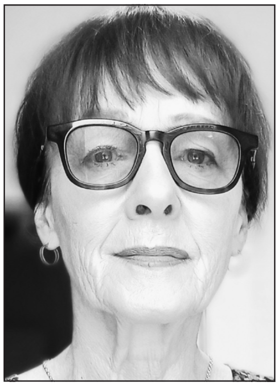

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INTEGRATIVE REVIEW: Does behaviour therapy improve well-being in adults living with epilepsy?

ABSTRACT

Background: Epilepsy poses challenges in both treatment and daily life due to unpredictable seizures and the side effects of associated treatment. Adversities and comorbidities have a negative effect on well-being. Behaviour therapy has shown promise in enhancing self-management and well-being across various long-term conditions.

Aim: This integrative review aimed to identify whether behaviour therapy improves well-being in adults living with epilepsy.

Methods: An integrative review was undertaken using databases including MEDLINE Complete, Pubmed, CINAHL Complete, Science Direct, Clinical Key, PsycINFO, GALE Health & Wellness and GALE Academic. Studies published in English, using quantitative and qualitative methodologies, and presenting primary data analysis on the impact of behaviour therapy on the well-being of adults living with epilepsy were included in the review.

Findings: Sixteen studies were included in the review. Three themes emerged from the synthesis. Quantitative data from all studies demonstrated improvements in well-being. Barriers to adults living with epilepsy participating in and completing behaviour therapy varied, including transportation challenges, memory problems, and issues with technology literacy.

Conclusion: Although behaviour therapy was found to improve well-being in some people living with epilepsy, there are significant limitations in generalising the findings of this review to people living with epilepsy in New Zealand.

KEYWORDS

Epilepsy, behaviour therapy, well-being, quality of life

INTRODUCTION

Epilepsy is a common long-term neurological condition that can be challenging to treat and even more challenging to live with. Seizures can be unpredictable, and treatment is often associated with side effects. The adversities and comorbidities associated with epilepsy are well known to affect well-being negatively. Various behaviour therapy interventions help improve self-management and well-being in people living with various long-term conditions. This integrative review aimed to identify whether behaviour therapy improves well-being in adults living with epilepsy.

BACKGROUND

The World Health Organization estimates there are 50 million global cases of epilepsy, predominantly in low- to middle-income countries. In New Zealand, 45,000 to 50,000 individuals live with epilepsy, with 2000 new diagnoses annually. Characterised by “an enduring predisposition to generate epileptic seizures” (Fisher, 2014, p. 476), epilepsy involves brief, involuntary episodes from abnormal neuronal activity, impacting daily life. Seizures can compromise well-being, affecting employment, education, and daily activities. Due to the nature of epilepsy, self-management is an essential component in achieving and maintaining well-being (Banks, 2021), but well-being affects the ability of a person to be able to self-manage.

Behaviour therapy is effective in managing long-term conditions, and enhancing well-being, especially with comorbidities like depression and anxiety (Hofmann, 2021; Chan et al., 2016; Egan et al., 2015). It employs a client-centred, problem-focused approach, actively engaging individuals in goal-setting and behaviour change, with therapists providing education and support (Spiegler, 2016). With a diverse history since the 1920s, including variations like cognitive behavioural therapy and mindfulness, behaviour therapy offers a structured approach addressing cognitive processes, emotions, and behaviour modification (Blackwell & Heidenreich, 2021). Its evidence-based nature aligns with factors influencing well-being, suggesting its potential to improve well-being, especially in conditions like epilepsy (Cuijpers et al., 2008; Centers for Disease Control and Prevention, 2018).

Given the prevalence and long-term nature of epilepsy, along with its complex management, the objective of this integrative review was to report the impact of behavioural therapy interventions on the well-being of adults with epilepsy. This review will enable us to make recommendations to inform decision-making in current health practices and policies. The review question was: “In adults living with epilepsy, does behaviour therapy improve well-being?”

Table 1. PICo

Population	Adults living with epilepsy	Adults living with epilepsy, either self-reported, as per the International League Against Epilepsy (ILAE) definition or as diagnosed by a neurologist.
Intervention	Behaviour therapy	Studies which used behaviour therapy interventions. There are a range of interventions that fall under the behaviour therapy umbrella so descriptions of interventions needed to be based on behaviour therapy.
Comparison and outcome	Well-being	Well-being needed to be assessed before and after the intervention to identify any changes. The term well-being is used synonymously with quality of life in this review.

METHODOLOGY

Study design

This study followed Toronto’s (2020) methodology for integrative review. An integrative review systematically and rigorously explores a phenomenon of interest in published literature, and can be used to guide evidence-based practice. There are six steps when conducting an integrative review (Toronto, 2020):

1) Formulate purpose and/or review question(s)
2) Systematically search and select literature
3) Quality appraisal
4) Analysis and synthesis
5) Discussion and conclusion
6) Dissemination of findings

Formulate purpose and/or review questions

A review question was developed based on PICo (population, intervention, comparative outcome). Elements of PICo were identified, and the population was viewed as adults living with epilepsy; the intervention was behaviour therapy, and the comparative outcome was well-being. The PICO is presented in Table 1 (above right).

Table 2. Study search eligibility criteria

	Inclusion	**Exclusion**
Population	Adults living with epilepsy	Children
Intervention	Behaviour therapy	
Outcomes	Well-being or quality of life	
Types of studies	Primary research which included well-being or quality of life data in the outcomes	
Quality assessment	JBI checklists for randomised controlled trials and quasi-experimental studies	
Date limits	2012-2022	Prior to 2012

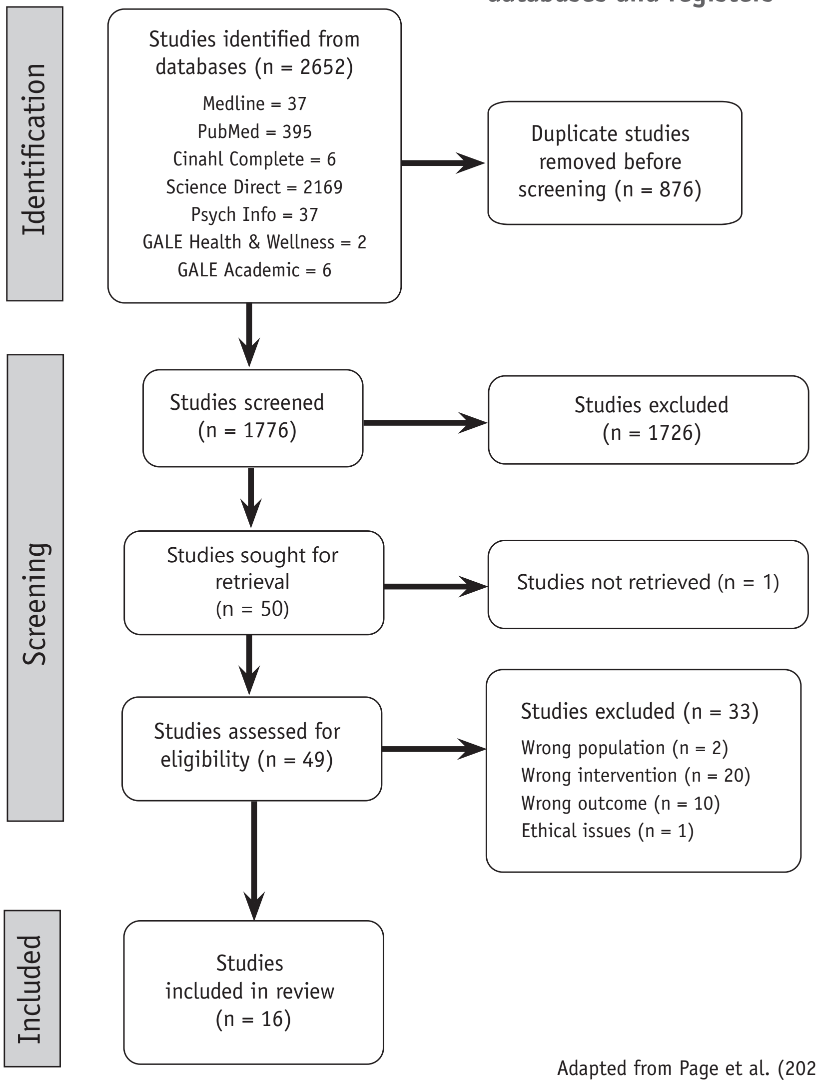
The inclusion and exclusion criteria for the review are shown (above) in Table 2.

