

The impact of brief lifestyle self-management education for the control of seizures

Karen-leigh Edward, Mark Cook, John Stephenson and Jo-Ann Giandinoto

ABSTRACT

Aim: this study examined a brief lifestyle self-management intervention, based on self-determination theory, to manage seizure frequency, and its effects on health-related quality of life and resilience in people with epilepsy aged over 18 years. **Background:** most people with epilepsy can identify factors that may trigger seizures and may try to avoid these; however, education from clinicians on this varies. **Design:** a cohort study with control design. **Method:** sixty participants were purposively sampled and allocated to an intervention or a control group. **Results:** moderate correlations were found, particularly between: resilience and satisfaction with life; medication adherence and psychological quality of life; and psychological quality of life and satisfaction with life. The mean seizure occurrences between the control and intervention groups were 12.71 (SD 24.55) and 6.76 (SD 13.40) respectively after the intervention. While the study was not powered to assess this, the intervention may be most effective regarding medication adherence and physical health quality of life. **Conclusion:** the relationship between self-efficacy and seizure management appeared to be strengthened by the programme. This study is the first known to measure resilience in relation to lifestyle self-management for seizure control in people with epilepsy. **Relevance to practice:** nurses are well placed to work with patients' strengths towards self-efficacy and potentially resilient coping.

Key words: Epilepsy ■ Self-management ■ Resilience ■ Psychological adaptation ■ Quality of life ■ Seizure control

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Epilepsy—the occurrence of two unprovoked epileptic seizures—affects more than 60 million people each year worldwide (Ngugi et al, 2011). Epilepsy is a long-term condition, and living with a chronic condition is an individual experience, with some people reporting a high sense of self-efficacy and having some sense of control over their symptoms while others do not (DiIorio et al, 2006).

As seizures can be triggered by several factors, seizure management can be extended beyond the limitations assumed for a physical, neurological disorder to encompass control by psychosocial methods (Lundgren et al, 2008). We hypothesised that educational programmes to inform people with epilepsy about behavioural self-management strategies may significantly benefit them and should form part of a comprehensive epilepsy treatment plan.

Background

Self-management is understood to be the ability to manage one's health status by using problem solving, resource utilisation, resilience and an ability to take action on one's behalf (Lorig and Holman, 2003). In addition, good lifestyle management has been found to improve seizure control significantly, where lifestyle interventions can improve seizure control in almost 43% of patients, a figure comparable to the introduction of new pharmacological agents (Kobau and DiIorio, 2003).

Furthermore, the majority of people with epilepsy can identify some factors that may trigger seizures, resulting in attempts to reduce seizure frequency by avoiding recognised precipitating factors (Spector et al, 2000). Despite this, patients are not generally assisted to identify their specific triggers for seizures and deploy non-pharmacological strategies to improve seizure control (Aliasgharpour et al, 2013; Kralj-Hans et al, 2014).

Moreover, research identifies disparities between practitioner and patient perspectives regarding programme emphasis (goal-setting, coping skills or educational objectives), in addition to differences in problem severity ratings (Johnson et al, 2012).

A recent systematic review noted that education programmes

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can improve self-management strategies so may boost health-related quality of life (HRQoL) in people with epilepsy (Edward et al, 2015). Edward et al (2015) also highlight that what the educational information covers and its delivery mode should be carefully considered, supporting the findings of Fraser et al (2011).

Aim and objectives

The aim of this study was to develop, deliver and evaluate the impact of a brief education intervention regarding lifestyle self-management in the control of seizures that was informed by theory (ie self-determination theory was used to build the intervention, undertaken by the three expertly qualified members of the research team) and peer reviewed (ie the intervention was reviewed by experts in the field of neurology).

The objectives of the study were to:

- Provide pilot data regarding the impact of a brief lifestyle self-management intervention on seizure frequency
- Evaluate satisfaction with life, resilience and HRQoL for people with epilepsy who undertake the intervention
- Inform clinical research for further inquiry in care practices.

Methods

Intervention

Self-Management and Lifestyle Education for Adults Living with Epilepsy was a theory-informed, evidence-based and peer-reviewed education package developed specifically for the purpose of this study.

Self-determination theory (SDT) was used as the theoretical framework for this educational package (Ryan and Deci, 2000; Deci and Ryan, 2010). The concept of this framework includes three constructs: perceived competence, autonomous motivation and controlled motivation. SDT is centred on supporting people's natural tendencies to behave in ways that promote and maintain their health.

