**Experiences and support needs of parents/caregivers of children with cancer through the COVID-19 pandemic in the United Kingdom: a longitudinal study.**

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**Abstract**

**Objective:**

To explore the experiences, information and support needs of parents/caregivers of children with cancer and how these changed as the COVID-19 pandemic evolved.

**Design:**

Online survey containing closed and free text questions on experiences, information and support needs were completed at four time points (between April 2020-October 2021) during the COVID-19 pandemic. Descriptive statistics of closed items and content analysis of qualitative data were conducted.

**Setting:** Online**.**

**Participants:** Parents/caregivers of children with cancer.

**Results:**

335 parents/caregivers completed the survey over 4 time points. Findings revealed that parents’/caregivers’ worry about the virus and vigilance about their child’s virus symptoms decreased over time. Parents reporting the need for support on how to reduce their worries and/or family members during the virus outbreak were low, however parents reported a slight increase in need for support at T3 when schools re-opened. Qualitative findings reported the following themes: 1) Psychological wellbeing of parents/caregivers, 2) Changing perceptions of risks/priorities, 3) Adjusting to COVID-19: Living with continued caution, 4) Healthcare and treatment provision, 5) Information seeking and needs during COVID-19.

**Conclusions:**

The COVID-19 pandemic disrupted people’s lives and routines in relation to access to support, finances, education and social lives, leading to psychological distress. Parents highlighted the need for timely, up to date and personalised information in relation to COVID-19 and their child with cancer. Further consideration of the development of technology based health solutions may provide an efficient and safe way to connect with and support parent/caregivers.

**Keywords**

Pandemic, COVID-19, children with cancer, SARS-CoV-2, mental health, wellbeing

**What is already known on this topic**

* Children with cancer and their parents were suggested to be vulnerable to psychological issues because of already high stress levels due to the child’s cancer diagnosis and treatment and worries about the potential impact of COVID-19 to their child.
* Cross sectional studies on parents who have a child with cancer in the early stages of the pandemic reported fear, anxiety about their child’s health, changes to cancer care, and the social and economic impact of isolation as a family.
* Little evidence has been published on the longer term experiences of COVID-19 on families’ lives and what support they may need moving forward.

**What this study adds**

* Worries about the virus and child’s virus symptoms reduced over time, but worry is still relatively high.
* Parents need for additional support was low, except regarding information about COVID.
* Information needs changed throughout different stages of the pandemic.
* Significant psychological impact of shielding and lockdowns, however families appear to adjust and many continue living with caution in COVID times.
* Clear and consistent information/communication can help alleviate parental concerns.

**How this study might affect research, practice or policy**

* Understanding parents’ worries and needs over time can help the development of information provision, resources and guidance tailored to vulnerable children and their parents.

**INTRODUCTION**

Coronavirus disease 2019 (COVID-19); caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2)[1] has been a cause of major worry and anxiety for many families.[2] COVID-19 continues to have a significant impact on health services globally.[3] At the beginning of the pandemic, it was presumed that immunocompromised children with malignancies undergoing treatment were at higher risk for COVID-19.[3] More recent studies highlight that most paediatric cancer patients experience clinically mild to moderate symptoms of COVID,[4-8] although it is still possible for severe disease and fatalities to occur.

In the United Kingdom (UK), the government initially considered children and young people with cancer to be “extremely clinically vulnerable” to COVID-19 and they were therefore advised to ‘shield’- remain at home at all times and have no physical contact with anyone outside the household unless to attend to medical needs. Research has shown a negative impact on the health-related quality of life of children with and without serious conditions, through the implementation of social distancing and lockdowns, resulting in increasing children’s and parents’ feelings of isolation and loneliness.[9-11] Psychological wellbeing and general quality of life worsened in this time compared to prior to the pandemic.[12, 13]

The COVID-19 pandemic also caused major psychological, social and economic impacts for parents of children with cancer. The pandemic brought about worries about their child’s health and their own if they were infected, including concerns about transmitting the virus to their child.[10] Parents missed their support networks and struggled with going to food stores as they did not want to expose themselves to the virus.[10] Family members were excluded or limited from attending patient appointments or visiting patients, affecting their access to information and ability to support the patient.[14] For some, treatments were delayed causing worry to both patients and families.[14]

This study aimed to explore the changing experiences, information and support needs of parents of a child with cancer through the COVID-19 pandemic, using a longitudinal survey approach to identify and develop strategies to improve the quality of life for these families and to prepare for comparable future events.

