

Impact case study (REF3b)

Institution: St Mary's University College
Unit of Assessment: 33: Theology and Religious Studies
Title of case study: Respecting life, accepting death: Faith-based bioethics applied to public policy
1. Summary of the impact (indicative maximum 100 words) <p>This case study will focus primarily on the ethics of end-of-life care as an illustration of the impact of David Albert Jones' research. Jones has engaged in theological and philosophical research in bioethics at St Mary's University College (SMUC) since 2002. This research has covered a broad range of issues from the status of the human embryo, to organ donation, to the creation of novel human-nonhuman organisms. Jones's research on bioethics from a Catholic perspective has had a significant impact on understanding of these issues within the Catholic Community and on the character and level of public debate. It has also had a demonstrable effect on public policy</p>
2. Underpinning research (indicative maximum 500 words) <p>Jones's research in bioethics covers work on the human embryo (and especially the influence of a particular reading of the Christian tradition within contemporary debates). He has written on the ethics of organ donation from a Catholic perspective, including the problem of diagnosing death in patients whose heart is still beating. He has also contributed to reflection on the perplexing moral status of embryonic creatures that are part-human, part-nonhuman. In each of these areas his research has had a significant impact. This case study will focus primarily on the influence of his research on end-of-life care.</p> <p>Jones' doctoral research at Oxford University (1997 to 2001) examined the theology of death. Between 2002 and 2013 Jones expanded this research and applied it more specifically: to proposals for legislative change in relation to assisted suicide and euthanasia; and to the ethical analysis of end-of-life care.</p> <p>There is a paradox in Christian theological reflection on death, in that while the gospel promises hope of redemption through and from death, the Church has consistently opposed suicide and mercy killing, more so than either ancient pagan culture or than modern secular society. This paradox discloses a truth that is also accessible to reason: an ethical approach to the end of life must simultaneously respect life and accept death. The former requirement implies, among other things, that death should never be the aim of our action or inaction. The latter implies that we should not flee from the inevitable by seeking every possible treatment. It is sometimes thought that respect for life and acceptance of death are incompatible so that one must choose between them, and it is common for people to emphasise one or the other (and fall into the opposite failures of undertreatment or overtreatment). However, virtue consists in recognising the validity of both principles.</p> <p>In relation to assisting suicide and euthanasia, Jones has shown how legislative proposals typically fail to grant equal respect for the lives of those who are disabled or terminally ill. In relation to end-of-life care, he has argued that problems associated with end-of-life care pathways should not be addressed by treating all patients as though they were curable.</p> <p>Jones was appointed to a full-time position at SMUC in March 2002 and remained there until June 2010 in a role which included research, lecturing and academic leadership. He was programme director of the MA in Bioethics from September 2002 until June 2010. In 2007 he was appointed professor on the basis of research and in 2008 he co-founded a centre for research, teaching, and dialogue: <i>The Centre for Bioethics and Emerging Technologies</i> (CBET). His research during this period (2002 to 2010) was shaped not only by personal interests and the needs of curriculum development but also through engagement in public policy debates and the deeper questions these raised.</p>

In July 2010 Jones was appointed director of the Anscombe Bioethics Centre in Oxford which is not formally affiliated to any HEI. His research in this period built on work done between 2002 and 2010. In July 2013, he returned to SMUC as a part-time (0.2 FTE) research fellow.

3. References to the research (indicative maximum of six references)

- David Albert Jones, *Approaching the End: a theological exploration of death and dying* (Oxford: Oxford University Press, 2007).
This was published following peer review by Oxford University Press. It was an output in RAE 2008, UoA 61, SMUC and can be supplied by the HEI on request. This book is based on the 2002 Oxford DPhil, but significantly reworked while at SMUC.
- David Albert Jones, 'Is there a logical slippery slope from voluntary to non-voluntary euthanasia?' *Kennedy Institute of Ethics Journal* Volume 21, Number 4, December 2011: 379-404.
This article is based on a paper given at the Royal Society of Medicine prior to its publication in a peer review journal. It is included in REF2 having been through an external peer review process in which it was assessed as 3.*
- David Albert Jones, 'Loss of faith in brain death: Catholic controversy over the determination of death by neurological criteria', *Clinical Ethics* (2012) 7: 133–141. doi: 10.1258/ce.2012.012m07.
This article is based on a paper given at Swansea University prior to its publication in a peer review journal. It is included in REF2 having been through an external peer review process in which it was assessed as 3.*
- David Albert Jones, 'Death by Equivocation: A manifold definition of terminal sedation' in S. Sterckx K. Raus and F. Mortier (eds.) *Continuous sedation at the end of life: Ethical, Clinical and Legal Perspectives* (Cambridge: Cambridge University Press, 2013).
This chapter is based on a paper given at an international conference at Ghent University, Belgium and was subject to peer review prior to its publication.
- David Albert Jones and Calum MacKellar (eds). *Chimera's Children: Ethical, Philosophical and Religious Perspectives on Human-Nonhuman Experimentation* (London: Continuum, 2012).
This book is included in REF2 having been through an external peer review process in which it was assessed as 2. This illustrates Jones's research in diverse areas of bioethics.*
- David Albert Jones, *The Soul of the Embryo: An enquiry into the status of the human embryo in the Christian tradition* (London: Continuum, 2004).
This book was the subject of a seminar in the House of Lords in 2005 convened by Bishop Richard Harries and including, among others Baroness May Warnock, Sir Anthony Kenny and Suzi Leather (then chair of the Human Fertilisation and Embryology Authority). The book was shortlisted for the Michael Ramsey Prize for Theological Writing 2007. It was an output in RAE 2008, UoA 61, for SMUC and can be supplied by the HEI on request. This further illustrates Jones's research in diverse areas of bioethics.

