



The  
**Health Policy  
Partnership**

**SNO**  
Society for NeuroOncology

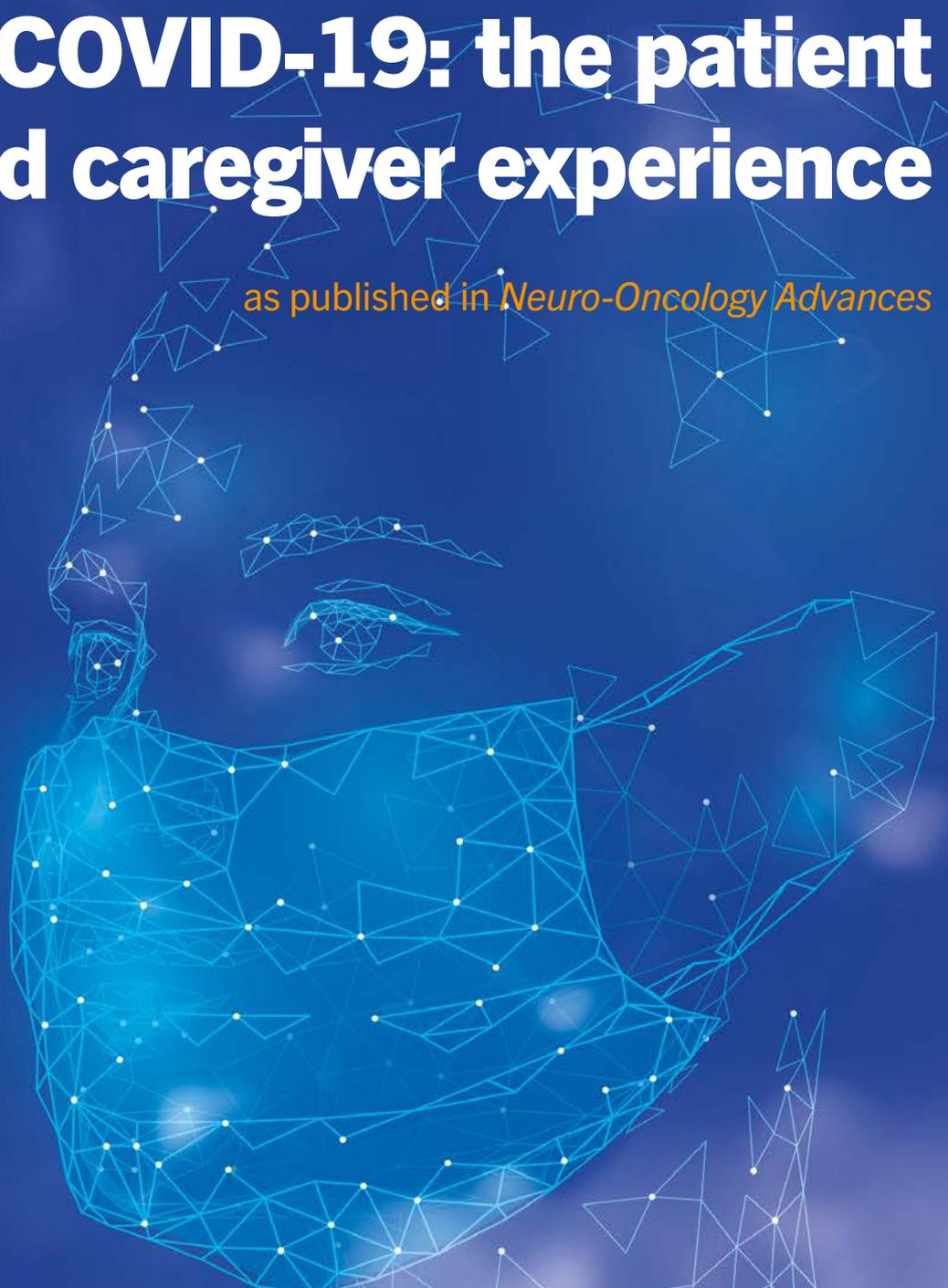


Surgery  
**UNIVERSITY OF TORONTO**

A lay summary of the paper

# Brain tumours and COVID-19: the patient and caregiver experience

as published in *Neuro-Oncology Advances*



## AUTHORS

Suzanne Wait, PhD<sup>1</sup>, Mathew R. Voisin, MD<sup>2</sup>, Tess Chee<sup>3</sup>, Gelareh Zadeh, MD, PhD, FRCSC<sup>2</sup>, Stuart Farrimond, BMBS, BMedSci (Hons)<sup>4</sup>, Kathy Oliver, BA<sup>4</sup>

### The authors of the original survey and paper on which this lay summary is based are:

Mathew R. Voisin, MD<sup>2</sup>, Kathy Oliver, BA<sup>4</sup>, Stuart Farrimond, BMBS, BMedSci (Hons)<sup>4</sup>, Tess Chee<sup>3</sup>, International Brain Tumour Alliance Senior Advisors, including: Jean Arzbaecher, RN, APN<sup>4</sup>, Carol Kruchko<sup>4</sup>, Mary Ellen Maher, RN, MSN, APN, CNRN<sup>4</sup>, Chris Tse BE (Hons)<sup>4</sup>, Rosemary Cashman, MA, MSc(A), NP(A)<sup>4</sup>, Maureen Daniels, BScN, RN<sup>4</sup>, Christine Mungoshi, MSc, BA (Hons)<sup>4</sup>, Sharon Lamb, RN<sup>4</sup>, Anita Granero<sup>4</sup>, Mary Lovely, PhD, RN, CNRN<sup>4</sup>, Jenifer Baker<sup>4</sup>, Sally Payne<sup>4</sup>, Gelareh Zadeh, MD, PhD, FRCSC<sup>2</sup>

<sup>1</sup> The Health Policy Partnership, London, United Kingdom

<sup>2</sup> Division of Neurosurgery, Department of Surgery, University of Toronto, Toronto, Ontario, Canada

<sup>3</sup> McMaster University, Hamilton, Ontario, Canada

<sup>4</sup> International Brain Tumour Alliance (IBTA), Tadworth, United Kingdom

For more information please contact Kathy Oliver, International Brain Tumour Alliance: [kathy@theibta.org](mailto:kathy@theibta.org)

