

CoRDS

Rare Disease Registry



Summary Report as on (14-December-2020 19:21)

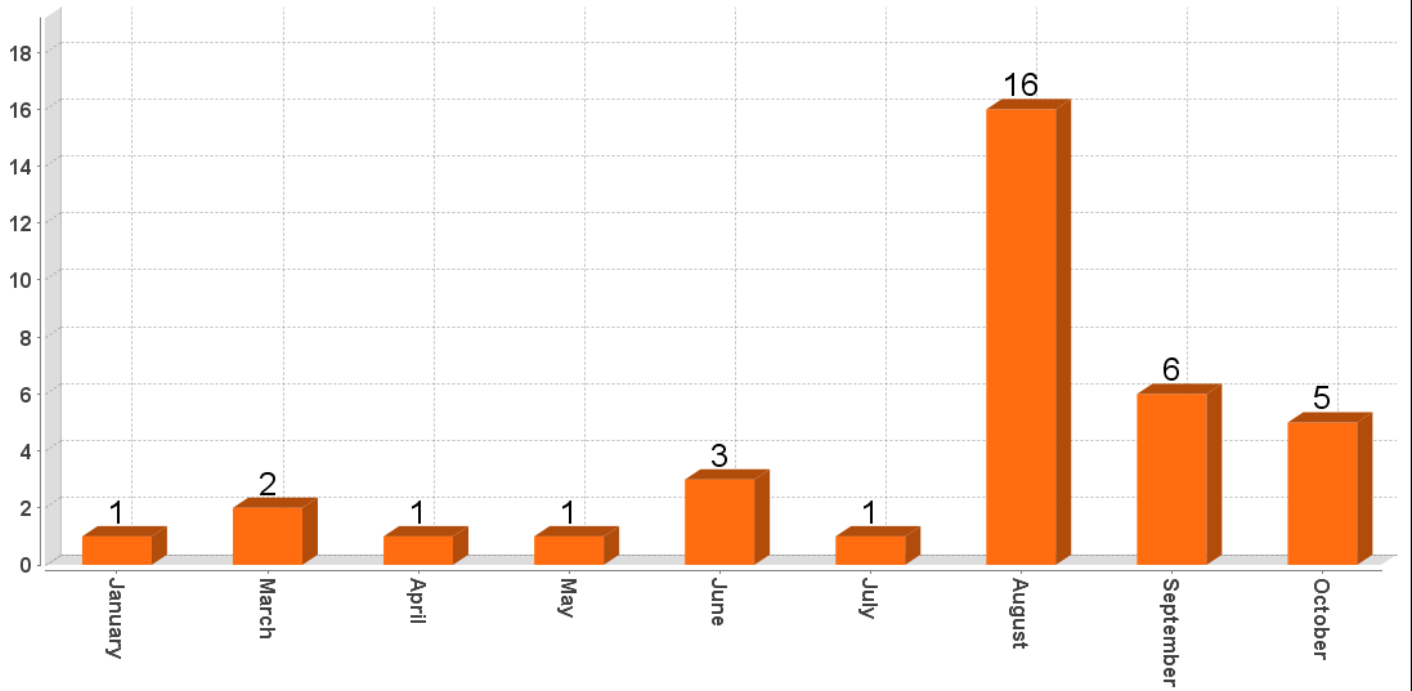
Participant Information

Number Of Participants Currently Enrolled

100

Enrolled Participants By Month

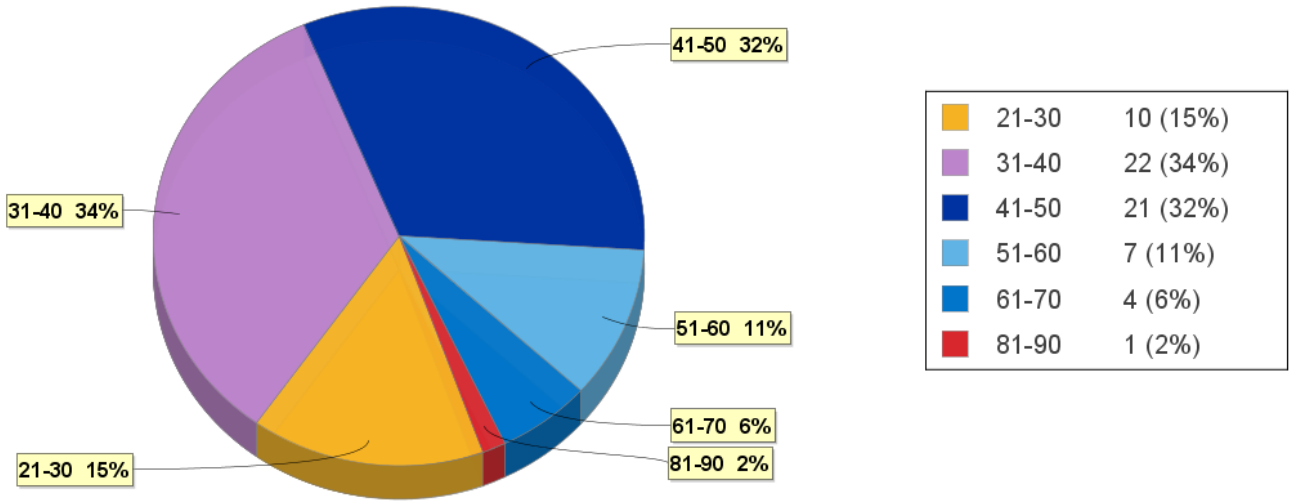
Enrolled Participants
Hypnic jerking



Age of Enrolled Participants

Age of Enrolled Participants

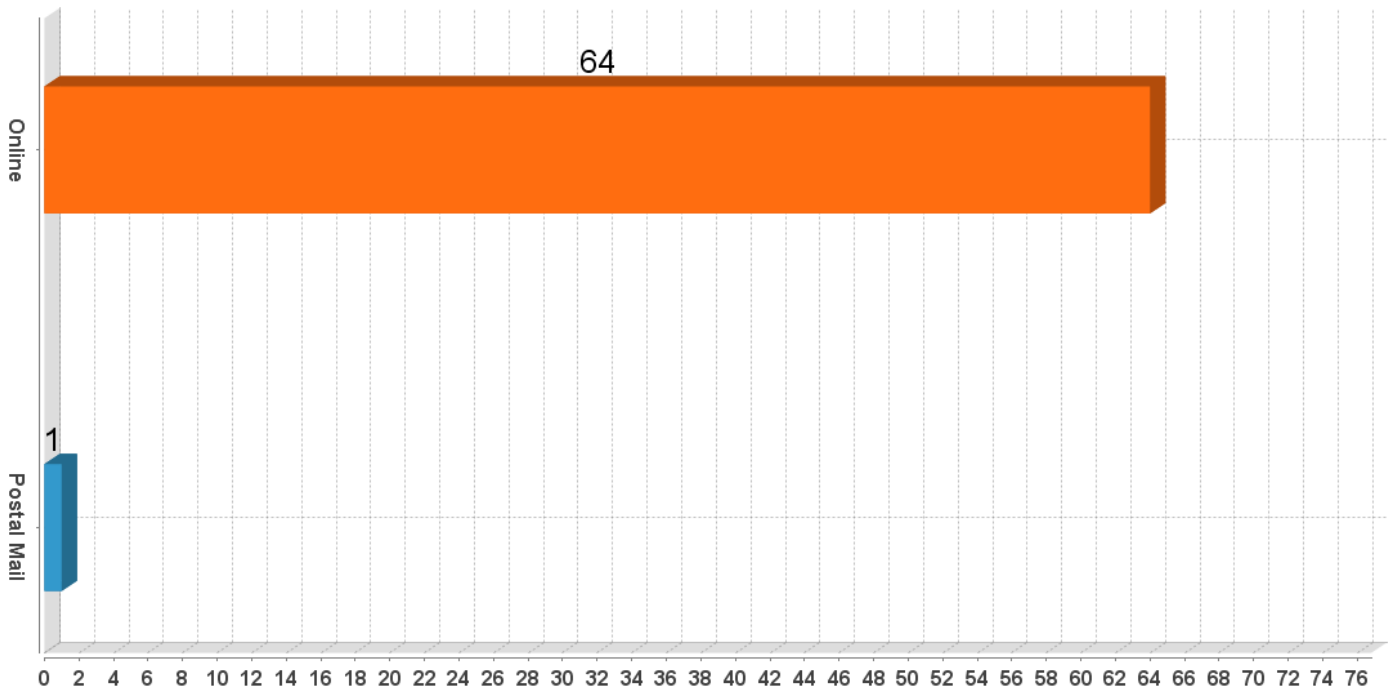
Hypnic jerking



Enrolled Method Of Enrolled Participants

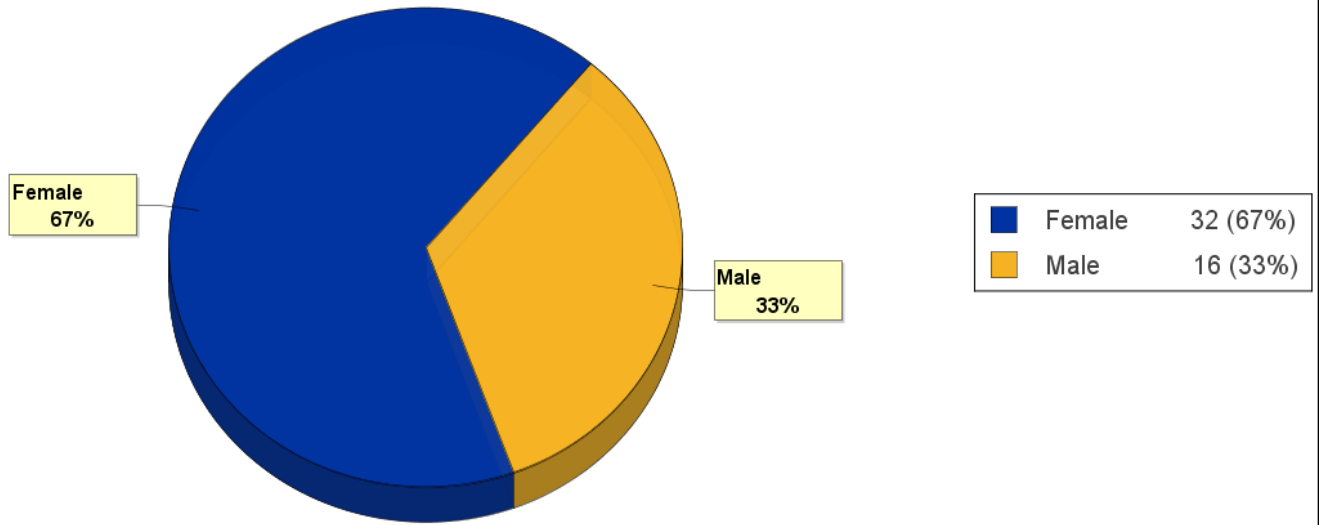
Enrolled Method Of Enrolled Participants

Hypnic jerking



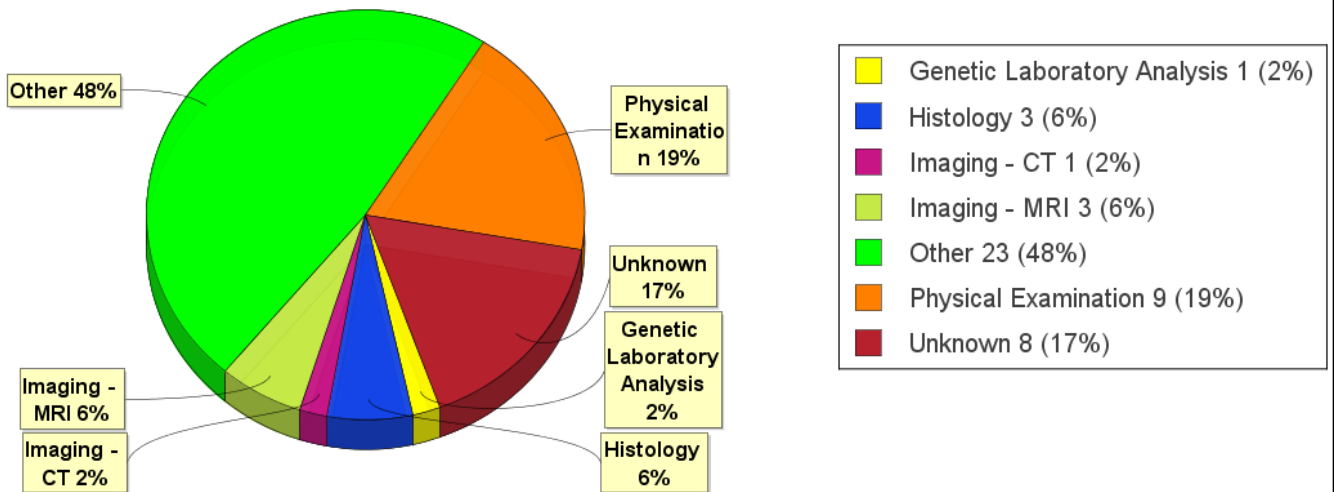
Enrolled Gender Of Participants

Sex Hypnic jerking



Diagnosis Determination Of Enrolled Participants

How was the diagnosis determined? Hypnic jerking



State Of Enrolled Participants

State	Count	Percentage
Arizona (AZ)	1	1.64%
Arkansas (AR)	1	1.64%
California (CA)	1	1.64%
Florida (FL)	1	1.64%
Georgia (GA)	1	1.64%
Hawaii (HI)	1	1.64%
Illinois (IL)	1	1.64%
Indiana (IN)	2	3.28%
Kentucky (KY)	1	1.64%
Massachusetts (MA)	1	1.64%
Michigan (MI)	1	1.64%
Missouri (MO)	3	4.92%
Nebraska (NE)	1	1.64%
Nevada (NV)	1	1.64%
New Hampshire (NH)	1	1.64%
New Jersey (NJ)	2	3.28%
New York (NY)	1	1.64%
Not In USA (NoUSA)	24	39.34%
Not Indicated	6	9.84%
Ohio (OH)	1	1.64%
Oregon (OR)	1	1.64%
Texas (TX)	3	4.92%
Utah (UT)	1	1.64%
Washington (WA)	2	3.28%
