INTRODUCTION

“A gilded cage is still a cage” - Lady Hale

Dementia and End of Life Care - Implications of Deprivation of Liberty Safeguards in England

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“Every person who is not in liberty is deprived of his or her liberty (unless) in accordance with a procedure prescribed in law” - Article 5 of the Human Rights Act states. Everyone has the right to liberty and security of person. No one shall be deprived of his or her liberty (unless) in accordance with a procedure prescribed in law. In England, in 17% of Clinical Commissioning Group areas in England 2-5 in 5 people die with dementia mentioned on their death certificate (Figure 3). About 140,000 people in England receive care near the end of life in a care home. 58% of people who die in care homes and 29% in hospital have dementia or sensitivity on their death certificate. There are concerns that people approaching the end of life with dementia or even frailty may have their liberty inappropriately restricted, especially in care homes. The Deprivation of Liberty Safeguards (DoLS) (2009) England are a legal framework to ensure that individuals, who lack mental capacity to consent to care which results in “deprivation of liberty”, (restricting freedom of choice or movement) have their arrangements independently assessed (authorisation) to ensure they really are in the person’s best interests. There are concerns both about the deprivation of liberty for terminal patients and the impact of DoLS on dignity and wellbeing in End of Life Care (EoLC) and distress to the family. Both Houses of Parliament have been critical of the current situation.

METHODS

Review of published and grey literature and comparison of data derived from the National End of Life Care Intelligence Network (NEoLCIN) England and data available from the NHS Digital Annual Report of data derived from the Mental Capacity Act 2005, Deprivation of Liberty Safeguards (DoLS) data 2015-16 and 2016-17.2

Aim: To assess variation across England and the implications for End of Life Care.

RESULTS

In 2015/16 Care homes made 150,355 applications, hospices 715 and acute hospitals 27,855. In 2016/17 68% of the DoLS applications were made by care homes (nursing and residential) with an almost equal split between them at national level but differing at regional level. As can be seen from the comparison of the graphs and maps below there is no apparent correlation between applications and age distribution of regions, prevalence of dementia or numbers of care home beds.

The Policing and Crime Act 2017 introduced changes that the coroner no longer has to hold an automatic inquest for a person dying under a DoLS authorisation which had been very distressing for relatives.

DISCUSSION

The data show that the people for whom DoLS applications are made are primarily people who because of their age, advanced dementia and residence in care homes are likely to be approaching the end of their life. Indeed, the data show that many people die before their application has been completed and while still on a DoLS. This could mean that there is a failure to correctly assess their approaching death and that their liberty is inappropriately deprived. It is also problematic to distinguish between intensive nursing and care and deprivation of liberty. The Supreme Court in the judgement in March 2014, In re X (A Patient) 2014, 2014/01802/P, stated: “The court must assess whether a person is being deprived of their liberty. The questions which should be asked are: Is the person subject to continuous supervision and control? Is the person free to leave? The Supreme Court judgement has led to a massive increase in the number of applications. NHS Digital has investigated the particularly high rate of applications in the North East Region and concluded this is at least in part related to multiple applications per individuals for short time periods (<90 days).

There is a concern that patients being transferred from acute hospitals to nursing homes under NHS fast track arrangements or who themselves or relatives decide to fund their own care are not informed about the potential deprivation of liberty which may be associated with a care home and how this may impact on their quality of life.

CONCLUSIONS

The people for whom DoLS applications are most prevalently applied for are people with short life expectancies because of their age and conditions and care home residence. The apparent unwarrented geographical variations in DoLS applications, approvals and waiting times as well as the lack of relationship with demographics, care home places per 100 people aged >75 years, or dementia as a cause of death combined with Concerns raised by the CQC and Local Government Ombudsmans raise concerns about dignity and autonomy for people at the end of life and further possibly improved arrangements have been proposed.

REFERENCES

4. https://files.digital.nhs.uk/publicationimport/pub21xxx/pub21814/dols-eng-1516-
7. The Data on DoLS statistics is collated and published by NHS Digital as official statistics reports.