This lay document summarises the findings of an international survey of brain tumour patients and their caregivers conducted by the International Brain Tumour Alliance in collaboration with the Society for Neuro-Oncology, which aimed to better understand how COVID-19 has affected the brain tumour patient and caregiver community around the world.

It is based on a publication of survey findings in the journal *Neuro-Oncology Advances*, entitled “Brain tumours and COVID-19: the brain tumour patient and caregiver experience” (available from <https://doi.org/10.1093/noajnl/vdaa104>). This lay summary is produced with the agreement of the authors of the original report and the Society for Neuro-Oncology.

# INTRODUCTION

The COVID-19 pandemic, which has transformed the world since early in 2020, has forced all of us to make daily decisions about how to balance the risk of contracting COVID-19 with meeting our other needs – not only health-related, but also social and financial. For people living with a life-threatening condition like a brain tumour, this balancing of risks is particularly challenging. To protect themselves from the risk of becoming infected with COVID-19, some patients have been asked to modify their original plan of care. Scheduled visits with their healthcare team have, for many people, been cancelled, postponed or converted to virtual meetings. In some cases, tests and treatments have also been cancelled, postponed or changed to reduce visits to the hospital or clinic.

This situation has created considerable anxiety for brain tumour patients and their caregivers. It adds to the fear and uncertainty that already accompanies a brain tumour diagnosis, when patients ask themselves:

- Is my disease curable or not?
- What kind of treatments are available for me?
- How will progression of my tumour affect my ability to function?
- Can I still work?
- What will my quality of life be like?