Wisconsin (WI)	1	1.64%
Wyoming (WY)	1	1.64%
Total:	61	100.00%

Country Of Enrolled Participants

Country	Count	Percentage
Australia	4	6.56%
Canada	3	4.92%
Finland	1	1.64%
France	1	1.64%
Germany	1	1.64%
India	2	3.28%
Ireland	1	1.64%
Luxembourg	1	1.64%
Malaysia	1	1.64%
Not Indicated	5	8.20%
Philippines	1	1.64%
Spain	1	1.64%
United Kingdom	8	13.11%
United States of America (USA)	31	50.82%
Total:	61	100.00%

Race Of Enrolled Participants

Race	Count	Percentage
Asian - Chinese	2	4.44%
Asian - Filipino	1	2.22%
Asian - Indian	1	2.22%
Asian - Vietnamese	1	2.22%
Black or African American	1	2.22%
Other/Unknown/Refuse to Answer	1	2.22%
White	38	84.44%
Total:	45	100.00%

Ethnicity Of Enrolled Participants

Ethnicity	Count	Percentage
Ashkenazi Jewish	1	2.86%
Hispanic/Latino - Cuban	1	2.86%
Not Hispanic or Latino	21	60.00%
Other	5	14.29%
Unknown/No answer	7	20.00%
Total:	35	100.00%

MEMORANDUM

To: Alyssa Mendel
From: Tyler Sang, Ph.D.
Date: December 8, 2020
Subject: Hypnic Jerk Sleep Myoclonus

Results

Overall responses: 93

Table 1. Variable: quality_Life
In general, would the participant say his/her health is...

Missing responses: n=16, 17.2%

Response	Count	Percent
Excellent	8	8.6
Very good	24	25.8
Good	33	33.5
Fair	11	11.8
Poor	1	1.1

Figure 1. Variable: quality_Life
In general, would the participant say his/her health is...

