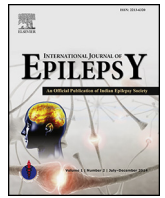




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Research paper

Does being 'well off' help people with epilepsy cope better? The social impact of epilepsy

Christine Walker^{a,b}, Chris L. Peterson^{b,c,*}^a Chronic Illness Alliance Victoria, Australia^b Epilepsy Foundation, Surry Hills, Victoria, Australia^c School of Humanities and Social Sciences, College of the Arts, Social Science and Commerce, Plenty Rd, Bundoora, La Trobe University, Bundoora, Australia

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ABSTRACT

Introduction: Studies demonstrate that there is a positive association between socioeconomic status (SES) and personal control where higher SES groups are likely to have higher personal control and better health outcomes. People with epilepsy however usually show lower levels of personal control. This paper aims to explore the relationship between self-rated prosperity and personal control in an epilepsy sample.

Methods: Using the results of the 2013 Australian Epilepsy Longitudinal Survey (AELS) a group was identified who perceived themselves as prosperous or very comfortable. Hypothesising that prosperity would provide greater personal control, we compared this group with other groups from HILDA Wave 11, a random sample of the Australian population surveyed in 2011. HILDA is a household, labour and income study funded by the Australian government.

Results: All respondents in Wave 3 (AELS) had lower levels of personal control than the HILDA Wave 11 groups. In a comparison between Wave 3 of those reporting themselves as prosperous or very comfortable with similar groups in HILDA Wave 11, prosperous people from Wave 3 demonstrated much lower levels of personal control than the HILDA Wave 11 group.

Conclusion: Personal control is considered to have far-reaching consequences for people's health. The effects of stigma and the unpredictability of epilepsy far outweigh the effects of prosperity for people with epilepsy compared to a random sample of the Australian population.

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1. Introduction

Evidence exists that beliefs in personal control are linked to better health outcomes, both psychological and physical.^{1–3} Evidence also exists that there is an association between socioeconomic status (SES) and personal control in relation to health and well-being.^{4–5} Peterson and Stunkard⁶ argued that personal control is based around the beliefs persons have about how they might achieve positive outcomes and avoid negative events. Pearlin and Schooler⁷ have also linked personal control and its effects on stress and consequent health. Other concepts are associated with personal control and sometimes used

interchangeably: self-efficacy, powerlessness, learned helplessness and mastery.^{8,9}

A number of factors influence the extent to which a person considers him/herself as having control over their own lives.¹⁰ These include educational level, occupation, income and social position.^{11,12} These are also the domains that comprise SES which may be defined as differential access to scarce resources including health¹³ and thus there are studies that show there is a positive association between SES and perceptions of personal control.^{4,14,15}

This association has implications for health, in terms of self-rated health, health outcomes^{4,5} and health maintenance or self-management.¹⁶ Some studies have demonstrated a strong relationship between higher SES and better health outcomes. For example Ferrie¹⁷ reports that Marmot's civil service study found that higher SES was linked with lower incidence of coronary heart disease (CHD), while Goldman and Smith¹⁸ demonstrate that higher SES is related to better health maintenance in both diabetes and HIV. However with some conjecture on the link between wealth and personal control for epilepsy McLaughlan et al.¹⁹ have

* Corresponding author at: School of Humanities and Social Sciences, College of the Arts, Social Science and Commerce, Plenty Rd, Bundoora, La Trobe University, Bundoora, Australia.

E-mail addresses: cwalker@chronicillness.org.au (C. Walker), c.peterson@latrobe.edu.au (C.L. Peterson).

argued that previous research into personal control in epilepsy has been particularly limiting and the results conflicting.

Hermann and Jacoby²⁰ have argued that the experience of dealing with epilepsy may affect people's worldviews and locus of control. They cite studies which have shown a lower sense of personal control amongst epilepsy populations compared to other medical conditions and the general population. Children with epilepsy have been shown to have poorer sense of control compared to those with diabetes and children with orthopaedic conditions.

In this article the study presents data on SES in the epilepsy sample and then analyses the relationship between self-perceived prosperity and personal control. The study investigates that the association between SES and personal control observed in other populations such as people with insulin-dependent diabetes¹⁸ will be similar to that between self-perceived prosperity and personal control for people with epilepsy. It also examines the extent to which seizure frequency and stigma affect personal control. The study examines the relationship between self-perceived wealth and personal control for the sample of people with epilepsy and compares it with an Australian random sample from the HILDA study (HILDA All), and from part of the HILDA sample, being people with a long term health conditions, disability or impairments.

