysis were undertaken.

**Findings**

171 parents/caregivers completed the survey. 85% were worried about the virus and they were vigilant about virus (92%) or cancer symptoms (93.4%). For two-thirds (69.6%) hospital was no longer considered a safe place. Eight overarching themes, were identified related to the virus: 1) risk of infection, 2) information, guidance and advice, 3) health care provision, 4) fears and anxieties; or related to lockdown/isolation: 5) psychological and social impact, 6) keeping safe under lockdown, 7) provisions and dependence, and 8) employment and income.

**Conclusions**

This is the first study, to the best of our knowledge, to report experiences of parents of a child with cancer during the SARS-CoV-2/COVID-19 pandemic. The majority of parents are worried about SARS-CoV-2, and worried about transmitting the virus to their child. Hospital was no longer a safe place, and parents were worried about suboptimal cancer care. Parents describe fear and anxiety and the psychological, social and economic impact of isolation.

**Introduction**

In the United Kingdom (UK), the administrations in England, Wales and Scotland, initially considered children and young people with cancer to be “extremely clinically vulnerable”, a phrase used to designate indivduals who were believed to be at high risk of developing severe COVID-19 disease if they were to contract SARS-CoV-2. children with cancer were designated as such due to immune suppression as a result of anti-cancer treatment. They were recommended to ‘shield’ – to remain at home at all times and have no face-to-face contact with anyone outside of their household, except to attend to medical needs. The general population also entered ‘lockdown’ (23 March 2020), with restrictions of movement outside of the home other than for specific designated purposes (i.e. exercise, shopping for essentials, and ‘key workers’ defined as employees who provide vital services maintaining health and essential infrastructure). During this period of time the understanding of the transmissibility of SARS-CoV-2 was uncertain, and the nature of the symptoms was evolving. In the country at large panic buying (stockpiling) was seen, concerns increased about financial vulnerability, and availability and implementation of personal protective equipment (PPE) in the healthcare setting varied. Through this time, comprehensive and updated advice for parents of children with cancer was compiled and disseminated through national charities and professional organisations in the UK.1

The experience of clinical and charity teams revealed families were worried about sars-cov-2 infection. This was in keeping with the documented experience of families under quarantine for recent severe respiratory viruses (sars-cov-1, middle east respiratory syndrome - MERS) where a systematic review showed very high levels of traumatic distress.2 Parents believed their child with cancer was vulnerable to developing covid-19.1 The data available show while cases are few,3 and the disease caused by infection has been relatively mild, ongoing surveillance of the disease manifestations is encouraged.4-6

Children and young people undergoing treatment face ongoing compromises to the immune system, even without a pandemic, this forces families to manage infection risks regularly. The pandemic heightened the need to understand family decision-making, around continuing treatment, “shielding” (isolation within the home) and accessing hospital.7

This DECISION MAKING IS made even more difficult as new information emerges, for instance with the reporting on multi-system inflammatory disease in children.8,9

In general, when information changes, choices change, producing inconsistencies and difficulties.10-12 For example, fewer visits by children in emergency departments in the early phases of the pandemic were recorded.13

Families of children with cancer indicated, on social media groups, they felt forgotten, with their voice not represented in decision making by governments and health care systems. Existing professional networks of charities, clinicians, academics and parents were mobilised to develop the current study. The aim of the study was to use a survey to gather quantitative and qualitative data specifically about the experiences, information and support needs, as well as decision-making of these families.

**Aims**

To explore experiences, information and support needs, and decision-making of parents of a child with cancer in response to COVID-19.

**Methods**

This study included a survey of parents of a child with cancer, assessing experiences, information and support needs, and decision-making. The findings presented here are part of a larger longitudinal study (the SHARE study) assessing experiences of parents and children with different paediatric conditions, over time (baseline, two months, six months and twelve months) which will allow comparisons over time and between subgroups. The survey opened to responses on 6 April 2020 and closed on 4 May 2020, capturing experiences and needs of parents during the first wave, and lockdown, of the COVID-19 pandemic within the UK. The study was approved by the University of Southampton and UK NHS Health Research Authority Research Ethics Committees (IRAS nr. 282176).

**Participants**

Participants were parents of a child with cancer aged between 0-18 years able to read and respond in English. Parents were recruited through two principal treatment centres in the UK (by parents being directly contacted by their clinical team regarding the study (via email, text message or through outpatient clinics)), and through social media, national charities and targeted closed Facebook groups, to minimise the burden on the health system during the pandemic. Electronic consent was obtained before completing the online survey. Approximately 150-200 respondents were intended to be recruited to ensure sufficient numbers of participants to map the range of issues and experiences, identify common issues across them14-16 carry out meaningful subgroup analyses, and provide rich data from the open text qualitative data.

