Article title: The Burden of Caring for Individuals with Tuberous Sclerosis Complex (TSC) Who Experience Epileptic Seizures: A Descriptive UK Survey

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ESM3

TSC Carer Impact Survey

Section 1: About the person you care for

The following questions are about the health and background of **the person you care for with Tuberous Sclerosis Complex (TSC)**. Your answers will help us understand the impact TSC has on you as a carer and your family as a whole.

Some of these questions may not be relevant to the person with TSC you care for. Please answer the questions the best way you can. If you care for more than one person with TSC, please complete this survey thinking of the person whom you spend most time caring for.

1. What is your relationship to the person you care for?
   - □ I am their (step-/foster-) parent
   - □ I am their partner/spouse
   - □ I am their sibling
   - □ I am their child
   - □ I am another relative of theirs
   - □ Other

2. How old is the person you care for?
   |_|_| years old

3. What is the sex of the person you care for?
   - □ Male
   - □ Female
   - □ Other

4. How old was the person you care for when they **first had signs or symptoms** of TSC?
   Please provide an estimate if you are not sure of the exact age.
   |_|_| years|_|_| months
   - □ Don't know/can't remember

5. How old was the person you care for when they were **diagnosed** with TSC by a medical doctor or healthcare professional?
   Please provide an estimate if you are not sure of the exact age.
   |_|_| years|_|_| months
   - □ Don't know/can't remember

6. In which areas of the body does the person you care for currently have benign growths (lumps)?
   Please select all that apply
   - □ Brain
   - □ Kidneys
   - □ Skin
   - □ Heart
   - □ Lungs
   - □ Mouth
   - □ Eyes
   - □ Other
   - □ None of the above

7. Has the person you care for ever had epileptic seizures?
   - □ Yes
   - □ No

8. How old were they when they first experienced epileptic seizures?
   Please provide an estimate if you are not sure of the exact age.
   |_|_| years |_|_| months
   - □ Don't know/can't remember

9. Are they **currently** taking any treatments for their epileptic seizures?
   - □ Yes
   - □ No

10. In total, how many epileptic seizures of any type have they had in the last week?
    Please provide an estimate if you are not sure of the exact number.
    |_|_|_| seizures

11. **'Generalised seizures'** are characterised by all the following:
    - Loss of consciousness, which can result in you appearing unaware of surroundings.
    - Involuntary movements, such as blinking repeatedly, smacking of lips or chewing movements or hand movements
    - Muscles suddenly becoming stiff, and then relax and tighten so that your **entire body** jerks and/or shakes intensively
    - Falling if unsupported

    How many *generalised seizures* has the person you care for had in the last week?
    Please provide an estimate if you are not sure of the exact number.
    |_|_|_| generalised seizures

12. **'Focal seizures <u>with</u> impaired awareness'** are characterised by the following:

- **Impaired/altered consciousness**, which can result in you appearing unaware of surrounding
- **One part** of the body jerking involuntary

How many focal seizures **<u>with</u> impaired awareness** has the person you care for had in the last week?
Please provide an estimate if you are not sure of the exact number.
|_|_|_| focal seizures with impaired awareness

13. **'Focal seizures <u>without</u> impaired awareness'** are characterised by the following:
    - Remaining in **full consciousness**
    - **One part** of the body jerking involuntary

    How many focal seizures **<u>without</u> impaired awareness** has the person you care for had in the last month?
    Please provide an estimate if you are not sure of the exact number.
    |_|_|_| focal seizures <u>without</u> impaired awareness

14. How often has the person you care for undergone surgical procedures related to their TSC?
    Please provide an estimate if you are not sure of the exact number
    |_|_|_|

15. How would you describe the intellectual ability of the person you care for?
    - □ Normal intellectual ability
    - □ Mild-moderate intellectual disability
    - □ Severe-profound intellectual disability

