
Bioethics Outlook

Plunkett Centre for Ethics

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Sydney Catholic Archdiocesan Stem Cell Grant awarded to Professor Robert Graham

In 2002 the Commonwealth Parliament removed the prohibition on research on human embryos which involved their destruction. In fact, it went even further and legalized the creation of human embryos specifically for research purposes: the fact that the Parliament said that the embryos must be destroyed after 14 days is an indication that even *they* sensed that they had crossed an ethical Rubicon.

Why did it happen? Well, scientists and other 'service providers' had long wanted this change in the law. But their chance came with the discovery of stem cells, those remarkable cells which have the potential develop into many different cells types and thus to be a kind of internal repair system in our bodies. It was said that we needed to be able to extract them from human embryos. Not necessarily so, as it has turned out. There are plenty of other sources of stem cells in the body.

In this issue

We publish the introduction of Professor Robert Graham, the winner of the Archdiocesan Stem Cell Grant 2017, to the Sydney Catholic Business Forum Lunch on 25th May 2018.

We also publish the 'Consensus Statement' from the most recent meeting of the International Association of Catholic Bioethics in Rome in June 2017.

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The Plunkett Centre is a Centre of Australian Catholic University and St Vincent's Health, Australia, Sydney

www.acu.edu.au/plunkettcentre/ Tel: +61 2 83822869 Fax: +61 2 93610975

Email: Plunkett@plunkett.acu.edu.au

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It was in that context that the then Archbishop of Sydney (Cardinal George Pell) decided that, given its long history of conducting first rate medical research and clinical practice here in New South Wales, the Catholic community of Sydney should lend its support to this promising new field of therapy. And so was inaugurated the Sydney Archdiocesan Adult Stem Cell Grant which is now awarded, on a competitive basis, every second year. I know of no other diocese in the world to follow suit. The Archbishop set up an independent panel to assess applications in the light of their scientific excellence, the likelihood that they would have therapeutic applications, the novelty of their experimental approach, the track record of the researchers and the significance of the grant to the whole undertaking. The researchers had to obtain matching funds from another source, and of course had to comply with the ethical standards set out in the *Code of Ethics for Catholic Health and Aged Care Services in Australia*. The panel, Prof Colin Thomson, Dr Peter McCullagh and myself, rely heavily on referees' report. Applicants suggest some referees; we identify others. In this regard, Professor John Shine from the Garvan and Emeritus Professor Jack Martin from St Vincent's in Melbourne, are reliable backstops.

The first recipient, Dr Alan Mackay-Sim, went on to become Australian of the Year because of his ground-breaking work using nerve cells in the nose to repair damage to the spinal cord. Since then, others have won the award for proposals to investigate the therapeutic potential of stem cells from all over our body including skin, blood, dental pulp and the umbilical cord. Recipients of the grant have come from Peter McCallum in Melbourne, Hanon Institute in Adelaide, from St Vincent's in Melbourne and from University of New South Wales. Last year, Prof Graham from the Victor Chang, on the campus of St Vincent's in Sydney, won the award.

Robert Graham was appointed as the inaugural Executive Director of the Victor Chang Cardiac Research Institute in 1994. In 2003 he was awarded his own chair as the Des Renford Professor of Medicine, UNSW. His research for many years has focused on molecular cardiology. Recently, he has also been actively involved in studies of cardiac regeneration and the application of stem cells for the treatment of heart diseases. He is the author of over 260 peer-reviewed papers.

But listen to what his colleagues say of him: *"Bob is someone who is much loved and respected. By the Sisters of Charity, by his faculty and staff. And by the politicians, business leaders, community leaders, philanthropists and donors that are the friends and supporters of the Victor Chang. In the heat of the battle he is respectful and respected. His leads through consultation. As he likes to remind us often, he calls a spade a shovel. In addition to negotiating the metaphorical hills and valleys of science and medical research leadership, he is an avid cyclist, often making a holiday of it by tackling the hills and valleys of other continents. He recently cycled from Prague to Vienna. This keeps his body fit and his mind uncluttered. What distinguishes Bob is his dedication to family, to his Institute and to his mission. Scientifically, he leads from the front."*

William Butler Yeats said: *"Think where man's glory most begins and ends, and say my glory was I had such friends."* Bob Graham's glory consists not just in his scientific eminence but in the admiration and affection he inspires in those who work with him every day.

