

Chapter 4: Health Care Access and Coverage for Cancer Patients: An Ethical Imperative

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The ethical imperative voiced by colleagues from the Universidad Católica de Chile stresses the urgency of providing universal access to healthcare services on a global scale because health is a social good and a social right. On the one hand, health systems should promote innovations because they will contribute to greater sustainability and foster the sharing of health benefits to the different communities in the world. On the other hand, in healthcare practice, it is necessary to create more inclusive models of care that reach out to larger sectors of the population. Finally, interdisciplinary work is necessary to provide comprehensive care, considering the social determinants of health in the diverse social contexts where people live.

Globalization allows us to be more connected and have a better access to information among different countries. By this, problems around the world are known and comparisons between different cultures, populations, and communities are ineluctable. Focusing solely on the people, we can see that each one has personal resources available, but, at the same time, the environment in which they live will determine the level of health and risk factors and daily habits, that is, the social determinants of health. Culture is a strong determinant in the health of the population, but there are diseases that are transverse to it, such as cancer. Today, cancer is one of the leading causes of death worldwide. When considering the population growth rate, new sedentary lifestyles and aging, an increase of approximately 60 percent in the number of cases is

projected, being estimated up to 81 percent only in middle- and low-income countries by the year 2040.¹

Aging is a great challenge given that oncological problems occur more frequently in older people and that there is a change in the form of treatment, because chemotherapy and radiotherapy are being preferentially performed through ambulatory care, which allows reducing the costs associated with hospitalization. However, this approach requires nursing care or management of side effects at home, which ultimately results in a constant technological advance in care or interventions.²

These aspects unveil global and local differences between countries and communities given that populations in situations of vulnerability present lower quality of life, which will translate into aging in unfavorable conditions. If we add that homes do not have basic services or are exposed to pollutants, it will be more difficult for patients to recover from their health condition in an ambulatory way.

In relation to technological advances, even if they are available, not all people will have access to them in a fair way because they are not available in their country or have a high cost, among other reasons. The above scenarios show us that inequities have serious consequences, even more so if we consider access to health as a right for all people in the world. This means that all people, despite their genetics and lifestyle, may have the possibility of accessing interventions for promotion, prevention, rehabilitation, diagnosis or treatment.

This right of the most vulnerable people is a fraternal duty of all of us who live together in this “common home.”

¹ Solange Parra-Soto, Fanny Petermann-Rocha, María Adela Martínez-Sanguinetti, Ana María Leiva-Ordeñez, Claudia Troncoso-Pantoja, Natalia Ulloa, Ximena Díaz-Martínez, and Carlos Celis-Morales, “Cáncer en Chile y en el Mundo: Una Mirada Actual y Su Futuro Escenario Epidemiológico,” *Revista Médica de Chile* 148, no. 10 (2020): 1489–1495.

² Sanchia Aranda, “Creating Innovation in Cancer Care Delivery,” *Asia-Pacific Journal of Oncology Nursing* 5, no. 2 (2018): 134–136.

The ethical relevance of the good of health is such as to motivate a strong commitment to its *protection* and *treatment* by society itself. It is a duty of solidarity that excludes no one, not even those responsible for the loss of their own health. The ontological dignity of the person is in fact superior: it transcends his or her erroneous or sinful forms of behavior. Treating disease and doing one's best to prevent it are ongoing tasks for the individual and for society, precisely as a tribute to the dignity of the person and the importance of the good of health.³

Health, as a social right, means that everyone should receive care according to their needs. The ethic of public health is to protect and provide coverage to the essential collective needs of people.⁴ It also adds the fundamental ethical principles, including: protection, which ensures welfare, meaning that the state must respond to unpostponable needs; justice, which considers equity in the application of policies, strategies, and actions, with emphasis on the most vulnerable to avoid discrimination and unequal distribution of opportunities; reciprocity, considered as compensation for damages through a balance between benefits and burdens and as creating support measures for communities facing a situation of lower health protection; and accountability, being able to answer for the consequences of decisions.⁵

³ John Paul II, "Letter to the President of the Pontifical Academy for Life on the Occasion of a Study Congress on 'Quality of Life and Ethics of Health,'" February 19, 2005, www.vatican.va/content/john-paul-ii/en/letters/2005/documents/hf_jp-ii_let_20050219_pont-acad-life.html.