Literature search

A systematic search was carried out using the terms derived from the PICo. This search was undertaken using the following databases: MEDLINE Complete, Pubmed, CINAHL Complete, Science Direct, Clinical Key, PsycINFO, GALE Health & Wellness and GALE

Academic. The inclusion criteria for this integrative review included: primary research studies where participants were exposed to behaviour therapy, research published from 2012-2022, and well-being assessed at baseline and following the intervention. Additional relevant articles were handpicked from the reference lists of secondary research studies. The PRISMA process diagram (Figure 1, right) identifies the studies selected at each stage.

FIGURE 1. PRISMA FLOW DIAGRAM – Identification of studies via databases and registers



Adapted from Page et al. (2021).

Search results

The search yielded 2652 records, of which 876 were removed, some being duplicates and some deemed irrelevant by title alone. The titles and abstracts of 1776 studies were screened, and full texts were obtained for 51 studies. These were loaded in the Covidence systematic review manager to review against the inclusion and exclusion criteria. The screening process led to 17 studies being identified as relevant for this review and to be assessed for quality. Two studies were excluded based on population criteria, 20 studies were excluded based on intervention criteria and 10 studies were excluded based on insufficient information on the effect of the intervention on well-being. This process is summarised in the PRISMA flow chart in Figure 1.

Quality appraisal

Each study was critically appraised for methodological quality, using the relevant Joanna Briggs Institute (JBI, 2020) critical appraisal tools for primary research studies. One study by Dewhurst et al. (2015) met all the inclusion criteria and so was initially included in this review but was later excluded based on the lack of ethical considerations reported in the study. This appraisal led to 16 studies being included for analysis.

ANALYSIS AND SYNTHESIS

Qualitative and quantitative data were extracted from each study and collated into tables. The studies used in this review did not examine well-being in isolation but also examined other aspects of quality of life, such as insomnia and depression. Review matrixes were created to organise the data into tables. This process allows the reviewer to assimilate information, compare findings from all sources, and identify patterns and themes (Dwyer, 2020).

Characteristics of the studies

The characteristics of the studies are shown in Table 3 (pp24-28). Studies were carried out globally, but none were conducted in New Zealand. Most studies were conducted in Germany (n=3), and the remainder were from Iran (n=2), Mexico (n=2), USA (n=2), Australia (n=2), China (n=1), Canada (n=1), Malaysia (n=1) and The Netherlands (n=1). The interventions varied between studies, with some studies using cognitive behaviour therapy, some using multicomponent self-management education with behaviour modification strategies, one using mindfulness alone, and one using behaviour change with a psychotherapist. The duration of interventions varied greatly, ranging from three weeks to one year. There were a variety of settings, with some studies providing interventions virtually and some being carried out in person. Some interventions were carried out in group settings, and others were one-on-one. All of the studies used questionnaires before and after interventions, and some studies also provided qualitative data. The participants' mean ages ranged from 28.69 years to 49.3 years. All of the studies had more female than male participants except for Gandy et al. (2014), where 50 per cent of participants were female; Leenen et al. (2018), where 46.2 per cent were female; and Pakpour et al. (2015), where 32.8 per cent were female.

Table 3. Characteristics of studies

Authors	Title	Journal	Country	Setting	Study design	Objectives	Inclusion criteria
Ahorsu et al. (2020)	Testing an app-based intervention to improve insomnia in patients with epilepsy: A randomized controlled trial	Epilepsy & Behaviour	Iran	App-based	Double-blinded randomised controlled trial	To assess the effect of an app-based cognitive behavioural therapy on insomnia symptoms and social psychological factors in people with epilepsy.	1) A diagnosis of epilepsy according to the International League Against Epilepsy criteria. 2) Aged 18 years or older. 3) Moderate or severe insomnia as indicated by a score of 15 or higher on the Insomnia Severity Index (ISI). 4) Speak, understand and write in Persian. 5) No surgery planned in the next six months. 6) Access to an Android smartphone or a desktop computer with internet access.
Brandalise et al. (2019)	Effects of a brief psychotherapeutic intervention on resilience and behaviour in patients with drug-resisitant mesial temporal lobe epilepsy	Epilepsy & Behaviour	Brazil	One-on-one in-person weekly meetings for four weeks with the same psychotherapist	Clinical trial	To evaluate the impact of a psychotherapeutic intervention on levels of resilience, behavioural symptoms and quality of life.	1) Aged 18-65 years. 2) Presurgical diagnoses of TLE-MTS[1] confirmed through video-electroencephalography (VEEG). The diagnosis of TLE was performed in accordance with the International League Against Epilepsy (ILAE) classification. 3) Clear magnetic resonance imaging (MRI) findings consistent with MTS. 4) Follow-up for at least one year.
Caller et al. (2016)	A cognitive behavioural intervention (HOBSCOTCH) improves quality of life and attention in epilepsy	Epilepsy & Behaviour	USA	Conducted at Dartmouth-Hitchcock Epilepsy Center. The programme involved a group session followed by eight 45- to 60-minute telephone sessions conducted by nurses. A commercial gaming device was used for participants in one arm of the study.	Randomised controlled trial	To assess whether a cognitive behavioural intervention improves quality of life and attention in epilepsy.	1) Age 18-65 years. 2) Diagnosis of epilepsy. 3) With or without controlled seizures. 4) Subjective memory conmplaints.
Crail-Melendez et al. (2012)	Cognitive behavioural therapy for depression in patients with temporal lobe epilepsy: A pilot study	Epilesy & Behaviour	Mexico	Conducted at Mexico City's National Institute of Neurology and Neurosurgery. Cognitive behavioural therapy given by two certified CBT therapists over 16 weeks in group format.	Clinical trial	To evaluate if group cognitive behavioural therapy improves depression severity and quality of life.	1) Age 18-60 years 2) Diagnosis of temporal lobe epilepsy 3) Diagnosis of major depressive disorder 4) Not taking antidepressant therapy

Table 3. Characteristics of studies, continued

Authors	Title	Journal	Country	Setting	Study design	Objectives	Inclusion criteria
Gandy et al. (2014)	Cognitive behaviour therapy to improve mood in people with epilepsy: A randomised controlled trial	Cognitive Behaviour Therapy	Australia	The intervention was carried out at the University of Sydney Psychology Clinic. The intervention was one-on-one weekly sessions with a psychologist over 8 weeks.	Randomised controlled trial	To develop and assess the efficacy of a CBT programme for treating mood-related symptoms in adults with epilepsy.	1) Aged 18-65 years 2) Diagnosed with epilepsy 3) Provide written informed consent 4) Be of at least average range IQ 5) Be fluent in English
Gilliam et al. (2019)	A trial of Sertraline or cognitive behavioural therapy for depression in epilepsy	Annals of Neurology	USA	One-on-one in-person CBT sessions with a licensed therapist for 1 hour a week over 16 weeks vs Sertraline.	Clinical trial	To compare the effectiveness of Sertraline vs CBT for depression	1) Aged 21-75 years 2) Diagnosis of epilepsy 3) Occurrence of an absence, focal with impaired awareness, or generalized motor seizure within the past 12 months while taking a recommended dose of an approved anti-seizure medication 4) Score of >14 on the Centers for Epidemiological Studies Depression Scale 5) Diagnosis of current major depressive episode on the Mini International Neuropsychiatric Interview 6) Be able to read and understand study documents based on investigators' assessment
Hu et al. (2020)	Effect of intensive self-management education on seizure frequency and quality of life in epilepsy patients with prodromes or precipitating factors	Seizure: European Journal of Epilepsy	China	The intervention took place in the Department of Neurology at Sichuan Provincial Peoples Hospital. All participants received a single face-to-face self-management education session at the time.	Clinical trial	To explore the impact of intensive self-management education vs regular education on seizure frequency, quality of life and drug adherence.	1) Aged at least 18 years 2) At least a 1-year history of epilepsy 3) Prodromes or precipitating factors during the pre-seizure state reported 4) The types and doses of antiepileptic drugs remained unchanged for 6 months and did not change during follow-up.

