

Assessing The Feasibility and Acceptability of Ecological Momentary Assessment in Measuring the Everyday Experiences of Young Adults with Tuberous Sclerosis Complex

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Abstract

Background

Young adults with Tuberous Sclerosis Complex (TSC) face increased, often under-supported, daily challenges. Smartphone Ecological Momentary Assessment (EMA) can address limitations of cross-sectional assessments by capturing detailed fluctuations in daily life.

Methods

For 14 days, 18 young adults with TSC (17–35 years) and 18 age- and sex-matched without TSC completed four EMA prompts daily. Feasibility was assessed via completion rates, and acceptability through interviews.

Results

Young adults with TSC had similar completion rates (88.89%) to those without TSC (89.88%). Greater TSC symptoms were associated with lower completion rate. Acceptability was explored through six themes: convenience, health, usability, utility, motivation, and improvement suggestions. Daily routines differed between groups, including work/study time, socialising, and sleep.

Conclusions

The findings provide preliminary support for the feasibility and acceptability of smartphone EMA and highlight differences in daily experiences between young adults with and without TSC. This data can inform future personalised clinical interventions and self-management of TSC symptoms.

Introduction

Tuberous Sclerosis Complex (TSC) is a rare genetic condition characterised by the growth of benign lesions or hamartomas in multiple organ systems (Yates, 2006). Most young adults with TSC will experience physical manifestations such as epilepsy alongside TSC-associated neuropsychiatric disorders, known as TAND (De Vries et al., 2015). In young adulthood, this is most likely to manifest as internalising symptoms such as anxiety or low mood (Both et al., 2018; De Vries et al., 2020; Peron et al., 2018). These may persist from adolescence or emerge in response to stressful transitions in clinical care, family support, legal processes, education and employment (Both et al., 2018). Although it is clear that there are differences in TAND between children and adults, with adults presenting fewer behavioural difficulties and more internalising symptoms, nuanced profiles within adulthood are under-researched, limiting effective intervention and support (De Vries et al., 2020).

One technique to begin to explore TAND profiles within young adults is Ecological Momentary Assessment (EMA). Smartphone EMA captures an individual's in-the-moment thoughts, feelings, behaviour and context through repeated self-report questionnaires via smartphones (Myin-Germeys &

Kuppens, 2022). This methodology aims to overcome retrospective bias and collect data in real-time, real-world settings, thereby avoiding the unnaturalistic environment and lack of context inherent in lab-based data collection (Myin-Germeys & Kuppens, 2022). When analysing the associations between this data gathered remotely, EMA can provide insight into the dynamic relationships between an individual's behaviour, experiences, and natural context (Wen et al., 2017). Research studies have begun to explore the value of EMA for clinical populations and in clinical settings (Matcham et al., 2019; Simblett et al., 2018). Due to the highly heterogeneous and individual presentations of young adults with TSC, EMA may be key in understanding how their dynamic internalising symptoms manifest, alongside the relationships with the physical manifestations. This would enable timely prevention and support, improving quality of life outcomes. However, EMA has never been trialled in individuals with TSC and so its feasibility and acceptability must be assessed to ensure it has community and clinical relevance.

In the context of rare genetic conditions, the literature on EMA feasibility is sparse. In a recent review (Fifield et al., 2024), the only genetic condition to use EMA was 22q11.2 Deletion Syndrome (22q11) (Feller et al., 2021, 2022, 2024; Ilen et al., 2023). Across the four samples, acceptable completion rates were found (62–64%) and validity was demonstrated by comparing against current validated scales (Feller et al., 2021). Using EMA, significant differences in psychotic experiences and social interactions were demonstrated between adolescents and young adults with 22q11 and other clinical and non-clinical groups. Since 2024, EMA has been used to examine the relationships between cognition, affect and biomarkers in 21 adults with Phenylketonuria (PKU). Stable acceptable completion rates (average 70%) were recorded, and EMA was able to distinguish between-person differences and within-person variability in cognitive processes (Singh et al., 2025). EMA has also been explored in Duchenne muscular dystrophy (DMD), which is a fatal, rare genetic condition (Lionarons et al., 2024). It demonstrated significant symptom fluctuation during corticosteroid treatment; however, six of seven participants did not meet standard feasibility cutoffs (> 33% prompts completed), which compromises its validity. The participants reported the convenience and user-friendliness of the EMA, so the authors suggested increasing discussion of motivation in the pre-EMA briefing session. Across the above studies, demonstrating the feasibility and reliability of EMA enables its integration into clinical trials, increasing accessibility, equity, and improving patient monitoring, which is key to growing funding for the treatment of these rare conditions.

Previous qualitative research suggests that EMA is hypothetically acceptable for young adults with TSC (Fifield et al., 2026). However, these young adults were presented with a standard EMA protocol designed for non-clinical populations. As a result, many barriers were identified, and it was clear that major adaptations were required as well as systematic testing to determine feasibility within TSC individuals.

Unlike effectiveness or efficacy studies, which aim to determine whether an intervention works, feasibility studies focus on the practicality and acceptability of the research processes themselves, such as recruitment, adherence, data collection procedures, and study burden (Eldridge et al., 2016). Feasibility within an EMA context can be measured by completion rate, defined as the proportion of

notifications answered by a participant out of the total number of notifications sent (Myin-Germeys & Kuppens, 2022; Wen et al., 2017; Wrzus & Neubauer, 2023). Understanding the reliability and validity of EMA is also required, as internal states can be very subjective, with the meaning of emotions and affective experiences not being shared across individuals. Misunderstanding the affective states often asked in EMA can therefore be a potential source of error, for example, ambiguous statements. This language relies on participants' own definition, which can differ by personal experience, culture or education. This is especially important for individuals at risk of intellectual or developmental difficulties who may struggle to understand abstract concepts or articulate their internal experiences (DuBois et al., 2016). A way to detect these issues is to conduct post hoc qualitative acceptability interviews. In their handbook on EMA, Myin-Germeys and Kuppens (2022) support the use of a debrief session to assess the success of the EMA from participants' perspectives. This allows participants to explain any barriers, facilitators or perceived errors they experienced during the EMA (Kimhy et al., 2012) and indicate any potential bias warranting further investigation in quantitative analyses. Furthermore, exploring themes surrounding misinterpretations within your participant group can inform future EMA protocols and contribute to the evidence base for EMA in this group.

After determining the quality of the EMA data, the daily experiences of participants can be explored, such as the dynamic biological, psychological and cognitive processes concurrent with a participant's context (Shiffman et al., 2008). One advantage of EMA is that it allows for the analysis of both between-person differences but also within-person variability such as how much a person's experiences vary within themselves (Knouse et al., 2008; Myin-Germeys & Kuppens, 2022). For rare conditions, this is critical as it allows for multiple data points per individual, increasing reliability and statistical power in populations limited by sample size (Singh et al., 2025). It also allows for the detailed exploration of dynamic variable processes within an individual, which, for a condition like TSC that presents in such variable ways, can facilitate much-needed idiosyncratic symptom trajectories and personalised interventions (De Vries et al., 2018; Myin-Germeys et al., 2009; Nap-van der Vlist et al., 2021).