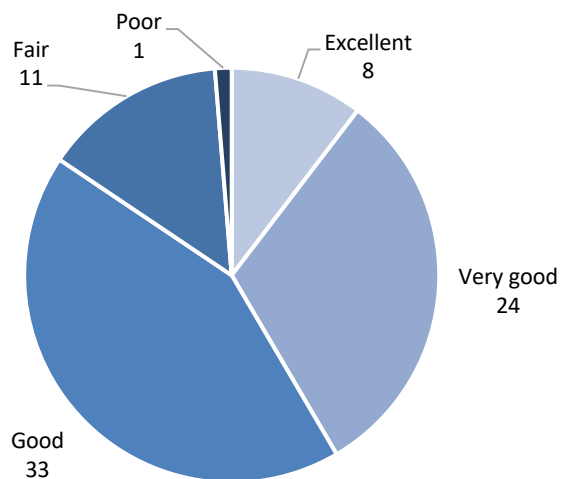


Table 2. Variable: quality_tired
How often does the participant feel tired?

Missing responses: n=17, 18.3%

Response	Count	Percent
Always	13	14.0
Often	41	44.1
Rarely	5	5.4
Sometimes	17	18.3

Figure 2. Variable: quality_tired
How often does the participant feel tired?

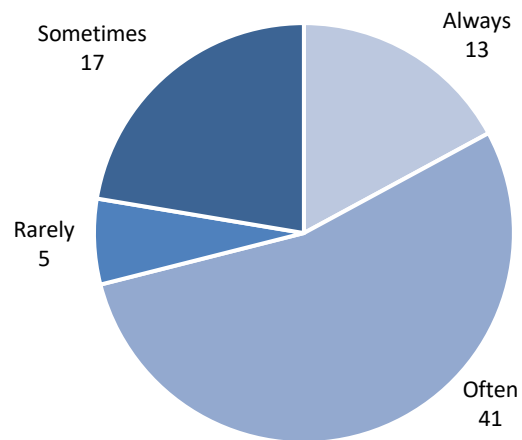


Table 3. Variable: quality_depressed
The participant feels depressed...

Missing responses: n=16, 17.2%

Response	Count	Percent
Always	8	8.6
Often	24	25.8
Sometimes	30	32.3
Rarely	11	11.8
Never	4	4.3

Figure 3. Variable: quality_depressed
The participant feels depressed...

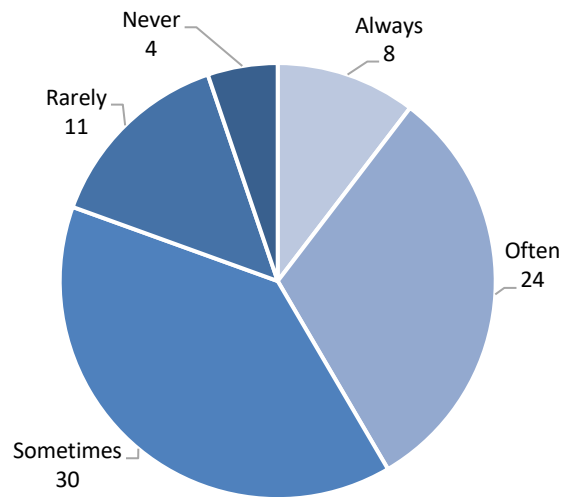


Table 4. Variable: prior_newMed

Q2. Just prior to the hypnic jerking onset, did the participant try a new medication or product?

Missing responses: n=17, 18.3%

Response	Count	Percent
Yes	39	41.9
No	33	35.5
Don't know	4	4.3

Figure 4. Variable: prior_newMed

Q2. Just prior to the hypnic jerking onset, did the participant try a new medication or product?

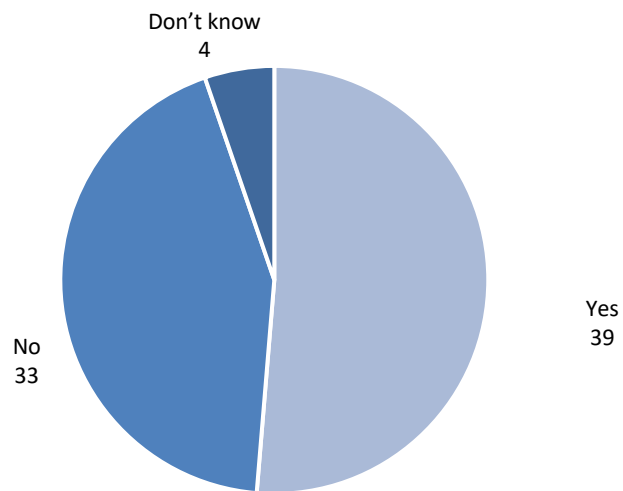


Table 5. Variable: prior_inj

Q3. Prior to the hypnic jerking onset, did the participant have a head/neck/back injury?

Missing responses: n=17, 18.3%

Response	Count	Percent
Yes	18	19.4
No	57	61.3
Don't know	1	1.1

Figure 5: Variable: prior_inj

Q3. Prior to the hypnic jerking onset, did the participant have a head/neck/back injury?

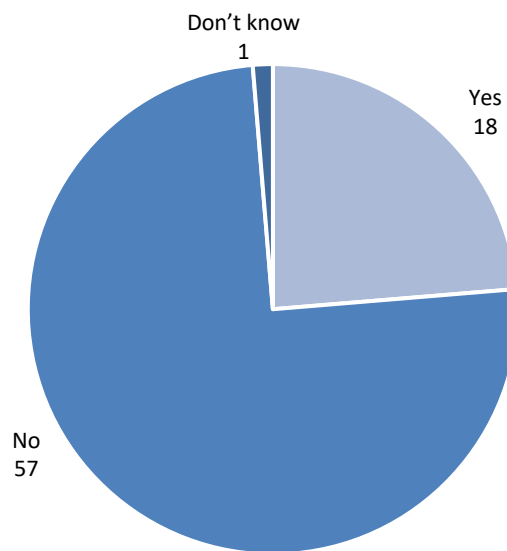


Table 6.Variable: prior_cond

Q5. *Prior to hypnic jerking onset, has the participant experienced an adrenal or anxiety condition?*

Missing responses: n=20, 21.5%

Response	Count	Percent
Yes	47	50.5
No	19	20.4
Don't know	7	7.5

Figure 6. Variable: prior_cond

Q5. *Prior to hypnic jerking onset, has the participant experienced an adrenal or anxiety condition?*

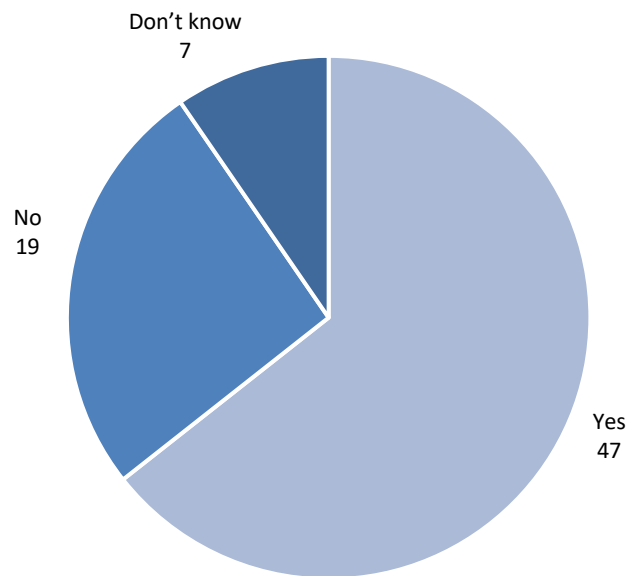


Table 7. Variable: prior_onset

Q8. Which of the following best describe the onset of the participant's hypnic jerking?

Missing responses: n=17, 18.3%

Response	Count	Percent
Gradual	15	16.1
Sudden	61	65.6

Figure 7: Variable: prior_onset

Q8. Which of the following best describe the onset of the participant's hypnic jerking?

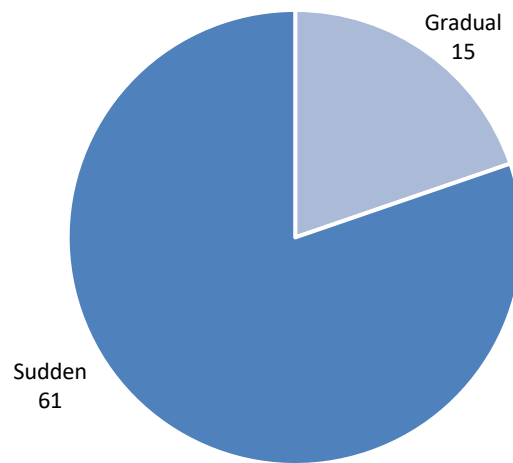


Table 8. Variable: prior_exp

Q12. How long has the participant been experiencing their hypnic jerking?