Mitochondrial Donation

A Plunkett Centre submission to Senate Standing Committee on Community Affairs

In order to appreciate the ethical status of mitochondrial replacement, it is important to begin by noting three things:

1 Consideration of any human proposal involves, or should involve, attention to all the features involved in ethical evaluation. It is not enough to say that only consequences matter or that good-enough consequences can make an otherwise bad act ethically permissible. It is not enough to say that only motives matter, that good-enough motives can make an otherwise bad thing ethically permissible. Indeed, the idea that some acts are ‘intrinsically evil’ means *not* that they are heinously wicked but rather that they are *wrong independently of their consequences*. This point was misunderstood by the writers of both the Lockhart Report and the Heerey Report. In both reports, it was argued that sufficiently beneficial outcomes could override inherent objections.¹ That said, both reports argued against removing the prohibition on using DNA from more than two persons.

2 So-called ‘mitochondrial donation’ is in fact the transfer of nuclear-DNA either between human eggs (maternal spindle transfer or MST) or between human embryos (pro-nuclear transfer or PNT).² The term ‘mitochondrial donation’ is thus misleading.³

3 Mitochondrial replacement does not cure anyone of mitochondrial disease. It is not treatment or therapy for an existing child or adult. So, in assessing the risks mitochondrial replacement involves for those who are produced and their descendants, it is important to start by noting that these risks are unnecessary. There are other ways in which women with

¹ Report of the Independent Review of the Prohibition of Human Cloning for Reproduction Act 2002 and Research Involving Human Embryos Act 2002, Canberra, 2011; 5.3

² In MST, an egg composed of DNA from two women is fertilized by sperm. In PNT, an embryo (formed by an egg which is free of mitochondrial disease and sperm) has its nuclear material removed and replaced with nuclear material from an egg or embryo of the woman who has mitochondrial disease.

³ Baylis, F. Human nuclear genome transfer (so-called mitochondrial replacement): clearing the underbrush. *Bioethics*, 31(1), 2017

mitochondrial disease may avoid passing on mitochondrial conditions (by avoiding having children or by using less risky methods).

Mitochondrial replacement is ethically problematic for the following reasons

In destroying human embryos, either at point of use (as in pro-nuclear transfer) or through prior embryo experimentation (as in both methods), mitochondrial replacement violates the respect owed to embryonic human life. Treating an embryo merely as a *means* and not also as an *end in itself* violates the respect owed to embryonic human life.⁴

In common with the other techniques of artificial reproductive technology, mitochondrial replacement exchanges procreation with manufacture.⁵ In addition PNT involves reproductive cloning: in PNT an embryo with faulty mitochondria and one without are combined and destroyed to produce a third embryo. Though a child born as a result of MST may be said to have ‘three genetic parents’, a child born as a result of PNT may be said to have ‘genetic ancestry’ but not ‘genetic parents’. Any procedure for the creation of a child should be consistent with the child’s right to a natural biological heritage.⁶ Mitochondrial replacement violates the child’s right to a natural biological heritage, that is, the right to be conceived from untampered-with biological origins, in particular, a right to be conceived from a natural sperm from one, identified, living, adult man and a natural ovum from one, identified, living, adult woman. Mitochondrial replacement ‘fragments’ motherhood: a child born of this technique inherits genetic material from a man and two women.⁷ Adoption has long given rise to concerns about the child’s right to knowledge of his or her biological heritage. However, in the context of assisted reproductive and genetic technologies, the clarification and restatement of that right has become more significant.⁸

⁴ Congregation for the Doctrine of the Faith. *Donum Vitae: Instructions on respect for human life in its origins and on the dignity of procreation*, 1987.

⁵ *Donum Vitae*, *ibid.* In 2005, the United Nations called on all members states to ‘prohibit all forms of human cloning inasmuch as they are incompatible with human dignity and the protection of human life’. Supporters of human cloning held that ‘inasmuch as’ means ‘to the extent that’. However, the ordinary meaning of the phrase is ‘because’. *UN Declaration on Human Cloning*, 2005.

⁶ Somerville, M. Children’s Human Rights to Natural Biological Origins and Family Structure, *International Journal of the Jurisprudence of the Family*, Vol 1, 2010.

