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# The strengths and limitations of empirical bioethics

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*The past two decades have been witness to an “empirical turn” in bioethics. Whereas once this field of study concerned itself purely with theoretical analysis of ethical issues emerging in the design and delivery of health care, increasingly bioethics has embraced a range of empirical research methods from the social sciences and humanities. The emergence of “empirical bioethics” has, however, been the subject of enormous debate, both in regard to its methods and its purpose. For the most part these criticisms fail to appreciate the assumptions that underpin empirical bioethics or misrepresent the claims that are made about its moral utility. This article provides a brief account of the assumptions, strengths and limitations of empirical bioethics.*

## MORAL PHILOSOPHY AND EMPIRICAL BIOETHICS

Moral philosophy is often subcategorised into metaethics, normative ethics, and applied or practical ethics – the last-mentioned including bioethics, environmental ethics, business ethics and legal ethics. Normative ethics and metaethics primarily rely on philosophical reasoning to determine how moral agents *should* act and behave and to delineate moral concepts and the nature of justification in moral theory.<sup>1</sup> In contrast, practical ethics and particularly bioethics may use empirical research methods from the social sciences and humanities not to describe how the world *ought* to be, but to describe the social world as it *is*.<sup>2</sup> It is thus “a form of descriptive ethics, focused on describing a particular state of affairs that has some moral or ethical relevance”.<sup>3</sup> In recent years there has been considerable interest in this type of inquiry, sometimes called the “empirical turn” in bioethics.<sup>4</sup>

Empirical studies have been conducted in many spheres of biomedicine in which ethical and legal issues arise, including euthanasia/physician-assisted suicide;<sup>5</sup> advanced care planning; end-of-life decision-making; withdrawal of treatment;<sup>6</sup> reproduction; abortion;<sup>7</sup> and genetic testing.<sup>8</sup> These

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<sup>1</sup> Sugarman J, “The Future of Empirical Research in Bioethics” (2004) 32 J Law Med Ethics 226.

<sup>2</sup> Leget C, Borry P and de Vries R, “‘Nobody Tosses a Dwarf!’ The Relation Between the Empirical and the Normative Reexamined” (2009) 23 *Bioethics* 226; Birnbacher D, “Ethics and Social Science: Which Kind of Co-operation?” (1999) 2 *Ethical Theory and Moral Practice* 319; Borry P, Schotsmans P and Dierickx K, “The Birth of the Empirical Turn in Bioethics” (2005) 19 *Bioethics* 49; Molewijk AC, Stiggelbout AM, Otten W, Dupuis HM and Kievit J, “Implicit Normativity in Evidence-based Medicine: A Plea for Integrated Empirical Ethics Research” (2003) 11 *Health Care Anal* 69.

<sup>3</sup> Sugarman, n 1 at 226.

<sup>4</sup> Borry, Schotsmans and Dierickx, n 2.

<sup>5</sup> Parpa E, Mystakidou K, Tsilika E, Sakkas P, Patirake E, Pisteveu-Gombaki K, Govina O, Panagiotou I, Galanos A and Gouliamos A, “Attitudes of Health Care Professionals, Relatives of Advanced Cancer Patients and Public Towards Euthanasia and Physician Assisted Suicide” (2010) 97(2-3) *Health Policy* 160; Dussel V, Joffe S, Hilden JM, Watterson-Schaeffer J, Weeks JC and Wolfe J, “Considerations About Hastening Death Among Parents of Children Who Die of Cancer” (2010) 164 *Arch Pediatr Adolesc Med* 231.

<sup>6</sup> Tamura MK, Goldstein MK and Perez-Stable EJ, “Preferences for Dialysis Withdrawal and Engagement in Advance Care Planning Within a Diverse Sample of Dialysis Patients” (2010) 25 *Nephrology Dialysis Transplantation* 237; Moore P, Kerridge I, Gillis J, Jacobs S and Isaacs D, “Withdrawal and Limitation of Life-sustaining Treatments in a Paediatric Intensive Care Unit and Review of the Literature” (2008) 44 J Paediatr Child Health 404.

studies, which are now an established feature of the ethical, medical, legal and social science literature,<sup>9</sup> use a range of different qualitative and quantitative methods.