Missing responses: n=27, 29.0%

Response	Count	Percent
Less than 1 year	30	32.3
1 to 5 years	28	30.1
Greater than 6 years	8	8.7

Figure 8. Variable: prior_exp

Q12. How long has the participant been experiencing their hypnic jerking?

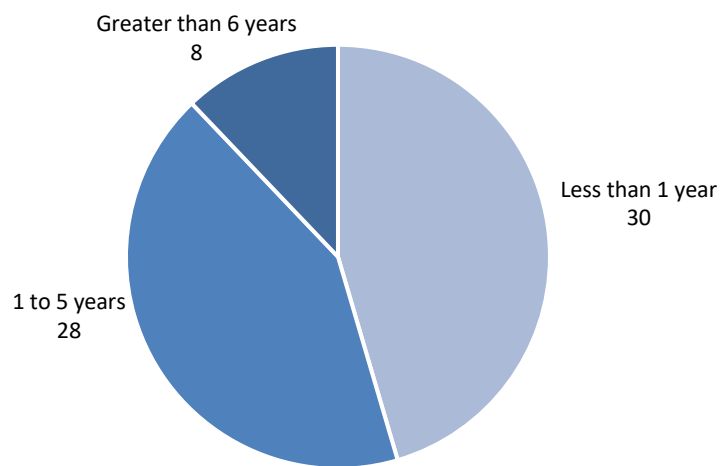


Table 9. Variable: cond_jerksExpWorst

Q16. Approximately how many hypnic jerks does the participant experience on their WORST sleep?

Missing responses: n=20, 21.5%

Response	Count	Percent
Under 5	2	2.2
Under 10	2	2.2
Under 50	32	34.4
More than 50	31	33.3
Unsure	6	6.5

Figure 9. Variable: cond_jerksExpWorst

Q16. Approximately how many hypnic jerks does the participant experience on their WORST sleep?

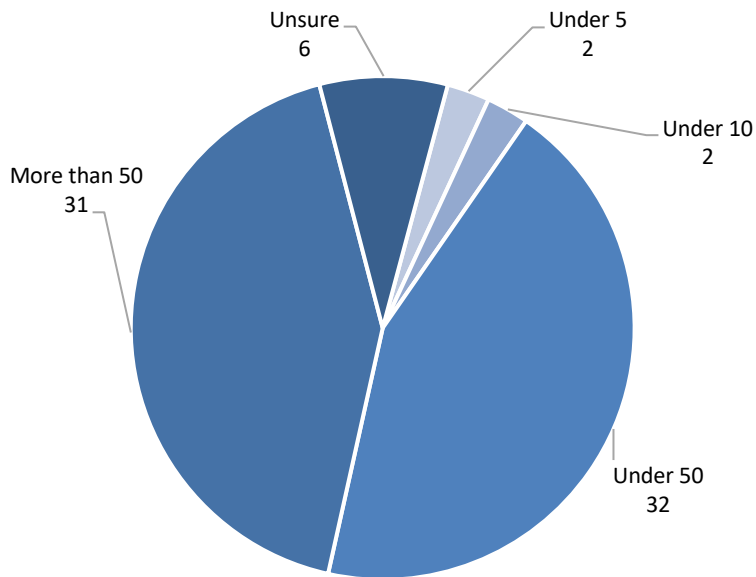


Table 10. Variable: cond_treatJerkWorst

Q17. Is the participant typically undergoing treatment while they experienced their WORST sleep?

Missing responses: n=19, 20.4%

Response	Count	Percent
Yes	30	32.3
No	42	45.2
Don't know	2	2.2

Figure 10. Variable: cond_treatJerkWorst

Q17. Is the participant typically undergoing treatment while they experienced their WORST sleep?

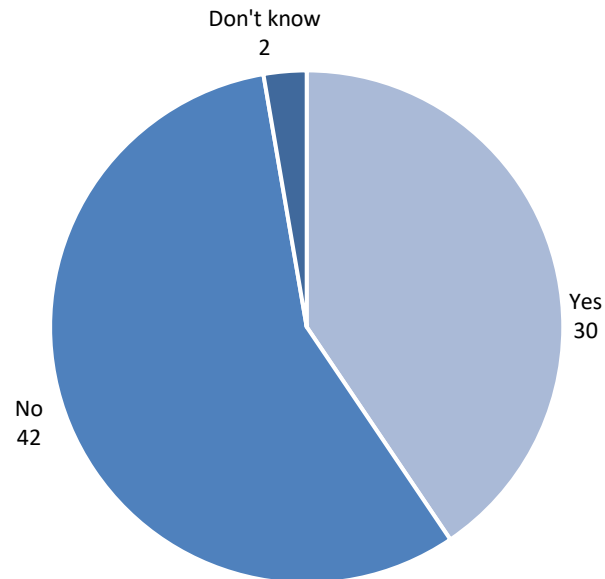


Table 11. Variable: cond_jerkLastWorst

Q18. How long does the participant's hypnic jerking last while they experienced their WORST sleep?

Missing responses: n=20, 21.5%

Response	Count	Percent
Less than 1 hour	2	2.2
Less than 2 hours	7	7.5
3 to 4 hours	17	18.3
More than 5 hours	45	48.4
N/A	2	2.2

Figure 11. Variable: cond_jerkLastWorst

Q18. How long does the participant's hypnic jerking last while they experienced their WORST sleep?

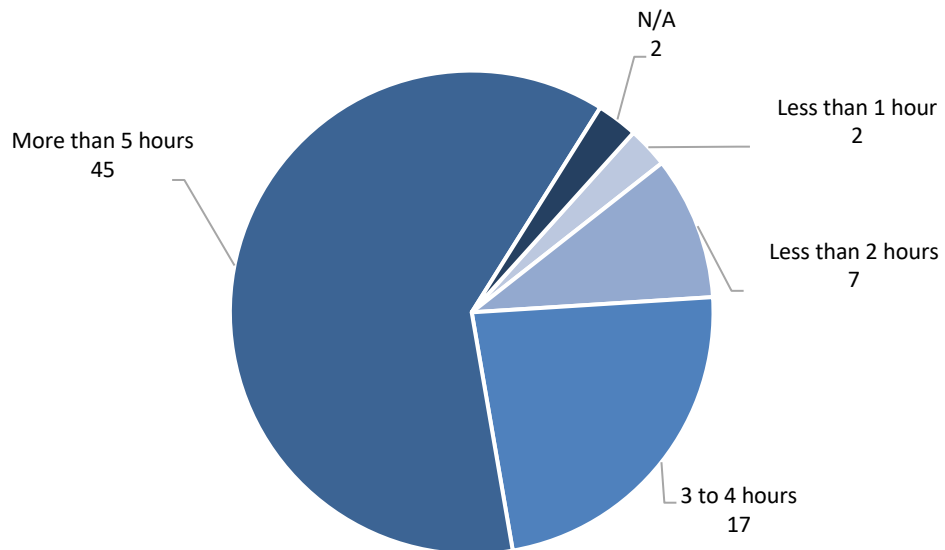


Table 12. Variable: cond_jerkin

Q19. What is the intensity of the participant's hypnic jerking?

Missing responses: n=18, 19.4%

Response	Count	Percent
Mild	9	9.7
Moderate	42	45.2
Severe	24	25.8

Figure 12. Variable: cond_jerkin

Q19. What is the intensity of the participant's hypnic jerking?

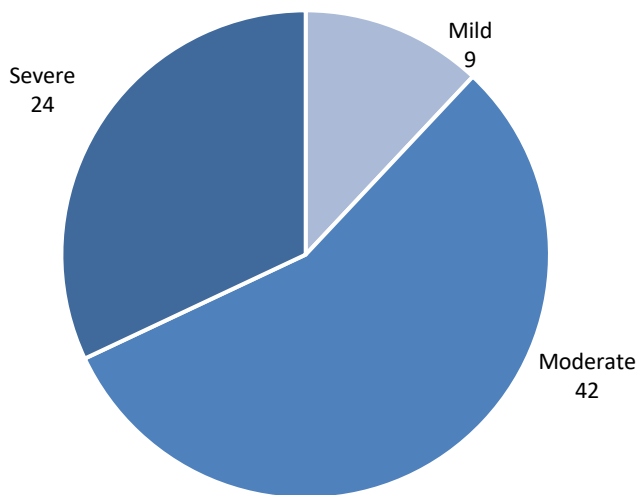


Table 13. Variable: cond_jerkNap

Q25. Does the participant experience jerks while napping?