⁷ Enthusiasts for legalizing the technique often downplay the significance of the contribution of the woman who provides the mitochondrial DNA. Even if the genetic contribution is numerically small, it is nonetheless crucial: if the technique is successful it will be this part of the DNA which will lead to a child free from mitochondrial disease. Hens et al, reporting a study of professionals’ views on the use of mitochondrial replacement, that the contribution of egg providers was as area of debate amongst their interviewees, and that ‘the status of the donor of the mitochondria may evolve as more become known about the role of mtDNA’. Hens, K. Dundorp, W. de Wert, G. A leap of faith? An interview study with professionals on the use of mitochondrial replacement to avoid transfer of mitochondrial diseases. *Human Reproduction*, doi: 10.14093/humrep/dev056 (in press); as cited in Haimes, E & Taylor K. Rendered Invisible? The absent presence of egg providers in U.K. debates on the acceptability of research and therapy for mitochondrial disease. *Monash Bioethics Review*, 33, 2015; 360-378

⁸ Tobin, B. Donor-conceived people: are they entitled to identifying information about their biological parents? *Bioethics Outlook*, 24 (1), 2013.

Mitochondrial replacement is a risky way of enabling a small number of women who wish to have a child to whom they are genetically related, to avoid passing on mitochondrial disease.⁹ Risks exist for the intending mother, the ova donor, a gestational surrogate (if one is used), the embryo, and the children he or she may have after reaching adulthood. Arguably, however, the greatest health risks will be faced by the children who begin life as embryos modified in this way and by their descendants.¹⁰ For this reason, mitochondrial replacement arguably violates the duty of parents not to subject their children to undue risks. It also raises extraordinarily difficult challenges to the principles of 'informed consent' (the principle that, except in cases of emergency treatment, physical treatments should not be administered to any competent person until all relevant information has been discussed and considered and the person's free and adequately informed consent has been given) and 'anticipatory consent' (the principle that, if we cannot reasonably assume that someone - for example, the 'to be born child' - affected by our decision, who is not present, would consent if present, it is not ethical to proceed¹¹).

In modifying the germline, mitochondrial replacement represents the 'opening of the door' to eugenic germline genetic manipulation. It is presented in a way which suggests that its use will be restricted to eradicating disease, that it will be controlled and regulated to a small defined population. In fact, it offers a technique by which (a) lesbian couples could have a child who is genetically related to both parties (one contributing the nuclear DNA, the other contributing the mitochondrial DNA), and (b) older women with lower levels of fertility might improve their chances of having a child.¹² Thus it constitutes one more step in an increasingly-permissive Australian regulatory regime which began with the removal of the prohibition on research which involves the destruction of human embryos and allowed their creation for (destructive) human research.

⁹ Although proof of safety is, by definition, impossible in this situation, the evidence so far is far from reassuring. Most of the work has been done on early-stage embryos; basic research on epigenetic and other interactions among nuclear and mitochondrial genes is lacking; animal studies are preliminary. HFEA first required that the techniques be tested on animals, and then dropped that requirement - after US researchers found the technique to be unsuccessful in macaques. Darnovsky, M. A slippery slope to human germline modification, *Nature*, Vol 499, July 2013.

¹⁰ In this regard, there are four categories of concern regarding the embryo: (i) epigenetic harm caused by nuclear transfer, (ii) mitonuclear mismatch, (iii) other effects that mitochondria may have on the developing embryo, and (iv) the carry-over of mutated mtDNA. Lee, K. Ethical implications of permitting mitochondrial replacement, *National Catholic Bioethics Quarterly*, Vol 16 (4), 2016; 619-632

¹¹ Somerville, M. op cit.

¹² Smyth, C. Allow three-parent IVF to help older women too, says pioneer. *The [London] Times*, 9 February, 2015. As cited in Dimond, R & Stephens, N. Three person, three genetic contributors, three parents: mitochondrial donation, genetic parenting and the immutable grammar of the 'three x x'. *Health*, Vol 22 (3), 2018, 240-258.