Aims of the current study

As there is no literature on the use of EMA in individuals with TSC, this study aims to address gaps in understanding the daily experiences of young adults with TSC by employing this novel digital methodology. Although this study focuses on TSC, this condition represents a complex condition where physical manifestations, neurodevelopmental traits, and internalising symptoms are closely intertwined, reflecting challenges commonly observed across a range of neurodevelopment and chronic health conditions. Using a co-produced Patient and Public Involvement (PPI) developed EMA protocol, current TAND difficulties will be assessed, followed by the feasibility and acceptability of EMA. Feasibility will be measured against retention (dropout rates) and completion rates (% of completed prompts) (Myin-Germeys et al., 2009; Trull & Ebner-Priemer, 2013; Wen et al., 2017). Acceptability will be measured against themes of accessibility, convenience, usability, motivation and perceived utility (Kimhy et al., 2012; Simblett et al., 2018). Reliability and validity will be measured against discriminant validity and

careless responding (Curran, 2016; Myin-Germeys & Kuppens, 2022; Stone et al., 2023). Assessments of technology use, quality of life, neurodevelopmental, emotional, cognitive and TSC-specific symptomology will be used to explore the impact on feasibility. Finally initial exploration of the daily context of the young adults' lives will occur. Because this research is exploratory, no specific hypotheses were formulated.

Methods

The present study followed the recommendations of the adapted STROBE Checklist for Reporting EMA Studies (CREMAS) (Liao et al., 2016) to enhance reproducibility and reliability (See Additional file 1, Table A1). See detailed description of research process and instruments in Additional file 1.

Methodological Disclosure

We report how we determined our sample size, all data exclusions, all manipulations, and all measures in the study

Design

This was a mixed-method study based on a two-week intensive longitudinal design using EMA, questionnaires and semi-structured interviews.

Rationale and PPI

The EMA training and protocol were drafted based on a previous systematic review of EMA studies (Fifield et al., 2024) and qualitative themes (Fifield et al., 2026). To ensure the protocol was designed in line with young adults with TSC priorities and needs, an advisory group was utilised. Two young adults with TSC (aged 22–23 years old) with diverse ethnic, academic and TSC symptomology were recruited to act as advisors and co-produce the EMA protocol. See Additional file 1, Table A2 for discussions and decisions made during the group and Table A3 for GRIPP2 reporting checklist (Staniszewska et al., 2017).

Ethics

Participants

Eighteen young adults with TSC and 18 participants without TSC, aged 17 to 35 years, consented to participate in the study. The sample size was based on previous recruitment rates (Fifield et al., 2026) and EMA literature which suggests studies with more than 15 participants can achieve significant results

(Oleson et al., 2022). No young adults or participants without TSC withdrew during the study. All participants without TSC and 17 young adults with TSC completed all baseline assessments. One young adult with TSC completed partial baseline assessments. See Table 1 for a description of study sample characteristics. See Fig. 1 for procedure flowchart and Fig. 2 for participant flowchart. See the Additional file 1 for detailed description of the research process.

Insert Fig. 1.

Insert Fig. 2.

Insert Table 1.

EMA protocol

EMA questions were sent through the m-Path smartphone app (Mestdagh et al., 2023). As per the PPI advisors' decisions (see Additional file 1, Table A2), participants were prompted with a notification four times a day, semi-randomised over a two-hour block with at least one hour between each notification over a maximum 14-hour block. Participants were sent a reminder notification 30 minutes after the initial prompt, and the questionnaire became unavailable 60 minutes after the first notification. The EMA protocol lasted two weeks (14 days). The questionnaire included up to 29 questions, depending on branching and time of day notification. Depending on time of day, questionnaires contained items assessing mood, context (e.g., TSC symptoms, subjective cognition, social context, subjective feasibility, sleep and medication). See Additional file 1 for detailed description.

Setting

The whole study procedure was conducted via the telephone and online. All cognitive assessments, training and interviews were conducted using Microsoft Teams and a visualiser. All questionnaires and consent forms were completed via Qualtrics (Qualtrics, 2020).

Instruments

Technology use, quality of life, neurodevelopmental characteristics, cognitive ability, reading ability, internalising symptoms and TSC characteristics including the TAND checklist (Heunis et al., 2023) were all recorded at baseline. EMA usability was assessed at post. See Additional file 1 for detailed description of instruments.

Data analyses

All analyses were conducted using R (version 2024.12.0 + 467). Visualisations were produced using the ggplot2 and dplyr packages. Survey responses were extracted from Qualtrics. Descriptive statistics were calculated for baseline assessments and sociodemographic variables. Due to the small sample size and non-normal distribution, non-parametric tests were used, and medians with interquartile ranges (IQRs)

are reported. The alpha level was set at .05 due to the exploratory nature of the study, with no correction for multiple testing. Effect sizes for group comparisons were calculated using rank-biserial correlation (r) and interpreted using Cohen's benchmarks ($r = .10$ = small, $.30$ = medium, $.50$ = large). For linear mixed models, effect sizes were calculated using Cohen's f^2 and partial eta squared (η^2). Missing data were handled using listwise deletion.

Feasibility was assessed via completion rate (the number of completed prompts divided by the total number of prompts). Mann–Whitney U tests compared completion rates between participant groups and associations between completion and baseline assessments/participant characteristics were analysed using non-parametric methods. Discriminant validity was assessed using Spearman's rho correlations between mood items. Internal reliability was evaluated using Wilcoxon signed-rank tests comparing average affect scores across the two weeks. Careless responses were identified using criteria outlined by Curran (2016), criteria based on response consistency and latency. The proportion of flagged responses was calculated per participant. A generalised linear mixed-effects model (GLMM) with participant ID as a random effect identified individuals with elevated careless responding ($z > 2$). Predictors of careless responding were examined using linear regression with completion rate as the independent variable. A multiple regression assessed the effects of completion rate, group, and their interaction

All post-study interviews were audio and video recorded, transcribed verbatim and checked. All transcripts were anonymised. Qualitative analysis was conducted using NVivo (version 14; QSR international, Melbourne, Australia). Framework analysis (Ritchie & Spencer, 2002) was applied as there were predefined areas to understand (facilitators and barriers to EMA) but the analysis was also open to emergent codes and themes within the context of the participant's experience of TSC and EMA. The initial codebook was informed by three previous studies: Fifield et al. (2026) which explored the feasibility and acceptability of smartphone EMA in adults' post-encephalitis and Simblett et al. (2018), which explored barriers to and facilitators of engagement with remote measurement technology. After familiarisation, KF coded using the initial codebook, making slight adaptations. A research assistant (KB) then used this codebook to recode 50% of the data. KF and KB then discussed the final iteration to develop the final codebook or 'framework'. See Additional file 1, Table A5 for final codebook. Participants' quotes were then summarised within the framework and overall summaries for each category and case were defined. Patterns and concepts were then sought and labelled as themes and sub-themes.

EMA responses proportions were calculated per participant, and group differences were analysed using Mann–Whitney U tests. Mixed-effects models accounted for within-subject clustering. Linear mixed-effects models examined sleep duration and sleep quality, with group as a fixed effect and random intercepts for repeated measures, interactions tested differences by group.

Results

Sample characteristics and current TAND Profile

TAND-SQ

All participants with TSC completed the TAND-SQ checklist. The most frequently reported symptoms were anxiety (100%) and depressed mood (88.9%). The top reported cluster was the mood/anxiety cluster (77.8%). See Fig. 3 for visualisation. The Total TAND Severity Score (TTSS) was calculated as the mean of all item severity ratings, following Chambers et al. (2025). The average TTSS was 3.8, SD 1.94 (range 0.5:7.97). There was a significant positive correlation between TTSS and TAND-related distress over the past month, Spearman's $\rho = .592, p = .020$.

Insert Fig. 3.

Baseline assessments

Physical health, quality of life, autism traits, ADHD traits, IQ, depression and internalising symptoms were all significantly different between the non-TSC and TSC group at baseline ($p > 0.05$) (see Table 2).