16. Would you say the person you care for has any developmental delays?
    - □ Yes
    - □ No
    - □ Don't know

17. Has the person you care for ever received a diagnosis of the following?
    Please select all that apply.
    - □ Autism Spectrum Disorder (ASD) (e.g., autism, Asperger's)
    - □ Attention Deficit Hyperactivity Disorder (ADHD)
    - □ Anxiety (e.g., panic, phobia, separation anxiety disorder)
    - □ Depression
    - □ Obsessive Compulsive Disorder
    - □ Psychotic Disorder (e.g., schizophrenia)
    - □ Other
    - □ None of the above
    - □ Don't know

18. Does the person you care for experience any sleep problems (e.g., difficulty falling and remaining asleep)?
    - □ Yes
    - □ No

19. Which of the following best describes the school the person you care for currently attend or have attended in the past? *Please select all that apply.*
    - □ Mainstream school
    - □ Mainstream school with special needs support
    - □ Special needs school

20. If applicable which of the following best describes the occupation of the person you care for?
    - □ In education or training
    - □ Employed full-time
    - □ Employed part-time
    - □ Unemployed/ looking for work
    - □ Unable to work due to their health
    - □ Other

21. Which of the following best describes their training/education?
    - □ Mainstream education, training or apprenticeship
    - □ Mainstream education, training or apprenticeship with special needs support
    - □ Education or training for people with special needs
    - □ Other, please specify:

22. Do they attend a day care centre for people with learning disabilities?
    - □ Yes
    - □ No
    - □ Prefer not to answer

23. Which of the following types of support, if any, does the person you care for receive for their condition?
    Please select all that apply
    - □ Disability allowance
    - □ Psychological counselling
    - □ Support from social services
    - □ Support from social worker
    - □ Help completing benefit applications
    - □ Other
    - □ None of the above

24. How satisfied are you with the paediatric healthcare services that the person you care for receives or has received in the past?
    - □ Extremely satisfied
    - □ Satisfied
    - □ Neither satisfied nor unsatisfied
    - □ Unsatisfied
    - □ Extremely unsatisfied

25. How satisfied are you with the adult healthcare services that the person you care for receives?
    - □ Extremely satisfied
    - □ Satisfied
    - □ Neither satisfied nor unsatisfied
    - □ Unsatisfied
    - □ Extremely unsatisfied

26. How satisfied are you with their overall experience of transitioning from paediatric to adult healthcare services?
    - □ Extremely satisfied
    - □ Satisfied
    - □ Neither satisfied nor unsatisfied
    - □ Unsatisfied
    - □ Extremely unsatisfied

    Do you have any comments about their transition from paediatric to adult healthcare services?

27. Thinking about the epileptic seizures of the person you care for, which of the following best describes how decisions about the use of a new medication are typically made?
    - □ We are told by the doctor to try a new medication
    - □ The doctor recommends a new medication, and we discuss with the doctor whether to try it
    - □ We ask the doctor for a new medication, and we discuss with the doctor if it is possible to try it

28. When the person you care for starts a new medication for their epileptic seizures, which of the following best describes **your preferred approach** to starting a new medication?
    - □ Starting with a low dose and increasing the dose, depending on the response to the medication

- □ Starting with a high dose, and depending on the response to the medication, reduce the dose
- □ Not sure

Section 2: About the care you provide for the person with TSC

The following questions are about **the care you provide** for the person with Tuberous Sclerosis Complex (TSC) and any impact of this on your work/career and financial situation.

Some of these questions may not be relevant to you. Please answer the questions the best way you can.

29. In which of the following ways do you care for the person with TSC?
    - □ Care related to their daily activities
    - □ Care related to their medication and medical care
    - □ Care while they were having a seizure or recovering from a seizure
    - □ Providing emotional support
    - □ Other, please specify:

30. In total, how much time did you spend caring for them in the last week?
    Please provide an estimate if you are not sure of the exact amount of time.
    |_|_| hours **in total during the last week**
    OR
    |_|_| hours **per day during the last week**

    Do you have any comments about the total amount of time you spend caring that you would like to share?