In the current pandemic era, patients and their caregivers will have additional concerns about contracting COVID-19 and how disruptions caused by the pandemic will affect patients' access to high-quality care.

The potential impact of this situation is of grave concern to all those working in the brain tumour community. Between April and May 2020, the International Brain Tumour Alliance (IBTA), as part of its collaborative work with the Society for Neuro-Oncology's (SNO) COVID-19 Task Force, organised a survey to understand the pandemic-related concerns of brain tumour patients and their caregivers, with a view to inform future support and service development. This document presents a lay summary of these survey findings, which were published in full in the journal [\*Neuro-Oncology Advances\*](#) on 23rd August 2020.

## ABOUT THE SURVEY

---

Administered online through more than **120** brain tumour not-for-profit organisations and charities worldwide, as well as through treating physicians

---

**79** questions, both closed and open-ended

---

Translated into **seven** languages (English, French, German, Italian, Spanish, Polish, Japanese)

---

Completed between **22 April and 30 May 2020**

---

**1,989** survey respondents from 33 countries, with representation from different geographic regions (The Americas – North, Central and South, Europe, Africa/Asia/Oceania)

---

Respondents included **1,459** patients: 1,284 adults (18 years or older) and 175 paediatric patients (under 18 years old, with the parent's or legal guardian's assistance) – and **530** caregivers

---

Over **30** different types of brain tumours represented

---

## WHAT THE SURVEY TOLD US

### A time dominated by fear and anxiety

The pandemic has undoubtedly been an incredibly stressful time for brain tumour patients and their caregivers. Among respondents to the survey, caregivers were significantly more anxious than patients about the risk of contracting COVID-19. Six patients and one caregiver had been diagnosed with COVID-19 at the time of the survey.



48% of patients felt they were at increased risk of contracting COVID-19 compared to the general population



61% of patients either did not want to go to hospital for a routinely scheduled test or appointment, or were willing to go but very anxious about it



69% of caregivers were worried about their loved one contracting COVID-19



43% of caregivers were worried about taking their loved one with a brain tumour to hospital

The biggest fear of patients was that their brain tumour-related care would be delayed due to the pandemic – and most patients were unwilling to compromise their care despite any increased risk of contracting COVID-19 in hospital. Among patients who were given the choice to delay treatment, fear of contracting COVID-19 accounted for just over half of all influencing factors, suggesting that other factors, such as their concerns over recurrence, may loom just as large in patients' minds.



68% of patients actively undergoing treatment were unwilling to skip their next treatment



[I'm worried] that my brain tumor is back and I cannot get the necessary testing done for fear of exposure [to COVID-19].

## An increased burden on caregivers

**A striking finding from the survey is the increased anxiety, sense of responsibility and burden for caregivers because of the pandemic.** As mentioned above, caregivers overall were significantly more anxious than patients about COVID-19; they were also more anxious about their loved one's brain tumour.

The need for brain tumour patients and their caregivers to self-isolate has focused everything on the home. This has invariably increased demands on caregivers in addition to the challenges they already face in providing care and maintaining the quality of life of their loved one with a brain tumour.



Close to 50% of caregivers felt their care burden had increased since the pandemic began

In their comments, some caregivers wrote of the added strain and worry the pandemic restrictions caused them.



As a caregiver you want to keep maintaining the patient's quality of life. Restricting access to family and [the] ability to go out to eat or hike on popular trails or shop in a favourite grocery store or be confined to home on a cold/rainy day – these are things that reduce quality of life.

Some caregivers commented on the difficulty of no longer being able to rely on friends and family to help them care for their loved one.



I miss the help and company of other family members due to travel and isolation restrictions at this time.

Additionally, caregivers felt the emotional toll of not being able to accompany their loved ones to medical appointments.

“ I’m not allowed to go to any appointments or treatments [with my loved one]. We have to be separated during the darkest days of our lives.