Table 2
Comparison of Baseline Assessments Between Participant Group

Baseline variable	TSC		Non-TSC		U	p	r
	Median	Range	Median	Range			
Tech Self-Efficacy	84	31:100	89	67:100	202.5	.205	0.21
SF36 MCS	39.85	5.47:13.51	57.1	13.92:95.09	190	.389	0.15
SF36 PCS	62.09	-12.46:99.28	80.69	55.51:109.96	239	.014*	0.41
SRS-2 Total	61.5	46:90	49.5	39:66	39	< .001***	-0.65
CAARS ADHD Index	55	31:90	43.5	34:65	84.5	.025*	-0.41
FSIQ-2							
BDI Total	13	0:50	6.5	0:19	93.5	.031*	-0.36
BAI Total	17	0:51	5	0:27	103.5	.066	-0.31
SDQ Emotion	5	2:10	1.5	0:5	44	< .001***	-0.62

Note. MCS = Mental Component Summary. PCS = Physical Component Summary. r = rank biserial correlation (effect size), U = Mann–Whitney U statistic. *p < .05. **p < .01. ***p < .001.

Is smartphone EMA feasible in young adults with TSC?

Each participant was asked to complete 56 assessments, resulting in a total of 2016 assessments being sent to participants. In the TSC group, participants completed 896/1008 prompts, resulting in an overall completion of 88.89% (range = 60.71–100%). In the non-TSC group, participants completed 906/1008 prompts, resulting in an overall completion of 89.88 (range = 76.79–100%). Overall, all participants completed 1802/2016 prompts, resulting in an overall completion of 89.38 (range = 60.71–100%). All participants completed over the inclusion threshold (> 33%) and participant retention was 100% (no dropouts). Completion rates were not significantly different between the two groups $W = 148.5$, $p = .679$, $r = -0.071$.

Associations with completion

TSC

Completion was not significantly associated with demographic variables or baseline assessments nor with genotype, IQ nor TSSS ($p > .05$). Completion was weakly negatively associated with total current and lifetime TSC symptoms (see Table 3 for all associations).

Having an epilepsy diagnosis was not significantly associated with completion rates. However, within participants who have epilepsy ($n = 13$), completion was positively associated with lifetime total epilepsy severity ($p = 0.69$, $S = 113.40$, $p = .009$) and frequency of seizures at most severe ($p = 0.57$, $S = 58.16$, $p = .044$). See Supplementary Material, Table A6 for all correlations with epilepsy variables.

Non-TSC

In the non-TSC group, completion was not significantly associated with age, sex, employment, education, IQ or baseline assessments ($p > 0.05$; Table 3).

Reasons for missing prompt

In response to “Why did you miss the last prompt?” during the EMA, sleeping was the most common reason for both participants with and without TSC. The second most common reason among participants with TSC was socialising, whereas among participants without TSC, the most common reason for missing the notification was studying (Fig. 4).

Table 3
Participants with TSC Characteristics and Baseline Assessments Associations with Completion.

Test		TSC			Non-TSC		
		ρ / H / U	p	r	ρ / H / U	p	r
Characteristics							
Age	Spearman rho	0.01	.695		0.17	.505	
Sex	Mann-Whitney U	35	.488	0.18	28	1	0
Employment	Kruskal-Wallis	4.53	.339	0.04	1.022	.906	-0.229
Education	Kruskal-Wallis	2.07	.559	-0.07	5.713	.057	0.248
FSIQ-2	Spearman rho	0.14	.576		-0.11	.678	
TSC Characteristic							
Genotype	Kruskal-Wallis	0.58	.748	-0.10			
Total current symptoms	Spearman rho	-0.48	.043*				
Total ever symptoms	Spearman rho	-0.54	.019*				
TSSS	Spearman rho	-0.13	.62				
Epilepsy severity	Mann-Whitney U	46.5	.182	0.31			
Baseline assessment							
SF36 MCS	Spearman rho	0.01	.695		-0.07	.785	
SF36 PCS	Spearman rho	0.15	.546		0.27	.286	
SRS-2 total	Spearman rho	-0.41	.094		0.03	.91	
CAARS ADHD	Spearman rho	-0.26	.307		-0.15	.55	
BDI	Spearman rho	0.01	.972		-0.25	.325	
BAI	Spearman rho	-0.18	.479		0.14	.586	
SDQ Emotion	Spearman rho	-0.19	.459		0.04	.86	

Note. ρ = Spearman's rank-order correlation coefficient; r = rank biserial correlation (effect size), * $p < .05$.

** $p < .01$. *** $p < .001$.

Insert Fig. 4.

Is smartphone EMA reliable and valid in young adults with TSC?

Discriminant validity

Stress, anxiety, and tiredness were positively associated, while happiness and relaxation negatively correlated with these emotions. However, excitement was positively associated with stress, angry, sadness and tiredness were positively associated with confidence and excitement (see Table 4).

Table 4
Correlation Matrix Between EMA Mood Items.

N = 18	happy	angry	confident	sad	anxious	excited	tired	relaxed
stress	-0.38**	0.67**	-0.2**	0.64**	0.67**	0.14**	0.44**	-0.39**
happy		-0.23**	0.74**	-0.28**	-0.25**	0.31**	-0.32**	0.66**
angry			-0.1**	0.74**	0.63**	0.2**	0.41**	-0.35**
confident				-0.14**	-0.13**	0.41**	-0.25**	0.56**
sad					0.65**	0.16**	0.39**	-0.36**
anxious						0.21**	0.51**	-0.4**
excited							0.07*	0.12**
tired								-0.32**

Note. * $p < .05$. ** $p < .01$. *** $p < .001$.

Careless responding

5.1% of all valid responses flagged as careless (6.1% TSC; 4.1% non-TSC). Completion rate was not a significant predictor of careless responding ($F(1, 34) = 2.19$, $p = .15$, $R^2 = .06$) although a small positive, non-significant trend was observed ($b = 0.37$, $SE = 0.25$).

A multiple regression model including completion rate, group (TSC vs non-TSC), and their interaction did not significantly predict careless responding ($F(3, 32) = 0.79$, $p = .51$, $R^2 = .07$, $f^2 = 0.07$). None of the predictors were significant (all p 's > 0.5).

Quantitative Acceptability

Debrief

In the post-study debrief survey, most participants reported overall that the EMA had little influence on their daily experiences, the two weeks using the EMA were 'normal' and that they were able to express

their experiences via the EMA app. See Additional file 1, Table A7 for the results of the debrief survey.

Post Study System Usability Questionnaire

For participants with TSC, the median total score on the PSSUQ was 1.37 (ranging from 1 to 2.20), suggesting the app was 'highly usable'. For participants without TSC, the mean total score on the PSSUQ was 1.38 (ranging from 1 to 2.31), suggesting the app was highly usable. There was no significant difference in total usability score between the participant groups ($U = 146.5$, $p = .496$, $r = -0.14$).

Qualitative analysis of young adults with TSC post-study interviews

See Fig. 5 for the post-study themes and codes developed from the framework analysis, which explored the participants' experiences of EMA and its barriers and facilitators. See Additional file 1, Table A8 for description of sub-themes and quotes.

Theme I: Convenience or accessibility:

Overall, daily routines and distractions, social situations and having a limited response window were reported as barriers to the convenience or accessibility of the EMA. Facilitators were noted as the ease and simplicity of the app, low distraction environments, supportive external environments and personalisation features.