Table 3. Characteristics of studies, continued

Authors	Title	Journal	Country	Setting	Study design	Objectives	Inclusion criteria
Hum et al. (2019)	Do distance delivery group interventions improve depression in people with epilepsy?	Epilepsy & Behaviour	Canada	The programmes were delivered in small groups over the telephone for 1-hour sessions once a week for 8 weeks.	Randomised controlled trial	The study examined the effect of distance-delivery programmes on depression and quality of life.	1) Older than 18 years. 2) Diagnosis of epilepsy for minimum of 1 year. 3) Resided in the province of Onatario. 4) Had access to a computer, internet and phone. 5) Experienced some depressive symptoms as reflected by a minimum score of 12 on the Center for Epidemiologic Studies Depression Scale Revised. 6) Had a reading comprehension score greater than 7 on an Education Quality and Accountability Office Junior Division Assesssment of Reading or a listening comprehension assessment score greater than 18 on the Wechsler Individual Achievement Test.
Lai et al. (2021)	Mindfulness-based intervention to promote psychological well-being in people with epilepsy: A randomised controlled trial	Epilepsy & Behaviour	Malaysia	The intervention was conducted at the University of Malaysia Medical Center neurology clinic and involved six 2.5-hour sessions per week for six weeks in a group setting. This was led by a PhD candidate with a master's degree in health psychology.	Randomised controlled trial	The study investigated the efficacy of a mindfulness-based intervention on psychological well-being.	1) Older than 16 years. 2) Diagnosis of epilepsy. 3) Able to read and write English.
Leenen et al. (2018)	Effectiveness of a multi-component self-management intervention for adults with epilepsy (ZMILE study): A randomized controlled trial	Epilepsy & Behaviour	The Netherlands	The intervention was led by two nurse practitioners at several locations in the southern part of the Netherlands. There were five weekly group sessions of two hours each.	Randomised controlled trial	The aim was to compare the effectiveness of a multi-component self-management intervention to care as usual.	1) Older than 18 years. 2) Diagnosed with epilepsy. 3) Living at home. 4) Using anti-seizure medication 5) Understood the Dutch language 6) Willing and able to use e-Health devices belonging to the MCI
Meyer et al. (2019)	Effects of an epilepsy-specific internet intervention (Emyna) on depression: Results of the ENCODE randomized controlled trial	Epilepsia	Germany	Internet intervention with CBT techniques and exercises which could be accessed over 180 days.	Randomised controlled trial	The aim of the study was to evaluate whether an internet-based CBT intervention could reduce depression symptoms and other issues such as anxiety.	1) Older than 18 years 2) Diagnosis of active epilepsy as defined by having taken antiepileptic drugs within the past five years or having experienced seizures within the past 10 years 3) Diagnosis of a current depressive disorder 4) At least moderate depression severity 5) Ability to read and speak German. 6) Internet access

Table 3. Characteristics of studies, continued

Authors	Title	Journal	Country	Setting	Study design	Objectives	Inclusion criteria
Hum et al. (2019)	Do distance delivery group interventions improve depression in people with epilepsy?	Epilepsy & Behaviour	Canada	The programmes were delivered in small groups over the telephone for 1-hour sessions once a week for 8 weeks.	Randomised controlled trial	The study examined the effect of distance-delivery programmes on depression and quality of life.	1) Older than 18 years. 2) Diagnosis of epilepsy for minimum of 1 year. 3) Resided in the province of Onatario. 4) Had access to a computer, internet and phone. 5) Experienced some depressive symptoms as reflected by a minimum score of 12 on the Center for Epidemiologic Studies Depression Scale Revised. 6) Had a reading comprehension score greater than 7 on an Education Quality and Accountability Office Junior Division Assesssment of Reading or a listening comprehension assessment score greater than 18 on the Wechsler Individual Achievement Test.
Lai et al. (2021)	Mindfulness-based intervention to promote psychological well-being in people with epilepsy: A randomised controlled trial	Epilepsy & Behaviour	Malaysia	The intervention was conducted at the University of Malaysia Medical Center neurology clinic and involved six 2.5-hour sessions per week for six weeks in a group setting. This was led by a PhD candidate with a master's degree in health psychology.	Randomised controlled trial	The study investigated the efficacy of a mindfulness-based intervention on psychological well-being.	1) Older than 16 years. 2) Diagnosis of epilepsy. 3) Able to read and write English.
Leenen et al. (2018)	Effectiveness of a multi-component self-management intervention for adults with epilepsy (ZMILE study): A randomized controlled trial	Epilepsy & Behaviour	The Netherlands	The intervention was led by two nurse practitioners at several locations in the southern part of the Netherlands. There were five weekly group sessions of two hours each.	Randomised controlled trial	The aim was to compare the effectiveness of a multi-component self-management intervention to care as usual.	1) Older than 18 years. 2) Diagnosed with epilepsy. 3) Living at home. 4) Using anti-seizure medication 5) Understood the Dutch language 6) Willing and able to use e-Health devices belonging to the MCI
Meyer et al. (2019)	Effects of an epilepsy-specific internet intervention (Emyna) on depression: Results of the ENCODE randomized controlled trial	Epilepsia	Germany	Internet intervention with CBT techniques and exercises which could be accessed over 180 days.	Randomised controlled trial	The aim of the study was to evaluate whether an internet-based CBT intervention could reduce depression symptoms and other issues such as anxiety.	1) Older than 18 years 2) Diagnosis of active epilepsy as defined by having taken antiepileptic drugs within the past five years or having experienced seizures within the past 10 years 3) Diagnosis of a current depressive disorder 4) At least moderate depression severity 5) Ability to read and speak German. 6) Internet access

Table 3. Characteristics of studies, continued

Authors	Title	Journal	Country	Setting	Study design	Objectives	Inclusion criteria
Michaelis et al. (2021)	Process oriented and personalized psychotherapeutic care for epilepsy: Interim results of a feasibility study	Epilepsy & Behaviour	Germany	Conducted in the outpatient clinic of the neurology department of a community hospital in Germany. 60-minute individual sessions with a therapist were provided over 12 weeks.	Feasibility study	The aim of this study was to evaluate the effect of psychotherapeutic care on health-related quality of life and psychiatric comorbidity. The relationship between outcome socres, the number of attended sessions and history of childhood trauma were also assessed.	1) Older than 18 years 2) Diagnosis of epilepsy 3) Interest in taking part in psychotherapeutic treatment
Orjuela-Rojas et al. (2015)	Treatment of depression in patients with temporal lobe epilepsy: A pilot study of cognitive behavioural therapy vs. selective serotonin reuptake inhibitors	Epilepsy & Behaviour	Mexico	The study was conducted at the National Institute of Neurology and Neurosurgery in Mexico City. There were 2 arms to the study with 1 group receiving SSRI and the other group receiving CBT in group format for 90 minutes a week over 12 weeks.	Pilot study	The aim of the study was to evaluate the effect of both interventions on quality of life, symptoms of depression, anxiety, suicide risk and frequency of seizures.	1) Older than 18 years 2) Diagnosed with temporal lobe epilepsy 3) Diagnosed with major depressive disorder 4) Literate
Paardekooper et al. (2015)	A randomized controlled multimodal behavioural intervention trial for improving antiepileptic drug adherence	Epilepsy & Behaviour	Australia	A condensed version of CBT for insomnia was provided in group format over four 2-hour sessions.	Randomised controlled trial	The aim of this study was to evaluate the effectiveness of CBT on quality of sleep and quality of life.	1) Aged 18-65 years 2) Diagnosis of epilepsy 3) Fluency in English 4) Poor sleep quality
Pakpour et al. (2015)	A randomized controlled multimodal behavioural intervention trial for improving antiepileptic drug adherence	Epilepsy & Behaviour	Iran	Three weekly face-to-face meetings were held within a neurologic clinic and lasted 40-60 minutes. The facilitator was a male health psychologist.	Randomised controlled trial	The aim of this study was to assess the effectiveness of a multicomponent intervention on adherence to antiseizure medication. Quality of life was also assessed.	1) Older than 18 years 2) Diagnosis of epilepsy 3) Be prescribed anti-seizure medication 4) Have independence in daily living activities or be responsible for taking their medications
Schroder et al. (2014)	Efficacy of a psychological online intervention for depression in people with epilepsy: A randomized controlled trial	Epilepsia	Germany	Internet-based CBT intervention over 9 weeks.	Randomised controlled trial	This study aimed to evaluate the effect of an internet-based CBT intervention on depressive symptoms and quality of life.	1) Adults 2) Self-reported epilepsy 3) Self-reported depression

Before and after well-being test scores were assessed to identify which studies achieved a statistically significant improvement in well-being following behaviour therapy. A review matrix was created to identify any themes that may characterise statistically significant or statistically insignificant studies (see Appendix 1, p36). Qualitative and quantitative data related to well-being or quality of life were used in this review and are shown in Appendix 2 (p38). This table also includes limitations to identify any similarities between limitations. Each review matrix was analysed to identify themes, and this process was guided by three questions that were closely aligned with the review purpose:

1) What was the effect of behaviour therapy on well-being in adults living with epilepsy?
    - Identify any participant feedback/qualitative data on how the intervention affected well-being.
    - Identify which studies showed a statistically significant improvement in well-being.
2) Were there any similar characteristics between studies deemed to improve well-being?
    - Type of behavioural intervention
    - Duration of intervention
    - Mode and delivery of the intervention
    - Characteristics of the participants
3) Was behaviour therapy an acceptable intervention?
    - Identify any characteristics that were considered acceptable or unacceptable.
    - Consider participation and/or completion of the intervention

FINDINGS

Three primary themes emerged from the synthesis: 1) the effects of behaviour therapy interventions on well-being, 2) common characteristics between studies deemed to improve well-being, and 3) the acceptability of the interventions.