Missing responses: n=18, 19.4%

Response	Count	Percent
Yes	66	71.0
No	1	1.1
Don't know	8	8.6

Figure 13. Variable: cond_jerkNap

Q25. Does the participant experience jerks while napping?

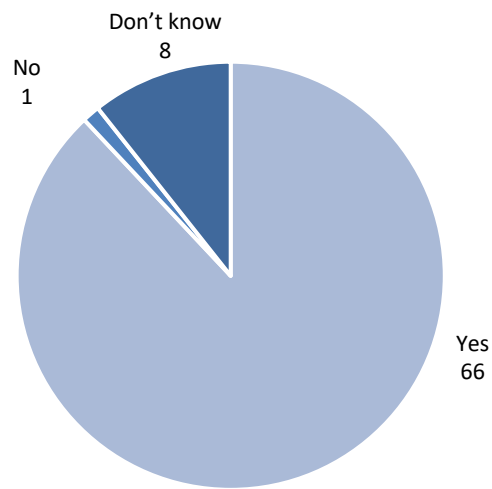


Table 14. Variable: cond_dreamFreq

Q27. How often does the participant experience vivid dreaming?

Missing responses: n=17, 18.3%

Response	Count	Percent
All of the time	7	7.5
Most of the time	22	23.7
Some of the time	38	40.9
Never	9	9.7

Figure 14. Variable: cond_dreamFreq

Q27. How often does the participant experience vivid dreaming?

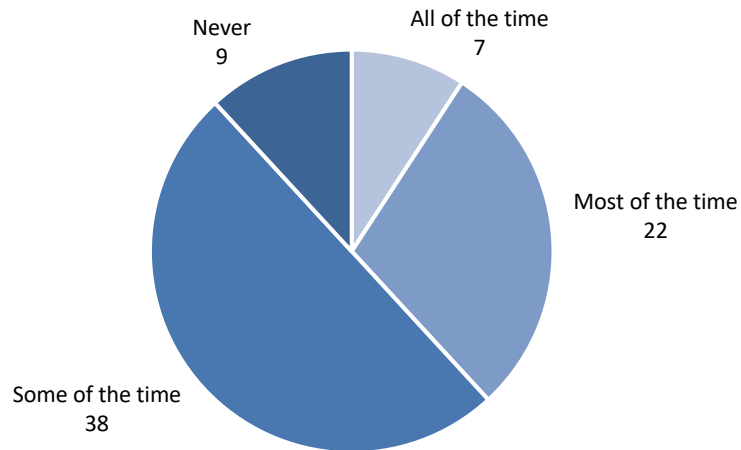


Table 15. Variable: cond_sleepTreat

Q31. If applicable, on an average night WITH treatment (medications and/or supplements), how much TOTAL sleep does the participant get?

Missing responses: n=22, 23.7%

Response	Count	Percent
1 to 3 hours	2	2.2
4 to 5 hours	20	21.5
6 to 8 hours	42	45.2
8 hours or more	7	7.5

Figure 15. Variable: cond_sleepTreat

Q31. If applicable, on an average night WITH treatment (medications and/or supplements), how much TOTAL sleep does the participant get?

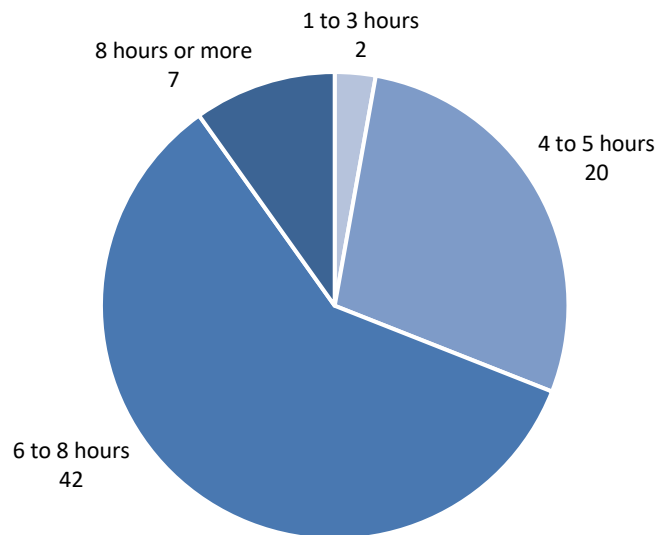


Table 16. Variable: cond_sleepNoTreat

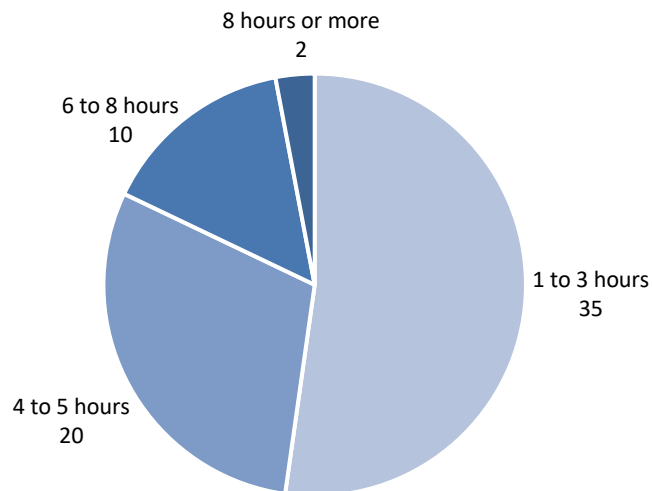
Q32. If applicable, on an average night WITHOUT treatment (medications and/or supplements), how much TOTAL sleep does the participant get?

Missing responses: n=26, 28.0%

Response	Count	Percent
1 to 3 hours	35	37.6
4 to 5 hours	20	21.5
6 to 8 hours	10	10.8
8 hours or more	2	2.2

Figure 16. Variable: cond_sleepNoTreat

Q32. If applicable, on an average night WITHOUT treatment (medications and/or supplements), how much TOTAL sleep does the participant get?



Variable: cond_nightLong

Q39. What is the longest number of consecutive days the participant has gone without sleep?

Mean: 4.36

SD: 5.55

Table 17. Variable: doc_condEx

Q43. Has the participant received an explanation to the cause of their hypnic jerking by a medical professional?

Missing responses: n=17, 18.3%

Response	Count	Percent
Yes	19	20.4
No	56	60.2
Don't know	1	1.1

Figure 17. Variable: doc_condEx

Q43. Has the participant received an explanation to the cause of their hypnic jerking by a medical professional?

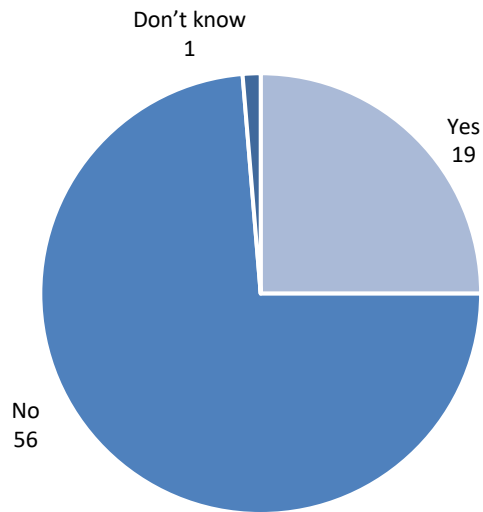


Table 18. Variable: doc_studyRes

Q45. Which of the following best describes the participant's sleep study results?

Missing responses: n=17, 18.3%

Response	Count	Percent
Normal	16	17.2
Inconclusive	16	17.2
Abnormal	6	6.5

Figure 18. Variable: doc_studyRes

Q45. Which of the following best describes the participant's sleep study results?

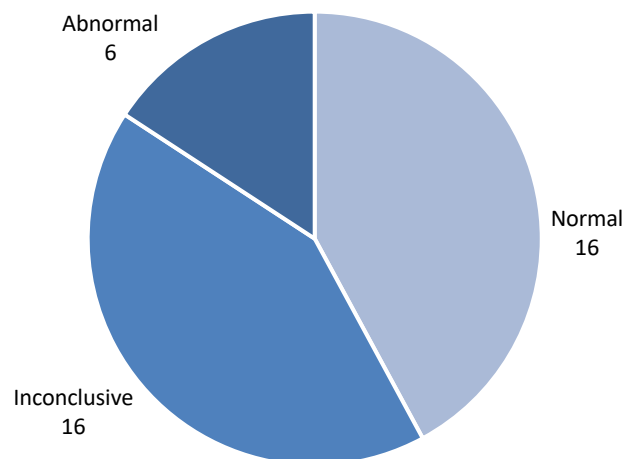


Table 19. Variable: doc_jerkSym

Q48. Has the participant had a physician ever diagnose their hypnic jerking as a symptom of a different illness/disease?

