Quality of life, length of life: ethical aspects
a Response

Prof David Smith
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RCSI DEVELOPING HEALTHCARE LEADERS WHO MAKE A DIFFERENCE WORLDWIDE
Acknowledgements

• Professor Göran Hermerén

• Dr Joan McCarthy
Fundamental Questions

1. What do we know?
2. What do we want?
3. What are we able to do…?

- Research in Ireland
Hospice Friendly Hospitals Programme (2007-12)
An Ethical Framework for End-of-Life Care (2011)
Consortium:
RCSI and UCC; backgrounds in law, philosophy, theology and nursing
1. Empirical research: ‘what is’ (Jan 2008 - Dec 2009)
Qualitative and quantitative research:
- Literature Reviews
- Media analysis
- Concerns of the general public
- Health practitioners’ views
- Legislators’ views
2. Theoretical Research: ‘what ought to be’ (Jan 2008-Dec 2011)

- Principles
- Ethical theories and approaches
- Professional guidelines
- Legal situation
### Attitudes Towards Death and Dying (n = 682) (McCarthy et al 2010)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agree strongly</th>
<th>Agree somewhat</th>
<th>Neither</th>
<th>Disagree Somewhat</th>
<th>Disagree strongly</th>
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</thead>
<tbody>
<tr>
<td>Severely ill; keep alive at all costs</td>
<td>11</td>
<td>12</td>
<td>10</td>
<td>20</td>
<td>47</td>
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<td>Severely ill; doctors make decisions</td>
<td>20</td>
<td>22</td>
<td>6</td>
<td>23</td>
<td>29</td>
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<td>Quality of life more important than length</td>
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<td></td>
<td>63</td>
<td></td>
<td>18</td>
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<td>Fear helpless dependence &gt; death</td>
<td>52</td>
<td>20</td>
<td>10</td>
<td>10</td>
<td>8</td>
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<tr>
<td>Severely ill; spiritual and religious support</td>
<td>49</td>
<td>24</td>
<td>9</td>
<td>8</td>
<td>10</td>
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<tr>
<td>Every competent adult has right to refuse</td>
<td>43</td>
<td>27</td>
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<td>10</td>
<td>14</td>
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Practitioners’ Perspectives (Quinlan and O’Neill 2009)
15 hospitals; 14 focus groups; 57 interviews; 102 written

Findings include:

• Dying patients had very individual needs

• Decision-making more social less medical exercise

• Inappropriate treatment continued unnecessarily

• Little or no documentation of patients’ wishes

• Lack of planning; moment by moment decisions
An Ethical Framework for End-of-Life Care
(McCarthy, Donnelly, Dooley, Campbell, Smith 2010)

8 Modules of Learning (combining ethics, laws and professional guidelines)
1. Explaining Ethics
2. The Ethics of Breaking Bad News
3. Healthcare Decision-making and the Role of Rights
4. Patient Autonomy in Law and Practice
5. The Ethics of Pain Management
6. The Ethics of Life Prolonging Treatments
7. The Ethics of Confidentiality
8. Ethical Governance in Clinical Care and Research

Available (free) online at:
http://hospicefoundation.ie/publications/ethics/
Developed 8 Study Sessions (2011)

8 sessions map on to 8 modules; A4 card
3-10 healthcare staff – 50-60 minutes

Content:
+ 1 Case + Group Discussion + Suggested Professional Responsibilities + Key Terms + 3 Key Readings

V. successfully piloted and evaluated in 2013

V. positive reviews from international journals e.g.

- *Irish Times* Editorial 7 October 2010
What can the Ethical Framework do?

- Ethics cannot just be left to ethical “experts”
- Ethics cannot just be left to the clinical “experts”
- Ethics is the responsibility of all
- It is impossible to draft clear legal and professional guidelines that apply to every situation.
An ethical approach

- Accepts that decisions are complex and can be contested
- Needs to appreciate that personal values impact on decision-making
- Assumes that moral expertise is communal and that meaning and decision-making arises out of dialogue and context
- Promotes ethical development rather than reliance on ethical formula or absolutes
- Offers ways of systematically considering moral intuitions
- Offers tools for thinking about difficult problems and cases
- Suggests ways of resolving problems and disagreements
Ethical Framework considers **professional integrity** as well as patients’ rights

Patients decisions may not always be what could be considered clinically right or reasonable

It is important to:

• recognize the **ethical work** of health professionals
• acknowledge that it may come at a personal cost – **moral distress**
• see a need for **ethical leadership** and **moral teamwork**
• see a need for **ethically healthy** organisations that encourage open, inclusive and respectful dialogue about ethical, professional and legal issues .... so that
  – nagging doubts and uncertainties can be expressed and shared
  – the personal cost of acting ethically is not unbearable
  – sight is not lost of the fundamental bond between professional and patient
Future Directions

1. What do we know?
2. What do we want?
3. What are we able to do…?
Thank you for your attention
References