Healing relationships and transformations in health care: Ethical discernment & practical recommendations

Consensus statement of the 8th International Colloquium of the International Association of Catholic Bioethics¹ June 2017

1 Healing relationships are essential to good quality health care.² Some significant transformations in health care, however, are affecting the relationship of patients and their families to healthcare professionals. For example, patients today are likely to receive care from several healthcare professionals; public health interventions offered by healthcare professionals target populations rather than individual patients; decision making in health care is increasingly supported by analysis of health information from large numbers of patients (“big data”) and economic factors that determine the care that particular patients receive; patients are accessing health information through Internet search engines and social media; they sometimes receive health advice from their health professionals through e-mail or electronic consultations. Health care has become increasingly specialized and the provision of health care is often fragmented; it is difficult to maintain continuity of relationships of patients and their families to healthcare professionals particularly when care is complex or when there are transitions to different systems of care. Changes such as these are having an impact on the quality of health care, both for good and ill.

2 From June 4-9, 2017, 55 bioethicists, healthcare and other professionals, patient and family advocates from 12 countries were invited to participate in the 8th international colloquium organized by the International Association of Catholic Bioethics (IACB) and sponsored by the Order of Malta. They met at the Villa Palazzola near Rome to discuss the topic of healing relationships and transformations in health care. The following consensus

¹ William F. Sullivan, John Heng, Christopher De Bono, Gerry Gleeson, Gill Goulding, Christine Jamieson, Bernadette Tobin, Jos Welie and participants in the 8th International IACB Colloquium. The IACB is sponsored by the Order of Malta, a 970-year-old Catholic organization that provides health care and humanitarian aid around the world. The aim of the IACB is to promote faith-guided reflection and discussion regarding emerging ethical issues in biomedical research and health care and implications for improving health care of patients and their families, particularly those who are least regarded in society and most neglected. The Order of Malta offers material and other support to the IACB but does not determine the outcome of its deliberations. The statement is published in the *National Catholic Bioethics Quarterly*, vol 18, no 2, 2018.

² Riedl D, Schüßler G. The Influence of Doctor-Patient Communication on Health Outcomes: A Systematic Review. *Zeitschrift für Psychosomatische Medizin und Psychotherapie* 2017;63(2):131-150; Dibbelt S, Schaidhammer M, Fleischer C, Greitemann B. Patient-Doctor interaction in rehabilitation: The relationship between perceived interaction quality and long-term treatment results. *Patient Educ Couns.* 2009;76(3): 328-35. See also Pierre Mallia’s discussion of how the ethical principles of beneficence (care), non-maleficence, respect for autonomy and justice in health care are aspects of the doctor patient relationship. They are derived from and properly understood in light of the bond in this relationship: Mallia P. *The nature of the doctor-patient relationship: Health care principles through the phenomenology of relationships with patients.* Heidelberg and New York: Springer, 2013, especially chapter 4.

statement presents the main conclusions of this colloquium and offers patients and their families, healthcare professionals, healthcare organizations and policy makers some recommendations for ethical discernment and action.

Ethical discernment

3 Humans desire a flourishing life that includes physical, mental, social and spiritual well-being.³ Fragility, illness, losses and the anticipation of death, however, are also human realities. From these experiences of limitation emerge the need of persons for healing (or restoration to wellbeing) and for finding ultimate meaning and value in life.

4 Because humans are social beings, healing of the whole person will always require relationships with other persons.⁴ Healthcare professionals participate in healing by applying their specialized knowledge and skills to cure or prevent injury and disease, protect, restore or improve physical, cognitive and psychological functioning, and caring in other ways that accompany, bring comfort to and promote coping of people who experience disability, illness or loss. Enhancing the quality of the relationship and the reciprocal and dialogical nature of the “therapeutic alliance” of patients to healthcare professionals is the core of what has been called patient- or person centered health care.⁵

5 Fundamental to healing relationships in health care is regard for the intrinsic dignity and worth of the patient. This involves promoting the patient’s integral good and the patient’s participation in making decisions regarding her or his health care. Healthcare professionals should attend to being with patients and their families and not only providing them with assessments and interventions. Being-with includes being reliable, being present, being attentive, listening, showing compassion and empathy, being trustworthy, facilitating communication, supporting decision making and inviting input to improve the health and

³ Daniel P. Sulmasy, “A Biopsychosocial-spiritual Model for the Care of Patients at the End of Life,” *Gerontologist* 42 special number 3 (Oct. 2002):24-33. Pontifical Council for Pastoral Assistance to Health Care Workers, *New Charter for Health Care Workers*. English edition (Philadelphia: The National Catholic Bioethics Center, 2017), no. 2: “...to protect, recover and improve physical, psychological, and spiritual health means to serve life in its totality.”