**Survey**

The survey content was developed based on currently available literature,17-19 expert clinician input, and parental review. It contained the following sections and number of closed statement items: Experiences (n=6), Information (n=7), Decisions (n=7) and Support needs (n=5; Figure 1). The Response options for the closed statement items were Not at all, A little, Quite a bit, Very much (except for two conditional questions with Yes/No as response options). Each section started with a free text box for comments, with simple introductory questions Experiences ‘*Can you tell us about your experiences and views on the virus in relation to your child with cancer?*’; Information: *‘Can you tell us where you get information on the virus and what other information you might need*?’; Decisions: *Can you tell us how you make decisions about looking after your child in relation to the virus?,* Support: ‘*What additional support would you like, at home or in hospital, in relation to the virus?*’. These were intended to be completed prior to the closed questions, which guided the respondent’s thinking. A final free text question asked respondents whether they had any further comments.

For simplicity, SARS-CoV-2 was referred to as “the virus”. Demographic information was collected from parents, including parent age, child age, child’s diagnosis and child being on or off treatment. The number of items was purposely small, allowing for rapid analysis and dissemination and increased likelihood of completion. Prior to distributing the survey, feedback from parents in our parent/patient involvement group was sought about the value and timing of the research, along with detailed questions about the survey in terms of content, phrasing and completeness, and changes were made accordingly.

**Data analysis**

Descriptive statistics were carried out using IBM Statistical Package for Social Science (SPSS)20 to summarise the demographic data, and undertake simple descriptive statistics of the closed statement items (collapsing the lowest two response options (Not at all, A little), and the highest two response options (Quite a bit, Very much) into a binary outcome).

Subgroup analyses were carried out on an item level, using Chi-squared analyses, according to child’s age (split around the median, age 7 years), treatment (on/off treatment), and diagnosis (Acute Lymphoblastic Leukemia (ALL), solid tumour, Central Nervous System (CNS) tumour, or other).

Open text box data were subjected to a thematic content analysis, informed by a three-stage coding process:21-22 stage 1) Initial sample of 35 comments were open coded into broad comment categories by two researchers (SS and RW), developing an initial framework, and resolving any conflicts with a third researcher (ASD); stage 2) the framework used to categorise all comments from the data, with further refinement; stage 3) overarching themes were identified from analysis of similarities in the content between categories. The number of comments were counted, to identify weight of themes. Given the overlap in comments to categories the total number of comments did not match the number of participants.

**Results**

**Participants**

171 respondents completed the survey, of which the majority were mothers (n=143, 83.6%), and nine fathers (Table 1). The child’s median age was 7 years (range 1-24 years). The majority were on treatment (67.3%) and 28.7% were off treatment less than 5 years. The majority of patients were children with ALL (75, 43.9%), and 43 (25.1%) with a solid tumour (Wilms, Rhabdomyosarcoma, Germ Cell tumour, Osteosarcoma, Fibrolamellar Hepatocellular Carcinoma, Neuroblastoma, Retinoblastoma, Ewings Sarcoma, Renal Cell Carcinoma), 12 Lymphoma (7.0%), 11 CNS/brain (6.4%), and six with AML (3.5%). The majority of parents (132; 77%) were recruited through Facebook (although we do not have knowledge of which specific Facebook site), and the remaining participants through accessing the survey directly (18, 10%; i.e. without knowledge of which route, for example via twitter link), The UK charities Children with Cancer (n=1) and CLIC Sargent (n=1), University Hospitals Southampton (n=2) and the University of Southampton (n=15), with missing data from 15 participants (9%)’.

**Closed statement items**

A large percentage of parents – those responding ‘Quite a bit’, or ‘Very much’ - worried about the virus (85.4%), and the majority of parents described being vigilant about virus symptoms (92%) or cancer symptoms (93.4%). For two-thirds (69.6%) of the respondents hospital was no longer considered a safe place. Parents received information from their clinical team (48.8%) and accessed information on social media (83.9%), which for some led to feeling anxious (40.6% of those who accessed social media information). Many parents indicated they isolated their child from except from immediate family (81.9%). Parents also worried about their own health (81.1%) and about the child contracting the virus from them (89.1%). The reported worries did not lead to parents stopping or reducing chemotherapy (only 2.3% did so). The desire for support to reduce worries for themselves or others was reported by 20-30% of parents. Group differences in terms of age (0-7 years versus 7-18 years) were found for two items. Parents of younger children were more worried about nurses/carers visiting at home (p=0.001), and more likely to want information on ways to support family members (p=0.002). Parents with a child on treatment were more likely to report that the child should be isolated from everyone except parents/caregivers (p=0.025). No differences were found according to cancer type.

**Open text boxes**

A total of 591 comments were coded: 130 in the Experiences section, 124 in the Information section, 122 in the Decision-Making section, and 112 in the Support section (and a final 103 in the ‘other’ box).

