

Title of the study

**Observational study on COVID pandemic effect in neuro-oncological patients and their caregivers**

**Study Code: Neo-CO**

vers 1.0, 04.05.2020

**COVID-19 (CORONAVIRUS SARS-CoV-2) PANDEMIC ERA: THE EXPERIENCE OF NEURO-ONCOLOGICAL PATIENT AND HIS CAREGIVER**

**PATIENT INTERVIEW (schedula A)**

CODE \_\_\_\_\_

**DEMOGRAPHIC DATA:**

**1. AGE**

- ☐ 18 - 25
- ☐ 25 – 40
- ☐ 40 – 55
- ☐ 55 – 70
- ☐ Over

**2. SEX**

- ☐ Male
- ☐ Female

**3. NAZIONALITY**

- ☐ Italian (if yes, specify the region) \_\_\_\_\_
- ☐ foreign (if yes, specificity) \_\_\_\_\_

**CLINICAL DATA:**

**4. DISEASE DIAGNOSIS**

- ☐ glioma (including GBM)
- ☐ meningioma
- ☐ ependimoma
- ☐ medulloblastoma
- ☐ PCNSL
- ☐ neurinoma
- ☐ other (specify) \_\_\_\_\_

**5. SINCE THE DISEASE WAS DIAGNOSED?**

- ☐ Less than 3 months

- ☐ 3-6 months
- ☐ 6-12 months
- ☐ More than 1 year
- ☐ More than 5 year

**6. TRATTAMENTI ALREADY DONE:**

- ☐ cerebral biopsy
- ☐ neurosurgery
- ☐ Radiotherapy
- ☐ Chemotherapy
- ☐ Immunotherapy
- ☐ rehabilitation/speech therapy
- ☐ therapy (specify) \_\_\_\_\_

**7. ONGOING TREATMENTS:**

- ☐ Radiotherapy
- ☐ Chemotherapy
- ☐ Immunotherapy
- ☐ rehabilitation/speech therapy
- ☐ therapy (specify) \_\_\_\_\_

**8. ARE YOU ENROLLED IN A CLINICAL TRIAL?**

- ☐ Yes (specify) \_\_\_\_\_
- ☐ No

**9. ANY SIGNS OF THE DISEASE:**

- ☐ Speech/comprehension impairment (e.s: aphasia)
- ☐ Sensitive abnormalities
- ☐ Cognitive (memory, attention, spatial- temporal orientation, etc.) deficit
- ☐ Motor Deficit
- ☐ seizures
- ☐ headache
- ☐ other (specify) \_\_\_\_\_
- ☐ No

**COVID 19 RELATED DATA:**

**10. HOW IS YOUR PERCEPTION OF THE RISK OF CONTRACTING THE VIRUS Coronavirus SARS CoV-2?**

- ☐ same risk of general population
- ☐ higher risk of general population
- ☐ lower risk than general population

**11. HAVE YOU BEEN TESTED FOR Coronavirus SARS-CoV-2?**

- ☐ yes
- ☐ No

**12. HAVE YOU COMPLAINED ANY SYMPTOMS RELATED TO COVID-19?**

- ☐ yes (specify) \_\_\_\_\_
- ☐ No

**13. HAVE YOU GOT Coronavirus SARS-CoV-2 INFECTION?**

- ☐ yes
- ☐ No

**14. DO YOU KNOW PEOPLE WHO GOT Coronavirus SARS-CoV-2 INFECTION?**

- ☐ yes (specify) \_\_\_\_\_
- ☐ No

**DATA RELATED TO DISCOMFORT LINKED TO THE PRESENT LIFESTYLE OR WAY /CONDITION OF LIFE?:**

**15. HOW DO YOU FEEL IN THIS PERIOD?**

- ☐ I feel I have sufficient resources to deal with the situation
- ☐ I'm worried
- ☐ I feel I've exhausted my resources
- ☐ Other (specify) \_\_\_\_\_

**16. HOW IT WOULD ASSESS ITS ANXIOUS STATE RELATED TO THE DIAGNOSIS OF BRAIN CANCER? ON A SCALE OF 1 TO 10 (where 1 indicates total absence and 10 the highest level of anxiety)**

1      2      3      4      5      6      7      8      9      10

**17. HAVE YOU ADOPTED ANY STRATEGIES TO COMBAT ANXIETY? IF YES, WHICH ONES?**

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**18. HOW WOULD YOU ASSESS YOUR ANXIETY ABOUT THE PERCEIVED RISK OF CONTRACTING COVID-19? ON A SCALE OF 1 TO 10 (where 1 indicates total absence and 10 the highest level of anxiety)**