⁴ Edmund D. Pellegrino, “The Reconstruction of Medical Morality,” *The American Journal of Bioethics*, 6.2 (March/April 2006): 65–71; Paul Ricoeur, *Les trois niveaux du jugement médical*. In: Ricoeur P. *Le Juste* 2 (Paris: Editions Esprit, 2001), 227-243; Jean Vanier, *Becoming Human* (Toronto: Anansi Press, 1998), 1-68; Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids, MI: Brazos Press, 2008), 48-52. The *Catechism of the Catholic Church* (1992) proposes that “[t]he human person needs to live in society.+ Society is not for him an extraneous addition but a requirement of his nature. Through the exchange with others, mutual service and dialogue with his brethren, man develops his potential; he thus responds to his vocation.” (no. 1879) An ethics of reciprocity and relationality, which applies to healing relationships in health care, can also be based theologically on the Christian understanding of human participation in the Trinitarian life of God. See: Ferrari A. *Trinità ed etica*. Rome: Città Nuova Editrice, 2016.

⁵ Although the use of the terms *patient-centred care* and *person-centred care* is widespread, the meaning of these terms is not identical or universally accepted. At the 8th International IACB colloquium, Dr. Luis Salvador-Carulla helpfully provided definitions for these terms as follows: *Patient-centred care* is generally applied at the level of the individual who is a health service user and already within the system. *Person-centred care* involves care approaches and practices that see the person as a whole with many levels of needs and goals coming from that person’s personal and social determinants of health. Person-centred health care proposes that the whole person and the person’s goals are at the centre of care. Accordingly, health care is organized in relation to an individual’s needs and goals rather than around disease-specific service silos. It is guided by the ethical principle of respect for the autonomy, dignity and responsibility of each person. It considers the person and the person’s family as the experts on their own context and situation. It refers to both non-patients and patients or groups who have health-related needs in terms of being at risk, require protective or preventative interventions as individuals, rather than a set of conditions or diagnoses

healthcare experiences of patients and their families. Such ways of relating are possible and should be fostered in any healthcare setting or encounter.⁶

6 Continuity in healthcare relationships can offer support to patients and their families during significant periods of change in their lives, such as during transitions to adulthood, parenthood, aging or the end of life.⁷

7 Because humans are spiritual beings, healing of the whole person will entail addressing the person's relation to ultimate meaning and value.⁸

8 Because there are aspects of human healing that go beyond what any individual can offer, cooperation with other healthcare professionals and with the patient's caregivers and community is often necessary for good holistic care.⁹

9 Communities have a responsibility to pursue a good of order or common good¹⁰ that enables healing by promoting the just distribution of healthcare resources to all.

10 Healing in health care is facilitated by healthcare professionals' knowledge of the patient, her or his family, community, culture, environment as well as perspectives and values. This familiarity is normally gained through establishing stable, long-term relationships and their family members to healthcare professionals. In any clinical encounter (including those that are one-time only or intermittent), healthcare professionals should learn as much as possible about the patient and her or his context and invite patients and their family members to share their perspectives and values relating to health goals and interventions. Discussing these matters takes time and effective communication. It sometimes entails exchange and integration of health information regarding the patient between two or more healthcare professionals and organizations.

⁶ Recent authors have criticized ethical theories such as virtue ethics or ethics of care, which support attending to healing relationships in health care because such approaches to health care can generate unrealistic expectations and moral distress for healthcare professionals who are unable to meet these expectations, e.g., nurses in healthcare settings that do not provide sufficient resources and support. This is a problem that needs to be addressed by funders and healthcare systems that allocate healthcare resources.

⁷ Michiels E, Deschepper R, Van Der Kelen G, Bernheim JL, Mortier F, Vander Stichele R, Deliens L. The role of general practitioners in continuity of care at the end of life: a qualitative study of terminally ill patients and their next of kin. *Palliat.Med.* 2007 Jul;21(5):409-415.