**Experiences open text box**

In total, 130 parents (76% of the total) responded to the question about experiences. Overall, the responses to this question covered 38 subthemes (Table 2, including illustrative quotes) which were organised into the following eight overarching themes, related to the virus (four themes) or lockdown and isolation (four themes; Figure 2). Virus: 1) risk of infection, 2) information, guidance and advice, 3) health care provision, and 4) fears and anxieties; Lockdown and isolation: 5) psychological and social impact, 6) keeping safe under lockdown, 7) provisions and dependence, 8) employment and income (Table 2).

**Virus**

The largest number of comments (n=44) related to the compromised immune system of their children and their perceived greater susceptibility to the virus. The second largest number of comments (n=22) described safety concerns relating to hospital visits either for outpatient appointments or overnight stays.

Safety of the home environment was felt to be compromised by the virus being brought in by family members who were engaged in a designated ‘essential occupation’ (known as keyworkers in the UK), visiting (community) health professionals or visits to the hospital.

Concerns relating to limited or unclear information from both the hospital and the government were voiced by 17 parents.

Another strong theme (n=14) involved a concern amongst parents that the response to the COVID-19 situation would lead to suboptimal cancer care or had already led to postponed or cancelled clinic appointments, and several parents were concerned that relapses would be missed.

Parents described feeling ‘scared’, ‘terrified’ or ‘petrified’ of the risk of their child becoming infected.

**Lockdown and isolation**

Parents described the psychological impact (n=14) of the emergence of the virus and subsequent lockdown and classification of the child as ‘shielded’, for both themselves and their children. They described their children struggling mentally, and missing out on life, particularly for those with a limited life expectancy. For parents with children who had recently completed treatment, the lockdown brought with it several frustrations relating to delayed resumption of normality. Parents also described difficulties in coping with the uncertainty of the situation, lack of control, and limited support mechanisms in place which was particularly true for lone parents. Some parents described strategies for coping with the stressful situation, such as the avoidance of or restricted access to news broadcasts and social media.

While under lockdown, parents (n=10) were also concerned about the lack of respect for social distancing shown by some members of the public, the delayed response by the government, and some (n=3) expressed concern about how things might change when restrictions are relaxed.

Concerns were identified over access to food home delivery, for families with a child classified as ‘shielded’, and lack of recognition of parents as needing priority status (rather than just the child) (n=13).

Financial and employment concerns were also expressed (n=10): parents described having to give up paid work to ‘shield’ their child. In addition, parents expressed frustration in terms of not being eligible for furlough (the government’s Coronavirus Job Retention Scheme, which allowed employers to continue paying wages via a government subsidy).

**‘Information’ free text response**

18 parents wanted more information, specifically (n=4) in relation to safety of hospitals, information tailored to children with cancer rather than to adults, information relevant to children with rare cancers and those off treatment, and their child’s level of risk of catching the virus given their particular situation (on or off-treatment) or diagnosis.

For the majority of parents (n=89) charities provided them with information regarding the virus, followed by clinical staff (n=50) and news outlets (n=41).

**‘Support’ free text response**

99 parents described a need for additional support related to the provision of more information, specifically more guidance or support from the hospital. The need for information and reassurance surrounding the safety of the hospital environment including the availability and use of personal protective equipment (PPE) as well as testing of staff was further reinforced by 22 parents. In addition, four parents proposed remote contact with hospital staff and services delivered within the community as an option to protect their child.

**‘Decisions’ free text response**

Parents were more likely (n=44) to turn to clinical staff when making decisions about their child’s care, while 35 parents described relying on their own judgements based on their knowledge of their child and past experience and 6 were also led by their child when making decisions.

**‘Other’ free text response**

**Positive**

Some parents (n=5) highlighted the positives of the lockdown in terms of bringing the family together and the social restrictions making them ‘feel safe at home’, providing them with a ‘protective bubble’. Some parents (n=3) suggested that things could be worse, or drew comparisons between the isolation imposed during cancer treatment and that of the virus and that they were better equipped than most to face the challenges. In addition, 12 parents took the opportunity to use the survey to communicate their gratitude to the hospital and charities for the care and support they had received.