The first key construct, perceived competence, refers to self-belief in one's own ability to perform. The education package comprised behavioural approaches to enhance this aspect by placing an emphasis on positive reinforcement and specific skill feedback during the programme.

Autonomous motivation, the second construct, relates to behaviour that is directed by an individual's freedom of choice. Therefore, autonomy is high when people feel they are engaging in activities of their own choosing. Autonomy was boosted by offering participants choice over topic content and by promoting self-identification of successful actions they had previously used.

The remaining component of SDT, controlled motivation, arises when a sense of 'feeling under pressure' from internal or external sources influences an individual's behaviour. A supportive environment characterised by a non-pressurised approach and informational feedback is congruent with SDT.

Hence the education session was interactive and took a problem-solving approach that facilitated learning and solution generation sourced and directed by the participants.

People with epilepsy prefer an individualised approach to self-management education (Wedlund et al, 2013) and, while this point may not differ vastly from clinicians' perspectives, the content of education packages can vary.

Considering the available evidence, the education package for this study was developed as one 120-minute session, scheduled during a weekday and delivered face to face. A booklet of the programme's content was given to each participant for their later review and reflection.

The education package was divided into four education modules: Managing Epilepsy and Medical Care; Socialising on a Budget; Leading a Healthy Lifestyle; and Emotional Self-Management. Including these topics addresses some key triggers that can bring on a seizure in people with epilepsy. For example, common triggers include poor medication adherence (addressed by the Managing Epilepsy and Medical Care module), stress (stress management strategies are included in Emotional Self-Management), and a lack of sleep and alcohol (these triggers are covered in Leading a Healthy Lifestyle).

The education intervention facilitators were clinical nurse specialists in neurosciences, who were trained by a research team member qualified in SDT and training in the module content, and had received instructions on how to conduct sessions.

Study design and sample

A cohort with control study design was adopted. Participants were allocated to either of the two groups in a 1:1 manner unless they could not attend the face-to-face session for geographical or personal reasons and were allocated to the control group.

As the study was developed to investigate the potential for enhanced self-management of epilepsy, only adults (>18 years) who had been diagnosed with epilepsy were eligible.

People with a history of seizures from causes other than epilepsy, such as acute trauma, were not included in this study unless the comorbidity existed in addition to a diagnosis of epilepsy. Furthermore, as documents were available only in English, people with limited English comprehension were excluded as well as any those who were unable to give informed consent.

Recruitment and group allocation

The participating sites were two large hospitals in Melbourne, Australia, one public and one private. Participants ($n=60$) meeting the inclusion criteria were recruited through the neurology wards and consulting clinics of neurologists in 2015. The participants were approached by a member of the research team, given information about the study and included once they had given written consent.

Once the 60 participants had been recruited, they were recontacted and allocated to the intervention or control group. Random allocation to groups was used; however, if a participant was unable to attend the intervention face-to-face session, they were placed into the control group by the researcher responsible for participant group allocation.

Ethical considerations

Ethical approval was sought and obtained from the hospital and university human research ethics committees.

Power calculations

No power calculations were undertaken for this study as it was a pilot.

Table 1. Participant demographics (all participants; n=60)					
Characteristic	Category	Control group: frequency/percentage (total n=37)		Intervention group: frequency/percentage (total n=23)	
Sex	Male	22	59.5%	9	39.1%
	Female	15	40.5%	14	60.9%
Age	18–24	4	10.8%	3	13.0%
	25–34	11	29.7%	8	34.8%
	35–44	7	18.9%	6	26.1%
	45–54	7	18.9%	2	8.7%
	55–64	7	18.9%	3	13.0%
	Over 64	1	2.7%	1	4.3%
	Average (years)	40.2 (SD 12.6)		39.9 (SD 15.1)	
Diagnosis duration	<6 months	0	0%	1	4.3%
	6–12 months	3	8.1%	2	8.7%
	1–5 years	3	8.1%	3	13.0%
	5–10 years	4	10.8%	4	17.4%
	>10 years	27	73.0%	13	56.5%
Distance from city	<25 km	19	51.4%	13	56.5%
	25–50 km	5	13.5%	4	17.4%
	50–100 km	1	2.7%	2	8.7%
	>100 km	12	32.4%	4	17.4%
Victorian Epilepsy Foundation education session (past 3 months)	Yes	1	2.7%	0	0%
	No	36	97.3%	23	100%

Data collection

To evaluate the frequency of seizures, all participants were asked to keep a seizure diary for the duration of the study.