⁸ Edmund D. Pellegrino and David C. Thomasma, *For the Patient's Good: The Restoration of Beneficence in Health Care* (Oxford: Oxford University Press, 1987). For Christians, ultimate meaning and value (what Pellegrino calls the "spiritual good of the patient") is communion with God. Pontifical Council for Pastoral Assistance to Health Care Workers, *New Charter for Health Care Workers*. English edition (Philadelphia: The National Catholic Bioethics Center, 2017), no. 1: "...man has unassailable value: he possesses an eternal vocation and is called to share in the Trinitarian love of the living God." Questions regarding ultimate meaning and value also arise for atheists and agnostics.

⁹ For example, family members of patients and others who give care, the patient's community of supporters, those who address the social determinants of health, and those who provide spiritual care.

¹⁰ The *Compendium of the Social Doctrine of the Church* (Pontifical Council for Justice and Peace, 2004) explains the Catholic understanding of the common good in these terms: "*The principle of the common good, to which every aspect of social life must be related if it is to attain its fullest meaning, stems from the dignity, unity and equality of all people. According to its primary and broadly accepted sense, the common good indicates 'the sum total of social conditions which allow people, either as groups or as individuals, to reach their fulfilment more fully and more easily.'*" (no. 164) This understanding of the common good is different from the utilitarian notion of the greatest good for the greatest number of people.

11 Support for ethical deliberation is an important aspect of healing relationships in health care. In ethical deliberation, patients and their healthcare providers each have specific roles but both strive through dialogue to discern which healthcare assessments and interventions are medically appropriate and acceptable to the patient. Input from patients and their family aids healthcare professionals' diagnosis and offer of appropriate interventions. Ethical deliberation involves the patient and family's discerning goals of care and medically sound ways of pursuing those goals, with a view of identifying preferred interventions based on their values.¹¹ In supporting their decision making, healthcare professionals should be prepared to articulate and discuss the values behind their recommended interventions and why these are worthy of consideration by patients and their families.¹² When patients, family members and healthcare professionals cannot agree on goals of care or interventions, they should together seek solutions that maintain mutual respect and trust. Arriving at such solutions might require mediation by an impartial third party like an ethicist or arranging for transfer of care.

Practical recommendations

In light of the ethical considerations above, participants at the 8th IACB International Colloquium discussed four transformations that are or have the potential of having an impact on healing relationships in health care. They concluded with the following recommendations:

12 Health care provided by several healthcare professionals and systems

Healthcare teams and networks should be supported and promoted to provide holistic care of patients, especially patients with complex health needs. Such teams and networks should adopt an integrated interdisciplinary approach to caring for patients. There should be support for facilitating health information exchange and discussion within healthcare teams and networks. In consultation with the patient and family members, someone (e.g., a case manager) in each team or network should be designated to be responsible for coordinating care and communications. Healthcare professionals should be provided with education to develop skills for effective integrated interdisciplinary teamwork and supports to cope with the challenges of such work.

13 Health information technologies (HIT)

The use of health information technologies (e.g., electronic medical records) can be supported if the end is to increase the efficiency of healthcare practices and systems to enable healthcare professionals to focus on the personal and relational aspects of care. Some information technologies (e.g., at-home health monitors) can enhance healthcare professionals' knowledge of patients and factors that increase their health risks (e.g., of an adverse event or reaction to medications or other interventions) or trigger a behavioural or mental health crisis. The use of such technologies is acceptable and encouraged if they support patients and their families in communicating with healthcare professionals to improve health monitoring, prevention and care.

¹¹ As an example, advance care planning and ethical deliberation with patients and their families regarding their goals of care at the end of life can counteract the medicalization of death.

¹² See the discussion of the "deliberative model" in E.J. Emanuel and L.L. Emanuel, "Four Models of the Physician-Patient Relationship," *JAMA* 1992 Apr. 22; 267(16): 2221-6.