Theme II: Health status

For some participants, their health status mediated their use of the app. Fatigue was highlighted as a common barrier to completing the EMA, not just for accessing the app but for also reflecting on current emotional states. Many participants also highlighted seizures and subsequent cognitive difficulties (such as confusion or short-term memory loss) as challenging to manage alongside the EMA during the two weeks. Only one participant described how their negative mental state made it difficult to complete the questionnaires.

Theme III: Usability

Overall, repetitiveness of questions, limited flexibility in response options and difficulty identifying emotions were identified as barriers to the usability of the EMA. Training and support, independence in app use, simple and visual features and anonymity of the app facilitated EMA use. There were mixed experiences regarding the impact of the EMA on the participants, with some feeling negatively influenced and others reporting no emotional impact. Similarly, some participants reported that their responses would influence their mood or behaviour, whereas others did not.

Theme IV: Perceived Utility

Overall, the limited relevance of some of the questions (E.g. anger or loneliness) and the impact of external therapy were barriers to the utility of the EMA. Some questions were seen as highly relevant (sleep, anxiety, memory) and having a reflective opportunity as well as a sense of achievement and competence were facilitators to the utility of the EMA.

Theme V: Motivation

Overall, personalisation and rewards were mostly seen as having no impact on the participants' motivation to use the app, and some participants were concerned about their motivation if asked to continue for longer. However, some participants were willing to continue due to extrinsic (commitment to research and to helping others) and intrinsic (personal emotional or cognitive benefits) motivation. Participants reported minimal impact of seeing their answers on their motivation.

Theme VI: Suggestions for improvement

The most common suggestion for improving the access and utility of the EMA app was adapting the questions to better reflect the experiences of young adults, such as providing more category options to "What are you doing right now?" e.g., housework. Additionally, changing the order of the questions or the mode of answering was also suggested to counteract the repetitive nature of the EMA and complacency reported by participants.

Insert Fig. 5.

Do daily life experiences captured by smartphone EMA differ between young adults with and without TSC?

Context

Participants with TSC spent significantly less time working/studying or socialising with friends ($U = 229.5$, $p = 0.034$, $r = -0.42$), and more time resting than participants without TSC ($U = 96$, $p = 0.038$, $r = 0.41$).

Social

Participants with and without TSC reported being alone at a similar rate (50% vs 55.6%) with no group differences in desire for social contact when alone ($U = 193.5$, $p = 0.324$, $r = -0.19$) or solitude when with others ($U = 148$, $p = 0.662$, $r = 0.09$).

Memory

Participants with TSC reported more memory problems on average (2.72 vs 1.50) and at a higher proportion of prompts (5.9% vs 2.94%). However, group differences were not significant ($b = 0.33$, $SE = 0.84$, $z = 0.39$, $p = .69$).

Epilepsy

Six participants with TSC reported at least one definite seizure during the two-week period, and one reported a possible seizure. On average, participants had not recovered by the next prompt (mean = 1.32, range = 1–3).

Sleep

Participants with TSC slept longer than those without TSC (8.87 vs 7.81 hours, $b = 1.06$, $SE = 0.38$, $t(33.39) = 2.79$, $p = .009$), but reported lower sleep quality (57.9 vs 64.4). Sleep durations was positively associated with subjective sleep quality in both groups (TSC $b = 0.024$, $SE = 0.004$, $t(192.8) = 5.39$, $p < .001$; Non-TSC $b = 0.019$, $SE = 0.004$, $t(204.3) = 5.05$, $p < .001$) (Additional file 1, Figure A4).

Medication

Daily medication use was reported by 16 participants with TSC and 8 without TSC. Participants with TSC used a broader range of medications including TSC medication, antipsychotics, antidepressants, hormonal contraceptives, anti-seizure medication, biguanides, pain relief, antihistamines, vitamins, antispasmodics and beta blockers. For participants without TSC, medication included hormonal contraceptives, pain relief and supplements. On average, participants with TSC reported more medication types (2.67 vs 0.72).

Discussion

In the current study, the feasibility and acceptability of smartphone EMA on the daily lives of young adults with TSC were explored. Smartphone EMA was found to be feasible and acceptable, with no significant differences in feasibility between young adults with and without TSC. Differences in daily experiences were identified using EMA across work/study, social interactions, and sleep.

The high completion rate of 89% with no dropouts is a strong indicator of EMA feasibility within this population, consistent with prior research on rare genetic EMA (Feller et al., 2021, 2022, 2024; Ilen et al., 2023). Furthermore, no differences in completion rates were found among matched-age and sex participants without TSC. Subtle evidence suggests that the combination of physical and TAND symptoms of TSC may pose a greater barrier to completion than just TAND symptoms alone. This corroborates the qualitative findings in this study, that fatigue and seizures, alongside mental health status and cognitive difficulties, were described as barriers to completion. These findings may have broader implications for populations characterised by the interplay of physical and mental health conditions. Evidence from prior qualitative research (Fifield et al., 2026), suggests that participants anticipated thinking ability would be a potential barrier but did not identify any other physical health or TAND symptoms. This demonstrates the need to systematically test feasibility to reveal barriers and facilitators rather than relying on hypothetical themes. Within EMA literature, there is little exploration of the impact of physical health burden on completion rates compared to mental health status. For

example, in adults with sickle cell disease, greater pain severity has been associated with reduced EMA engagement (Abrams et al., 2024), whereas in a non-clinical young adults, lower mood and higher stress predict noncompletion (Murray et al., 2023). A review of EMA in youth clinical populations (< 18 years old), found no effect of disease status (physical and mental health conditions) on completion rate (Wen et al., 2017), although this may reflect the influence of caregiver support in youth EMA research, which was largely absent in the current sample. Overall, future EMA research on young adults with chronic conditions should explore the range of cognitive, physical and mental health symptoms, and their severity in detail. Co-production methods should be used to create support systems for young adults to overcome these barriers to reduce disengagement from EMA.

The discriminant validity of the EMA was largely supported with expected patterns of positive low-arousal emotions (happy-confident) and negative high-arousal emotions (angry-sad) associating (Eisele et al., 2021). However, there was evidence of arousal-related confounds, such as the association between 'excitement' and 'anxiety', likely reflecting shared high psychological arousal. Emotions, like 'excitement' may also be ambiguous, encompassing both positive enthusiasm or nervous agitation, with all potentially being labelled under the same emotion category (Brooks, 2014; Swerdlow et al., 2022). These confounds may also reflect atypical affective states found in neurodevelopmental populations (Speyer et al., 2023; van der Linden et al., 2021). Although the EMA affect items were co-developed by the advisory group and tested with participants during training, more detailed strategies like real-time cognitive interviewing during the EMA protocol development could enhance discriminant validity and ensure participants interpret the EMA construct, time range, and response options as intended (Stone et al., 2023).

Quantitatively, EMA was well tolerated by participants with TSC with little impact on daily life reported, indicating genuine engagement rather than task fatigue or boredom. Qualitative findings further supported this with ease and quickness of assessments, visual and straightforward questions, sufficient training, support from external commitments and the ability to personalise the app, all facilitating usability of the app. Barriers included privacy concerns in social settings, distracting daily life routines, repetitive questions, static response options and restrictive one-hour response windows. These findings strongly corroborate the hypothetical facilitators and barriers discussed in previous work (Fifield et al., 2026) and emphasises the importance of integrating EMA into diverse daily routines alongside balancing privacy concerns and personalisation with research constraints. This is consistent with Bos et al. (2022), who demonstrate through co-produced human-centred EMA design that tailoring protocols and embedding systems within clinical infrastructures can enhance usability while maintaining privacy compliance

A further barrier to the app was the health status of the participants, with fatigue and cognitive challenges (e.g., confusion, memory loss post-seizure) hindering participation. This aligns with general challenges discussed in epilepsy care, where cognitive challenges after seizures lead to increased reliance on caregivers to support self-tracking and management (Min et al., 2023). Again, this corroborates "thinking ability" as a barrier and highlights the potential need to involve key support

persons of young adults with TSC to ensure valid data collection. Unlike other EMA findings (Bos et al., 2019; Murray et al., 2023; Rintala et al., 2020; White et al., 2023), the mental health status of the participants was a less prominent barrier to completion, although some participants still reported difficulties in answering the EMA when feeling low.