**METHODS**

The findings presented here form part of the SHARE study which assessed the experiences of the pandemic for parents, and children and young people with different long-term conditions.[10, 15-18]The survey for parents of children with cancer was open at four time points when changes to restriction policies were enforced: capturing the experiences and needs of parents during the first lockdown of the COVID-19 pandemic within the UK (April-May 2020; T1); the time around the UK government announcement that those who were shielding can meet groups of up to six outdoors and form a support bubble with one other household (June-August 2020; T2); the third lockdown (February-March 2021; T3); and the removal of restrictions (October 2021-January 2022; T4) (Figure 1). The study was approved by the University of Southampton and NHS Health Research Authority Research Ethics Committees (IRAS nr.282176).

**Participants**

Eligible participants were parents of a child with cancer aged between 0-18 years and able to read and respond in English. Parents were recruited through social media (website and targeted closed Facebook groups), national charities and two tertiary principal treatment centres in the UK. Parents who took part in earlier surveys and provided their email address were invited to take part in subsequent survey(s) but their responses not linked. Electronic consent was embedded in the introduction to the online survey.

**Survey structure**

An advisory group consisting of clinicians, patients and parents, alongside literature[19-22] informed the initial survey content. The surveys contained sections on experiences, information and support needs. An open-ended question began each section followed by a number of closed item statements (Table 1). Responses to closed statements were Not at all, A little, Quite a bit, Very much. The surveys included a small number of items to allow for rapid completion, analysis and dissemination.

|  |  |  |
| --- | --- | --- |
| **Section** | **Core open questions assessed at each survey:** | **Core closed items assessed at each survey:** |
| **Experiences** | * Can you tell us about your experiences and views on the virus in relation to your child with cancer? (survey 1)
* Can you tell us about your experiences and views on the virus (worries, thoughts, experiences), and how things have changed since the start of the pandemic? (survey 2,3)
* Can you tell us about your experiences and views on the virus (worries, thoughts) and how things have changed since restrictions have been lifted over the summer? (survey 4)
 | Worry about the virus |
| Vigilance about child’s virus symptoms |
| Worry the hospital is no longer a safe place |
| **Information** | Can you tell us where you get information on the virus and what other information you might need? | Child’s clinical team has given information about the virus |
| Feeling overwhelmed with information about the virus |
| **Support** | What additional support would you like, at home or in hospital, in relation to the virus? | Support on how to reduce worries about the virus |
| Information on ways to support family members during the virus |
| School/college/university support for child |

**Table 1: Summary of core closed and open items in surveys**

**Data analysis**

Descriptive analysis was undertaken using IBM Statistical Package for Social Science (SPSS). The response options (Not at all, A little) and (Quite a bit, Very much) were collapsed into a binary outcome for each dataset across the four time points.

Open text responses were analysed using thematic content analysis. Responses were coded by two investigators to identify common themes, developing a coding framework which was developed and refined after discussion. Remaining differences were resolved through discussion with a third researcher. 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. To facilitate longitudinal analysis, time-ordered sequential matrices were generated,[[23] which consisted of the key themes from responses to the experiences open text section for each survey. These were used to generate overarching themes across the four survey time points and explore the evolution of themes over the timeframe of the study.

**RESULTS**

**Participants**

A total of 335 parents/caregivers completed the survey- T1 (n=171), T2 (n=103), T3 (n=36) and T4 (n=25). The majority were from mothers (Table 2). The mean age of parents was 40 years (range 22-64 years). Most children/young adults were on-treatment n=208 (63.8%), or off-treatment less than 5 years (33.7%).

|  |
| --- |
| **Demographics** |
|  | **T1****Lockdown 1** | **T2****Support Bubbles** | **T3****Schools reopen-outdoor gathering of 6 or more** | **T4****No restrictions** |
| **Participants (n)** | 171 | 103 | 36 | 25 |
| **Completed by** |  |  |
| **Mothers** | 143 (83.6%) | 89 (86.4%) | 34 (94.4%) | 25 (100%) |
| **Fathers** | 9 (5.3%) | 5 (4.9%) | 2 (5.6%) | 0 (0%) |
| **Parent** | 9 (5.3%) | 4 (3.9%) | 0 (0%) | 0 (0%) |
| **Other** | 4 (2.3%) | 0 (0.0%) | 0 (0%) | 0 (0%) |
| **Missing** | 6 (3.5%) | 5 (4.9%) | 0 (0%) | 0 (0%) |
| **Caregiver mean age, years, (range)** | 39 (22-67) | 40 (27-63) | 40 (27-63) | 42 (35-64) |
| **Child’s treatment status, n (%)** |  |  |
| **On treatment** | 115 (67.3%) | 69 (67.0%) | 19 (52.8%) | 5 (20.0%) |
| **Off treatment < 5 years** | 49 (28.7%) | 28 (27.2%) | 15 (41.7%) | 18 (72.0%) |
| **Off treatment > 5 years** | 5 (2.9%) | 2 (1.9%) | 1 (2.8%) | 1 (4.0%) |
| **Missing** | 2 (1.2%) | 4 (3.9%) | 1 (2.8%) | 1 (4.0%) |
|  |  |  |