31. Does the amount of time you spend caring vary over the course of a week?
    - □ Yes - please, specify how:
    - □ No

32. Of the hours you spend caring, how much time did you spend caring for them while they were having or recovering from a seizure in the last week?
    Please provide an estimate if you are not sure of the exact amount of time.
    |_|_| hours **in total during the last week**

    Do you have any comments about the amount of time you spend caring due to seizures that you would like to share?

33. Have you had to do any of the following in order to care for the person with TSC?
    Please select all that apply.
    - □ Stop working
    - □ Reduce your working hours

- □ Change jobs
- □ Not applicable

Do you have any comments about the impact of caring on your work and career that you would like to share?

34. If you are employed, on average how many hours do you miss of work per week due to caring for the person with TSC? *Please provide an estimate if you are not sure of the exact amount of time.*
    Average of |_|_| hours per week
    - □ Not applicable

35. Do you require childcare because you care for the person with TSC?
    - □ Yes
    - □ No

36. On average, how much money do you spend on costs relating to the care you provide for the person with TSC, e.g.:
    - Equipment (e.g., helmets)
    - Travel to and from medical appointments

    Please provide an estimate if you are not sure of the exact amount of time.
    |_ |_|_|_|_|GBP per year
    - □ Prefer not to answer

37. Do you receive any state-funded financial support for providing care for the person with TSC?
    - □ Yes - Carer's Allowance
    - □ Yes - Carer's Credit
    - □ Yes - other
    - □ No
    - □ Don't know

38. To what extent has the COVID-19 pandemic impacted on you as a carer of someone with TSC?
    - □ No impact
    - □ A small impact
    - □ A moderate impact
    - □ A large impact
    - □ A very large impact

    Can you tell us how the COVID-19 pandemic has or has not impacted you as a carer?

39. Have you used NHS services (e.g., doctor's appointments, counselling) to cope with mental or physical health impacts of caring with someone with TSC?

- □ Yes
- □ No

40. Which of the following NHS services have you used to cope with mental or physical health impacts of caring with someone with TSC?
    Please select all that apply.
    - □ Appointment(s) with a doctor or nurse at a general practice
    - □ Appointment(s) with a specialist doctor or nurse/doctor or nurse in a hospital
    - □ Counselling/other psychological therapy
    - □ Respite care
    - □ Other, please specify:

Section 3: Health-related quality of life

PedsQL™ Family Impact Module

For any information on the use of the PedsQL™, please contact Mapi Research Trust, Lyon, France.

Link: https://eprovide.mapi-trust.org/instruments/pediatric-quality-of-life-inventory-family-impact-module

Section 4: Emotional wellbeing

[Hospital Anxiety and Depression Scale (HADS)]

For any information on the use of the HADS, please contact Mapi Research Trust, Lyon, France.

Link: https://eprovide.mapi-trust.org/instruments/hospital-anxiety-and-depression-scale

Section 5: Unpaid care provided by others

The following questions are about **the care other(s) within your household provide** for the person with Tuberous Sclerosis Complex (TSC). This will help us understand the impact of TSC on your household as a whole.

41. **Apart from yourself**, how many other people in your household are involved in the care for the person with TSC?
    |_|_|

42. **Apart from yourself**, who else in your household is involved in the care for the person with TSC? *Please select all that apply.*
    - □ Your partner/spouse

- □ Your parent(s)/sibling(s)
- □ Your (other) child(ren)
- □ Another relative of yours
- □ Other

43. In which of the following ways, does [insert Q42 selected carer(s)] care for the person with TSC?
Please select all that apply.
    - □ Care related to their daily activities
    - □ Care related to their medication and medical care
    - □ Care while they were having a seizure or recovering from a seizure
    - □ Providing emotional support
    - □ Other

44. In total, how much time did they spend caring for them in the last week?
Please provide an estimate if you are not sure of the exact amount of time.
|_|_| hours **in total during the last week**

45. Of the hours they spend caring, how much time did they spend caring for them while they were having or recovering from a seizure in the last week?
Please provide an estimate if you are not sure of the exact amount of time.
|_|_| hours **in total during the last week**