Most participants with TSC vied a perceived utility of EMA, due to the relevant and reflective daily life questions, which could enable self-reflection and personal behaviour change. Enhancing these, alongside participants' motivation for personal benefits, could allow adoption of Ecological Momentary Interventions (EMIs) to support intervention or self-monitoring goals. Although the use of EMIs in young adults with chronic conditions remains limited, early evidence suggests potential benefits (Rauschenberg et al., 2021). Notably, EMA was linked with increased autonomy, responsibility, and sense of control, suggesting that fostering agency may be a key mechanism for improving engagement and sustained use of digital health tools.

Summary of Feasibility and Acceptability Findings

Overall feasibility was supported by (a) 100% retention, (b) a high completion rate (89%), (c) qualitative reports indicating acceptability in terms of usability, convenience, and perceived utility, (d) reliability and validity was evidenced by appropriate discriminant validity, and (e) low levels of careless responding.

Overall, the EMA was deemed acceptable by all participants, with the majority indicating a willingness to continue using this methodology. Significant improvements for future studies include expanding activity categories (e.g. housework or being with a pet), reordering questions to reduce monotony and increase flexibility in response formats and customisation.

Daily Life Experiences Captured by EMA

As the EMA was deemed feasible, reliable, valid, and acceptable, further analysis of the EMA results was conducted. Differences were observed in the daily lives of young adults with and without TSC, including variations in time spent working/studying, socialising with friends, resting, and sleep duration. The amount of time spent working and studying likely reflects the high percentage of university students in our comparison group, as well as the timing of data collection, which coincided with exams and end-of-term deadlines. It may also reflect the difficulties that young adults with TSC face in gaining employment (Fifield et al., 2026; Marcinkowska et al., 2022). Young adults with TSC also spent less time socialising with friends, likely reflecting social isolation and social wellbeing of youth and adults with TSC (Fifield et al., 2026; Jansen et al., 2020) and other chronic conditions (Feller et al., 2022). No meaningful differences were found in the desire for social interaction or solitude between the two groups, however, there were trends for young adults with TSC to desire less social interaction and increased solitude. This may reflect differences in social motivation, comfort with solitude, barriers to social engagement or increased social fatigue among young adults with TSC. This has been highlighted in EMA research in autism, where autistic traits were found to negatively impact the quality of social interaction not just the quantity (Fusar-Poli et al., 2023). Increasing sample sizes may reveal meaningful

social nuances that could inform the development of tailored social well-being support for individuals with TSC.

Young adults with TSC also reported longer sleep duration and more time spent resting. This may reflect the physical impact of TSC, especially epilepsy, which is well known to cause sleep disturbances, lower quality sleep and increased daytime fatigue (Van Eeghen et al., 2023). Despite this, EMA has been underutilised in capturing the daily impact of epilepsy, although emerging research is beginning to explore EMA and wearable technologies to monitor symptoms such as sleep (Bruno et al., 2020). The young adults with TSC also reported a diverse range of medications, indicating complex medical management, which may contribute to differences in fatigue, sleep and cognitive functioning.

Limitations

The main limitation is the size and representativeness of our sample. Due to ethical constraints, only young adults who could consent for themselves were eligible for the study. This will have excluded individuals who require legal guardianship. Furthermore, participants were required to have a predicted IQ above 70 to ensure they could independently use the smartphone EMA, limiting inclusion of those with a co-morbid intellectual disability, which represents roughly a third of all individuals with TSC (Curatolo et al., 2015). Additionally, all participants had to currently use a smartphone, excluding those who do not. This likely indicates that our sample is biased towards individuals who possess sufficient technology literacy and economic resources to own a smartphone. The comparison group, although matched on age and sex, were predominantly drawn from a single university institution, further limiting generalisability. Increased resources for larger and ID-focused EMA feasibility research may overcome these limitations.

The small sample likely limited the statistical power of the results. Within-person effects may have increased in power with more prompts per participant, however, after reviewing previous literature (Fifield et al., 2024) alongside advisory group guidance, a smaller number of prompts per day were selected to maximise completion in this exploratory study. The sample size was considered appropriate for feasibility research, consistent with recommendations of 10–20 participants (Hektner et al., 2007). However, the two-week EMA period limited the ability to capture longer-term emotional patterns, seasonal or hormonal effects, and fluctuations in TSC and TAND symptoms, such as epilepsy, which can vary over extended periods (Karoly et al., 2021; Northrup et al., 2013). A longer EMA protocol, potentially as a randomised control design with differing arms of number of prompts per day and number of assessment days, would determine the optimal protocol for feasibility and statistical power.

Although EMA can reduce recall bias, it cannot account for self-report bias or social desirability bias, which can be critical in small samples. One way to overcome this is by combining EMA with passive sensing that provide objective continuous measures (e.g., heart rate, sleep factors, step count, location via GPS) not subjected to social desirability biases. Using key support person reports may also help triangulate experiences, however, this may undermine the autonomy and independence highlighted by

participants. Further PPIE involvement would be required to develop the optimal integration of secondary data collection to minimise these biases.

Research and clinical implications

This study demonstrates that smartphone EMA may be feasible and acceptable for young adults with TSC, supporting expansion to larger-scale, multi-condition and longitudinal research. Recently, an EMA item quality assessment tool (EMA-Q) has been developed to help researchers develop or systematically evaluate EMA items (Eisele et al., 2025). In addition, exploring affect variability via EMA data, as well as average affect, may reveal meaningful markers or differences, providing key insights into the complex and changing experiences that young adults with TSC face. Improving sample inclusivity within TSC EMA research is also paramount, however, there is a need for co-production resources and methods specific to EMA to include the experiences of individuals with intellectual disability.

The high rates of internalising symptoms reported in this study confirm the need for proactive screening and targeted interventions for young adults with TSC. Notably, all the young adults with TSC in the study reported anxiety as having been a problem in the last month (as measured by the TAND-SQ). Furthermore, our EMA results highlighted reduced social activity and increased rest/sleep, emphasising the need for targeted support in employment, education and social participation, consistent with previous work (Both et al., 2018; Peron et al., 2018). Real-time monitoring of affect, physical symptoms, and potential cognitive changes (through cognitive EMA) can capture individualised fluctuations and lead to personalised clinical management, tracking treatment effects and supporting current intervention and talking therapies. Our results also suggest a positive secondary effect, indicating that EMA fosters autonomy and self-reflection in young adults with TSC, which may enhance patient empowerment and adherence to care and treatment.

Patient and Public Involvement Outcome

The advisory group allowed young adults with TSC to move beyond hypothetical (Fifield et al., 2026) to experiential feedback and develop and test out the EMA. For example, the advisory group found fewer daily questionnaires over more days felt less burdensome, even though prior research suggested total assessments, not structure, affect compliance. Despite this difference, the chosen design achieved high compliance, highlighting the value of real user feedback over hypothetical input. This underscores the importance of involving participants in shaping EMA studies through practical testing and discussion. However, limited early involvement within the current study led to a lack of PPI in analysis and writing, and resource and technical constraints reduced the overall impact of PPIE, highlighting the need to plan and resource it across all research stages.