**Discussion**

This is the first study to report experiences of parents of a child with cancer during the SARS-CoV-2/COVID-19 pandemic in the UK. The study has found that the majority of parents were worried about SARS-CoV-2, worried about their own health if they are infected, and worried about transmitting the virus to their child. They described vigilance about SARS-CoV-2 symptoms and cancer-related symptoms, and for a lot of parents the hospital was no longer a safe place during the first month of the lockdown. The qualitative findings show that the threat of SARS-CoV-2 led to concerns about getting infected and therefore to fear of the hospital and healthcare teams visiting the family at home. Parents got information from their medical team, and almost all parents looked at social media for information, which for some led to feeling anxious. Parents wanted clear information and guidance, which included the shielding policy in the UK. Changes in healthcare provision led some parents to think their care would be suboptimal, that care for COVID-19 patients was prioritised over that of cancer patients, and that the health service was strained. Parents were anxious about the unknown, and about who would look after their child if they get ill (or die). Remarkably, only around one quarter of parents expressed a wish for additional support, and some described how their experience with cancer treatment had made them better prepared for ‘lockdown’ than those without this background.

The lockdown and imposed isolation by the UK government led to parents worrying about the psychological impact in terms of children missing out, feeling bored, missing family and friends, as well as worrying about a delay in social and emotional development, mirroring evidence from studies focusing on young people’s mental health during the pandemic.23-25 Parents missed their support network, even though technology is available to help them connect with others. The designation of children as requiring ‘shielding’ provided particular challenges; the English Government advice described attempting to maintain complete isolation from all other people, even those living in the same household. This lack of age-related nuance may have increased the level of anxiety for some families, particularly around food shopping. Parents struggled with going out to grocery stores, as they did not want to expose themselves to the risk of getting the virus (and thus increasing the chances of the child becoming infected). In common with many people during the lockdown, parents WERE worried about employment and money; the study group of parents DESCRIBED the additional concern of transmitting the virus to their child.

Uncertainty and lack of clarity in communication were strong themes in the parents’ responses. A clearer, more open, and reasoned account of the various measures being planned and implemented may have assisted with reducing this distress. Much of the uncertainty arose from the true lack of knowledge about the effect of SARS-CoV-2, but few participants reflected this. The all-age signalling of government guidelines placed families in an invidious position – to apparently defy the government guideline and risk adversely affecting their child through infection, or to follow the guidelines strictly and adversely affect their child with restriction on activity and reduce family contact to only one parent, and exclude any other parent or siblings.26

Limitations of the study relate to the bias in the sample - although strenuous efforts were made to widely circulate the survey across children’s cancer interested social media, the respondents may not be representative of the whole population. The responses were mostly from mothers (86%), and the largest group of patients had ALL (46%). While this is disproportionate compared to the diagnoses made in the UK (where it accounts for around one quarter of malignancies), ALL is also treated for 2-3 years, in comparison with the shorter time frame (under 9 months) of most other treatment trajectories. No differences were noted between diagnostic groupings, but the low proportion of those with CNS tumours may mean this study has failed to clearly capture their unique concerns. The high proportion of mothers responding is in keeping with surveys about children,27 as well as the observation mothers being the primary caregiver for the vast majority of children. In addition, parents responding to the survey could have self-selected to represent those parents who were most concerned. Finally, subgroup analyses findings may be based on chance given the number of analyses carried out (n=23x3) and the number of group differences (n=3)

The information emerging from this survey was immediately placed into practice, shaping information delivery during this early phase of the pandemic. The data on concern about the safety of hospitals, along with reports of reduced attendances in paediatric emergency care facilities13 led the charities involved in the research along with local health providers and national paediatric bodies to promote the message of hospitals being ‘safe to attend’. Worries about the possible reduction in anti-cancer therapy were addressed with information co-produced by parents and medical professionals and disseminated through the same routes, explaining the process of contingency planning and the routes to these planned recommendations. The most marked change in care provision was the move to more remote/virtual follow-up appointments, and delay or omission of planned surveillance imaging for patients off treatment. Such imaging studies have rarely been shown to have significant survival advantage but contain great emotional weight.28

We believe this study demonstrates how the views and experiences of a classically ‘vulnerable’ population can be captured by using existing research networks, an agile governance response, and inclusion of patient partners from the commencement of the study. We found high levels of concern about the consequences of SARS-CoV-2 infection in children with cancer and the consequences of presumed preventative interventions to the children and their families. We hypothesise that true uncertainty, coarse recommendations, and a lack of clarity behind decision-making process in national administrations may have accentuated these experiences.

As the pandemic continues, survey studies such as this will be important in understanding the ongoing experience of families and tuning support and information to their changing needs. They may allow us to understand if our responses to the families’ concerns, which include providing trustworthy information highlighting the limits of our understanding and the current evolution of knowledge, has helped alleviate worries. Future research assessing modes of responding to uncertainty, and delivering changing information to a special population, is still required, along with comparative work with other chronic or life-threatening conditions in children.

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**Conflict of interest**

No conflicts of interest to report

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**TABLE** **1. Sample characteristics**

**TABLE 2. Themes and subthemes of open text boxes**

**FIGURE 1. Closed statements percentages (of those who agree Quite a bit or Very much)**

**FIGURE 2. Open text boxes overarching themes**