Psychological morbidity and HRQoL were examined using the SF-12 health survey at each time point. The SF-12 provides a summary measure of health status after combining the physical health score (PCS) and mental health score (MCS) (Ware et al, 1998).

Subjective wellbeing was measured using the Satisfaction with Life Scale (SWLS) (Diener et al, 1985), a short five-item instrument. The scale has shown strong internal reliability with a coefficient alpha of 0.87 and test-retest stability coefficient of 0.82.

The Connor–Davidson resilience scale (CD-RISC) was used to measure resilience (Connor and Davidson, 2003). It has been tested in the general population as well as in clinical samples, and demonstrates excellent psychometric properties, with good internal consistency and test-retest reliability.

Adherence to medication was measured using the Morisky Medication Adherence Scale (MMAS-8) (Morisky et al, 1986). This eight-item self-report tool for monitoring adherence comprises items to identify both unintentional and intentional behaviour relating to medications.

Participants were surveyed at the time of recruitment to provide baseline data (time point 1 was at recruitment). The survey was readministered to all participants after the education had been provided to the intervention group (time point 2 was 6 months after the intervention). While the baseline data were collected in person, follow-up data were collected verbally by telephone or completed on a web-based survey platform depending on participant preference.

Data analysis

Descriptive statistics on demographics were collected on all participants, and summaries provided for the entire cohort and those who completed both the before and after surveys on which inferential analysis was based. Primary inferential analysis is based on changes in measured outcomes before and after the test.

Mean change scores were compared using repeated measures analysis of variance (ANOVA), controlling for variation in demographic and health variables, which was included in the model as between-groups effects. Data were assessed for suitability of a multivariate analysis. The level of significance for all statistical tests performed was 0.05. The software package used was SPSS Statistics for Windows, version 22.0.

Table 2. Participant demographics (participants completing both surveys; n=35)

Characteristic	Category	Control group: frequency/percentage (total n=18)		Intervention group: frequency/percentage (total n=17)	
Sex	Male	11	61.1%	6	35.3%
	Female	7	38.9%	11	64.7%
Age	18–24	1	5.6%	2	11.8%
	25–34	5	27.8%	5	29.4%
	35–44	4	22.2%	5	29.4%
	45–54	4	22.2%	1	5.9%
	55–64	3	16.7%	4	23.5%
	Over 64	1	5.6%	0	0%
	Average (years)	42.7 (SD 13.0)		39.8 (SD 13.6)	
Diagnosis duration	<6 months	0	0%	1	5.9%
	6–12 months	2	11.1%	1	5.9%
	1–5 years	2	11.1%	2	11.8%
	5–10 years	2	11.1%	3	17.6%
	>10 years	12	66.7%	10	58.2%
Distance from city	<25 km	10	55.6%	11	64.7%
	25–50 km	3	16.7%	1	5.9%
	50–100 km	1	5.6%	1	5.9%
	>100 km	4	22.2%	4	17.4%
Victorian Epilepsy Foundation education session (past 3 months)	Yes	1	5.6%	0	0%
	No	17	94.4%	17	100%

Findings

Sixty participants were analysed at time point 1 (37 people in the control and 23 in the intervention group) (*Table 1*). Thirty-five participants were analysed at time point 2 (18 in the control and 17 in the intervention group) (*Table 2*). Little's MCAR test showed no evidence that data was not missing at random ($\chi^2_{(20)}=14.4$; $P=0.809$) so attrition bias was not expected.

Groups were well matched at baseline on all outcome measures, indicating the effectiveness of the group allocation procedures used, despite the small size of the sample.

The authors wished to evaluate satisfaction with life, resilience and HRQoL, and found some outcome measures were moderately correlated at time point 2, particularly resilience (CD-RISC) and satisfaction with life (SWLS) ($r=0.551$; $P=0.001$), MMAS-8 and MCS ($r=-0.546$; $P=0.001$), and MCS and SWLS ($r=0.518$; $P=0.001$). This suggests a multivariate approach might be appropriate for the main study.

Analyses of covariances were conducted on each of the outcomes, measured at time point 2, using groups as the controlling variable and controlling for baseline values recorded at time point 1. The actual results obtained suggest that the intervention may be most effective with respect to medication

adherence and physical health quality of life; they were ($P=0.376$ for medication adherence (MMAS-8); $P=0.129$ for physical health quality of life score (PCS); $P=0.487$ for the mental health quality of life score (MCS); $P=0.773$ for resilience (CD-RISC); and $P=0.826$ for satisfaction with life (SWLS).