46. Have [insert Q42 selected carer(s)] had to do any of the following in order to care for the person with TSC? *Please select all that apply.*
    - □ Stopped working
    - □ Reduced their working hours
    - □ Changed jobs
    - □ Not applicable

47. On average, how many hours do [insert Q42 selected carer(s)] miss work, school or college per week due to caring for your family member with TSC?
Please provide an estimate if you are not sure of the exact amount of time.
Average of |_|_| hours per week
    - □ Not applicable

48. Has [insert Q42 selected carer(s)] used NHS services (e.g., doctor's appointments, counselling) to cope with mental or physical health impacts of caring with someone with TSC?
    - □ Yes
    - □ No
    - □ Don't know

49. Which of the following NHS services have they used to cope with mental or physical health impacts of caring with someone with TSC?
    Please select all that apply.
    - □ Appointment(s) with a doctor or nurse at a general practice
    - □ Appointment(s) with a specialist doctor or nurse / doctor or nurse in a hospital
    - □ Counselling/other psychological therapy
    - □ Respite care
    - □ Other, please specify:

Section 6: About you and your family

In this section, we will ask you some background questions about you and your family to help us better understand your survey responses so far.

The following questions are about **your** health and background.

50. Have you yourself been **diagnosed** with TSC?
    - □ Yes
    - □ No
    - □ Prefer not to say

51. Do you have any symptoms related to your TSC?
    - □ Yes
    - □ No

52. Do you have any chronic health conditions? *Select all that apply.*
    - □ Arthritis
    - □ Anxiety
    - □ Cancer
    - □ Chronic kidney disease
    - □ Depression
    - □ Diabetes
    - □ Digestive pain / discomfort
    - □ Heart disease
    - □ Hypertension (high blood pressure)
    - □ Respiratory condition (e.g., Asthma, COPD)
    - □ Sleep problems
    - □ Stress
    - □ Other
    - □ None of the above
    - □ Prefer not to answer

53. What is your sex?

- □ Male
- □ Female
- □ Other
- □ Prefer not to answer

54. What is your age?
    |_|_| years old
    - □ Prefer not to answer

55. How would you best describe your employment status?
    Please select the response option that is most applicable.
    - □ (Self-)employed full-time
    - □ (Self-)employed part-time
    - □ Full-time homemaker/caregiver
    - □ Retired
    - □ Seeking work/unemployed
    - □ Long term sick leave
    - □ In education or training
    - □ Other, please specify:
    - □ Prefer not to answer

The following questions are about who else is in **your family** (household).

56. **Apart from yourself and the person you care for**, who else lives in your household?
    Please select all that apply.
    - □ My partner/spouse
    - □ My other child(ren)
    - □ My parent(s) or sibling(s)
    - □ Other relatives of mine
    - □ Prefer not to answer

57. **In total**, how many children do you have who live with you?
    |_|_| children

    How old are your child(ren)?
    Child 1: |_|_| years
    Child 2: |_|_| years
    Child 3: |_|_| years
    Child 4: |_|_| years

58. **In total**, how many children with TSC who have symptoms do you care for?
    |_|_| children with TSC symptoms

How old are your child(ren) with TSC symptoms?
Child 1: |_|_| years
Child 2: |_|_| years
Child 3: |_|_| years
Child 4: |_|_| years

Section 7: Social care

The following questions are about any professional social care the person with Tuberous Sclerosis Complex (TSC) you care for receives. This will help us better understand the care they need from people other than yourself and your family (household).

59. Does the person with TSC receive any professional social care (e.g., a support worker or personal care assistant)?
    - □ Yes
    - □ No

60. How many hours of **private care** and/or **state funded care** do they receive?
    |_|_|_| hours of private care per week
    |_|_|_| hours of state funded care per week

61. How much do you spend on private care for them per week?
    |_|_|_|_| GBP per week
    - □ Prefer not to answer

62. How much money do they receive for state funded care per week?
    |_|_|_|_| GBP per week
    - □ Prefer not to answer

This is the end of the survey.
Thank you very much for taking the time to take part in this research study.
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