

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. TRATTAMENTS 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?

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?

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?

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?

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

- YES, with any health professionalist
- Only with some
- No

32. ARE YOU SATISFIED ABOUT THENEURO-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?

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 fair
- 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 PATIEN?

- Patient's parent
- Patient's wife/husband
- Patient's partner
- Patient's siblin
- Other patient's relative
- Patient's friend
- other (specificy) _____

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)

1 2 3 4 5 6 7 8 9 10

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

10. 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

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

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

- health
- work
- social
- economic
- psychological
- other _____

DATA RELATIVE TO OVERALL CARE/SUPPORT:

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

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

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

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- social relationship
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- other (specify) _____

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

- Smartphone for voice call
- Smartphone for videocall
- Computer for hobbies
- Computer for information and education
- other (specify) _____

16. HOW DO YOU EVALUATE YOUR QUALITY OF LIFE NOWDAYS?

- optimal
- very good
- good
- unsatisfactory
- not at all satisfactory

THE FUTURE:

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

- yes
- No

18. IF YOU REPLIED "YES" TO QUESTION 17, HOW DO YOU PERCEIVE YOUR FUTURE:

- More uncertain

- modified, including also positive aspects
 - "Suspended"
 - Full of faith
 - Other (specify) _____
-
-

19. 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?