The use of health information technologies such as social media or electronic consultations for socially isolated patients and those who otherwise would be unable or unwilling to access health care is ethically justifiable, provided that accommodations and other efforts continue to be made to encourage and include them in more personal and relational forms of health care. Internet search engines and social media can help to inform patients and their families, prepare them for healthcare appointments and support their decision making. The use of such health information technologies, however, should never replace the role of healthcare professionals in helping patients and their family members to interpret health information in ways that are relevant and meaningful to the patient and family, to evaluate such information and to engage in ethical deliberation. Precision medicine (also known as stratified or personalized medicine), which is based on large-scale computer analysis of biological and other health-related data, can have many benefits, actual and aspirational, for supporting clinical decision making. These data, however, are limited and do not represent the health needs of specific patients or address the totality of the patient (e.g., they do not address their psychological, social and spiritual dimensions). While knowledge derived from precision medicine can be useful for healthcare professionals to consult in their diagnosis and judgments regarding possible effective interventions for patients, it should be integrated with a holistic understanding of the patient, her or his context, perspectives and values. The use of health information technologies can be supported for public health promotion and research purposes if privacy and confidentiality of health information obtained from patients and their families are safeguarded. Such safeguards also maintain the trust of patients and their families in healthcare professionals and organizations engaged in research. Access to health information technologies for the ends above should be equitable. Their use in health care should not lead to disparities in care between those who are able to use such technologies and those who are not. Information attained by precision medicine should never be used to discriminate against individuals or groups of individuals based on their susceptibility to illness or disability, poor response to interventions or other qualities. There should be regulation of ownership and control of health information technologies and ethical accountability for their use.

14 Economic factors influencing clinical decision making and health policy

Relationships in health care should never be regarded as negotiated contracts in which health care is treated merely as a commodity. The use of health information technologies to determine cost-effective interventions should be for the goal of improving health care of patients and promoting equity (ensuring that the benefits of health care are fairly distributed among all in society) not to maximize revenue for healthcare professionals or profits for healthcare organizations. There should be special concern in allocating healthcare resources for patients whose health needs are complex, who experience disparities or barriers to accessing the health care they need or who are not in a position to advocate for themselves. In allocating healthcare resources, priority should not be given to patients who have a certain quality of life or productivity that is abstractly or reductively defined, such as in clinical guidelines and policies that only maximize Quality-Adjusted Life Years (QALY) measures. Resources allocated to developing and using health information technologies should not displace more basic and urgent priorities in health care in the world today, e.g., access of everyone to a basic level of health care, which should include primary health care, preventive care and palliative care.

15 Maintaining the integrity and continuity of healing relationships

Healthcare professionals and organizations should attend especially to providing support and continuity of health care as patients and their families undergo challenging life-phase transitions and losses, such as transition to adulthood, old age and the end of life. This is an ethical responsibility not only for healthcare professionals and organizations but also of the entire community. Communities should encourage and adequately support complementary and informal networks of caregiving, e.g., by friends, neighbours and volunteer members of faith communities and service organizations. In some areas of the world, medical assistance in suicide and euthanasia are legally accepted or tolerated. Such practices are contrary to healing and compromise the trust that should be the basis of healing relationships in health care. The statement “The Value of Palliative Care: IACB Guidelines for Health Care Facilities and Individual Providers Facing Permissive Laws on Physician Assistance in Suicide and Euthanasia” provides ethical guidance for individuals, healthcare professionals and organizations who support palliative care as an ethical approach to accompanying and caring for patients who are living with a serious illness or disability.¹³ Research to improve the quality of and access to palliative care should be encouraged to assemble knowledge necessary for effective advocacy for palliative care.

16 Conclusions

Healing relationships are essential to good quality health care. They help patients and their families to find meaning and value in life while coping with illness, disability, losses and impending death. Some significant transformations in health care, however, are changing healing relationships, for good or ill. It is important for patients, their family members and healthcare professionals to be aware of these changes and their ethical implications. Healthcare organizations and policy makers should respond proactively by developing policies to ensure that these transformations are guided by the value of fostering and strengthening healing relationships. Healthcare professionals should be educated to understand how fostering and strengthening their relationship to patients and families can enhance quality of care and offer accompaniment to patients and families in their ethical deliberations. Healthcare professionals should also be trained and supported to integrate transformations in health care (e.g., interdisciplinary teams and health information technologies) with fostering healing relationships. Efforts to seek cost-effective healthcare interventions should not compromise quality of healing relationships in health care, equitable distribution of the benefits of health care or special concern for patients who experience barriers to accessing the health care that they need. Funders should prioritize research in clinical medicine and ethics on improving the personal and relational aspects of health care. Ensuring that there are resources and adequate support for promoting healing relationships in health care is the ethical responsibility not only of healthcare professionals and organizations but also of everyone in society.