The fit of all models was adequate and, in some cases, very good. The adjusted R^2 statistics ranged from 0.689 for the CD-RISC measure to 0.279 for the MCS measure. Residual plots were derived for each of the analyses, with standardised residuals being plotted against standardised predicted values in each case. No evidence was found for violation of regression assumptions (normality of residuals, homogeneity of variance, linearity) in any case. Standardised residuals and Cook's distances were evaluated for all data points in all models. Standardised residuals were within expectations for all models. Cook's distance revealed that no data point in any model exerted undue influence on the model. The mean seizure occurrences between the control and intervention groups were 12.71 (SD 24.55) and 6.76 (SD 13.40) respectively after the intervention at time point 2.

Parameters from inferential analyses conducted on all outcome measures are summarised in *Table 3*.

Table 3. Summary of parameters from inferential analyses conducted on all outcome measures (participants completing both surveys; $n=35$)

Variable	Time point	Control group (mean (SD))	Intervention group (mean (SD))	Difference in mean change scores (95% CI)	P value from ANCOVA model	Adjusted R ² value from ANCOVA model
MMAS-8	Baseline	2.05 (1.45)	1.65 (1.80)	−0.388 (−1.27, 0.493)	0.376	0.506
	After the intervention	1.72 (1.99)	1.76 (1.64)			
SF12-PCS	Baseline	52.6 (11.6)	48.9 (13.3)	−4.60 (−10.6, 1.42)	0.129	0.372
	After the intervention	47.8 (11.8)	52.1 (8.82)			
SF12-MCS	Baseline	41.0 (11.6)	42.0 (12.7)	−1.97 (−7.67, 3.74)	0.279	0.487
	After the intervention	46.8 (10.6)	47.3 (8.65)			
CD-RISC	Baseline	71.6 (15.1)	69.2 (14.0)	−0.79 (−6.32, 4.74)	0.773	0.689
	After the intervention	73.3 (16.0)	69.9 (12.1)			
SWLS	Baseline	22.6 (9.11)	25.3 (6.81)	0.527 (−4.32, 5.38)	0.826	0.131
	After the intervention	25.3 (7.44)	24.4 (7.83)			

MMAS-8: Morisky Medication Adherence Scale; SF12-PCS: SF-12 Health Survey physical health score; SF12-MCS: SF-12 Health Survey mental health score; CD-RISC: Connor-Davidson Resilience Scale; SWLS: Satisfaction With Life Scale

Discussion

This study's objectives were to evaluate satisfaction with life, resilience and HRQoL in people with epilepsy who have undertaken a brief, theory-informed lifestyle self-management education package for the management of seizure triggers.

Lifestyle self-management education may offer a means to fortify behavioural strategies that predict seizure initiation related to psychosocial triggers. In this study, the relationship between self-efficacy and seizure management appeared to be promoted by the brief educational programme offered.

The findings revealed moderate correlations between specific outcome measures when data was collected after the intervention (time point 2). For example, having a sense of wellbeing and satisfaction with life was associated with two other measures—resilience and QoL.

Importantly, the study results showed that QoL was significantly related to medication adherence.

Satisfaction with life and quality of life

Unsurprisingly, the relationship between QoL and satisfaction with life was apparent in this study. If poor QoL was experienced by participants, then a corresponding low level of general wellbeing and satisfaction was probable. This correlation does not determine causation. An equally valid observation is that the reverse direction is viable, that is, low levels of wellbeing and satisfaction may contribute to poor mental health and lower the QoL experienced.

Mental health quality of life and medication adherence

An important association pertains to the correlation between mental health quality of life and successful adherence to medication regimens.

Participants who had lower ratings for mental health were more likely to report poorer adherence to their prescribed medication schedules and, correspondingly, those with higher mental health scores were better at medication adherence.

Unsolicited responses from participants at time point 2 demonstrated investment in strategies that supported medication adherence. Several reported the use of automatic reminders on mobile devices, while others commented that their medication was 'the first thing I pack' when they had travel plans.

People with epilepsy often have a long-term need for pharmacological treatment and adverse effects are common (Beretta et al, 2014). Inclusion of information on self-management strategies related to medication adherence, including understanding and coping with adverse drug effects, may further assist in reducing unnecessary hospital admissions and health-related costs (Kralj-Hans et al, 2014).

