# Healing Relationships and Transformations in Health Care

## IACB Consensus Statement on Ethical Discernment and Practical Recommendations

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in the Eighth International IACB Colloquium

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1.  Healing relationships are essential to good-quality health care.[1] Some significant transformations in health care, however, are affecting how patients and their families relate to healthcare professionals. For example, patients today are likely to receive care from multiple healthcare professionals or a healthcare team; public health interventions offered by healthcare professionals target populations rather than individual patients; healthcare professionals increasingly use analysis of health information from large numbers of patients ("big data") and are asked to consider

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1.  D. Riedl and G. Schüßler, "The Influence of Doctor–Patient Communication on Health Outcomes: A Systematic Review," *Zeitschrift für Psychosomatische Medizin und Psychotherapie* 63.2 (2017):131–150; and S. Dibbelt et al., "Patient–Doctor Interaction in Rehabilitation: The Relationship between Perceived Interaction Quality and Long-Term Treatment Results," *Patient Education and Counseling* 76.3 (2009): 328–335. 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: see P. Mallia, *The Nature of the Doctor–Patient Relationship: Health Care Principles through the Phenomenology of Relationships with Patients* (New York: Springer, 2013), esp. ch. 4.

economic incentives and costs as the most important factors in determining the care that particular patients receive; patients are accessing health information through Internet search engines and social media; and they sometimes receive health advice from their health professionals through email or electronic consultations. Health care has become increasingly specialized, and the provision of health care is often fragmented; as a result, it is difficult to maintain continuity of relationships of patients and their families with healthcare professionals, particularly when care is complex or when there are transitions to different systems of care, such as from pediatric to adult healthcare services. Changes such as these are having an impact on the quality of health care, for both good and ill.

2.   From June 4 to 9, 2017, fifty-five bioethicists, healthcare professionals, and patient and family advocates were invited to participate in the Eighth 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 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.[2] Fragility, illness, losses, and the anticipation of death, however, are also experiences of human limitation. From these experiences of limitation emerge the need of persons for healing (or restoration to well-being) 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.[3] Healthcare professionals participate in

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2.   Daniel P. Sulmasy, "A Biopsychosocial-Spiritual Model for the Care of Patients at the End of Life," *Gerontologist* 42, spec no. 3 (October 2002): 24–33; and Pontifical Council for Pastoral Assistance to Health Care Workers, *New Charter for Health Care Workers* (Philadelphia: National Catholic Bioethics Center, 2017), n. 2: "To protect, recover and improve physical, psychological, and spiritual health means to serve life in its totality."

3.   Edmund D. Pellegrino, "The Reconstruction of Medical Morality," *American Journal of Bioethics* 6.2 (March–April 2006): 65–71; Paul Ricoeur, "Les trois niveaux du jugement médical," in *Le Juste 2* (Paris: Editions Esprit, 2001), 227–243; Jean Vanier, *Becoming Human* (Toronto: Anansi Press, 1998), 1–68; and 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 "the 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" (n. 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 A. Ferrari, *Trinità ed etica* (Rome: Città Nuova Editrice, 2016).

healing by applying their specialized knowledge and skills to cure or prevent injury and disease, protect, restore or improve 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 therapeutic alliance of patients with healthcare professionals is the core of what has been called *patient-* or *person-centered health care*.[4]

5. Fundamental to healing relationships in health care is the positive 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 healthcare experiences of patients and their families. Such ways of relating are possible and should be fostered in all healthcare settings or encounters.[5]

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.[6]

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4. Although the use of the terms *patient-centred care* and *person-centred care* is widespread, the meanings of these terms are not identical or universally accepted. At the Eighth 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 characteristics and social determinants of health (e.g., education, income). 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 caregivers as the experts on their own context and situation. It refers to both patients and non-patients or groups who have health-related needs in terms of being at risk of various conditions and requiring protective or preventative interventions as individuals to mitigate these risks, rather than a set of conditions or diagnoses.

5. 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 such expectations, e.g., nurses in healthcare settings that provide insufficient resources and support. We understand this as a problem that needs to be addressed by funders and healthcare systems that allocate healthcare resources, and not as a fundamental philosophical problem with virtue ethics or ethics of care.

6. E. Michiels et al., "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," *Palliative Medicine* 21.5 (July 2007): 409–415.

7. Because humans are spiritual beings, healing of the whole person will entail supporting the possibility of discussing questions regarding ultimate meaning and value.[7]

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 family caregivers and community is often necessary for good holistic care.[8]

9. Communities have a responsibility to pursue a good of order or common good[9] 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, and environment as well as perspectives, goals, and values. This familiarity is normally gained through healthcare professionals establishing stable, long-term relationships with patients and their family caregivers. 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 caregivers 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.

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, and both strive, through dialogue, to discern which healthcare assessments and interventions are medically appropriate and acceptable. Input from patients and their family caregivers aids healthcare professionals' diagnoses and

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7. 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*, n. 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 those who consider themselves to be atheists and agnostics.