Studies of the attitudes of public and/or professional groups regarding various ethical concerns have tended to favour quantitative methods, particularly surveys, to further claims of generalisability. For example, one study on the attitudes of physicians and the general public towards withdrawal of treatment upon a patient's request in order to hasten their death utilised postal questionnaires mailed to 1,200 physicians and 1,202 individuals in Sweden.<sup>10</sup> The findings from this study revealed strong public and professional support for a patient's right to request the withdrawal of life-sustaining treatments – a finding that directly challenged the professional guidelines in Sweden that forbid physicians from participating in actions that hasten death. These findings led the authors to suggest that honouring a competent patient's wishes, even where doing so could be termed "euthanasia", may not be considered ethically unacceptable.

An example of a qualitative study that was used to inform ethical and legal deliberation was a study of the views of lay and expert stakeholders of biobanking using in-depth, semi-structured interviews to qualitatively examine the perceived trustworthiness of biobankers and their institutions and the impact that this had on decisions about participation in biobanking.<sup>11</sup> This study found that although there was an assumption of public mistrust within the literature on biobanking,<sup>12</sup> academic biobankers, scientists and their respective institutions were actually perceived as highly trustworthy by members of the general public. The conclusion of the authors was that this suggested that consent requirements should recognise the importance of trust, and that research institutions should emphasise transparency and communication rather than narrow project-specific consent.

Other empirical studies published in the *Journal of Law and Medicine* that have informed ethico-legal discourse and the critique and/or development of practices, policies, regulation and legislation include an assessment of the communication and education needs of key stakeholders in the assisted reproductive technology industry (in vitro fertilisation clinic staff),<sup>13</sup> a study of nurses' attitudes towards, and knowledge of, legislation mandating the reporting of child abuse and neglect,<sup>14</sup> and an exploration of the usefulness of advance directives for palliative care patients.<sup>15</sup>

Although there are various approaches to empirical ethics, broadly speaking all are based on a number of common assumptions.<sup>16</sup> First, that ethically meaningful information can be gained from the study of people's expressed attitudes, moral beliefs, intuitions, reasoning and behaviour. Secondly, that

<sup>7</sup> Szymanska M and Knapp P, "Opinions of Gynaecologists on Prenatal Diagnostics in First/Second Trimester and Abortion – Ethical Aspect" (2007) 52 *Advances in Medical Sciences* 182; Stern JE, Cramer CD, Green RM, Garrod A and Devries KO, "Determining Access to Assisted Reproductive Technology: Reactions of Clinic Directors to Ethically Complex Case Scenarios" (2003) 18 *Hum Reprod* 1343.

<sup>8</sup> Rabino I, "Genetic Testing and Its Implications: Human Genetics Researchers Grapple with Ethical Issues" (2003) 28 *Sci Technol Human Values* 365.

<sup>9</sup> Borry P, Schotsmans P and Dierickx K, "Empirical Research in Bioethical Journals. A Quantitative Analysis" (2006) 32 *J Med Ethics* 240.

<sup>10</sup> Lindblad A, Juth N, Furst CJ and Lynoe N, "When Enough is Enough; Terminating Life-sustaining Treatment at the Patient's Request: A Survey of Attitudes Among Swedish Physicians and the General Public" (2010) 36 *J Med Ethics* 284.

<sup>11</sup> Lipworth W, Morrell B, Irvine R and Kerridge I, "An Empirical Reappraisal of Public Trust in Biobanking Research: Rethinking Restrictive Consent Requirements" (2009) 17 *JLM* 119.

<sup>12</sup> Levitt M and Weldon S, "A Well Placed Trust?: Public Perceptions of the Governance of DNA Databases" (2005) 15 *Critical Public Health* 311.

<sup>13</sup> Petrillo T, "Assessing Stakeholder Needs for the Introduction of Assisted Reproductive Technology Legislation" (2009) 17 *JLM* 138.

<sup>14</sup> Mathews B, Fraser J, Walsh K, Dunne M, Kilby S and Chen L, "Queensland Nurses' Attitudes Towards and Knowledge of the Legislative Duty to Report Child Abuse and Neglect: Results of a State-wide Survey" (2008) 16 *JLM* 288.