Conclusion

This study is the first to systematically test the feasibility and acceptability of smartphone EMA in young adults with TSC, providing preliminary evidence of its reliability, validity, and acceptability. While further

research with larger samples, other chronic conditions, and clinical settings is needed, these findings support the potential of EMA to capture real-time affect, context, and physical symptoms that may be missed in retrospective assessments. This is the first step to bridging the gap in psychological and emotional well-being support that these individuals critically need. It also contributed to building a first-class, co-produced evidence base for the introduction of real-time data monitoring and, in the future, intervention in standard clinical practice and services.

Declarations

Ethical approval and informed consent statements

The study was approved by King College London Health Faculties Research Ethics Subcommittee (HR/DP-23/24-39750). All participants provided informed consent.

Consent for publication

Not applicable.

Data availability statement

The datasets generated and/or analysed during the current study are not publicly available due to information that could compromise research participant privacy/consent but are available from the corresponding author on reasonable request.

Declaration of competing interest

The authors declare that they have no competing interests.

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Author contributions

In line with Contributor Roles Taxonomy (CRediT) guidelines, KF was responsible for conceptualization, methodology, software, investigation, data curation, project administration, formal analysis, investigation, data curation, supervision, writing – original draft, writing – review and editing, and project administration. SS was responsible for supervision and writing – review and editing. TG was responsible for investigation, formal analysis, project administration and writing - review & editing. KB was

responsible for formal analysis and writing - review & editing. CT was responsible for supervision, and writing – review and editing. All authors read and approved the final manuscript.

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Table 1

Table 1
Participant Characteristics

		TSC (n = 18)	Non-TSC (n = 18)
Age (years), mean (range)		23.86 (18.50:34.67)	23.73 (18.50:34.17)
Gender, % (N)	Female	61.11 (11)	77.8 (14)
	Male	22.22 (4)	22.2 (4)
	Non-binary	16.67 (3)	-
Ethnicity, % (N)	White - English/Welsh/ Scottish/Northern Irish/British	100 (18)	16.7 (3)
	Asian/Asian British - Indian/Bangladeshi/ Chinese/Vietnamese/Korean	-	61.1 (11)
	Black/African/Caribbean/Black British - African		5.6 (1)
	White – not specified	-	5.6 (1)
	White Hispanic	-	5.6 (1)
	Any other ethnic group – not specified	-	5.6 (1)
Employment, % (N)	Employed full time	22.22 (4)	22.2 (4)
	Employed part-time	16.67 (3)	5.6 (1)
	Student	38.89 (7)	66.67 (12)
	Unemployed - looking for work	11.11 (2)	5.6 (1)
	Unemployed – not looking for work	11.11 (2)	-
Education, % (N)	Higher or secondary or further education	66.67 (12)	38.9 (7)
	Secondary school up to 16 years	16.67 (3)	-
	University	11.11 (2)	27.8 (5)
	Post-graduate degree	16.67 (1)	33.3 (6)
Home living, % (N)	Living with parents	72.22 (13)	44.4 (8)
	Living with a partner and children	16.67 (3)	-
	Living with partner	-	16.7 (3)

		TSC (n = 18)	Non-TSC (n = 18)
Age (years), mean (range)		23.86 (18.50:34.67)	23.73 (18.50:34.17)
	Living on own/with friends/roommates	11.11 (2)	38.9 (7)
FSIQ-II	Mdn (IQR)	96 (11.5)	121.0 (14.75)
	Range	73:116	103–142
TSC genotype, % (N)	TSC1	16.67 (3)	
	TSC 2	61.11 (11)	
	Not tested/Unknown	22.22 (4)	
Current TSC Symptoms, % (N)*	Brain	50 (9)	
	Nervous System	72.22 (13)	
	TAND	100 (18)	
	Kidney/Urinary Tract	61.11 (11)	
	Heart	27.27 (3)	
	Skin	33.33 (6)	
	Other – Lung, eyes, teeth	27.78 (5)	
Current Epilepsy, % (N)	Yes	72.22 (13)	
	No	27.7 (5)	