## Healthcare professionals as a trusted source of information

**Patients rated healthcare professionals, specifically doctors and nurses, as their most trusted source of information, followed by brain tumour patient groups.** Yet only 26% of patients had discussed with their healthcare provider what a diagnosis of COVID-19 might personally mean to them. This may be partly explained by the fact that the pandemic had only been present for a few months at the time of the survey and many patients only see their healthcare provider every six months. Still, it shows that patients expect and rely on their doctors and nurses to be available to provide them with accurate, up-to-date information during these uncertain times.

The survey asked about access to information during the pandemic, and most patients and caregivers felt the information provided to them was sufficient and helpful. But among those patients who said they wanted more information, there was a desire to know how COVID-19 would specifically affect them and their brain tumour.

“ How does [having a] brain tumor affect the likelihood of contracting COVID-19? How does it affect COVID-19 outcome?

## Disruptions to patient care

**In the early days of the pandemic, at the time the survey was carried out, one quarter of brain tumour patients had already experienced a delay in their treatment and care due to COVID-19.** This was most common among patients from Europe, who were also more fearful about delays than patients in other regions. Patients specifically mentioned delays in receiving chemotherapy and follow-up imaging tests.



**25% of patients** had experienced delays, modifications or cancellations in their care due to COVID-19

**Fewer than 50% of patients surveyed had access to remote or telehealth services during the pandemic.** Patients in the Americas were significantly more likely to have received these services, which may reflect greater availability of virtual services in this region, as well as patient preferences.

Patient preferences are a very important consideration for virtual consultations. There can be a lot of variability in the quality of virtual consultations, and a wide range of patient and provider experiences of telehealth. For example, some patients reported concerns about poorer communication during virtual assessments. Whilst virtual consultations can be very valuable and efficient for routine check-ups, they may be less appropriate for difficult conversations between patients and their healthcare providers.



For the first visit in two years, my clinician had to deliver disappointing news of growth – virtually.

## Participation in clinical trials

**COVID-19 does not seem to have affected the willingness of most brain tumour patients to participate in clinical trials.** Only one third of patients who responded to the survey were more reluctant to participate in a clinical trial during the COVID-19 era. In addition, most patients believed that their ability to participate in trials had not been affected.



Fewer than **20% of patients** had lost the ability to enrol in a clinical trial due to COVID-19



For patients already enrolled in a clinical trial, **15%** experienced protocol changes due to COVID-19 at the time of the survey

However, it is known that medical institutions started cancelling clinical trials as early as March, and most non-COVID-19 clinical trials remained closed during April and May, when the survey was conducted. It is likely that the positive response from patients about clinical trials is due to their limited knowledge of trials being cancelled at the time of the survey.

## Fear of losing employment and being unable to meet financial commitments

Beyond its impact on brain tumour care, the pandemic's significant economic impact is also reflected in survey responses. At the time of the survey, over a quarter of patients had a family member who had already lost their job due to the pandemic, and half of respondents – both patients and caregivers – felt their job was at risk.



Nearly half of patients and caregivers believed their job was at risk because of the pandemic

“ I am worried about other financial concerns – such as meeting mortgage repayments, bank loans, etc.

**Loss of employment is always a worry for brain tumour patients.** The evolving impact of their tumour and ongoing need for treatment may affect their ability to work and the willingness of some employers to employ them. Potential loss of employment is also a major worry for caregivers, as they are often financially responsible for their loved ones. When looking across regions, a larger proportion of patients in the Americas had lost their jobs because of the pandemic than in other regions at the time of the survey.

## Ways of coping

**Despite all the stress and anxiety brought on by COVID-19, the majority of patients (74%) felt they were coping relatively well with the fallout from the pandemic.** Patients reported that they usually relied on social distancing, use of personal protective equipment (PPE) and other recommended precautions to help them cope with concerns about contracting COVID-19.

**Patients relied mostly on family and friends to help them cope with the anxiety related to their brain tumour.** A number of patients also used mindfulness, exercise, yoga and other self-care practices.