Theme 1: Effect of behaviour therapy interventions on well-being

There were no qualitative data available on the effect of behaviour therapy on well-being in adults living with epilepsy. Quantitative data on the effect of behaviour therapy on well-being in adults living with epilepsy were available for every study included in this review. Nurses need to have an understanding of quantitative data but do not usually need to be fluent in statistics (Schroeder et al., 2022). Nurses usually either work with a statistician or receive formal training in statistics to avoid analytic errors (Grove & Cipher, 2017). The values used to examine statistical significance and change in well-being before and after interventions are *p*-values and t-tests. *P*-values indicate whether data is statistically significant or occurred by chance, and are important when measuring the quantitative outcome of research. A *p*-value of 0.05 or less means that there is a 5 per cent or less probability that the results may have occurred by chance and *p*-values of 0.05 or less are deemed statistically significant (Harvey & Land, 2022). T-tests are used to investigate the difference between samples with a distance from 0, whether positive or negative, providing a value to the difference (Grove & Cipher, 2017). Some t-test calculating tools are available online and were used in this review. Using t-tests and *p*-values, it was possible to calculate which studies produced statistically significant improvements in well-being.

The studies included in this review used a variety of tools to assess well-being, with the Quality of Life in Epilepsy (QOLIE) inventories being the tools most commonly used. The QOLIE Development Group (1993) developed the QOLIE-89, QOLIE-31 and QOLIE-10, based on analysis of data obtained from people living with epilepsy in the United States. The QOLIE-89 contains 17 multi-item measures, while the QOLIE-31 and QOLIE-10 are shorter forms of the QOLIE-89. The QOLIE-89 takes up to 45 minutes to complete, the QOLIE-31 about 10 minutes to complete and the QOLIE-10 takes about two to three minutes (Jones et al., 2020). These questionnaires cover several domains, including emotional well-being, social functioning, energy/fatigue, cognitive functioning, seizure worry, medication effects and overall quality of life (Vickrey et al., 1993). Overall scores are obtained using a weighted average; overall score values can range from 0 to 100, with higher values reflecting better quality of life. Thirteen studies used the QOLIE-31, one study used QOLIE-89 and one study used QOLIE-10. Meyer et al. (2019) used the QOLIE-10 and found a statistically significant improvement in QOLIE-10 scores after the intervention. Gilliam et al. (2019) used the QOLIE-89 and also found a statistically significant improvement in quality of life after the intervention.

Although Brandalise et al. (2019) used the QOLIE-31 inventory, the overall scores differed considerably from the other studies that used the same tool and were also higher than the scores the QOLIE-31 can achieve. The overall QOLIE-31 score is meant to range from 0 to 100; however Brandalise et al's pre-intervention mean overall QOLIE-31 score was 181.29 and the mean overall post-intervention score 191.12. The authors do not discuss why the overall QOLIE-31 scores do not fall between 0 and 100 but it is possible that they used raw scores rather than the recommended weighted scoring.

WHOQOL-BREF was used by Hum et al. (2019) and Schroder et al. (2014), who used this tool as well as QOLIE-31. WHOQOL-BREF is an abbreviated version of the World Health Organization Quality of Life assessment tool which was developed to increase focus on quality of life and well-being (Programme on Mental Health World Health Organization, 1996). This tool covers four domains, including physical health, psychological, social relationships and environment, and was developed through research in centres around the world. Higher scores are associated with a better quality of life. Hum et al. (2019) identified a significant improvement in WHOQOL-BREF scores following the behavioural change intervention. While both Hum et al. (2019) and Schroder et al. (2014) identified improvements in WHOQOL-BREF scores after the intervention, the improvement was not enough to achieve statistical significance.

In studies with small sample sizes, there needs to be a greater improvement in pre- and post-intervention scores for results to be statistically significant (Peacock & Peacock, 2011). Due to the small sample sizes of the studies used in this review, statistically significant results were difficult to achieve. Ten of the 16 studies found a statistically significant improvement in well-being in people living with epilepsy following behaviour therapy. The t-tests comparing pre- and post-intervention well-being scores showed a statistically significant improvement, with the *p*-value for the t-test scores being less than or equal to 0.05. Overall, more studies showed a statistically significant improvement in well-being than studies where the improvement was not statistically significant. Although some studies did not achieve a statistically significant improvement in well-being, all showed a trend of improved well-being following the intervention. The graph below shows the trends of QOLIE-31 scores before and after the intervention. Brandalise et al. (2019) scores were not included in this graph due to the scores being outside the accepted range for QOLIE-31 scoring.

Theme 2: Were there any similar characteristics between studies that improved well-being?

The only common characteristics between the studies that improved well-being were that the participants were adults living with epilepsy who were exposed to behaviour therapy. There was a trend for well-being to improve in all the studies, with statistically significant improvements in 10 of the 16 studies (See Appendix 1). No common characteristics were found between studies deemed to have statistically significant results compared to those with statistically insignificant results. The type of behavioural intervention, the mode of delivery, the age and gender of participants, the type of facilitator and the duration of intervention did not appear to affect whether an intervention achieved statistically significant improvements in well-being.

Theme 3: Acceptability of the interventions

All of the studies in this review required the voluntary participation of people living with epilepsy, and that the participants be motivated to engage in the interventions, but very little feedback from participants was published. Qualitative data was included alongside quantitative data in Appendix 2. Of the seven studies which included qualitative data, five discussed positive user satisfaction. Leenen et al. (2018) received positive feedback from neurologists who reported that participants were better prepared for consultations and consultations were more effective. Pakpour et al. (2015) identified an improvement in the relationships between participants and their doctors. Participants in Hum et al's (2019) study valued connecting with other people living with epilepsy. Hum et al. (2019) and Schroder et al. (2014) participants offered suggestions on how the interventions might be improved.

While most of the feedback was positive, Caller et al. (2016) and Leenen et al. (2018) participants struggled with the technology used in the interventions. Some participants in Meyer et al.'s (2018) study were concerned about data protection, felt pressured to undertake therapeutic exercises and were anxious about becoming too dependent on the intervention. Not all studies provided data on the number of people who did not meet inclusion criteria or who declined to participate. However, all studies provided data on drop-out rates. The number of people who did not meet exclusion criteria ranged from 0 per cent to 86 per cent, those who declined to participate ranged from 0 per cent to 85 per cent, and drop-out rates ranged from 0 per cent to 39 per cent. Only two studies identified barriers to participants enrolling and engaging fully with the interventions. Participation was negatively affected by transportation challenges, memory problems, poor internet/device literacy, low motivation, lack of support and health problems. The barriers that contributed to participating or completing the interventions are identified in Table 4 (pp29-30).

DISCUSSION

Quantitative data analysis revealed a trend for improvement in well-being following participation in behavioural interventions. Feedback from participants, where available, was mostly favourable. Superficially, the qualitative and quantitative data appear to identify an improvement in well-being in people living with epilepsy following the use of behaviour therapy. This could imply that behaviour therapy is useful in improving the well-being of people living with epilepsy, but there are many limitations to consider.