⁴ María Cristina Paredes, Karen Pesse, and Ximena Barros, "Ética de la Salud Pública: Propuesta Sobre los Principios Fundamentales Que Guían las Responsabilidades Éticas del Estado en el Contexto Pandemia COVID-19," *Revista Médica de Chile* 148, no. 10 (2020): 1481–1488.

⁵ Paredes, Pesse, and Barros, "Ética de la Salud Pública: Propuesta Sobre los Principios Fundamentales Que Guían las Responsabilidades Éticas del Estado en el Contexto Pandemia COVID-19"; Fermin Roland Schramm and Miguel Kottow, "Principios Bioéticos en Salud Pública: Limitaciones y Propuestas [Bioethical Principles in Public Health: Limitations and Proposals]," *Cadernos de Saude Publica* 17, no. 4 (2001): 949–956; World Health Organization, "Guidance for Managing Ethical Issues in Infectious Disease Outbreaks," 2016, apps.who.int/iris/bitstream/handle/10665/250580/9789241549837eng.pdf?sequence=1&isAllowed=y.

Another relevant aspect is the difficult decision on where to put the focus. This is the classic dilemma of whether to spend more on health promotion and disease prevention or on the treatment of patients already diagnosed. It is a relevant problem since protecting tomorrow's potential patients at the cost of suffering or shortening the lives of today's patients is difficult to justify. It is necessary to find strategies that adequately combine both aspects, using human resources with advanced competencies at both the primary and secondary levels of care.

Positioning ourselves in the context of care for people with cancer, we can see that protection, justice, reciprocity, and responsibility are not fully achieved in many situations, since there is a delay in care concerning timely diagnosis and access to effective treatment. There is an unequal distribution of opportunities: there are countries where medical care is scarce or, within the same nation, urbanized areas concentrate the greatest supply of health services and benefits compared to more rural areas, generating differences that have a negative impact on health due only to where you live.

This is also contrasted with the characteristics of the communities. Culture is a significant factor when it comes to implementing care or proposing new behaviors, since cultural factors are immersed in life habits and personal beliefs. For example, environmental management, whether it is considered globally, aimed at pollution, or locally, utilizing resources or services available to communities, has cultural implications on health management.⁶

Tumas, Pou, and del Pilar Díaz point out that biological, genetic, and environmental factors cause differences in risk, incidence, diagnosis, treatment, survival, and mortality in people with breast cancer.⁷ Other factors are aging, urbanization and fertility. In relation to urbanization,

⁶ Aranda, "Creating Innovation in Cancer Care Delivery."

⁷ Natalia Tumas, Sonia Alejandra Pou, and Maria del Pilar Diaz, "Inequidades en Salud: Analisis Sociodemografico y Espacial del Cancer de Mama en Mujeres de Cordoba, Argentina [Inequities in Health: Socio-Demographic and Spatial Analysis of Breast Cancer in Women from Cordoba, Argentina]," *Gaceta Sanitaria* 31, no. 5 (2017): 396–403.

we can see that the incidence rate of breast cancer is higher in urban areas, which is partly explained by a higher detection of cases. Urbanization leads to less healthy diets and less physical activities, and together with poverty, it is identified as a sociodemographic determinant of breast cancer incidence.

In Colombia, oral cancer has a higher incidence in the older adult population, in urban areas, and in situations of poverty or vulnerability. Moreover, this high incidence also highlights the presence of possible barriers of access to health services, which prevents timely diagnosis and treatment and frequently leads to finding the pathology in more advanced stages.⁸

In Chile, cancer is included in the program of Explicit Health Guarantees (GES), which assures access, opportunity, financial protection, and quality of care for certain types of cancer. However, this program focuses on treatment, not prevention. In addressing health problems, social responsibility has driven international research, and, at the same time, it allowed cross-cultural comparisons. Caring for affected people implies considering the people's culture, given that an understanding of the context is required for research, care, and for any type of advance that will have a beneficial impact on the population.⁹

Being a member of a society entails a mutual obligation to foster relationships between different people from all parts of the world. In addition, there are connected institutions and practices that are influencing each other in performing actions and having obligations of justice that arise between people by social processes. The social connectedness model points out that all agents contribute to the structural

⁸ Adriana Posada-Lopez, Marta Aida Palacio-Correa, and Andres A. Agudelo-Suarez, "Características Sociodemográficas y Clínicas de los Pacientes Tratados por Primera Vez por Cáncer Escamocelular Oral. Medellín, Colombia," *International Journal of Odontostomatology* 12, no. 3 (2018): 237–245.