People with epilepsy often experience significant mental health problems related to the management of their condition, including disorders such as depression and anxiety (Velissaris et al, 2012). While significant developments have been made in relation to the medical management of epilepsy, the same attention has not been given to managing the psychosocial aspects of the condition (de Boer et al, 2008).

The lifestyle self-management brief education in our study covered a number of key lifestyle topics that contribute to seizure triggers for many people with epilepsy, for example antiepileptic drugs, employment concerns, maintaining relationships, stigmatisation including self-stigma, and coping with a long-term condition. These important issues in the lives of people with epilepsy are not routinely discussed with their medical care team, as a standard approach to care and information provided often depends on practitioner knowledge and expertise rather than being routine practice.

Resilience/psychological adaptation

Participants who scored strongly on items relating to life satisfaction were also found to have high ratings for resilience. Resilience refers to the ability of an individual to thrive in adverse circumstances and is pivotal to successful adaptation to change, such as that required for long-term conditions (Connor



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and Davidson, 2003; Edward and Warelow, 2005).

An outlook on life that is characterised by optimism and self-confidence regarding one's own capabilities to adapt or cope with adverse situations has been studied in people with mental illness; those who have active and adaptable coping styles were more likely to achieve success with self-management in the presence of long-term conditions (Edward et al, 2009).

The lifestyle self-management education aimed to present information to participants that allowed them to freely reflect upon the successful coping mechanisms they had used in the past. Participants also explored practical strategies they could use to overcome some of the day-to-day burdens of living with epilepsy. While the results of this study cannot demonstrate that the intervention had any positive effects on participants' resilience, the results warrant further examination.

Seizure control

Medication adherence is a fundamental to controlling seizures, despite the sometimes-limited efficacy of pharmacological seizure control in some people.

Success in adjusting to epilepsy may be reliant upon self-management capabilities. Although not statistically significant, this study showed a reduction in seizure frequency within the intervention group, which may be substantiated in a study with a larger sample size than that used in this pilot.

Limitations

There are some limitations to take into account when considering the results of this study. The sample size does not allow generalisability; however, the findings do suggest a larger scale study is warranted.

The study was conducted at two hospitals that have the same national governance board, which further limits the potential for generalisability with regards to organisational-specific practices. However, the participating services do attract a diverse variety of patients across sociodemographic domains.

Practice implications

In a systematic review (Edward et al, 2015), only one study was found to explore the notion of resilience as a predictive factor for vulnerability in people with epilepsy. Given this, a knowledge gap in the evidence base remains.

Finally, rather than a dependence solely on pharmacological management for the treatment of epilepsy, educative interventions underpinned by SDT that are brief and easy for people to understand and engage with may well be the standard discharge from hospital information or information booklet offered by primary healthcare providers for patients.

Conclusion

This study is the first known to measure resilience in relation to lifestyle self-management for the control of seizures in people

KEY POINTS

- The majority of people with epilepsy know certain factors may trigger seizures but are not generally assisted to identify these and use non-pharmacological strategies to improve seizure control
- Those who had lower ratings for mental health were more likely to report poorer adherence to medication
- Quality of life was significantly related to medication adherence and improved self-management skills
- Those who scored strongly on items relating to life satisfaction were found to have high ratings for resilience
- Seizures were less frequent in the intervention group in this study

with epilepsy. The brief educational material offered to the intervention group correlated with improvements in resilience, satisfaction with life, medication adherence and mental health. This point is important as stress associated with daily living can trigger seizures.

This study provides a platform from which a full-scale study may be undertaken; such follow-up research should be suitably powered by a sufficient sample size to examine effect sizes. Although no statistically significant effects were identified in this study, the correlations between outcome measures and trends noted in seizure control across groups deserves further investigation to verify the effects noted in this paper.

Relevance to clinical practice

The chronic nature of epilepsy requires the long-term use of healthcare services for people living with the condition. Nurses are well placed in healthcare to work with patients' strengths towards self-efficacy and potentially resilient coping.

There is a need to introduce processes that facilitate working with patients' strengths towards resilient coping to help them better self-manage their seizures, potentially reducing reliance on the healthcare system. **BJN**

Declaration of interest: none

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CPD reflective questions

- What can nurses do in routine practice to extend care interventions beyond solitary dependence on pharmaceutical management for the treatment of epilepsy?
- How can healthcare organisations ensure people with epilepsy have lifestyle self-management skills to assist in controlling their seizures?
- How can nurses and other healthcare professionals ensure they work with people's strengths within standard care?