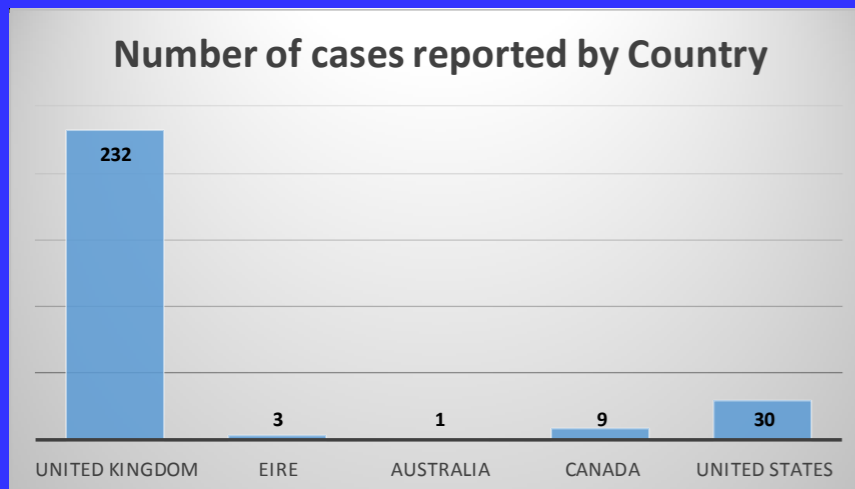


Background

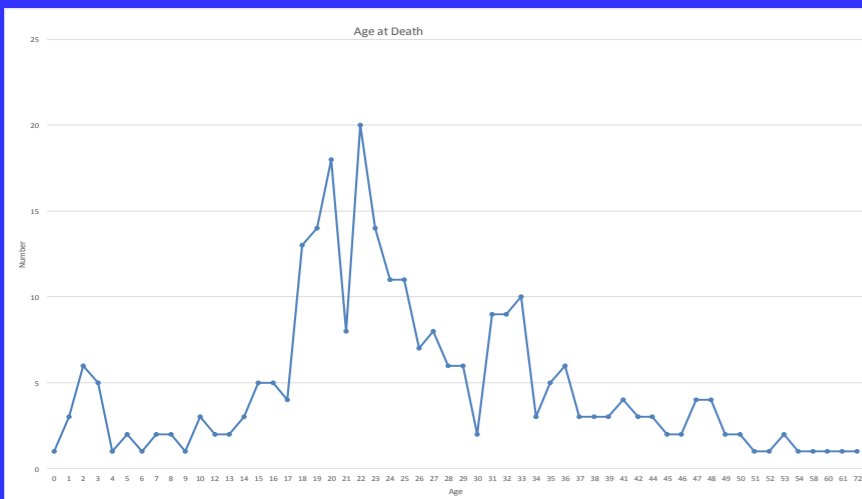
An on-line Epilepsy Deaths Register (EDR) was set up by SUDEP Action (UK) in March 2013 to gather information about SUDEP which can be used to help reduce epilepsy related deaths and to improve public awareness of Sudden Unexpected Death in Epilepsy (SUDEP). The EDR has been designed to enable family, friends or professionals to report a death. Demographic and descriptive data, including free text comments, of the circumstances leading to death, is collected to build a complete picture of the lifestyle and choices made by the person who died.

