



From bioethics to a sociology of bio-knowledge

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ABSTRACT

Growing recognition of bioethics' shortcomings, associated in large part with its heavy reliance on abstract principles, or so-called principlism, has led many scholars to propose that the field should be reformed or reconceptualised. Principlism is seen to de-contextualise the process of ethical decision-making, thus restricting bioethics' contributions to debate and policy on new and emergent biotechnologies. This article examines some major critiques of bioethics and argues for an alternative normative approach; namely, a sociology of bio-knowledge focussing on human rights. The article discusses the need for such an approach, including the challenges posed by the recent rise of 'the bio-economy'. It explores some potential alternative bases for a normative sociology of bio-knowledge, before presenting the elements of the proposed human rights-focused approach. This approach, it is argued, will benefit from the insights and concepts offered by various fields of critical scholarship, particularly the emergent sociology of human rights, science and technology studies, Foucaultian scholarship, and feminist bioethics.

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Introduction

In recent years, bioethics has attracted growing critical scholarly attention. The rapid development of the life sciences and related technologies – notably genetic testing and genome profiling, bio-banks, neuroimaging, and stem cell cloning – has underlined the limitations of bioethics' perspectives and reasoning for addressing emergent normative questions. A target of particular criticism has been the dominance of bioethics' 'principlism'. Principlism refers to 'the use of the moral principles to address issues and resolve case quandaries' (Dubose, Hamel, & O'Connell, 1994: 1, citing Fox & Swazey, 2008: 168). The most influential version of principlism in the United States and other countries has been that originally articulated by Tom Beauchamp and James Childress in their classic (and multiple-edition) text, *Principles of Biomedical Ethics* (2001; orig.1979); namely, autonomy, beneficence, nonmaleficence, and justice. Over the last three decades, these principles – particularly 'autonomy' – have come to constitute the touchstone for bioethical deliberation within research ethics committees and other forums (Fox & Swazey, 2008; Walker, 2009: 8). As critics have argued, principlism de-contextualises the process of ethical decision-making and in so doing limits bioethics' contributions to public debate and policy on new and emergent technologies (e.g. Corrigan,

2003; De Vries et al., 2007; Donchin, 2008; Evans, 2002; Fox & Swazey, 2008; Haimes, 2002; Hedgcock, 2004, 2010; López, 2004; Sherwin, 2008; Williams & Wainwright, 2010).

Proposals for addressing bioethics' lacunae have tended to be one of two broad kinds. The first is to seek to 'improve' or 'save' bioethics, by addressing its empirical deficits. It has been argued that the social sciences or sociology specifically can assist bioethics by offering empirical data on the process of ethical decision-making or the formation of ethical knowledge (see. e.g. Haimes, 2002; Hedgcock, 2004, 2010; Williams & Wainwright, 2010). Hedgcock, for example, proposes that bioethics' deliberations will be enhanced by grounding and contextualising its concepts in the specific settings in which bioethical 'dilemmas' arise (2004: 135–36). Ethnography is frequently posited as a key tool in this regard, by revealing the institutional routines, power relations, and interactions that underlie the political conflicts that actors seek to resolve through institutional mechanisms of ethical deliberation (e.g. De Vries, 2003; Fox & Swazey, 2008; López, 2004). Some writers seem to suggest that the social sciences or sociology should play a kind of 'handmaiden' role to bioethics, helping the field resolve the problems that it has identified. Others (e.g. Haimes & Williams, 2007) have argued that empirical social research will help establish a 'bridge' or common ground between the social sciences and bioethics – thus providing mutual benefits.

The second broad proposal, advocated mostly by feminist scholars (e.g. Donchin, 2008; Rawlinson, 2008; Sherwin, 2008), has been to radically reconstitute bioethics, to overcome the field's

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perceived inherent biases and epistemological ‘blind spots’. Feminist bioethicists represent diverse philosophical positions; however, they tend to take issue with the notion that ethical issues can be reduced to abstract, universal rules, without reference to the contexts of their use (Martin, 2001: 432). Feminist bioethics emerged in the 1990s as a response to bioethics’ focus on autonomy, individual rights, and rational decision-making and its neglect of questions of inequality, power and global justice. As some feminists have argued, a model of male rationality lies at the centre of bioethical reasoning, which denies the realities of women’s lives and experiences, especially in the private sphere (Little, 1996: 6; Wolf, 1996: 22–26). With its focus on individuals (‘the research subject’ or ‘the patient’), bioethics has overlooked the moral significance of groups and to differences among individuals (Wolf, 1996: 18). Other feminists point out that bioethics adopts a reactive approach, which entails responding to problems or positions posed by powerful actors (see, e.g. Donchin, 2001; Rawlinson, 2008; Sherwin, 2008). Feminist bioethicists have called for the abandonment of principlism, and a commitment instead to human rights and the promotion of a ‘nonhierarchical human community committed to mutual support and optimization of the health and well-being of all’ (Donchin, 2008: 156).