It can be challenging to achieve robust, valid results in hard-to-reach populations such as those affected by stigma. McLaughlin et al. (2019) call these groups "hidden populations" and report that research results on participants recruited from these populations may differ from people of the same population who did not participate in the research. This makes it difficult to estimate the size of the population as well as to identify the characteristics and needs of the population (National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Health Care Services; Division of Behavioural and Social Sciences and Education; Committee on National Statistics., 2018). Epilepsy is commonly associated with stigma, and the populations in the studies used for this review seem to reflect a similar phenomenon to McLaughlin's

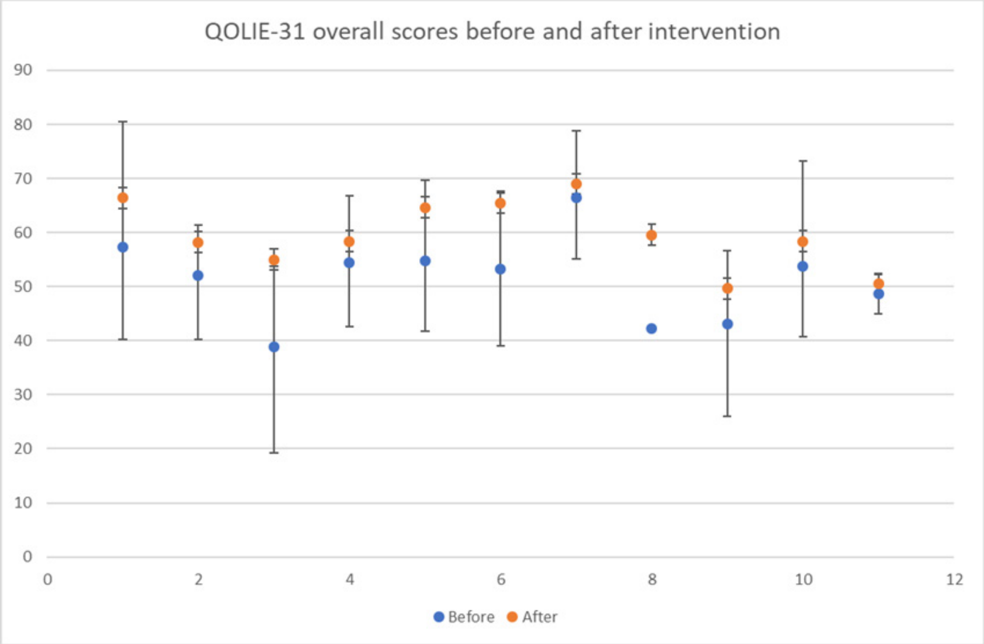


Table 4. Barriers to participating or completing intervention

Study	Did not meet inclusion criteria	Declined to participate	Dropout rate	Barriers to participating or completing intervention
Ahorsu et al.	58%	9%	4%	• Participants needed to have access to the internet and a smartphone or computer, as well as have an understanding of how to use the app. Reasons for discontinuing intervention not disclosed.
Brandalise et al.	47%	0%	0%	• Inability to attend all meetings resulted in many participants being excluded from the study. Other reasons for exclusion included transportation costs and/or lack of availability of caregivers and cognitive issues affecting the ability to complete questionnaires.
Caller et al.	9%	32%	34%	• People were excluded if they lacked reliable phone access. • Driving restrictions and transportation difficulties affected ability to complete the in-person follow-up visit. • Intervention required significant patient motivation. • Forgetting appointments. • Communication barriers where some participants were difficult to reach by phone. • Reasons for withdrawing from the intervention not disclosed. Some participants missed the follow-up visit and reasons for this were not disclosed.
Crail-Melendez et al.	0%	Not disclosed	30%	• Lack of family support to attend sessions. Lack of seizure control.
Gandy et al.	11%	Not disclosed	39%	• Work hours • Travel difficulties • Health problems • Not contactable • Not motivated • Poor memory Those who dropped out of the intervention had significantly poorer quality of life at baseline to those who completetd the intervention.
Gilliam et al.	86%	11%	28%	• Some eligible participants declined to participate due to time and travel restrictions. • Some declined to participate because they didn't want to take sertraline. • Some declined but did not give a reason. • Reasons for dropping out of the intervention included: * Lost to follow-up * Switched to sertraline * Withdrew consent * Worsening depression * Discontinued but no reason provided Death likely due to SUDEP
Hu et al.	Not disclosed	12%	8%	None disclosed.

Hum et al.	32%	6%	34%	• Forgetting to call in on time. • Forgetting to complete skill-building activities. • Struggling to remember some CBD concepts. Some participants were lost to follow-up, some did not attend all sessions and one discontinued the intervention. Reasons for this were not disclosed.
Lai et al.	81%	85%	21%	• Participants were given the opportunity to discuss barriers but these barriers were not published. • The majority of people who declined to participate said they were either not interested or had competing priorities. • Other reasons for not wanting to participate included seizure freedom, distant geographical location, pregnancy or epilepsy-related concerns. Two participants discontinued the intervention and one was lost to follow-up but reasons for this were not disclosed.
Leenen et al.	1%	57%	10%	• The app used in the intervention was not maintained and updated which meant that many of the participants experienced problems using the app. • Reasons for drop-out included: * Questionnaire too complex * Intervention did not meet expectations * Health problems Lost to follow-up
Meyer et al.	59%	Not disclosed	27%	• After providing consent and starting baseline questionnaires, 4% of individuals could not be reached for interview. • Participants needed to be motivated and be able to use the internet. • Some participants had concerns about data protection. • Some participants felt pressured to undertake therapeutic exercises. Some participants felt anxious about becoming too dependent on the programme.
Michaelis et al.	Not disclosed	Not disclosed	0%	The authors felt that low attrition rates in their study were due to the naturalistic setting and participants being involved in the scheduling of therapy sessions.
Orjuela-Rojas et al.	Not disclosed	Not disclosed	29%	• Not all participants who met the inclusion criteria were able to attend the weekly sessions due to either living far away or financial constraints so were allocated to the SSRI arm of the study. • Two participants dropped out of the CBT intervention due to health problems. • Memory issues were identified as a contributing factor to the ability to participate fully in sessions. 40% of people eligible to participate were unable to be reached by phone.
Paardekooper et al.	Not disclosed	Not disclosed	0%	One eligible participant was excluded as they were unable to commit to all group sessions.
Pakpour et al.	7%	1%	2%	• Participants were encouraged to identify potential barriers and identify ways to overcome them. Reasons for drop out were not disclosed.

"hidden populations". In the studies where data on refusal to participate was included, there were high numbers of people living with epilepsy who declined to participate in the studies for various reasons. People with poorer well-being are less likely to participate and more likely to have less motivation. People with better well-being and who are more able to participate may not have as much room for improvement in well-being as people who are less able to participate.

Gandy et al. (2014) identified that participants with lower quality-of-life scores, particularly the cognitive function subscale, were more likely to drop out of the intervention, indicating that the intervention may be less suitable for people with cognitive difficulties. It may be that behavioural interventions are not desirable or practicable for many people living with epilepsy. It is recommended that attention is paid not only to the populations who are invited to and engage with the research, but also to those who are missing (Baumann & Cabassa, 2020). Many of the studies required people interested in participating in research to contact the authors to participate. In these studies, it can be assumed that disenfranchised and less motivated people would be harder to reach and, therefore, less likely to participate. The limited qualitative data in the studies may indicate that measurable, quantitative data was valued more highly than participation and feedback on the interventions. As well, this lack of qualitative information on people's experience of living with epilepsy may increase the gap between what they value and desire and what is available to them.

While it seems that behaviour therapy improves well-being among some people living with epilepsy, it is important to consider other factors that may have improved well-being among the participants. Paardekooper et al. (2020) found that monitoring alone may act as a mediator for therapeutic change. Self-monitoring is a core component of behaviour therapy to identify where behaviour change is necessary (Psychology Tools, 2022). Completing the surveys and questionnaires required for participation in the studies may have contributed as mediators for change. Pakpour et al. (2015) had a multidisciplinary approach to the intervention whereby others involved in the participant's care, including GPs, nurses and family members, also received a motivational interviewing intervention session. The improvement in the well-being of people living with epilepsy will likely have been affected by the health-care team and family members having a better understanding of epilepsy and management. Social interaction has a considerable effect on well-being (Szemere & Jokeit, 2014), and increased social interaction related to most of the interventions may have positively affected participants' well-being.

Epilepsy affects slightly more males than females and is most prevalent in the 45 to 54-year age bracket. The mean ages of participants ranged from 28.69 to 49.3 years, and most were female. Epilepsy is more prevalent in lower socioeconomic groups, but it was not possible to identify the socioeconomic background of study participants from the available data. Ethnicity was also not identified in most of the studies, so it was impossible to determine if ethnic minorities were included. The exclusion of underserved populations is a common problem and creates "blind spots" in treatment and practice (Baumann & Cabassa, 2020). The studies in this review seem to have hefty "blind spots" due to the study populations varying considerably from general epilepsy populations. The difference between study population demographics and epilepsy population demographics also indicates "blind spots" and suggests that the study populations do not represent the general epilepsy population. This means that the results from the studies may not be transferable to the general epilepsy population. Also, these results indicate that behaviour therapy improves well-being in only some people living with epilepsy.