Results

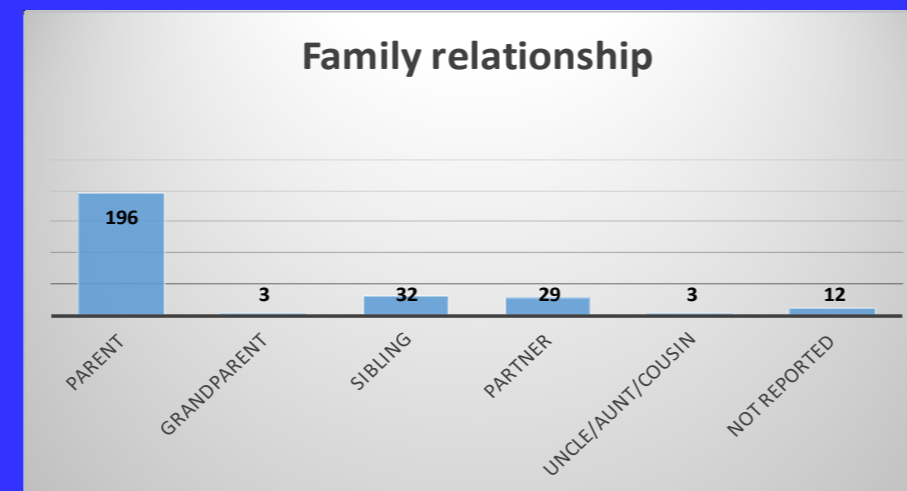
275 cases were reported from 5 countries between March 2013-February 2014. The majority of cases reported are from the UK, with 15% of cases from North America.



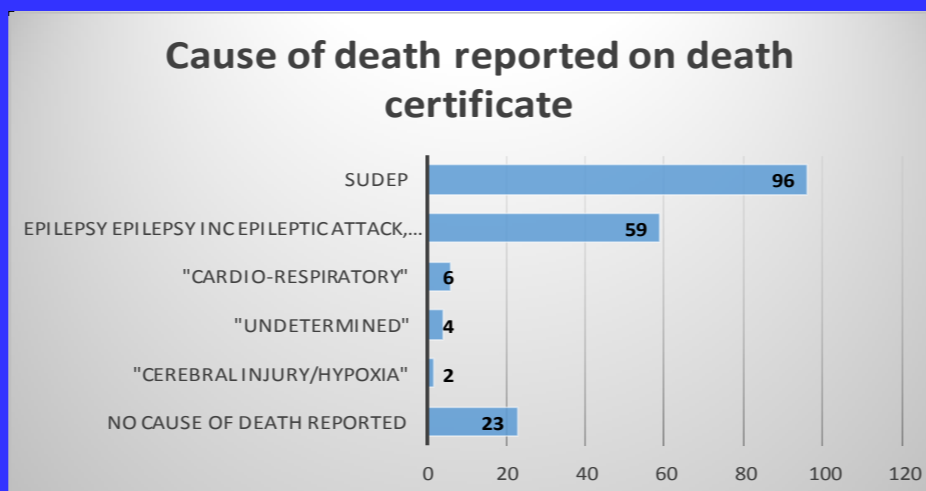
Over half of the cases reported are male (58%), with a broad age range (2—72). There is a peak between 18 and 35, reflecting findings from other studies



The majority of cases (97.7%) were reported by relatives, with 75% being reported by parents, One in ten cases were reported by partners or siblings.



69% (190) of cases reported having a death certificate issued, but 23 did not report the cause of death. The number of deaths recorded as SUDEP (96/190) suggests that the knowledge of SUDEP has increased.



Emergent themes from free text comments include:

Gaps in knowledge of the risk of SUDEP, from both families and health care professionals:

"...feel that if we had been told about SUDEP and how we could have helped reduce the risk or even prevent it, then R could still be here".

"We were invited to speak to T's GP, who was sympathetic but seemed unaware that people could die from epilepsy".

Gaps in Service or Support:

"After T's death I learned that the consultant was aware of SUDEP but believed patients should not be told of the risks".

The impact of death from SUDEP:

"I will never come to terms with losing my son who was a strapping healthy young man who had no problems other than suffering from seizures which were kept reasonably under control..."

Conclusions

The first year of data collection from the EDR, whilst a small sample, highlights a number of key points:

- ◊ Young people aged 20-30 years appear to be at most risk
- ◊ Parents are keen to report the death of their child
- ◊ There are still gaps in knowledge about SUDEP which need to be addressed

Additionally, the data provided by the EDR will be a valuable supplement to the registers of people monitored in EMU therefore providing a wider range of risk groups.

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