Responding to these critiques, this article argues for the development of an approach *beyond* bioethics; namely, a sociology of bio-knowledge focused on human rights. Such an approach, I contend, would address critics’ concerns about bioethics’ abstractness and empirical deficits and its neglect of questions of global justice. Sociology is well equipped to undertake this task given its reflexive stance, and resolute focus on context, group processes, the interrogation of dominant knowledge claims, and on exposing inequalities and the operation of power relations. The discipline offers an array of potentially valuable perspectives and methods, including (but not limited to) ethnography, for illuminating pertinent issues. While a sociology of bio-knowledge could take various directions, for example based on bioethics’ neglected principles, such as ‘justice’, ‘beneficence’ and ‘nonmaleficence’, or other ethical perspectives (e.g. virtue ethics, communitarian ethics, and ethics of care), it is argued that an approach that focuses on human rights is needed to advance global justice. Building on insights from the emergent sociology of human rights and various fields of critical scholarship, namely science and technology studies (STS), feminist bioethics, and Foucaultian scholarship, such an approach would seek to understand and assess the implications of the global proliferation of bio-knowledge and related practices. As I argue, developing such an approach is not without its challenges; however, it offers the best prospects for responding to the injustices arising from the development of ‘the bio-economy’.

The diversity of bioethics and bioethicists

Before proceeding further, some points of clarification and elaboration are in order since it might be objected (rightly) that ‘bioethics’ is a diverse field and that principlism is but one approach to ethical deliberation. As De Vries et al., note, ‘bioethics’ is not ‘a monolithic entity with a single perspective and mode of enquiry’ (2007: 2). The term ‘bioethics’ is ill defined, and the term is often used interchangeably with ‘medical ethics’, ‘clinical ethics’, and ‘research ethics’ (Hedgcock, 2004: 122), allowing it to be appropriated by different groups pursuing often very different agendas. Bioethics is informed by different philosophical/theoretical traditions, not all of which employ abstract principles.

Further, ‘bioethicists’ do not constitute a singular identity, but may include physicians, lawyers, theologians, philosophers, anthropologists, sociologists, historians, feminist scholars, and patient activists, with diverse perspectives on the field of bioethics

(De Vries, 2007: 2). These groups hold different views on the value of empirical data and on the relationship between ‘facts’ and ‘values’. Contrary to some social science characterisations of the field of bioethics (e.g. Corrigan, 2003; Hedgcock, 2004, 2010; López, 2004), some bioethicists *do* employ (or claim to employ) social science perspectives and undertake ethnographic or other empirical research, and *are* concerned with issues of justice (see, e.g. Herrera, 2008; Turner, L., 2009).

Some bioethicists object to the institutionalisation of principlism. Beginning in the early 1990s, many bioethicists in the US and other countries began to express concerns about the reliance on and the limitations of principlism, with a growing number of calls for the use of other approaches such as casuistry, virtue ethics, phenomenology, and hermeneutics (Fox & Swazey, 2008: 170). As early as 1992, for example, Hoffmaster (a philosopher) commented that the principles that constitute the core of theoretical medical ethics are ‘too general and vague to apply determinately to concrete situations’ and that when two or more principles conflict there is no way of resolving the conflict (1992: 1422). As Hoffmaster argued, philosophical ethics’ ‘fundamentally rationalist program’ is unable to resolve debates within the moral domain, such as the moral status of fetuses (1992: 1423). Beauchamp and Childress, themselves, have expressed concern about how their ideas have been taken up, claiming that it was never intended that their principles would be applied to specific cases in a deductive way (Wolf, 1996: 16; see also Fox & Swazey, 2008: 168–169).

However, despite these critiques of principlism, over the last two decades this approach has come to dominate many areas of ‘ethical’ deliberation. That is, an approach that has its genesis in the US (Fox & Swazey, 2008) in the context of the clinic and research projects of limited scope and duration has been applied globally, often without regard to the context, in relation to life science innovations that are unprecedented in scale, scope and potentially impact. These innovations tend to be prospective in nature and involve diverse networks of actors in the production, translation, and communication of knowledge. This includes population-wide biobanks (e.g. Gottweis & Petersen, 2008) and other genetic innovations (e.g. genome sequencing) (e.g. Rajan, 2006), stem cell research (e.g. Gottweis, Salter, & Waldby, 2009), nanotechnologies (e.g. Anderson, Petersen, Wilkinson, & Allan, 2009), and global pharmaceuticals (e.g. Petryna, Lakoff, & Kleinman, 2006). The tendency to apply bioethical principles to ever-growing spheres of life – what might be described as ‘bioethicisation’ (adapting Hisano, 2008) – has served to restrict debate, policy and action on the substantive issues arising from bioscience developments such as those above.

According to Evans (2000), the appeal of principlism can be explained by the fact that it meets the institutional demand for a rational logic, offering the prospect of calculability and predictability. It provides the basis for a ‘global moral economy’ enabling and legitimising the exchange of ideas across national and cultural boundaries (Salter & Salter, 2007: 555). Bioethics’ strong focus on ‘autonomy’ is compatible with neoliberal philosophies and policies that emphasise individual responsibility and ‘choice’ in healthcare (see Mamo, 2010: 176; Petersen, 2006). As Fox and Swazey observe in relation to the US, bioethics has had ‘problems of thinking socially and culturally’ since its inception. As they explain, these problems are associated with ‘certain characteristics of Western philosophical thought – especially those of Anglo-American analytic philosophy in its principlist form’; some ‘distinctive attributes of American values and beliefs, and of American medicine and law’; and the particular historical and public contexts within which bioethics emerged (2008: 13).

The limits of principle-based bioethics in responding to new and emergent innovations, however, have become increasingly evident. For example, the limits of consent in relation to biobanks and other

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