<sup>15</sup> Fisher JW, Brumley DJ, Ashby MA, Milliken J and Brown M, "Advance Directives in Action in a Regional Palliative Care Service: 'Road Testing' the Provisions of the Medical Treatment Act 1988 (Vic)" (2005) 13 *JLM* 186.

<sup>16</sup> Borry P, Schotsmans P and Dierickx K, "Editorial: Empirical Ethics: A Challenge to Bioethics" (2004) 7 *Med Health Care Philos* 1.

a range of research methods from the social sciences and humanities provide a way to access this information, including historical study, literary scholarship, surveys and other population-based methods, experimental methods, and qualitative empirical methods such as interviews, focus groups and observation. Thirdly, that empirical approaches to bioethics cannot be defined by a single methodology but rather by an intellectual commitment to using the findings from empirical research in ethical reflection and decision-making. And finally, that the primary outcome of empirical data is not the generation of moral truths or norms, but engagement with a particular ethical issue in a practical and direct way.

The strength of empirical research in bioethics is that it allows for:

- the description of the experience of individuals or populations with respect to morally relevant issues;<sup>17</sup>
- the description of the attitudes, beliefs, moral opinions, reasoning patterns and decision-making of those involved in a certain practice;<sup>18</sup>
- the generation of data which can challenge authority, dogma, convention, norms and experience by showing how practice varies;<sup>19</sup> and
- the identification of moral issues that have escaped the attention of ethicists, but are relevant in a specific context, including those that are not obvious because they are embedded in practice.<sup>20</sup>

Thus, empirical research may enrich normative arguments<sup>21</sup> and make ethical discourse more context sensitive and comprehensive.<sup>22</sup> This, in turn, may inform moral discourses and the formulation of policy, regulation and legislation.<sup>23</sup>

## CRITIQUES OF EMPIRICAL BIOETHICS

While there are acknowledged benefits of using empirical research methods in bioethics, a number of criticisms have been raised against empirical bioethics. The first relates to the quality of empirical research conducted under the rubric of bioethics, including concerns about study design, method and validity. These concerns are, however, not specific to bioethics but relate to the design, conduct, analysis and translation of research in any setting.<sup>24</sup> The second concern is that the empirical turn in bioethics risks obscuring normative content by generating seemingly “neutral facts”.<sup>25</sup> In other words, that over-emphasis on data may diminish the attention given to philosophical analysis. The third criticism is metaethical, and relates to what data are, and how they relate to the development of moral norms. Much of this debate involves claims that empirical ethics disregards the “is-ought” gap,

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<sup>17</sup> Fetters MD and Brody H, “The Epidemiology of Bioethics” (1999) 10 *J Clin Ethics* 107; Sugarman, n 1; De Vries R and Gordijn B, “Empirical Ethics and its Alleged Meta-ethical Fallacies” (2009) 23 *Bioethics* 193.

<sup>18</sup> Bimbacher, n 2; Borry P, Schotsmans P and Dierickx K, “What is the Role of Empirical Research in Bioethical Reflection and Decision-making? An Ethical Analysis” (2004) 7 *Med Health Care Philos* 41; De Vries and Gordijn, n 17; Sugarman, n 1.

<sup>19</sup> McHaffie HE, Laing IA, Parker M and McMillan J, “Deciding for Imperilled Newborns: Medical Authority or Parental Autonomy?” (2001) 27 *J Med Ethics* 104.

<sup>20</sup> Braddock CH, “The Role of Empirical Research in Medical Ethics: Asking Questions or Answering Them?” (1994) 5 *J Clin Ethics* 144; Brody BA, “Quality of Scholarship in Bioethics” (1990) 15 *J Med Philos* 161; De Vries and Gordijn, n 17; Sugarman, n 1.

<sup>21</sup> Sulmasy DP and Sugarman J, “The Many Methods of Medical Ethics (Or, Thirteen Ways of Looking at a Blackbird)” in Sulmasy DP and Sugarman J (eds), *Methods in Medical Ethics* (Georgetown University Press, Washington, 2001); De Vries and Gordijn, n 17.