2. Methods

Data on the social impact of epilepsy are collected by survey from the Australian Epilepsy Research Register for all Waves of the Australian Epilepsy Longitudinal Study. It is a community sample of people with epilepsy. Of the 883 participants eligible to participate in the 2013 Wave 3 of AELS, 324 (36.7%) responded. Inclusion criteria were having a diagnosis of epilepsy and being on the AELS register. Data have been collected over three Waves, in 2006, 2010 and in 2013, and in Wave 3 by paper survey and online. Wave 3 collected data on finances and social effects of having epilepsy.

The Wave 3 tool used validated questions to collect data on education, income and employment to compare responses to other longitudinal studies representing the Australian population, such as the Household, Income and Labour Dynamics in Australia Survey (HILDA). Wave 11 of HILDA was chosen as it is the most recent time (2011) that personal control data were collected (sample size 17,612). It is a random sample of the Australian population; a panel study that commenced in 2001 and inclusion criteria was all persons residing in private dwellings. Each Wave of the HILDA study is carried out approximately each year, with a different mix of questions for each wave. Those people with epilepsy and their families who perceive themselves as "well off" have been compared with the whole population in Wave 11 of the HILDA study as well as with a subset of Wave 11, a smaller sample from the same Wave of those only those with a long term health conditions, disability or impairments (adequate sample size 4133). Inclusion criteria were having a long term health condition such as a chronic illness or a disability. In the HILDA study data are collected by interview and self-completed questionnaire. The Wave 3 of AELS contained a version of Pearlin's Sense of Control scale and the Prosperity scale.

Note: The HILDA project was initiated and is funded by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and is managed by the Melbourne Institute of Applied Economic and Social Research (Melbourne Institute). The findings and views reported in this report, however, are those of the authors and should not be attributed to either FaHCSIA or the Melbourne Institute. These data are derived from Wave 11 (2011) of the HILDA survey.

Pearlin's Sense of Personal Control scale has seven questions. These refer to the extent to which a person has an internal locus of control, or mastery over events.⁷ Edwards et al.,²¹ report that the Pearlin scale is sound psychometrically, has good reliability and that it has convergent validity in a range of different populations. The scale has also been used extensively in Waves of the HILDA study in Australia. Internal reliability has been found in a Canadian population (Cronbach's alpha .76). In validity, low levels of control have been associated with poor mental and general health and with depression.²² A Cronbach alpha of .82 and an inter-item correlation of .40 for the 7 item univariate scale were reported in this study. As a univariate scale it has all seven questions in the one scale.

While recognising that the measurement of socioeconomic status has its challenges¹³ data on education, employment status and income was used to discuss the epilepsy sample. Education is regarded as a reliable measure on its own as it gives access to employment and income.²³ The study has combined this measure with employment status and income to provide a background to the prosperity of the sample.

Oakes and Rossi¹³ suggest that SES measurement aims at capturing 'how levels of inequality and variations in social context affect health outcomes'. They suggest that this requires more of the social context than just the data from these measures. On this basis the study has presented data on family income in the context of the Australian economic and welfare climate. The epilepsy sample has a lower than average family income and as such are more than the average likely to be recipients of government benefits. This may affect their experience of health and illness by limiting access to resources.

In this study a six item scale is used for a self-assessment of Prosperity to gauge the extent to which they perceive themselves as prosperous or poor. Respondents are asked 'given your current needs and financial responsibilities would you say that you and your family are' ... followed by six response categories from very poor to prosperous.

A scale of nine items was derived from Austin et al.,²⁴ for the stigma scale used in this study and has been previously discussed in a paper on the previous Wave 2 of the AELS.²⁵

Further, a subset of ten people from Wave 3 (epilepsy) who had high prosperity and levels of control that were as low as those 'just getting along' or even 'poor' was also analysed in order to understand more about this group of people with epilepsy. This is reported on at the end of the results section.

2.1. Data analysis

Frequencies and cross tabulations were used in order to gauge characteristics of all variables used in the study, and to identify key associations between prosperity and personal control. Oneway ANOVA have been used to identify and compare the three samples (Wave 3 (AELS), HILDA Wave 11 ALL and HILDA Wave 11 long term health conditions, disability or impairments) on levels of self-perceived prosperity in relation to level of personal control. The study has also used block recursive regression analysis to identify major determinants of personal control. This approach estimates total effects of all variables, which include direct and indirect effects through mediating variables.

The analysis was undertaken using the statistical package IBM Corp Released 2013 SPSS Statistics for Windows Version 22.0.

3. Results

Responses were received from three hundred and twenty four persons (or 36.7% of active registrants). Of these: 242 (76.6%) were people with epilepsy; 74 (23.4%) were people who completed the

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