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Figures

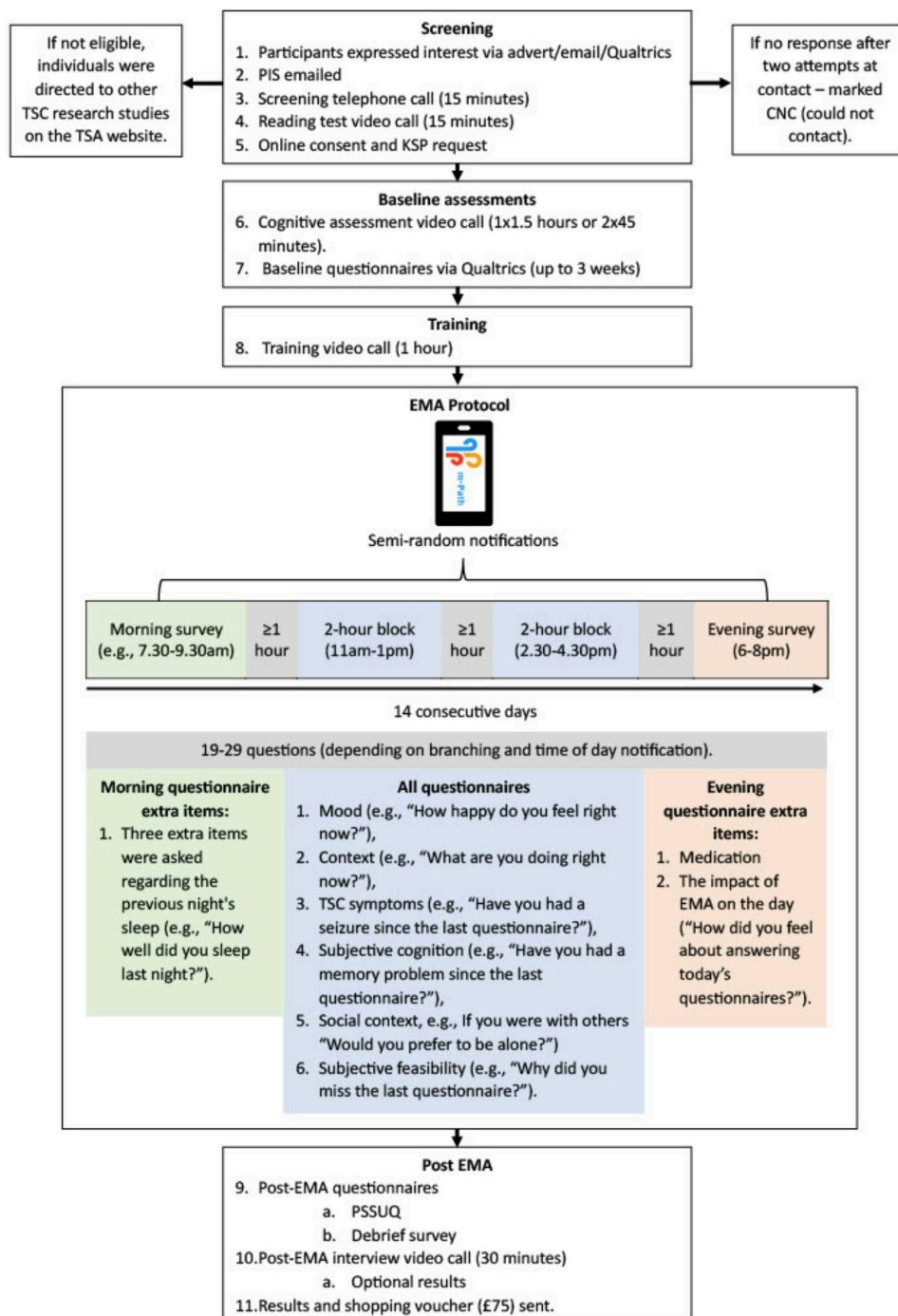


Figure 1

TSC Participant Process

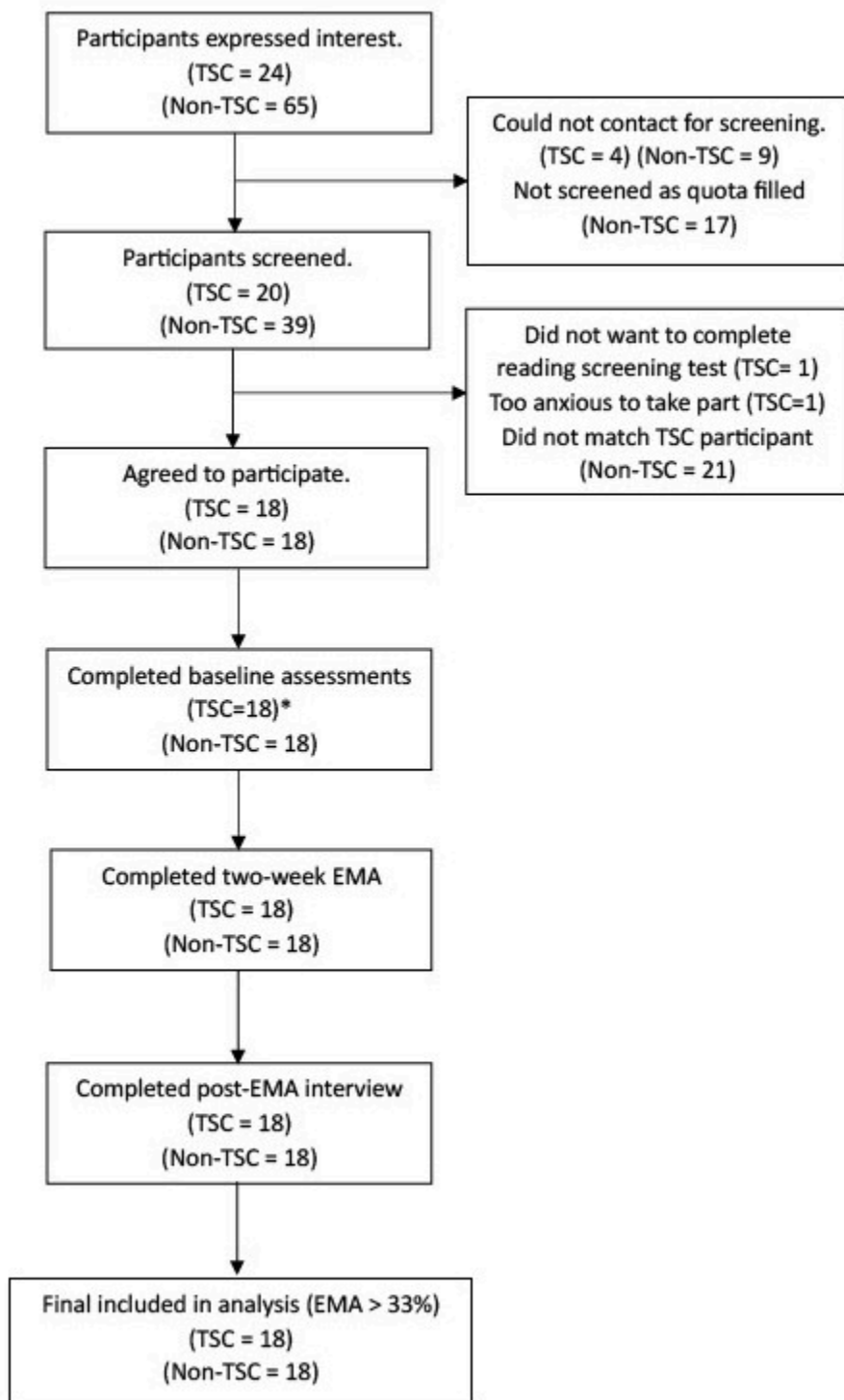


Figure 2

Participant Recruitment Flowchart

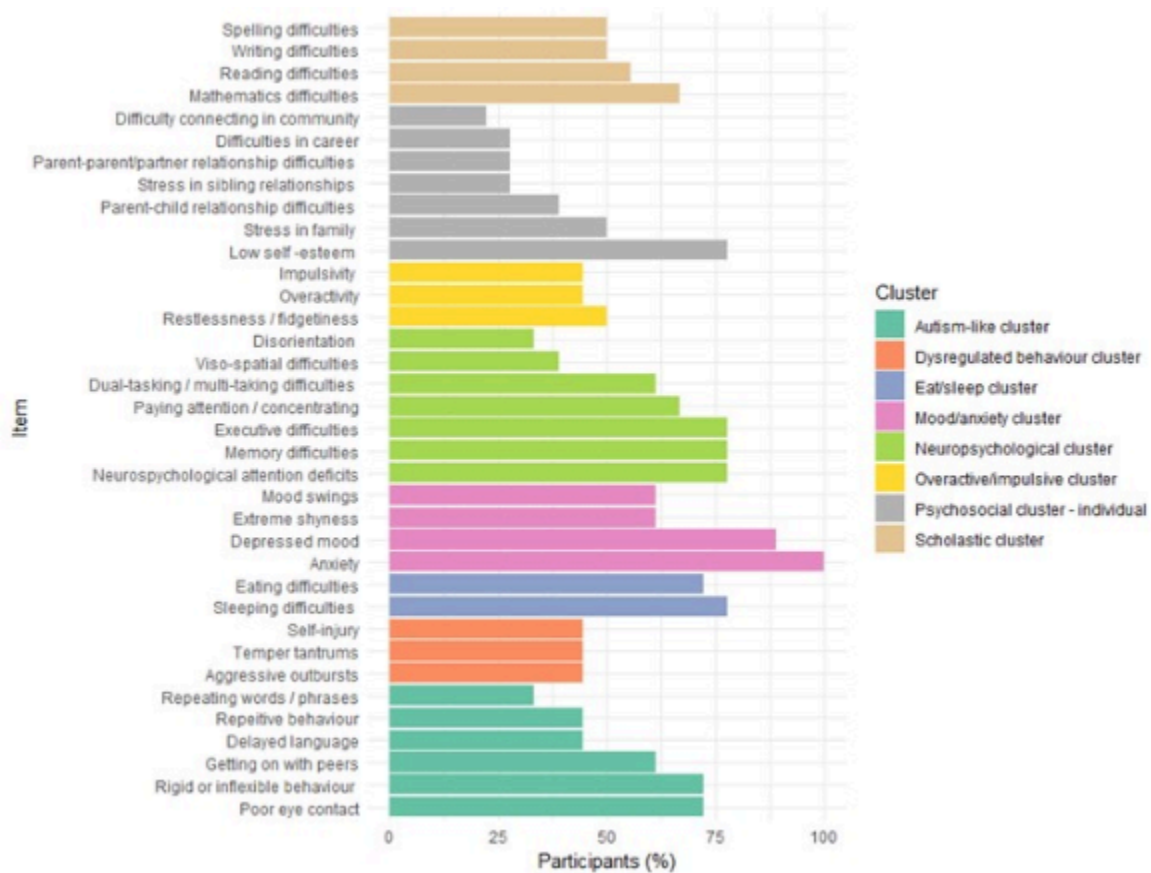


Figure 3

Proportion of Participants with TSC Reporting TAND-SQ items