8. These include, 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.

9. The *Compendium of the Social Doctrine of the Church*, by the Pontifical Council for Justice and Peace (Vatican City: Libreria Editrice Vaticana, 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'" (n. 164, original emphasis). This understanding of the common good is different from the utilitarian notion of the greatest good for the greatest number of people.

recommended interventions. Ethical deliberation involves the patient and family's discerning among proposed options, with a view to identifying preferred interventions based on their values and goals of care.[10] Clinical judgments and goals of care can be reconsidered as new questions and circumstances arise. Hence, a relationship of patients and family caregivers with a healthcare professional or team that is maintained over time is optimal for ethical deliberation. In such relationships, too, trust is more easily established, and healthcare professionals can articulate and discuss the values behind their recommended interventions and why these are worthy of consideration by patients and their family caregivers.[11] When patients, family caregivers and healthcare professionals cannot agree on goals of care or corresponding interventions, they should together seek solutions that maintain mutual respect and trust. Arriving at such solutions might require mediation by an impartial third party, such as an ethicist or, if this is unsuccessful, arranging for transfer of care.

## Practical Recommendations

In light of these ethical considerations, participants in the Eighth IACB International Colloquium discussed four transformations, listed below, that are having or have the potential to have an impact on healing relationships in health care, for good or ill. They concluded with the following recommendations:

12. *Health care provided by several healthcare professionals and systems*

a. Healthcare teams and networks should be supported and promoted to provide holistic care of patients, especially patients with complex health needs.

b. Such teams and networks should adopt an integrated interdisciplinary approach to caring for patients.

c. There should be support for facilitating health information exchange and discussion within healthcare teams and networks.

d. In consultation with the patient and family caregivers, someone (e.g., a primary care physician, nurse or case manager) in each team or network should be designated to be responsible for coordinating care and communications.

e. Healthcare professionals should be provided with education to develop skills for effective integrated interdisciplinary teamwork and supports to cope with the challenges associated with such work.

13. *Health information technologies* (*HIT*)

a. 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

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10. As an example, advance care planning and ethical deliberation with patients and their family caregivers regarding their goals of care at the end of life can counteract the excessive medicalization of dying.

11. See the discussion of the "deliberative model" in E. J. Emanuel and L. L. Emanuel, "Four Models of the Physician–Patient Relationship," *JAMA* 267.16 (April 22, 1992): 2221–2226.

and systems in order to enable healthcare professionals to focus more on the personal and relational aspects of care (e.g., coaching patients).

b. 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 family caregivers in communicating with healthcare professionals to improve health monitoring, prevention, and care.

c. 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 healthcare services, is justifiable ethically, provided that supports, accommodations, and other efforts continue to be made to encourage and include such patients in more personal and relational forms of health care.

d. 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 not replace the role of healthcare professionals in helping patients and their family caregivers to interpret health information in ways that are relevant and meaningful to the patient and family, to evaluate such information, and to engage with them in ethical deliberations.

e. 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 insofar as they 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 diagnoses and judgments regarding possible effective interventions for patients, it should be integrated into a holistic understanding of the patient and her or his context, perspectives, healthcare goals, and values.

f. 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 such research.

g. Access to health information technologies for the ends above should be equitable. Their use in health care should not lead to disparities in health care between those who are able to access and use such technologies and those who are not.

h. Information attained by precision medicine should never be used to discriminate against individuals or groups based on their susceptibility to illness or disability, poor response to interventions or other health-related characteristics.

i. There should be regulation of ownership and control of health information and related technologies and ethical accountability for their use.

14. *Economic factors influencing clinical decision making and health policy*

a. Relationships in health care should never be regarded as negotiated contracts in which health care is treated as a commodity only.

b. 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) and not for the goal of maximizing revenue for healthcare professionals or healthcare organizations.

c. 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 solely on the basis of certain quality-of-life or productivity assessments that are abstractly or reductively defined, such as in clinical guidelines and policies that are based on the goal of maximizing quality-adjusted life year (QALY) measures.

d. Resources allocated to developing and using health information technologies should not displace more basic and urgent priorities in health care in the world today, such as access of everyone to a basic level of health care, including primary health care, preventive care, and palliative care.

15. *Maintaining the integrity and continuity of healing relationships*

a. Healthcare professionals and organizations should attend especially to providing support and continuity of health care as patients and their family caregivers undergo challenging life-phase transitions and losses, such as transition to adulthood, old age, and the end of life.

b. This is an ethical responsibility not only of healthcare professionals and organizations but also of the entire community. Communities should encourage and adequately support complementary and informal networks of caregiving, for example, by friends, neighbours, and volunteer members of faith communities and service organizations.

c. In some areas of the world, medical assistance in suicide and euthanasia are permitted legally or tolerated. Such practices are contrary to the healing mission of health care and risk compromising 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.[12] Research to improve the quality of and access to palliative care should be encouraged

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12. Jos Welie, William F. Sullivan, and John Heng, "The Value of Palliative Care: IACB Guidelines for Health Care Facilities and Individual Providers Facing Permissive Laws

to assemble knowledge necessary for effective advocacy for palliative care. We especially encourage research in ethics and reflection on assessing patient vulnerability and fragility in patients diagnosed with neurodevelopmental or neurodegenerative disorders.

## Conclusions

16. Healing relationships are essential to good-quality health care. They help patients and their family caregivers 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 caregivers, 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 the 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 needed health care.

- 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.

## Signatories

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on Physician Assistance in Suicide and Euthanasia," *National Catholic Bioethics Quarterly* 16.4 (Winter 2016): 657–662.

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