Missing responses: n=24 25.8%

Response	Count	Percent
Yes	15	16.1
No	51	54.8
Don't know	3	3.2

Figure 19. Variable: doc_jerkSym

Q48. Has the participant had a physician ever diagnose their hypnic jerking as a symptom of a different illness/disease?

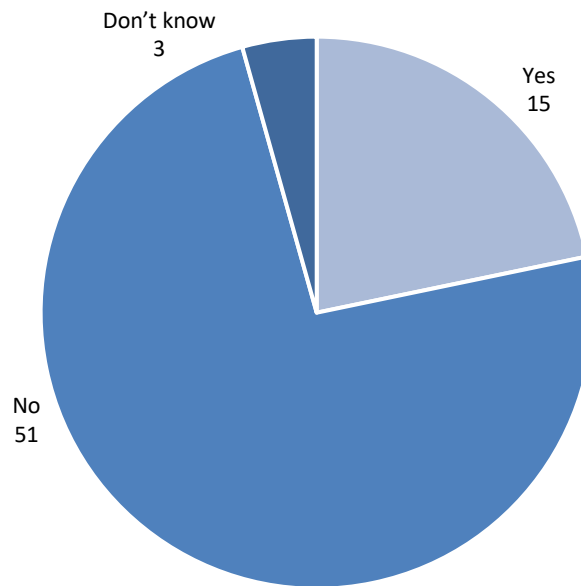


Table 20. Variable: treat_med

Q56. *Is the participant currently taking medication to address the jerking?*

Missing responses: n=18, 19.4%

Response	Count	Percent
Yes	36	38.7
No	38	40.9
Don't know	1	1.1

Figure 20: Variable: treat_med

Q56. *Is the participant currently taking medication to address the jerking?*

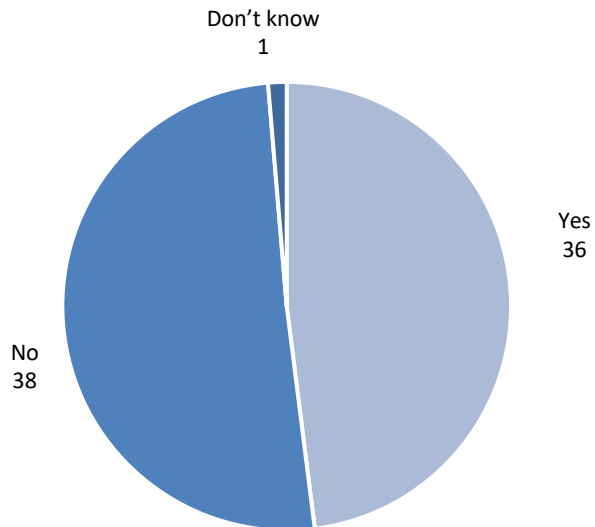


Table 21. Variable: oth_auto

Q63. Has the participant ever been diagnosed with an autoimmune disorder?

Missing responses: n=18, 19.4%

Response	Count	Percent
Yes	15	16.1
No	58	62.4
Don't know	2	2.2

Figure 21: Variable: oth_auto

Q63. Has the participant ever been diagnosed with an autoimmune disorder?

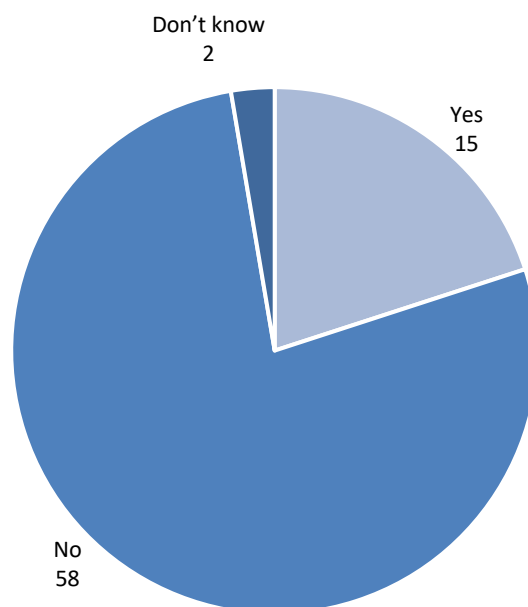


Table 22. Variable: oth_famEp

Q71. Does the participant have any FAMILY members diagnosed with epilepsy?

Missing responses: n=18, 19.4%

Response	Count	Percent
Yes	5	5.4
No	64	68.8
Don't know	6	6.5

Figure 22: Variable: oth_famEp

Q71. Does the participant have any FAMILY members diagnosed with epilepsy?

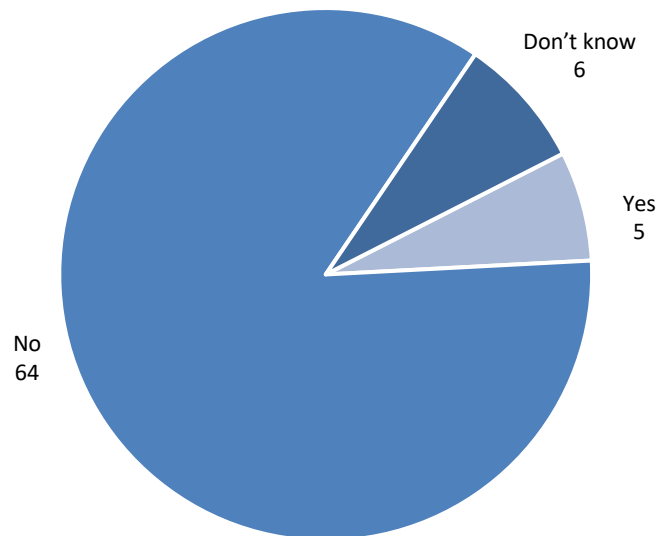


Table 23. Variable: qual_next

Q72. Has another person noticed the participant's jerking while sleeping next to each other?

Missing responses: n=19, 20.4%

Response	Count	Percent
Yes	51	54.8
No	15	16.1
Don't know	8	8.6

Figure 23: Variable: qual_next

Q72. Has another person noticed the participant's jerking while sleeping next to each other?

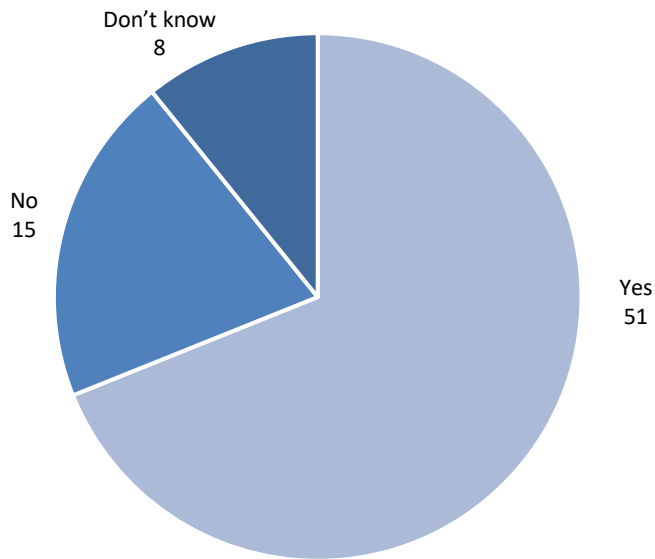


Table 24. Variable: qual_life

Q74. How often does the hypnic jerking interrupt the participant's daily life?

Missing responses: n=19, 20.4%

Response	Count	Percent
All of the time	19	20.4
Most of the time	20	21.5
Some of the time	30	32.3
Never	5	5.4

Figure 24: Variable: qual_life

Q74. How often does the hypnic jerking interrupt the participant's daily life?