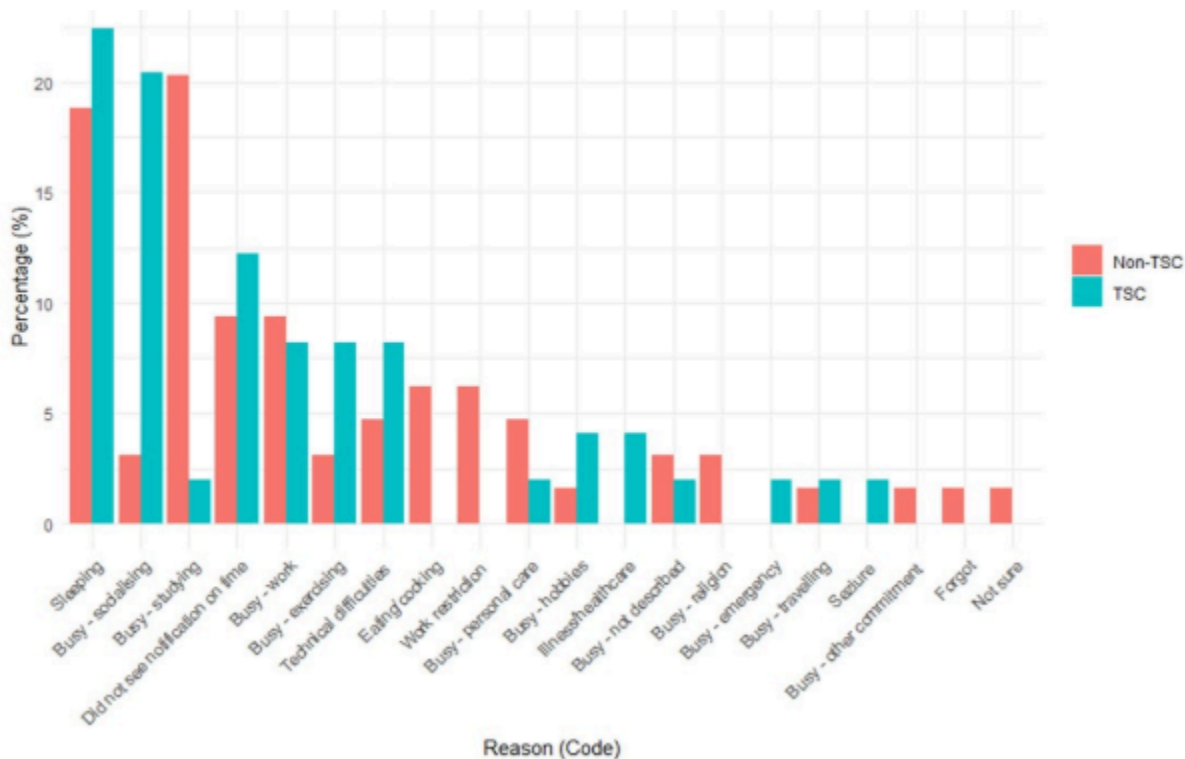


Figure 4

Bar Graph Showing Reasons for Missing EMA Notification Per Participant Group

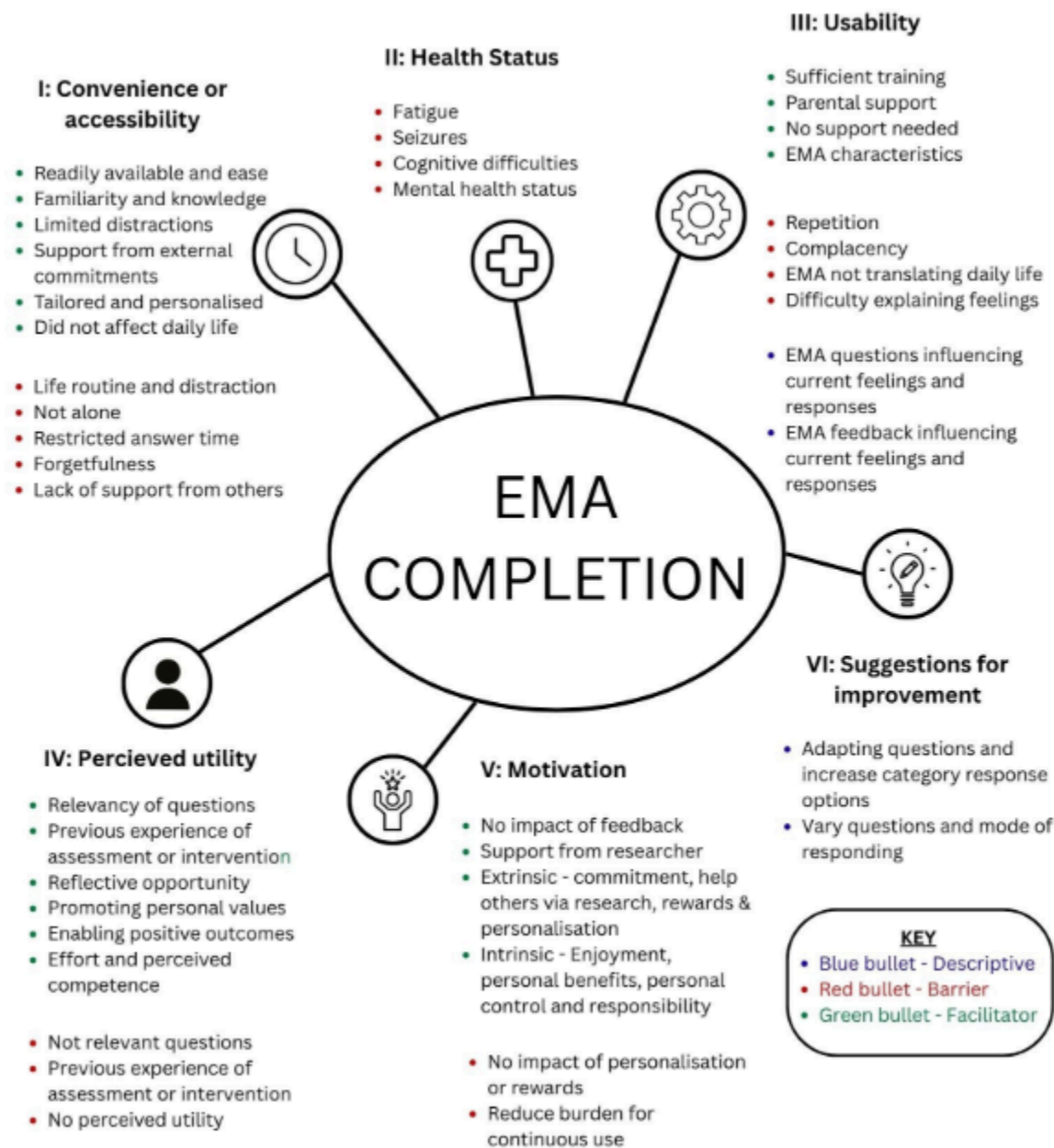


Figure 5

Diagram of EMA Completion Themes in Participants with TSC

Supplementary Files

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