4. Details of the impact (indicative maximum 750 words)

Jones's bioethical research has helped inform and shape thinking in the Catholic community and other faith communities; that of legislators, regulators and healthcare professionals; and thus has had a significant impact on those who access healthcare services or who support those who do. Jones has engaged widely with audiences outside the academy. He has given over 100 talks unconnected to any higher educational programme since January 2008 (to medical professionals, to Church groups and at interfaith events, to sixth form students, as well as open lectures for

members of the public). In the same period, Jones wrote 27 articles for wider audiences, both religious (for example in *The Tablet*, *The Pastoral Review*; or *Faith Today*) and secular (for example in *BioNews*; *Bioedge*; or *The Times Higher Education*).

During this period Jones has also authored 26 responses to consultations by parliament, regulatory or professional bodies and other organisations and on nine occasions has spoken in parliament and/or given oral evidence to parliamentary committees.

Jones has also authored a number of public letters, for example, one signed by 26 bioethicists from around Europe on the patentability of human embryo research (*Nature* 30 June 2011). Jones has also appeared on numerous occasions in the national media (for example on *Newsnight*, the *Today* programme, *Beyond Belief*) and has been cited in debates in parliament, for example in the closing speech of the debate on the human fertilisation and embryology bill (22 Oct 2008: Hansard Column 411). Since 2009 he has also been Vice-Chair of the MoD Research Ethics Committee. Three times in this period, guidance drafted by Jones has been sent to every Catholic parish in England and Wales (over 2,500 parishes). There is evidence that this encouraged participation in public policy, for example, in the Crown Prosecution Service consultation on assisted suicide, in that (1) the number of responses in that consultation was unusually high (over four thousand) despite the complexity of the consultation document (2) the pattern of Yes/No answers most commonly adopted was that advocated in Jones's guidance, and (3) the most common suggestion by the public was one highlighted in Jones's guidance.

In relation to end-of-life care, Jones undertook 'the lion's share of the drafting' of *The Mental Capacity Act & 'Living Wills': A practical Guide for Catholics* (2008) for the Department of Christian Responsibility and Citizenship of the Catholic Bishops Conference of England and Wales, at their request: and helped draft *A Practical Guide to the Spiritual Care of the Dying Person* (2010). These booklets are available online and have been widely distributed especially through hospital chaplaincies. *The Spiritual Care of the Dying Person* has also been translated into Italian and Spanish.

Jones also helped draft the General Medical Council guidance *Treatment and Care Towards the End of Life* (2010). Jones's influence on this guidance, though real, is not easy to quantify, being one member of a working group, but the impact of the guidance is significant. The GMC sets the standards to which all doctors in the United Kingdom must adhere.

An example of impact that is more quantifiable is Jones's involvement in the revision of the Interim Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide. Jones was principal author of a submission to the Crown Prosecution Service which both analysed the Interim Policy and suggested specific changes. The submission was discussed and agreed by all the Catholic bishops of England and Wales and was sent to all Catholic parishes. The submission emphasised that the life of all citizens merited the same degree of respect and protection by law irrespective of whether they are disabled or terminally ill. During the consultation period Jones, together with Archbishop Peter Smith, met privately with Kier Starmer QC, the Director of Public Prosecutions, and Jones subsequently engaged in an email correspondence with a member of staff at the CPS to clarify the ethical issues at stake. The final policy accepted all of the proposed changes in the bishops' submission. This can be verified by a comparison of the Interim Policy, the bishops' submission, and the Final Policy.

Another issue where Jones's research has had a major impact is the controversy surrounding the Liverpool Care Pathway for the Dying Patient (LCP). Jones has been a member of the LCP's National Reference Group from 2009 and his ethical analysis of the LCP was cited in a parliamentary debate on the issue (8 Jan 2013: Hansard Column 47WH). At the request of the Department of Christian Responsibility, Jones prepared a substantial submission (18,000 words and 150 footnotes) for the Independent Review of the LCP. Baroness Julia Neuberger, the chair of that review, found the submission 'a really thoughtful and detailed analysis of ethical issues'. She invited Jones to meet with members of the Review panel and later revealed that, 'Prof Jones's submission was among several that were particularly helpful to us in reaching our conclusions'.

Impact case study (REF3b)

The Independent Review made wide ranging recommendations, including the replacement of the LCP, recommendations accepted by the government, the Royal Colleges, the Care Quality Commission, the new Chief Inspector of Hospitals, the regulatory bodies for healthcare professionals and other interested parties. These recommendations are already starting to have a major impact on care of the dying in England.

5. Sources to corroborate the impact (indicative maximum of 10 references)

- Most of the submissions cited in this case study, as well as the CV of the Director of the Anscombe Bioethics Centre and other relevant information is available on the website of the Anscombe Bioethics Centre www.bioethics.org.uk
- Further information on activities and outputs (including submissions) are given in confidential annual reports which can be obtained from the Anscombe Bioethics Centre on request: Director's Report to Academic Panel (1 November 2009 to 1 November 2010); Director's Report to Academic Panel (1 November 2010 to 31 October 2011); Director's Report to Academic Panel (1 November 2011 to 31 October 2012); and Director's Report to Academic Panel (1 November 2012 to 30 September 2013).
- The publications of the department of Christian Responsibility and Citizenship are available from the CBCEW website: <http://www.cbcew.org.uk/CBCEW-Home/Departments/Christian-Responsibility-and-Citizenship/Healthcare/Downloads>
- The letter from the Chair of the Independent Review of the Liverpool Care Pathway to the Chair of the Anscombe Bioethics Centre (8 August 2013) is available on request from the Anscombe Bioethics Centre.
- The Catholic Bishops' Conference of England and Wales.