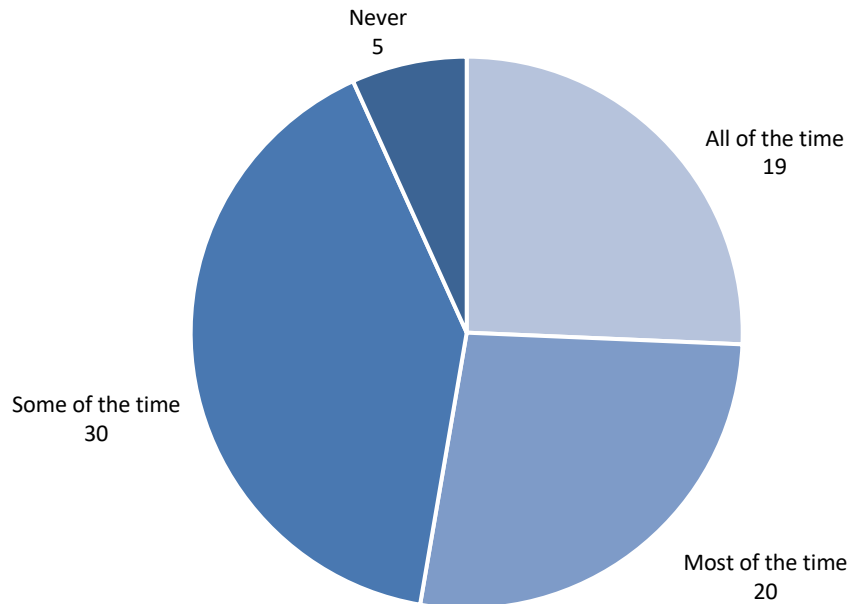


Table 25. Variable: qual_mood

Q75. Has the participant's hypnic jerking severely affected the participant's mood?

Missing responses: n=20, 21.5%

Response	Count	Percent
Yes	63	67.7
No	9	9.7
Don't know	1	1.1

Figure 25. Variable: qual_mood

Q75. Has the participant's hypnic jerking severely affected the participant's mood?

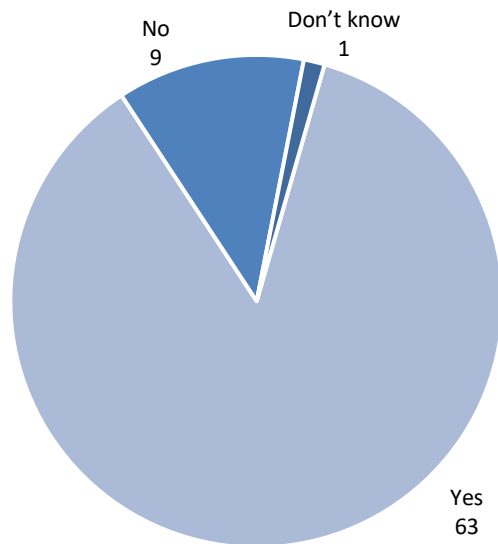


Table 26. Variable: cond_occur

Q20. When does the participant notice the jerking? Select all that apply.

Response	Count	Percent
Upon falling asleep	71	76.3
Upon awakening	27	29.0
During sleep	22	23.7
While awake	22	23.7
During or preceding menstrual cycle	17	18.3
Other	12	12.9

Figure 26. Variable: cond_occur

Q20. When does the participant notice the jerking? Select all that apply.

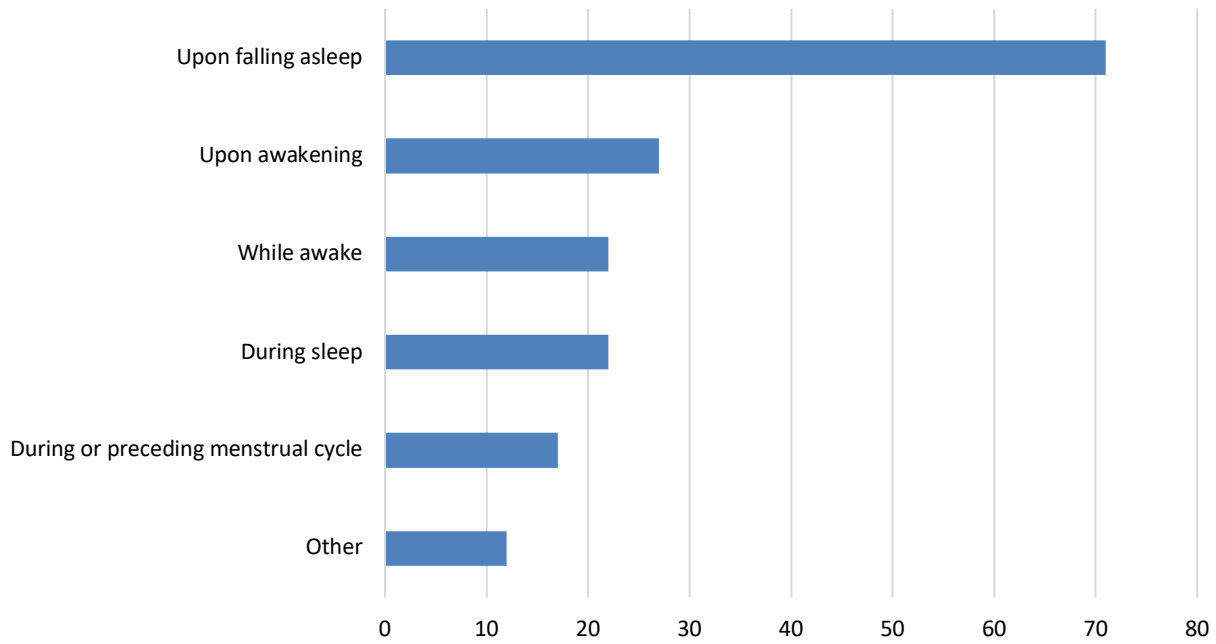


Table 27. Variable: cond_jerkExp

Q21. If applicable, which of the following does the participant experience along with their hypnic jerking? Select all that apply.

Response	Count	Percent
Anxiety	53	57.0
Heart racing or pounding	47	50.5
Energy surges or body revving	46	49.5
Body jitters or shaking	29	31.2
Pop or explosive feeling in head	29	31.2
Hallucination (at sleep start or sleep wake)	11	11.8
Heavy limbs	7	7.5
Dehydration or dryness	6	6.5

Figure 27. Variable: cond_jerkExp

Q21. If applicable, which of the following does the participant experience along with their hypnic jerking? Select all that apply.

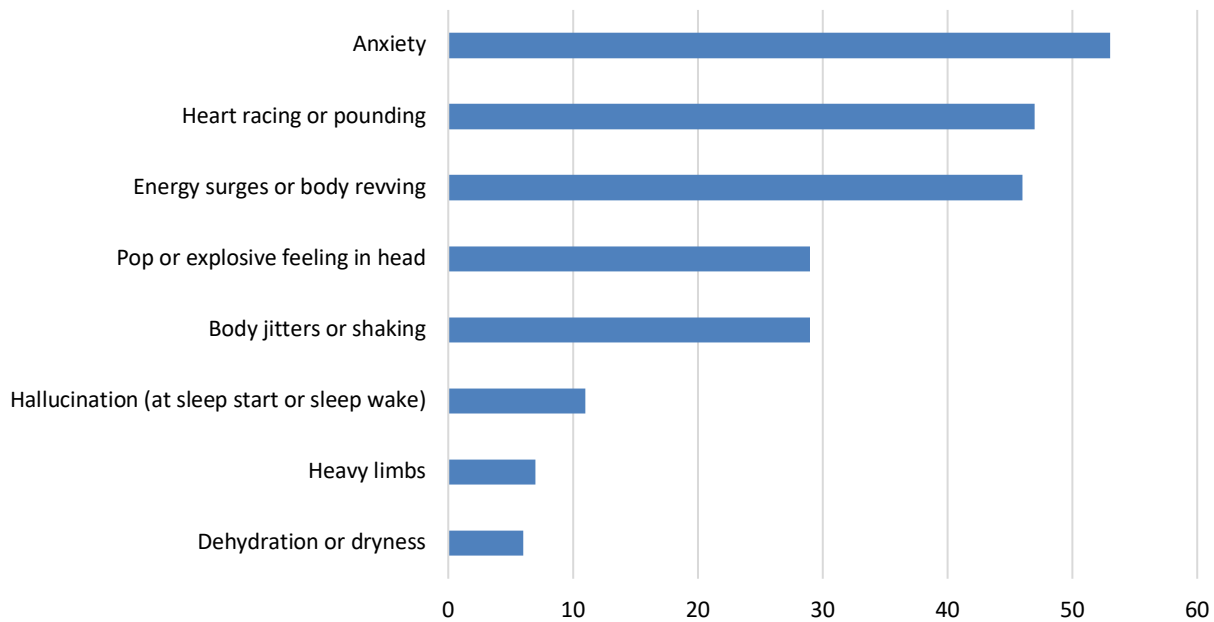


Table 28. Variable: cond_jerkArea

Q22. If applicable, which of the following body areas does the participant experience their jerks? Select all that apply.