**Table 2: Respondent characteristics**

**Closed statement items**

Parents’ worry about the virus and vigilance about their child’s virus symptoms decreased from T1 (85.4% and 92.0%) to T4 (48.0% and 66.7%) (Figure 2). At the beginning of the pandemic parents worried that the hospital was no longer a safe place during the virus outbreak (69.6%), decreasing over time (37.0%, 31.4%, 17.4%). Parents reporting that their child’s clinical team had given them information about what they needed to know about the virus varied across the different time points (48.8%, 58.9%, 30.6%, 48.0% respectively). Fewer parents reported feeling overwhelmed/confused with information about the virus at T4 (8.7%) compared to at T1 (35.7%). Few parents reported the need for support on how to reduce their worries and/or family members during the virus outbreak, however a slight increase in need for support was reported at T3 when schools re-opened. The number of parents reporting a need for more school/college/university support for their child increased at T2 (48.6%), when children’s classes were online, compared to T1 (20.2%), T3 (37.1%) and T4 (20.8%). Worries relating to nurses coming to visit the child at home, worries about their own health and possible transmission to their child varied over time (Suppl. File 1).

**Qualitative analysis of free-text responses**

An overarching theme of ‘evolving experiences, information and support needs through COVID-19’ emerged, referring to the impacts of COVID (isolation, financial and social disruptions, changes to healthcare provision etc.) and how parents’ management of these impacts (psychological responses, living with caution, seeking information to understand) were continually changing. Five core themes were also identified: *Psychological wellbeing of parent/caregivers, Changing perceptions of risks/priorities, Adjusting to COVID-19: Living with continued caution, Healthcare provision and treatment* and *Information seeking and needs during COVID-19* (Suppl. File 2).

**The evolving experiences, information and support needs through COVID-19**

***Psychological wellbeing of parents/caregivers***

Parents/caregivers described the varied psychological impact on themselves. The enforcement of lockdowns at T1 and T3 in particular caused anxiety, fear and stress to parents. Parents/caregivers reported mixed worries about COVID-19 variants- some felt it was not unexpected for a virus to mutate, however misinformation about variants caused anxiety. At T2 and T4, some parents reported less worry about the virus and its impact than at T1, feeling the need to get on with life as too much had been missed out on. Some parents highlighted the positives of the lockdowns in terms of bringing the family together and time for self/hobbies/exercise.

***Changing perceptions of risks/priorities***

Perceptions of risk and priorities varied for parents at different times through COVID, which could be potentially impacted by whether their child was on-treatment/off-treatment/relapsed/ receiving end of life care. At T1, parents reported difficulties with accessing food/home deliveries, and managing medications. A parent whose child was receiving end-of-life care reported frustration that their child was missing out on life and not able to enjoy simple pleasures such as visiting grandparents/being able to go out on day trips. At T2, some parents were less anxious but still experiencing issues with food access and isolation. Parents also expressed worry about their child returning to school at T2. At T3 (lockdown), some parents were less worried about the risks of their child catching COVID but were still limited in maintaining normality for their child with cancer, due to another lockdown. At T4, when there were no restrictions, parents whose children were on-treatment and off-treatment reported concerns about their child socialising with others, and the challenge in finding a balance in socialising and isolating.

***Adapting to COVID-19: Living with continued caution***

Although COVID-19 was a contributor of major anxiety and worry at T1, many parents reported feeling more relaxed about COVID at T2 due to updated guidance that the risk to children with cancer is lower than originally thought. At T3 many reported still being cautious about restrictions but more relaxed about going outside. At T4, parents reported living with continued caution by wearing masks, implementing hygiene practices, and social distancing, even when these were not required by government guidance.

***Healthcare provision and treatment***

Parents reported that changes to healthcare provision resulted in cancellations or postponement of clinical appointments which caused concern, particularly over missing relapses and reduced access to support. Families were also separated due to restricted visitation policies. Virtual consultations became common. Some parents preferred virtual appointments as it saved travel time, was felt to reduce infection risk, and was more accessible and convenient. However, some parents reported issues with poor internet connection and worry over the possibility of missed diagnoses or implications if their child was not physically examined.

