General Poster 04

Epilepsy Deaths Register: Awareness of epilepsy-death and post-death support

Ben Donovan[1], Jane Hanna[2], Tracy Cowdry[3], Rhys Thomas[4], Mike Kerr[5], Elaine Hughes[6]

1:SUDEP Action; 2:Royal Victoria Infirmary, Newcastle-upon-Tyne; 3:Institute of Neuroscience, Newcastle University; 4:Psychological Medicine and Clinical Neurosciences, Cardiff University; 5:Evelina London Children's Hospital; King's College Hospital NHS Foundation Trust

Introduction: In 2002, a qualitative study conducted alongside the National Sentinel Clinical Audit of Epilepsy-Related Death found that just 5% of bereaved relatives were informed of the risk of sudden epilepsy-related death beforehand.

The impact of sudden epilepsy death extends beyond the person who died and bereavement by epilepsy related death can be traumatic and result in a need for long term management of mental health conditions. Despite this, research has shown that many relatives of people with epilepsy are not aware of known risk factors and risk-minimisation measures until after a death. The Epilepsy Deaths Register (EDR) provides data by which experiences of people bereaved by epilepsy-related death change over time.

Method: The Epilepsy Deaths Register has collected over 600 death registrations from the UK since 2013, with the deaths dating from 1976 to 2020. The online questionnaire contains over 70 questions about the experiences of bereaved friends and relatives both prior to and after an epilepsy-related death. For this research, responses for unique death registrations were split into five comparison groups based on date of death.

Results: For deaths prior to January 2001, 60% of respondents reported that, before the death, they did not know that people could die from epilepsy. For each of the four comparison groups since then, the percentage gradually, and consistently, decreased to the lowest figure of 37% of respondents not knowing before deaths in the most recent category (January 2016 to August 2020).

For all comparison groups, the percentage of respondents who reported having circumstances of their loved one's death explained to them remained relatively unchanged (63-63%) and the percentage of respondents who reported that they had been invited to talk about the death with someone afterwards decreased from 46% in the earliest date-of-death group to just 27% in the most recent date-of-death group.

Conclusion: Despite considerable improvements in awareness-raising of risks associated with epilepsy deaths to relatives, too many families are left uninformed until it is too late. Furthermore, after a death, relatives of those who died are being left with unanswered questions about the death and without someone to talk to. The importance of clinical teams communicating about epilepsy risks to relatives of people with epilepsy is fundamental to promoting risk-conscious environments at home. Clinical teams being notified of a death and proactively contacting the bereaved family, providing signposting to specialist bereavement support, should be routine. Promotion and use of the EDR will help with these system failures.

ben.donovan@sudep.org