Response	Count	Percent
Legs	70	75.3
Arms	66	71.0
Fingers	45	48.4
Head	42	45.2
Other	38	40.9
Neck	36	38.7
Jaw	27	29.0
Face	26	28.0
Mouth	17	18.3
Toes	17	18.3
Throat	16	17.2
Eyes	6	6.5
Tongue	3	3.2

Figure 28. Variable: cond_jerkArea

Q22. If applicable, which of the following body areas does the participant experience their jerks? Select all that apply.

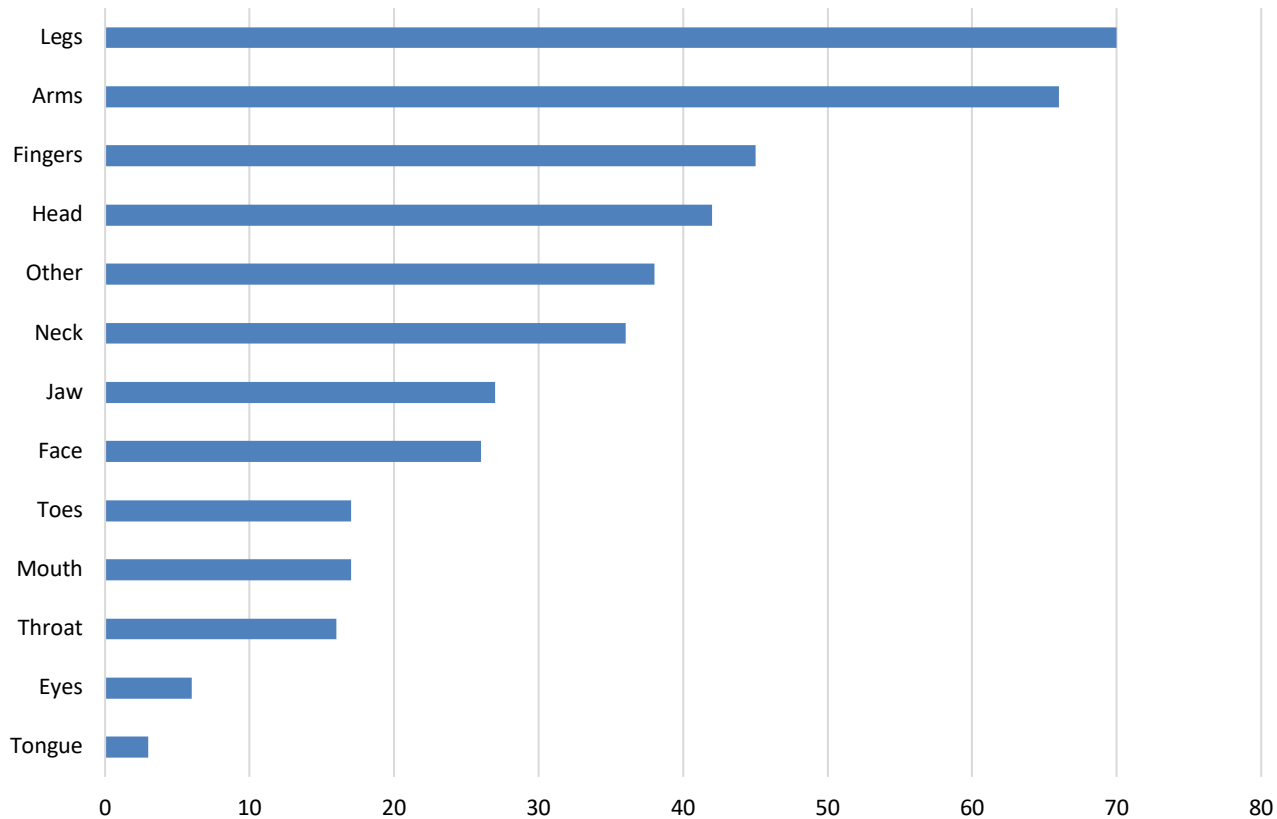


Table 29. Variable: cond_expExtJerk

Q29. If applicable, which of the following symptoms does the participant experience after nights of extreme jerking? Select all that apply.

Response	Count	Percent
Fatigue	72	77.4
Anxiety	59	63.4
Exaggerated startle	27	29.0
Other	22	23.7
Daytime jerking	19	20.4
Limb or body heaviness	17	18.3
Sore muscles	16	17.2
Increased energy	3	3.2
Soreness on scalp	3	3.2

Figure 29. Variable: cond_expExtJerk

Q29. If applicable, which of the following symptoms does the participant experience after nights of extreme jerking? Select all that apply.

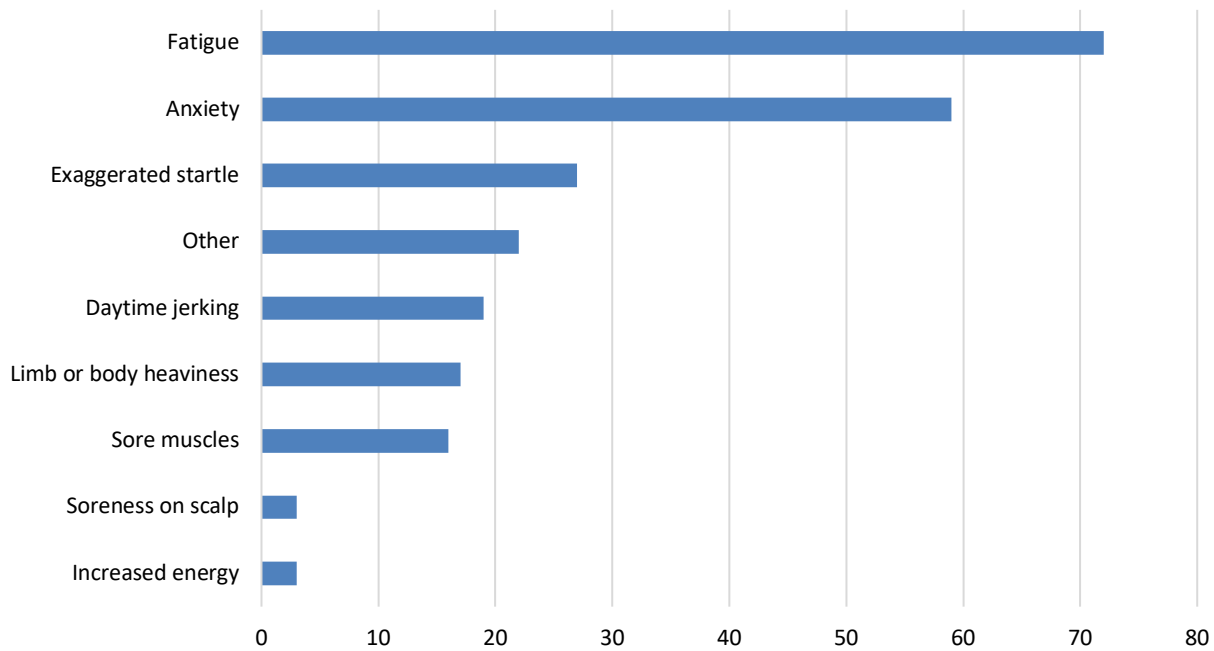


Table 30. Variable: qual_moodWhich

Q76. If applicable, which of the following describe how the participant's hypnic jerking has affected their mood?
 Select all that apply.

Response	Count	Percent
Created anxiety	43	46.2
Created depression	40	43.0
Increased existing anxiety	36	38.7
Created suicidal thoughts	22	23.7
Increased existing depression	18	19.4
Increased existing suicidal thoughts	3	3.2

Figure 30. Variable: qual_moodWhich

Q76. If applicable, which of the following describe how the participant's hypnic jerking has affected their mood?
 Select all that apply.