***Information seeking and needs during COVID-19***

The Children’s Cancer Leukaemia Group (CCLG)[24] were commonly reported by parents as a key source of information support across all surveys. The child’s clinical team and government updates were also a common way for parents to keep updated. Specific information needs at T1 were 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 contracting the virus given their particular diagnosis or situation (on- or off-treatment). At T2, parents wanted information regarding advice on whether to send their child to school, how to live with the virus, and clear and concise information in relation to the numbers of people testing positive in local areas. At T3 and T4, parents wanted more consistent, uniform information from different professionals.

**DISCUSSION**

Our study revealed that the COVID-19 pandemic had a far-reaching impact on the lives of parents of children with cancer. Families faced continually changing disruptions to aspects of their lives with the implementation and easing of restrictions affecting social lives, education, finances, access to social networks and health support. Parents were faced with challenges in accessing healthcare service support that they were accustomed to or depended on, as well as challenges in accessing grocery deliveries and medication in the first lockdown. Families affected by cancer and clinicians had to adapt to new ways of working, including being monitored through virtual clinic appointments. Lockdowns, self-isolation and social distancing further exerted pressure on these parents, and families experienced psychological distress contending with all these changes. Over time, parents’ worry about the virus decreased, likely due to the increasing evidence that children with cancer were less likely to be severely affected by COVID infection as well as the roll-out of vaccinations. Findings from a study investigating the impacts of COVID-19 on caregivers of childhood cancer survivors share similarities with our findings regarding caregiver concerns around lack of information, interruptions to care and educational disruptions.[25]

Although few parents reported the need for support on how to reduce their worries, the need for information as a form of support was reported more commonly across the time points. Parents obtained information related to COVID-19 and cancer from three main sources: the CCLG, their clinical team and government updates. Some parents reported distrust in government guidance as the COVID-19 situation progressed, particularly as guidance varied across the country. Parents’ information needs were continually changing, however their need for timely, consistent, clear and tailored information across all sources remained a priority concern throughout all time points. Clinical teams and charity organisations being sought most commonly for information and support highlight their importance in educating families and addressing concerns. Mobilising evidence quickly to inform clinical strategies and having a consistent and a trusted space where evidence-based information related to the virus and cancer was uploaded, updated, and accessed by parents helped address this need. Using technology to support healthcare can override issues regarding distancing constraints caused by COVID-19 and provide opportunities for enhanced connection and communication to address unique challenges cancer patients and their caregivers face.[19, 26, 27]

Whilst legal restrictions in the UK were removed in July 2021, many still live with caution through continuation of these measures. A diagnosis of cancer is a significant disruption for families, and with the evolving situation with COVID, families have had to adjust, manage and navigate their way through new challenges. These disruptions may have lasting consequences that impact on clinical outcomes and quality of life for parents and their child with cancer.[28] Future research should focus on the development and implementation of strategies and services to ensure psychosocial care needs are being met, in particular for families who may be struggling with the long term impacts of COVID-19 on their family life and own wellbeing.

Although the pandemic led to significant challenges in caring for and protecting people with cancer and those who support them, it has also brought about valuable opportunities to rethink and learn how we could manage these impacts should a future pandemic arise. Firstly, the views expressed support of an approach to utilise telehealth to maintain connection and receive support. Development of ‘safe areas’ should be considered where children/young people with cancer, parents and clinicians can meet in person, particularly for those without access to online resources or support or when remote consultations are not appropriate [29]. Secondly, it is critical that parents are provided with clear and consistent information, ideally delivered by clinicians and cancer specific charities; and relevant, responsive research to inform this is essential. Ongoing real time conversations within the community may help in providing individualised care. At a higher level, there is a need to provide integrated, coordinated and consistent care across networks to ensure continuity of care, and thus alleviating concerns and providing reassurance to parents and children/young people with cancer.

Our study is limited by indirect exclusion of participants who not have access to digital media, or have English-language literacy issues. The majority of parent respondents were mothers; the findings are not representative of the views of fathers and other key caregivers. Parents responding to the survey may represent parents who were most concerned. We acknowledge that participant numbers decreased with time and trends need to be interpreted with caution.It is possible that the lower survey completion rate over time may be due to exhaustion with surveys, life and generally improved widespread availability of information.

**CONCLUSION**

This study explored the experiences, information and support needs of parents of a child with cancer to understand their ongoing experiences at key points in the pandemic. There was marked psychological distress; parents experienced high levels of anxiety and worry at the start of the pandemic, however this decreased over time as new information was found and the vaccine rollout commenced. Uncertainty, and lack of timely, consistent and personalised information may have magnified negative experiences for these families. Further consideration is needed of using/incorporating technology to help connect parents, their child with cancer, clinical professionals and charities. In particular, how to coordinate support and information effectively to meet families’ needs and help them navigate the continuing impact of COVID-19.

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**Conflict of Interest**

None.

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