This review has revealed how little is known about people living with epilepsy in New Zealand and how little is known about their needs. None of the studies were performed in New Zealand, so differences in health-care systems and cultures are likely. There is no data on the epidemiology or demographics of epilepsy in New Zealand, which makes it difficult to compare our epilepsy population with other populations. The absence of epilepsy demographics in New Zealand suggests that the impact of this relatively common condition is undervalued in this country. New Zealand's "hidden population" of people living with epilepsy would be a challenging group to engage with, creating large gaps between people able and willing to participate in research and this disenfranchised population. This means that the information gathered from this review may not be able to be generalised to New Zealand's epilepsy population.

RECOMMENDATIONS

The results of this review imply that behaviour therapy can improve well-being and that it is an acceptable intervention in some people living with epilepsy. To identify the usefulness of behaviour interventions in people living with epilepsy in New Zealand, further research is needed. The starting point of any future research is identifying the demographics of this population. The stigma associated with epilepsy and the isolation which commonly occurs as a result of this makes this a challenging group of people to reach, so considerable effort is required in gathering accurate data. New Zealand is currently incorporating SNOMED CT clinical terminology, which will be used in all areas of health (Ministry of Health, 2022). Once the demographics of epilepsy in New Zealand have been established, it would then be possible to identify the needs of people living with epilepsy as well as the needs of people working with this population.

This review has shown that behaviour therapy improves well-being in some people living with epilepsy but was unable to identify the needs of harder-to-reach people living with epilepsy. Building trust in this community would be necessary as it would be challenging to identify the demographics and needs of people who are "hidden". There is no simple way to identify the needs of "hidden populations" but specialised sampling methods such as targeted sampling, time-location sampling, respondent-driven sampling and snowball sampling have been developed to target hard-to-reach populations. Education of health-care workers and the New Zealand public may help in raising awareness and reducing the stigma associated with epilepsy which may help reveal the needs of those living with epilepsy as well as those who care for them.

Further research into the needs of people living with epilepsy in New Zealand should be considered. Rather than investigate the effectiveness of behaviour therapies on the well-being of people living with epilepsy, research into what are the wants and needs of people living with epilepsy and those who care for them should be performed. Once these needs have been identified, feasibility studies should be performed to assess the effectiveness and practicality of any interventions. Specialised sampling methods would enhance participation. While quantitative data helps present data in a way that is meaningful for policymakers, qualitative data would be essential if wishing to identify data that is meaningful for people living with epilepsy, their whānau and health-care workers.

Any further research or plans to change practice should acknowledge the barriers to participation. Because transport was an issue that affected many study participants, it would be necessary to facilitate access to any interventions by using virtual and face-to-face delivery modes. Some participants struggled with technology, so appropriate support with any virtual interventions is essential. Memory and cognitive difficulties were also common problems and would need to be considered when creating any interventions or plans for further research. Many people living with epilepsy are socially isolated, and participants in these studies valued the opportunity to connect with other people living with epilepsy, so group interventions should be considered.

This review identifies that many people living with epilepsy have coexisting depression, memory concerns and poor motivation, yet these issues are rarely detected or acknowledged when managing epilepsy in New Zealand. These issues affect an individual's ability to attend appointments, take appropriate treatment and participate in self-management. The well-being assessments identified in this review were useful in recognising overall concerns with well-being and some more specific areas such as physical, psychological and social well-being. It may be helpful to use similar assessment tools in everyday practice to place more of a focus on well-being, rather than epilepsy or "illbeing". While this approach is unlikely to affect epilepsy management on a systemic level, it may lead to a better understanding of individual needs and improve an individual's health-care experience.

LIMITATIONS

The limitations of the included studies are set out in Appendix 2. There are challenges in applying research findings conducted in other countries to the New Zealand context. Cultural differences are also likely present in the countries of origin, which may not be representative of the cultural diversity within their populations (Ahorsu et al., 2020; Gilliam et al., 2019; Lai et al., 2021; Leenan et al., 2018). The allocation of participants to interventions in some studies was not able to be blinded (Gilliam et al., 2019; Hu et al., 2020), and some studies had a small sample size (Hum et al., 2019; Michaelis et al., 2021; Orjuela-Rojas et al., 2015; Paardekoop et al., 2015) or a high participant dropout rate (Caller et al., 2016; Crail-Menendez et al., 2012; Gandy et al., 2014; Meyer et al., 2019). The interventions in some studies required internet access or visits to clinics which may have excluded some participants (Caller et al., 2016; Brandalise et al., 2019; Gandy et al., 2014; Orjuela-Rojas et al., 2015; Meyer et al., 2019).

CONCLUSION

This review identifies the characteristics of behavioural interventions that successfully improve the well-being of people living with epilepsy. Considerable effort is required to identify New Zealand's epilepsy demographics and how to meet the needs of these people. This review has shown that behaviour therapy does improve well-being in some people living with epilepsy, but it is not possible to generalise these findings to New Zealand's population. The participants of the studies in this review are a small sample of people living with epilepsy in countries with different health systems and different cultures. The first step in improving the well-being of people living with epilepsy in New Zealand is to identify who they are and how their condition burdens them, their whānau and the country. This will be a massive undertaking but will make it possible to identify the needs of this population and the health-care system. Only once this has been achieved can change be made at a systemic level.

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APPENDIX 1 – Characteristics of statistically significant and statistically insignificant interventions

Study	Intervention	Delivery	Timeframe	Facilitators	Participants
Statistically significant studies					
Ahorsu et al.	CBT and education via mobile map	Individual, virtual	6 weeks	Online with support assistant for help with the online programme	Adults aged 38.37 ± 13.45 60.6% female
Caller et al.	Cognitive training, behaviour modification strategies & multidimensional self-management intervention	Group, telephone	8 weeks	Epilepsy specialised advanced registered nurse practitioner or registered nurse trained as memory coach	Adults aged 49.3 ± 9.2 66% female
Crail-Melendez et al.	CBT psychotherapy	Group, in person	16 weeks	CBT therapists	Adults aged 34.1 ± 8.9 98% female
Gilliam et al.	CBT	Individual, in-person where possible	16 weeks	Licensed therapist	Adults aged 39.1 ± 12.1 60% female
Hu et al.	CBT and emotional therapy and intensive self-management education	Individual,mostly telephone (single in-person session)	1 year	Epileptologists	Adults aged 28.69 ± 7.29 60% female
Lai et al.	Mindfulness-based CBT	Group, in-person	6 weeks	PhD candidate with master's degree in health psychology	Adults aged 34.1 ± 14.3 71.4% female
Meyer et al.	CBT	Individual, virtual	3 months	Online only	Adults aged 40.53 ± 12.90 65% female
Michaelis et al.	CBT	Individual, in-person or virtual	12 weeks	Neurologist and psychotherapist	Adults aged 48 75% female
Orjuela-Roja et al.	CBT	Group, in-person	12 weeks	A licensed therapist and a companion therapist	Adults aged 33.8 86% female

Pakpour et al.	Multicomponent intervention involving motivational interviewing targeting behaviour change	Individual, in-person	3 weeks	Male health psychologist	Adults aged 41.37 ± 16.25 32.8% female

Statistically insignificant studies

Study	Intervention	Delivery	Timeframe	Facilitators	Participants
Brandalise et al.	Highly encouraged to change behaviour	Individual, in-person	4 weeks	Psychotherapist	Adults aged 40.9 ± 10.4 82.0% female
Gandy et al.	CBT	Individual, in-person	9 weeks	Psychologists	Adults aged 41 ± 12 50% female
Hum et al.	Mindfulness-based CBT	Group, telephone	8 weeks	A licensed mental health professional and a person living with epilepsy	Adults aged 36.90 ± 2.9 80% female
Leenen et al.	Multicomponent self-management education[1]	Group, in-person and e-health tools	8 weeks	Nurse practitioners	Adults aged 40.0 ± 13.1 46.2% female
Paardekooper et al.	CBT	Group, virtual	4 weeks	Not disclosed	Adults aged 39.18 ± 10.87 82% female
Schroder et al.	CBT	Individual, virtual	9 weeks	Online only	Adults aged 35.03 ± 9.99 80% female

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[1] This included education and goal-setting skills covering self-monitoring, risk evaluation and management, shared decision making/concordance, and Aspinwall and Taylor's five stages of proactive coping.