¹³ Jos Welie, William F. Sullivan, John Heng, “The Value of Palliative Care: IACB Guidelines for Health Care Facilities and Individual Providers Facing Permissive Laws on Physician Assistance in Suicide and Euthanasia,” *National Catholic Bioethics Quarterly* 16.4 (Winter 2016): 657-662

Signatories

Camille Abettan	(Bioethics; Psychiatry; Philosophy)	France
Shara Ally	(Nursing)	Canada
Rev. Mr. Stepan Bilynskyy	(Bioethics; Spiritual and Pastoral Care)	Canada
Robert Boyko	(Family Medicine)	Canada
Ian Casson	(Family Medicine)	Canada
Gaspere Castagna	(student)	Canada
Fr. Paul Chummar, C.CMI	(Moral Theology; Bioethics)	Kenya
Maria Cigolini	(Palliative Care)	Australia
Claudia Clausius	(English; Cultural Studies)	Canada
Gladys Cook	(Patient and Family Advocate)	Canada
Jérôme Cornuau	(Bioethics; Medicine)	France
Michael Crawford	(Biology)	Canada
Christopher De Bono	(Bioethics; Spiritual and Pastoral Care)	Canada
Didier de Broucker	(Bioethics; Palliative Care; Bioethics)	France
Mark Dunphy	(Patient and Family Advocate)	Canada
Pauline Dunphy	(Patient and Family Advocate)	Canada
Fr. Stephen Fernandes	(Moral Theology; Bioethics)	India
Archbishop Anthony Fisher, OP	(Moral Theology; Bioethics; Law)	Australia
Fr. Gerry Gleeson	(Bioethics; Philosophy)	Australia
Sr. Gill Goulding, CJ	(Systematic Theology)	Canada
Franz Graf von Harnoncourt	(Medicine)	Germany
Kate Griffin	(Spiritual and Pastoral Care)	UK
Fr. Nigel Griffin	(Bioethics; Spiritual and Pastoral Care)	UK
Fr. Jean-Marie Gueullette, OP	(Theology; Bioethics)	France
Andreas Hartmann	(Bioethics; Medicine)	Austria
John Heng	(Bioethics; Philosophy)	Canada
Amalia Issa	(Bioethics; Neuropharmacology; Public Health)	USA
Christine Jamieson	(Systematic Theology; Bioethics)	Canada
Sr. Nuala Kenny, SCH	(Bioethics; Pediatrics)	Canada
Archbishop Jean Laffitte	(Moral Theology; Bioethics; Prelate)	SMOM
Dominique de La Rochefoucauld-	(Grand Hospitaller)	SMOM
Pierre Mallia	(Bioethics; Family Medicine)	Malta
Hazel Markwell	(Moral Theology; Bioethics)	Canada
Matthew McQueen	(Pathology and Molecular Medicine)	Canada
Moira McQueen	(Bioethics; Law; Moral Theology)	Canada
André A. Morin	(Law)	Canada
Elizabeth O'Brien	(Spiritual and Pastoral Care)	UK
Fr. Robert E. O'Brien	(Spiritual and Pastoral Care)	Canada
Sr. Rafaella Petrini, FSE	(Theology; Social Ethics)	Italy
Fr. Alex Rödlach, SVD	(Anthropology)	USA
Luis Salvador-Carulla	(Psychiatry)	Australia
Linda Scheirton	(Bioethics)	USA
Diane Smylie	(Patient and Family Advocate)	Canada
Ursula Sottong	(Bioethics; Geriatric Medicine)	Germany
Kyle Sue	(Family Medicine; Palliative Care)	Canada
Irene Sullivan	(Economics)	Canada
William F. Sullivan	(Bioethics; Family Medicine; Philosophy)	Canada
Elsie Sze	(English; Education; Library and Information Science)	USA
Michael Sze	(Actuarial Science; Mathematics)	USA
Paulina Taboada	(Bioethics; Internal Medicine; Philosophy)	Chile
Bernadette Tobin	(Bioethics; Philosophy)	Australia
Fr. Bert Vanderhaegen	(Bioethics; Spiritual and Pastoral Care)	Belgium
Neil Weir	(Bioethics; Otolaryngology)	UK
Jozef (Jos) Welie	(Bioethics; Medicine; Law)	USA
Ruth Wilson	(Family Medicine)	Canada