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Coláiste na hOllscoile Corcaigh

End-of-Life Care in Ireland: ethical challenges and solutions

Opening Statement to the Joint Committee on Health and Children

Dr. Joan McCarthy 24 October 2013

INTRODUCTION

1. In end-of-life care, health professionals, patients and families must often make difficult decisions in tense, demanding, emotionally fraught and constrained circumstances. In this context, recent research carried out under the auspices of the Irish Hospice Foundation, indicates that the general public in Ireland have little understanding of end-of-life treatment and care terminology or the processes of dying and death. They are also confused about the role of families in relation to receiving information and making decisions for incompetent patients.[1] In addition, Irish health professionals are uneasy and unsure about patient autonomy rights and they can feel pressurized by family members into denying patients relevant information and carrying out treatments that they consider futile.[2]

2. An understanding of the ethical challenges at the end-of-life is central to good end-of-life care because lack of knowledge and uncertainty about ethical obligations and responsibilities, lack of confidence in expressing nagging doubts and fear of litigation and professional accountability can and do lead to oversight, error and poor practice. Currently, Irish legislative and regulatory bodies are driving reform in relation to medical practices in end-of-life care. This is long overdue and is to be welcomed. However, if the reforms envisaged in documents such as the National Consent Policy (2013) and the Assisted Decision Making Bill (2013) are to be fully realized; there has to be a cultural shift in healthcare organisations and practices as well as among the general public. Ultimately, it makes good clinical, social and economic sense to develop

[1] See Weafer (2009), Weafer et al (2009) and McCarthy et al (2010). Given that the sample surveyed in Weafer et al (2009) (n = 667) was representative of the general population and that the study's findings are consistent with related research undertaken in Ireland, confidence can be placed in the representativeness of the survey results.

[2] See Quinlan and O'Neill (2009) for more information about their research involving 14 focus groups; 57 interviews; 102 written submissions with different health care staff in 15 hospitals (both acute and community) around Ireland.

educational strategies and support to ensure that clinical practice is ethically and legally sound.

3. We might live in an age of instant solutions but ethical problems in end-of-life care are not easy to resolve because they involve value-laden opinions and strong personal beliefs and emotional responses. The increasing diversity of the Irish population and the need to respect different cultural values and religious perspectives also demand greater sensitivity, deeper understanding and more inclusive policies and practices. Ethics is increasingly everyone's business: we can't just leave ethics to the ethical 'experts'; nor can we assume that clinical expertise implies ethical expertise.

SUGGESTED SOLUTIONS

4. It follows that we need to put **educational strategies and supports** in place to engage conversation and debate about the processes of death and dying in Irish healthcare organisations and community settings. While legal challenges in relation to assisted suicide and euthanasia might capture the public imagination, clarity and understanding are also needed in relation to more usual but also complex and contested decisions and interventions such as starting, stopping and de-escalating treatment, sedation and pain management and the provision of nutrition and hydration.

5. One set of educational resources that has already contributed to demystifying ethical issues that arise in relation to death and dying is the Ethical Framework for End-of-Life Care (2011).[3] The outcome of a unique collaboration between University College Cork, the Royal College of Surgeons in Ireland and the Irish Hospice Foundation, this is a set of resources for health and allied professionals, educators and the general public that considers ethically challenging situations in end-of-life care in the light of important ethical values, professional codes and laws.

6. In this presentation, I would like to propose 2 important simple, practical and economic initiatives that will consolidate and extend the impact of the Ethical Framework in Irish healthcare settings.

[3] The Ethical Framework is available (free) online at: http://hospicefoundation.ie/publications/ethics/ It is also published by Cork University Press: *End-of-Life Care: Ethics and Law* (2011)

A National Network of Clinical Ethics Committees

7. Introducing Clinical Ethics Committees into Model 1-4 hospitals and other healthcare organisations in Ireland would bring us into line with international best practice. In Canada, Europe, the UK, US and Australia such multidisciplinary committees perform a threefold function:

a. Ethics education for health professionals, hospital/community staff, patients and families
b. Formulation and review of healthcare policies
c. Consultation to support staff with complex and difficult clinical cases.

8. Each Committee would be linked at local, regional and national levels with other Clinical Ethics Committees. It is envisaged that the economic cost of each Committee would be minimal (largely administrative) while a small task force in the Department of Health and Children would be responsible for coordinating and supporting the Network at a regional and national level.

A National End-of-Life Healthcare Ethics Observatory

9. The Observatory would be the joint initiative of institutes and universities in partnership with hospital education centres and professional bodies in Ireland. Building on the collaboration between UCC and RCSI that resulted in the development of the Ethical Framework, the work of the Observatory would include:

a. Providing educational support to the general public
b. Improving the training and continuous professional development of clinicians and healthcare staff involved in caring for dying patients
c. Developing and updating the Ethical Framework to ensure that it is current, relevant and fit for purpose
d. Initiating 4th level educational programmes (PhDs and clinical doctorates) in clinical ethics and bioethics in Ireland

10. Given current economic constraints the Observatory might begin as a Virtual Observatory (supported by a network of suitably qualified individuals and housed in one or more third level institution) with a view to finding accommodation in the longer term in a large national or regional hospital.

Conclusion

11. Finally, when the Liverpool Care Pathway was found to have contributed to poor care for dying patients and their families in the UK earlier this year, the reviewers called on the British government to ensure that 'guidance on care for the dying is properly understood and acted upon, and tick-box exercises are confined to the waste paper basket for ever'.[4]

12. If we accept that care for the dying is a complex art; it demands a range of ethical skills and competencies so that sight is not lost of the fundamental bond between professional and patient. Where ethics support is a standard part of healthcare organisations, the international evidence indicates that healthcare staff are more ethically literate leading to improved patient and family outcomes and less moral stress, desensitization and burnout.

13. The National Network of Clinical Ethics Committees and the National End-of-Life Healthcare Ethics Observatory working together can make a real contribution to achieving this kind of ethical literacy. They also represent an opportunity for Ireland to take a leadership role internationally in advancing ethically and legally sound clinical practices in end-of-life care.

[4] Independent Review of the Liverpool Care Pathway (2013) More Care, Less Pathway, A Review of the Liverpool Care Pathway. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf; page 11.