**Many patients and caregivers commented that the pandemic had allowed them to slow down and spend more time together, and had helped improve family relationships.**

“Our adult daughter moved [back] home just before the lockdown and we now have dinner together every night. We haven't spent so much time together since she was in high school nearly eight years ago.

**The survey also confirmed the considerable role that brain tumour patient organisations have been playing** in providing support and information to patients and their families. Most patients (85%) felt satisfied or very satisfied with the support they were receiving from brain tumour charities or not-for-profit organisations during the COVID-19 pandemic.

“They have stepped up their personal, direct communication with the brain tumor community and came up with creative ways for events to still take place.

This being said, it was surprising that under a quarter of surveyed patients and caregivers had ever attended an online or in-person brain tumour support group. Reasons behind this were not explored in the survey and this finding may warrant further investigation.

## LOOKING AHEAD

**This is the first international, multilingual survey asking about the experience of people with brain tumours and their caregivers during the COVID-19 pandemic.** The survey revealed that patients' and caregivers' greatest fear is missing out on needed brain tumour care because of the pandemic. This is an important reminder that the redeployment of health services towards COVID-19, whilst fundamental to address the risks and effects of the pandemic, may come at a significant cost to patients living with brain tumours and their families. It is too early to tell what impact disruptions to care have had on overall outcomes for patients – but this question is certainly prominent in the minds of patients and their caregivers.

**As the pandemic continues to evolve, it is important to address the concerns expressed by survey respondents.** Providing brain tumour patients and their caregivers with up-to-date, reliable information on how COVID-19 may specifically affect their treatment and prognosis is essential. As we await the emergence of strong evidence to support healthcare decisions, brain tumour charities around the world have stepped in to provide crucial support to patients and caregivers, but healthcare teams should also be mindful of their patients' needs for personalised information. Previous research has shown that cancer patients generally need to trust their physician and want them to be knowledgeable and accompany them through their illness experience. Despite the challenging circumstances they are working in during the pandemic, healthcare professionals should take time to gain and strengthen patients' trust through open communication and address their patients' individual concerns about how COVID-19 might affect them.

**The survey also has important implications for all patient care beyond brain tumours.** As the pandemic continues to disrupt non-COVID-related care plans, we need to take a careful look at our healthcare systems and ensure that continuity and quality of care for all patients is protected. For example, careful consideration is needed as to when virtual consultations and telehealth are appropriate and when face-to-face interactions are in the patient's best interest. Appropriate training for healthcare professionals is important to help them adapt to these new ways of working – with clear information for patients to manage their expectations as well. We also need to learn from evolving data which patients may be at greater risk of the impact of COVID-19, to build appropriate risk stratification into treatment pathways.

**Finally, a key message from this survey is how important it is to protect and support caregivers.** The burden of responsibility placed on them by the pandemic is substantial. This is reflected in the anxiety expressed by respondents in the survey. Caregivers of people with brain tumours are known to be at increased risk of depression and anxiety, and decreased quality of life. In addition, the pandemic may result in significant financial insecurity for caregivers: nearly 50% of caregivers in our survey felt they were at risk of losing their jobs, potentially putting them and their families into financial jeopardy.

**In conclusion, the pandemic has undoubtedly been a very stressful time for brain tumour patients and their families.** Notwithstanding the need to protect this vulnerable population from the risk of contracting COVID-19, we should also not lose sight of the ongoing clinical, psychosocial and emotional needs related to their brain tumour. Finding a way to achieve these aims must be the foundation of our duty of care as a society if we are to continue to improve outcomes for these patients and protect the resilience of our healthcare systems at the same time.



The  
**Health Policy**  
Partnership

**SNO**  
Society for NeuroOncology



Surgery  
**UNIVERSITY OF TORONTO**

© 2020 The International Brain Tumour Alliance on behalf of the authors of this report. This work is licensed under the Creative Commons Attribution – Non-Commercial – No Derivatives (CC BY-NC-ND) 4.0 International License. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc-nd/4.0/>