1      2      3      4      5      6      7      8      9      10

**19. HAVE YOU ADOPTED ANY STRATEGIES TO COMBAT SUCH ANXIETY (RELATED TO COVID)? IF YES, WHICH ONES?**

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**20. ARE YOU AFRAID OF THE CURRENT HEALTH STATUS RELATED TO COVID-19 (Coronavirus)?**

- ☐ yes
- ☐ No

**DATA RELATIVE TO OVERALL CARE/SUPPORT:**

**21. HAVE YOU EVER PLANNED (OR SOMEONE PROPOSED TO YOU) ANY TYPE OF PSYCHOLOGICAL SUPPORT?**

- ☐ Yes, I'm following a psychological therapy
- ☐ No

**22. WHAT DO YOU THINK COULD HAVE HELPED YOU IN THIS PERIOD OF LIFE?**

- ☐ support groups -si chiamano così?
- ☐ Support material
- ☐ social relationship
- ☐ Interaction with other professionals to get more information
- ☐ other (specify) \_\_\_\_\_

**23. In this period of limitation of movement and social contacts, technology can play an important role in reducing the isolation? Which tool you use?**

- ☐ Smartphone for voice call
- ☐ Smartphone for videocall
- ☐ Computer for hobbies
- ☐ Computer for information and education
- ☐ other (specify) \_\_\_\_\_

**DATA RELATED TO QUALITY INFORMATION OBTAINED ON COVID-19 (Coronavirus):**

**24. WHAT SOURCES OF INFORMATION DO YOU CONSULT OR CONSULT?**

- ☐ General doctor
- ☐ specialist
- ☐ Tv and newspaper
- ☐ Internet
- ☐ Relatives/friends
- ☐ other (specify) \_\_\_\_\_

**25. ARE YOU SATISFY OF THE INFORMATION QUALITY?**

- ☐ yes, because \_\_\_\_\_
- ☐ No, because \_\_\_\_\_

**26. IF YOU REPLIED "NO" AT QUESTION 25, PLEASE SPECIFY WHICH INFORMATION YOU WILLING TO HAVE?**

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**DATA RELATIVE TO TUMOR MANAGEMENT:**

**27. HAVE YOU POSTPONED ANY NEURO-ONCOLOGICAL THERAPY OPTION DUE TO COVID-19 PANDEMIC?**

- ☐ Yes (specify) \_\_\_\_\_
- ☐ No

**28. HAVE YOU OPTED TO MODIFY NEURO-ONCOLOGICAL THERAPY DUE TO COVID-19 EPIDEMIC?**

- ☐ Yes (specify) \_\_\_\_\_
- ☐ No

**29. ARE YOU WORRIED ABOUT COVID-19 ANY TIME YOU ACCESS TO THE HOSPITAL FOR NEURO-ONCOLOGICAL DISEASE EVALUATION/THERAPY?**

- ☐ yes
- ☐ No

**30. IF YOU REPLIED "YES" TO THE QUESTION 29: ARE THERE ANY STRATEGIES THAT THE HEALTH PERSONNEL COULD BE ADOPT TO DCREASE YOUR DISCOMFORT?**

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**31. DO YOU FEEL ANY CHANGE WITH YOUR HEALTH PERSONNAL DURING COVID-19 ERA?**

- ☐ YES, with any health professional
- ☐ Only with some
- ☐ No

**32. ARE YOU SATISFIED ABOUT THE NEURO-ONCOLOGICAL TREATMENT MANAGEMENT?**

- ☐ yes (specify) \_\_\_\_\_
- ☐ No (specify) \_\_\_\_\_

**33. DO YOU HAVE ANY SUGGESTIONS TO IMPROVE THE QUALITY OF INTERACTION BETWEEN YOU AND THE HEALTH PROFESSIONIST STAFF?**

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**EVERYDAY LIFE:**

**34. WITH WHOM DO YOU LIVE?**

- ☐ alone
- ☐ with relatives
- ☐ other \_\_\_\_\_

**35. ARE YOU PRESENTLY ISOLATED DUE TO COVID-19 (Coronavirus)?**

- ☐ Yes
- ☐ No

**36. IF YOU ARE A WORKER: DO YOU THINK THAT YOUR WORK WILL BE AT RISK BECAUSE OF COVID-19?**

- ☐ Yes
- ☐ No

**37. WHICH ARE THE ASPECTS OF YOUR LIFE THAT HAVE BEEN MORE INFLUENCED BY COVID-19 PANDEMIC?**

- ☐ health
- ☐ work
- ☐ Social
- ☐ Economic
- ☐ Psychological
- ☐ Other

**38. HOW IS YOUR QUALITY OF LIFE NOWDAYS?**

- ☐ Optimal
- ☐ Very good
- ☐ good
- ☐ unsatisfactory
- ☐ not at all satisfactory