APPENDIX 2 – Findings and limitations

Authors	Sample	Demographics	Data collection	Types of analysis	Findings	Limitations
Ahorsu et al.	320 I^1 = 160 C^1 = 160	I: Age 38.37 ± 13.45; 60.6% female; 82.5% married; 68.1% unemployed; 8.75 ± 5.06 years of education C: Age 37.99 ± 9.88; 56.2% female; 78.5% married; 65.6% unemployed; 8.31 ± 4.51 years of education	Pittsburgh Sleep quality Index, Insomnia Severity Index, Self-report Behavioural Automaticity Index, Hospital Anxiety and Depression Scale and the Quality of Life in Epilepsy-31 Inventory. Objective and subjective data on sleep and behaviour were also collected.	CONSORT guidelines used Intention-to-treat analyses carried out Linear mixed models (PROCMIXED) performed SAS version 9.3 software used	Intervention deemed to be successful. QOLIE-31 scores improved in both groups but there was more significant improvement in intervention group. Intervention difference in QoL : T = 4.01; P = <0.0001 (considered to be extremely statistically significant)	Study acknowledges that the participants were not representative of the population of Iranian people living with epilepsy. Significant cultural differences between NZ and Iran. Both the intervention and the control group received education on insomnia so both groups received care that was different to usual care. Significant number of exclusion criteria (561 of 973 participants excluded based on exclusion criteria). Participants not able to be blinded to the intervention which could result in a placebo effect.
Brandalise et al.	50	I: Age 40.9 ± 10.4; 82.0% female; 64.0% married; 72.0% employed; 62.0% had high school or college education	Interictal Dysphoric Disorder Inventory, Neurological Disorders Depression Inventory for Epilepsy, Connor-Davidson Resilience Scale and the Quality of Life in Epilepsy Inventory-31	ANOVA Wilcoxon test for paired samples SPSS 24.0 statistical analysis software used	There were significant improvements in QoL and resilience scores, but the difference in QoL scores were not statistically significant. There was a positive correlation between resilience and QoL. There was a negative correlation between depressive symptoms and resilience and QoL. Intervention difference in QoL: T = 1.57; P = 0.12 (considered to not be statistically significant)	The population was very specific so cannot be generalised to all people with epilepsy Exclusion criteria were cognitive impairments affecting the ability to answer questionnaires, presence of other epileptic syndromes at the neurological investigation, and inability to attend all four weekly meetings. 45 out of 95 patients were excluded due to meeting exclusion criteria, mainly due to not being able to attend the sessions in person, this is likely to be a common barrier among people with epilepsy.
Caller et al.	66 I = 22 I+ = 22 C = 22	I & I+: Age 49.3 ± 9.2; 66% female; 31% employed; 59% had college education C: Age 41.4 ± 11.2; 65% female; 45% employed;	Quality of Life in Epilepsy Inventory-31, Patient Health Questionnaire-9, Repeatable Battery for the Assessment of Neuropsychological	SAS version 9.4 statistical analysis software used Chi-square test T-test Linear regression model	Significant improvement in overall QOLIE-31 scores in intervention groups No significant difference between the 2 intervention arms Significant improvement in	High drop-out rate. Participants reported dissatisfaction with the gaming device. Both interventions required internet access, high levels of motivation and compliance.

		55% had college education	Status, the Functional Assessment of Cancer Therapy-Cognitive scale, Behaviour Rating Inventory of Executive Function-Adult and a satisfaction survey.		cognitive performance No statistically significant change in depression scores Intervention difference in QoL: T = 2.48; P = 0.02 (considered to be statistically significant) User satisfaction survey showed that most of the participants found this telephone delivered intervention to be "useful, beneficial, and convenient" (p. 114), but there were frustrations with device and tasks related to improving cognitive function.	
Crail-Melendez et al.	23	Age 34.1 ± 8.9; 98% female; 38% married; 38% employed; 12 ± 0.80 years of education	Mini-International Neuropsychiatric Interview, the Beck Depression Inventory and the Quality of Life in Epilepsy-31 inventory.	PSS Version 13 statistical analysis software used Descriptive analysis ANOVA Paired-sample Student T for quantitative variables χ^2 tests for categorical variables	CBT had a significant positive effect on depression symptoms and QoL Intervention difference in QoL: T = 2.92; P = 0.006 (considered to be very statistically significant) A user satisfaction survey suggested that the intervention was beneficial and useful to the majority of participants	High drop-out rate.
Gandy et al.	59 I = 31 C = 28	I: Age 41 ± 12; 50% female; 65% married; 50% employed; 60% high school education C: Age 38 ± 13; 76% female; 56% married; 76% employed; 44% high school education	Hospital Anxiety Depression Scale, Neurological Depressive Disorders Inventory-Epilepsy and Quality of Life Inventory in Epilepsy-31.	IBM SPSS Statistics Software Version 2.0 T-tests χ^2 analyses ANOVA	Significant improvement in depressive symptoms No significant improvement in anxiety symptoms Greater improvement in QOLIE-31 scores in intervention group than control group, but not statistically significant Intervention difference in QoL: T = 1.11; P = 0.27 (considered to be not statistically significant)	Small sample size so underpowered High motivation needed to complete intervention Participants found work commitments, health and travel restrictions to be barriers to attending sessions High drop out rate in intervention group Extensive exclusion criteria

Gilliam et al.	140 CBT = 68 SSRI = 72	CBT: Age 39.1 ± 12.1; 60% female; 85% white; 14.1 ± 2.4 years of education SSRI: Age 40.1 ± 10.7; 50% female; 82% white; 14.3 ± 3.0 years of education	Mini-International Neuropsychiatric Interview, the Beck Depression Inventory, the Centers for the Epidemiologic Studies Depression scale, Adverse Events Profile and Quality of Life in Epilepsy Inventory-89.	Results were entered into a database and managed by a statistician Descriptive analysis	There was a statistically significant improvement in QOLIE-89 in both groups. The study showed that more than one-half of PWE and depression will experience remission of depression and improved QoL following treatment with either sertraline or CBT. There was a trend towards fewer seizures with both interventions. CBT: T = 4.42 P = <0.0001 Considered to be extremely statistically significant Sertraline: T = 5.11 P = <0.0001 Considered to be extremely statistically significant	A placebo-control group was not used as recommended by the review group based on ethical considerations so it was not possible to compare results to a control. It was not possible to blind participants and investigators, but investigators were blind to the results Employment not disclosed. Likely to be cultural differences
Hu et al.	99 I = 49 C = 50	I: Age 28.69 ± 7.29; 60% female; 69% married; 35.6% high school education C: Age 31.87 ± 9.79; 57% female; 64% married; 36.2% high school education	Quality of Life Inventory in Epilepsy-31 and Morisky Medication Adherence Scale.	SPSS 21.0 statistical analysis software used T-test U-test Chi square test Descriptive analysis	Greater improvement in QOLIE-31 scores in the intervention group Rate of accidental injuries decreased Medication adherence increased Intervention difference in QoL: T = 3.43; P = 0.0009 (considered to be extremely statistically significant)	Age and gender not representative of true epilepsy population Likely to be cultural differences Significant exclusion criteria Employment not disclosed Intervention provided by epileptologists who were not blinded so there was a risk of bias
Hum et al.	73 CBT = 29 Ed = 29 C = 15	CBT: Age 36.90 ± 2.9; 80% female; 90% Caucasian Ed: Age 37.17 ± 2.6; 63% female; 62.5% Caucasian C: Age 29 ± 2.3; 73% female; 63.6% Caucasian	Quick Inventory of Depressive Symptomatology, the Neurological Disorders Depression Inventory for Epilepsy and the World Health Organization Quality of Life questionnaire.	IBM Statistical Package for the Social Sciences software used Open-ended participant feedback coded and analysed by NVivo 11 software Descriptive analysis	QIDS, NDDIE & WHOQOL-BREF improved for both UPLIFT and EpINFO groups, but not for WLC There was an improvement in QoL but it is not possible to determine if the results were statistically significant.	Small sample size Difficult to assess whether results were statistically significant as pre- and post-treatment QoL scores not disclosed and the authors do not say if the results were statistically significant or not. Age, gender and ethnicity not an accurate representation of epilepsy population Years of education and employment not disclosed

WHOQOL-BREF change score was 6.9 ± 2.6 for UPLIFT and 5.0 ± 2.6 for EpINFO – difficult to see whether this study assesses QoL. Participants valued the opportunity to connect with other people living with epilepsy despite the intervention taking place over the telephone. Meeting other people living with epilepsy made participants feel like they weren't alone and participants felt that they could learn from other participants' experiences The behavioural intervention participants found that mindfulness-based strategies were a useful adjunct to management but some participants found it challenging to use mindfulness meditations without guided instruction Participants valued learning about the impact mindfulness-based strategies have on mood and concentration Overall, the participants found the skills and knowledge acquired useful and the social interaction with other people living with epilepsy valuable Participants felt the intervention could be improved by there being: * A greater focus on social-emotional functioning and coping * Longer sessions * More opportunity for discussion * Opportunities to stay connected with other participants	Because QoL improved in both groups, it's unclear if any intervention or if just a specific intervention is needed Qualitative data covered participant feedback on the structure and content of the groups rather than whether they felt that well-being had improved