<sup>22</sup> Bimbacher, n 2; De Vries and Gordijn, n 17.

<sup>23</sup> Goldenberg MJ, “Evidence-based Ethics? On Evidence-based Practice and the ‘Empirical Turn’ from Normative Bioethics” (2005) 6 *BMC Med Ethics* E1; Sugarman, n 1; Kon AA, “The Role of Empirical Research in Bioethics” (2009) 9 *American Journal of Bioethics* 59.

<sup>24</sup> ten Have H and Lelie A, “Medical Ethics Research Between Theory and Practice” (1998) 19 *Theor Med Bioeth* 263.

<sup>25</sup> Goldenberg, n 23.

commits the naturalistic fallacy, and/or violates the fact–value distinction.<sup>26</sup> In general, the argument is that while empirical ethics can map the moral domain and tell us how people behave, it “cannot generate normativity or determine what is good or evil, right or wrong”.<sup>27</sup>

To some extent, these criticisms misunderstand both empirical bioethics and moral philosophy and misrepresent what empirical bioethics claims to do.<sup>28</sup> Normative ethics inevitably draws upon assumptions and evidence about the world, human nature and behaviour, while empirical ethics describes aspects of the world that are, in turn, value laden and socially constructed.<sup>29</sup> And while supporters of empirical bioethics point to its value in informing the development of moral norms, in general they do not argue that empirical data, *in itself*, is sufficient for the generation of normative claims.<sup>30</sup> The final critique of empirical bioethics relates to the lack of clarity as to how one translates the findings of empirical research into normative theory or the generation of moral norms. A number of different approaches have been described for integrating empirical research and normative ethics, with some prioritising moral theory and others empirical data.<sup>31</sup> Ives and Draper describe one such approach, which they call “normative policy or practice oriented bioethics” (NPOB).<sup>32</sup> This approach “seeks to make normative judgments, requires the incorporation of moral theory and philosophical reasoning to produce rigorous and consistent ethical analysis, and yet it also requires empirical work” to practically situate the issues that are in question.<sup>33</sup> While approaches like NPOB have intuitive appeal, the degree to which they can truly guide action or policy is open to question and it remains unclear how empirical data can or should be integrated into normative theory, how much weight it should be given when it contradicts philosophical reasoning and how far the moral obligation extends (if indeed there is one) to collect and consider empirical data.

## CONCLUSION

The importance of empirical research in bioethics is that it may reveal clinical, legal, emotional and philosophical factors influencing decision-making. While moral theory and careful philosophical analysis is fundamental to consideration of bioethical issues, without attention to empirical data such analysis may misunderstand certain details of specific practices or decisions and/or omit some factors which have considerable moral relevance.<sup>34</sup> Empirical research cannot, of course, replace philosophical analysis and cannot generate normativity. But what it can do is elucidate the attitudes, experiences, values and processes involved in decision-making and so enable the construction of policy and law, the critique of moral norms and the appreciation of the experience of those faced with issues raised by bioethically contentious topics.

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<sup>26</sup> Borry P, Schotsmans P and Dierickx K, *The Birth of the Empirical Turn in Bioethics*; Hume D, *A Treatise of Human Nature* [1739, 1740] (London, 1969); Moore GE, *Principia Ethica* [1902] (Buffalo, NY, 1988).

<sup>27</sup> Borry, Schotsmans and Dierickx, n 18 at 51.

<sup>28</sup> Ives J and Draper H, “Appropriate Methodologies for Empirical Bioethics: It’s All Relative” (2009) 23 *Bioethics* 249.

<sup>29</sup> Parker M, “Two Concepts of Empirical Ethics” (2009) 23 *Bioethics* 202.

<sup>30</sup> Ives and Draper, n 28; Parker, n 29.

<sup>31</sup> Molewijk, Stiggelbout, Otten, Dupuis and Kievit, n 2; Leget, Borry and de Vries, n 2.

<sup>32</sup> Ives and Draper, n 28.

<sup>33</sup> Ives and Draper, n 28 at 251.

<sup>34</sup> Braddock, n 20; Brody, n 20; De Vries and Gordijn, n 17; Sugarman, n 1.