**THE FUTURE:**

**39. SINCE COVID-19 PANDEMIC, DO YOU CHANGE YOUR PERCEPTION ABOUT THE FUTURE?**

- ☐ yes
- ☐ No

**40. IF YOU REPLIED "YES" TO QUESTION 39, HOW DO YOU PERCEIVE YOUR FUTURE:**

- ☐ More uncertain
- ☐ modified, including also positive aspects
- ☐ "Suspended"
- ☐ Full of faith
- ☐ Other (specify) \_\_\_\_\_

**41. ARE THERE ANYTHING IN THE PRESENT DAYLIFE (MODIFIED DUE TO COVID-19), THAT COULD BE USEFUL FOR THE FUTURE ALSO?**

- ☐ Capacity to manage any emergency
- ☐ Higher sense of responsibility
- ☐ Better use of technologies
- ☐ Attention to social dimension
- ☐ to take care of myself
- ☐ other (specify) \_\_\_\_\_

Would you like to add other suggestions/comments?

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**COVID-19 (CORONAVIRUS SARS-CoV-2) PANDEMIC ERA: THE EXPERIENCE OF NEURO-ONCOLOGICAL  
PATIENT AND HIS CAREGIVER**

**CAREGIVER INTERVIEW (schedula B)**

CODE \_\_\_\_\_

**DEMOGRAPHIC DATA:**

**1. AGE**

- ☐ 18 - 25
- ☐ 25 – 40
- ☐ 40 – 55
- ☐ 55 – 70
- ☐ OVER

**2. SEX**

- ☐ Male
- ☐ Female
- ☐

**3. NAZIONALITY**

- ☐ Italian (if yes, specify the region) \_\_\_\_\_
- ☐ foreign (if yes, specificity) \_\_\_\_\_

**4. WHICH RELATIONSHIP TO YOU HAVE WITH THE PATIENT?**

- ☐ Patient's parent
- ☐ Patient's wife/husband
- ☐ Patient's partner
- ☐ Patient's sibling
- ☐ Other patient's relative
- ☐ Patient's friend
- ☐ other (specify) \_\_\_\_\_

**COVID-19 RELATED DATA:**

**5. ARE YOU WORRIED TO CONTRACT THE VIRUS Coronavirus SARS CoV-2?**

- ☐ I'm very worried
- ☐ I'm quite worried
- ☐ I'm not worried
- ☐ I already got it

**6. WHAT CONCERNS SHOULD YOU ADDRESS AS A CAREGIVER OF A PATIENT DIAGNOSED WITH BRAIN CANCER AT A TIME WHEN Coronavirus SARS-CoV-2 INFECTION HAS SPREAD?**

- ☐ I'm worried that the patient could not access to the treatment/follow-up
- ☐ I'm worried that the patient could get Coronavirus infection
- ☐ I'm worried to access to the hospital
- ☐ I am concerned about the burdens of the practical management of cancer disease in a difficult context such as that caused by COVID-19 (booking visits, travel, appointments, administration of therapies with attention to distance, masks, caution and attention)
- ☐ I'm worried about my work/economic situation
- ☐ I have no particular worries about covid-19 pandemic

**7. As a result of the spread of Covid-19 (Coronavirus), has the perceived burden of the assistance you provide to the person you are dealing with increased?**

- ☐ No, nothing changed
- ☐ Yes (please, add a description)\_\_\_\_\_

**DATA RELATED TO DISCOMFORT LINKED TO THE PRESENT LIFESTYLE OR WAY /CONDITION OF LIFE?:**

**8. HOW IT WOULD ASSESS ITS ANXIOUS STATE RELATED TO THE DIAGNOSIS OF BRAIN CANCER OF YOUR DEAR? ON A SCALE OF 1 TO 10 (where 1 indicates total absence and 10 the highest level of anxiety)**

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**11. HAVE YOU ADOPTED ANY STRATEGIES TO COMBAT SUCH ANXIETY (RELATED TO COVID)? IF YES, WHICH ONES?**



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**12. WHICH AREAS HAVE BEEN MORE AFFECTED BY COVID-19 PANDEMIC?**

- ☐ health
- ☐ work
- ☐ social
- ☐ economic
- ☐ psychological
- ☐ other \_\_\_\_\_

**DATA RELATIVE TO OVERALL CARE/SUPPORT:**

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