Lai et al.	28 I = 14 C = 14	I: Age 34.1 ± 14.3; 71.4% female; 21.4% married; 50% employed; 100% high school education C: Age 36.5 ± 13.1; 50% female; 42.9% married; 64.3% employed; 92.9% high school education	Beck Anxiety Inventory, Beck Depression Inventory, the Mindfulness Attention Awareness Scale, Satisfaction with Life Scale and Quality of Life in Epilepsy Inventory-31.	Statistical Package for Social Sciences version 19 used for statistical analysis ANOVA ANCOVA Chi-square test Jacobson's Reliable Change Index	The intervention was successful in reducing psychological distress, increasing levels of mindfulness and improving quality of life. Intervention difference in QoL: T = 2.12; P = 0.05 (considered to be statistically significant)	Small sample size with large number of exclusions (767 out of 953 excluded) Self-motivation needed – only 15% of eligible participants agreed to take part Cultural differences likely High numbers of people educated to at least high school level and demographics not a true representation of epilepsy population
Leenan et al.	102 I = 52 C = 50	I: Age 40.0 ± 13.1; 46.2% female; 46.1%; 46.2% employed; 86.5% high school education C: Age 43.5 ± 14.7; 56.0% female; 56.0%; 22.0% employed; 76.0% high school education	Epilepsy Self-Efficacy Scale, Medication Event Monitoring System, Medication Adherence Rating Scale, National Hospital Seizure Severity Scale, Hospital Anxiety and Depression Scale, Quality of Life in Epilepsy-31, Utrecht Proactive Coping Competence and Side-effects of antiepileptic drugs.	IBM SPSS statistics version 24 used for statistical analysis T-tests Chi-square tests Wilcoxon rank sum tests Descriptive analysis	There were improvements in side-effects and some subscales of QoL in the intervention group Intervention difference in QoL: T = 1.07; P = 0.29 (considered to be not statistically significant) Neurologists found that participants were more confident and better prepared for consultations and consultations were more effective The app used in the intervention was not maintained and updated which meant that many of the participants experienced problems using the app	Extensive exclusion criteria Demographics not a true representation of people with epilepsy Cultural differences The app used was not maintained/updated so not all participants were able to use it
Meyer et al.	200 I = 100 C = 100	I: Age 40.53 ± 12.90; 65% female; 48% employed; 92% high school education C: Age 40.07 ± 13.40; 62% female; 49% employed; 91% high school education	Patient Health Questionnaire-9, the Neurological Disorders Depression Inventory for Epilepsy, Generalised Anxiety Disorder-7, Depression Anxiety Stress Scales-21, Work and Social Adjustment Scale, and the Quality of Life in Epilepsy-10.	ANCOVA Intention to treat protocol Per-protocol analysis T-tests Descriptive analysis	82.26% of participants were satisfied with the intervention. Meaningful improvements in depression, anxiety, stress, social-occupational impairment and illness-related QoL. Intervention difference in QoL: T = 2.39; P = 0.02	Participants were recruited from hospitals, outpatient clinics, internet forums, social media and health insurance brochures so the intervention was made accessible to a range of PWE, but participants would need to be motivated to contact the study team Participants needed to be highly motivated There was some selection bias with participants needing to be able to access internet and be able to use the programme

					(considered to be statistically significant) Most participants were satisfied with the programme Participants reported fewer sick days and fewer days spent in hospital Some participants had concerns about data protection Some participants felt pressured to undertake therapeutic exercises Some participants felt anxious about becoming too dependent on the programme	Demographics not true representation of epilepsy population Only 60 participants completed the intervention so there was a high drop out rate There was a higher drop out rate among men
Michaelis et al.	20	Age 48; 75% female	Quality of Life in Epilepsy-31, Beck Depression Inventory, Hospital Anxiety and Depression Scale, Brief Symptom Inventory.	Reliable change index T-tests MathWorks inc., version R2018b used for statistical analysis Descriptive analysis	Significant improvement in QoL, depression and global distress Intervention difference in QoL: T = -2.56; P = 0.03 (considered to be statistically significant) Participants were seen for follow up after the intervention and reported a high overall satisfaction with the intervention	Very small sample size but no drop-outs Participants needed to be motivated The enrolment strategy may have resulted in selection bias Education level and employment status not disclosed
Orjuela-Rojas et al.	15 CBT = 7 SSRI = 8	CBT: Age 33.8; 86% female; 49% married; 43% high school education SSRI: Age 43.1; 63% female; 63% married; 100% high school education	Beck Depression Inventory, Hospital Anxiety and Depression Scale, Quality of Life in Epilepsy-31, Mini-International Neuropsychiatric Interview	SPSS version 17.0 used for statistical analysis T-test Fisher's x2 test Linear regression analysis Descriptive analysis	Significant decreases in mean BDI scores in both groups Remission of depression symptoms in 57% of CBT participants and 87% of SSRI participants Improvement in severity of anxiety Statistically significant improvement in quality of life in both groups. CBT and	Very small sample size Participants needed to be motivated to attend all CBT sessions Not an accurate representation of epilepsy population Lack of randomisation and control affects validity

					SSRI had similar effects CBT final QOLIE-31 score - 59.6 (improved by 17.25 points ± 20.5) SSRI final QOLIE-31 score - 56.4 (improved by 11.26 points ± 3.98)	
Paarde-koop et al.	20 I = 11 C = 9	I: Age 39.18 ± 10.87; 82% female; 13.22 ± 3.11 years of education C: Age 47.44 ± 12.19; 78% female; 12.00 ± 2.96 years of education	Pittsburgh Sleep Quality Index, Epworth Sleepiness Scale, Quality of Life in Epilepsy-31, Neurological Disorders Depression Inventory for Epilepsy, Dysfunctional Beliefs and Attitudes about Sleep Scale-16 and Sleep Hygiene Index.	Kolmogorov-Smirnov tests T-tests ANOVA Linear regressions Descriptive data	The intervention did not affect participants' sleep but did improve QoL. This was not statistically significant. Overall finding was that sleeping patterns can predict QoL with worse sleep associated with poorer QoL Intervention difference in QoL: T = 0.98; P = 0.33 (considered to be not statistically significant)	Small sample size Researchers were not blinded Motivation required to participate in intervention Improvements occurred in control and intervention groups suggesting that sleep monitoring alone affects sleep quality and QoL Cultural differences between Australia and New Zealand Demographics not a true representation of epilepsy population
Pakpour et al.	275 I = 137 C = 138	I: Age 41.37 ± 16.25; 32.8% female; 43.1% married; 27.7% employed; 7.03 ± 4.19 years of education C: Age 39.86 ± 15.01; 35.5% female; 47.8% married; 31.2% employed; 7.12 ± 3.81 years of education	Beliefs about Medications Questionnaire, Liverpool Seizure Severity Scale, Medication Adherence Report Scale, Quality of Life in Epilepsy-31, Liverpool Seizure Severity Scale and Self-Report Behavioural Automaticity Index.	Linear mixed models (PROCMIXED) Descriptive statistics	Intervention resulted in better medication adherence, higher levels of action planning, coping planning and self-monitoring. It was felt that the intervention improved relationships between participants and their physicians. It was felt that family/ significant other involvement was beneficial Intervention difference in QoL: T = 3.77; P = 0.0002 (considered to be extremely statistically significant)	Demographics quite different to other studies Male health psychologist in Iran which may have affected female participation People were excluded if there was major cognitive impairment or intellectual disability

Schroder et al.	78 I = 38 C = 40	I: Age 35.03 ± 9.99; 71% female; 58% high school education; C: Age 40.03 ± 11.85; 80% female; 58% high school education	Quality of Life in Epilepsy-31, Beck Depression Inventory, World Health Organization Quality of Life questionnaire and participant retrospective appraisal. Subjective appraisal	Intention to treat analyses Descriptive statistics	Improvement in depression symptoms in intervention group Most participants satisfied with the intervention and found it suitable for depressive symptoms in epilepsy. Most would have preferred the intervention as an adjunct to treatment rather than a substitute for psychotherapy. There was no significant group difference with QO-LIE-31 scores Intervention difference in QoL: T = 1.99; P = 0.05 (considered to be not quite statistically significant)	Small sample size with high drop out rate The recruitment process was slow which may have indicated a lack of interest in either online trials or the intervention Motivation required for intervention and intervention more likely to attract motivated participants