⁹ Margaret Lombe, Chrisann Newransky, Tom Crea, and Anna Stout, "From Rhetoric to Reality: Planning and Conducting Collaborations for International Research in the Global South," *Social Work* 58, no. 1 (2013): 31–40.

processes they produce.¹⁰ This means that even if one lives in an area with abundant resources and services, including health, one must still contribute to social equality.

Within this responsibility, we can consider innovation as a resource to which people should contribute. This approach, when applied to healthcare, ensures that treatments and care should be available to all people, including the most vulnerable and hard-to-reach populations.¹¹ Belonging to a society, a nation or community makes us part of a collective where we are in constant contact with other people and have a responsibility to address the social problems we face, including health problems.

Hence, why are there differences in disease outcomes? For the Pan American Health Organization (PAHO), a population's health is linked to the socioeconomic situation, the cultural context, and the social values fostered by governmental and private actions.¹² Knowing the impact of socio-demographic factors and the environment, it is necessary to implement a preventive care model able to reduce the incidence of cancer and detect cancer in early stages to achieve a better cancer prognosis.

For health systems, on the one hand, it is fundamental to promote innovations because they will contribute to greater sustainability and foster the sharing of health benefits to the different communities in the world.¹³ When we consider innovation in cancer care, we can refer to the initiative promoted by PAHO to support advanced practice nursing in Latin America. Moreover, it is essential to promote interdisciplinary work teams

¹⁰ Iris Marion Young, "Responsibility and Global Justice: A Social Connection Model," *Social Philosophy & Policy* 23, no. 1 (2006): 102–130.

¹¹ Beatrice Halpaap, Rosanna W. Peeling, and Francois Bonnici, "The Role of Multilateral Organizations and Governments in Advancing Social Innovation in Health Care Delivery," *Infectious Diseases of Poverty* 8, no. 1 (2019): 81, 10.1186/s40249-019-0592-y.

¹² Organización Panamericana de la Salud, ed., *La Salud y los Derechos Humanos: Aspectos Éticos y Morales*, Publicación Científica No. 574 (Washington, DC: Organización Panamericana de la Salud, 1999).

¹³ Halpaap, Peeling, and Bonnici, "The Role of Multilateral Organizations and Governments."

that could address all aspects of people's lives and thus make possible a care that is adapted to people's particular reality.

On the other hand, there are efforts to create more inclusive models of care that reach out to larger sectors of the population. In Chile, advanced practice nursing centered on oncology was promoted in order to reduce problems of access and coverage, by training healthcare professionals with the ability to diagnose, treat, and follow up. This approach helps to reduce the current gap in oncology specialists. Working complementarily with a consolidated oncology medical team, nurses expand care opportunities for patients. In Chile, the contributions of the nursing profession have been incorporated in the National Cancer Plan 2018–2028 and in the National Cancer Law, enacted on October 2, 2020.¹⁴

Within the problems of access and coverage, the great territorial extent of Chile makes having oncology care centers in all regions of the country strategically impossible. This limitation requires that people travel from one region to another to have access to treatment options, with greater difficulty for the elderly or people with disabilities. Therefore, it is expected that promoting nurses with advanced skills and expertise will facilitate a greater distribution of specialized care throughout Chile and, at the same time, will contribute to diagnosis in early stages of the disease, which will improve the life expectancy of patients.

More generally, interdisciplinary work is necessary to provide comprehensive care, considering the people's social context for determining the level of health care required. Poverty inhibits access to basic resources, like housing and food, that, in the case of an oncology patient, must be in optimal condition to avoid complications associated with the treatments. Likewise, poor people are caught in a vicious circle: Poverty generates ill health and ill health maintains poverty.¹⁵ An appeal by Mother

¹⁴ Ministerio de Salud, "Ley N. 21.258: Crea La Ley Nacional del Cancer, Que Rinde Homenaje Postumo al Doctor Claudio Mora," 2020, www.bcn.cl/leychile/navegar?idNorma=1149004.

¹⁵ Adam Wagstaff, "Pobreza y Desigualdades en el Sector de la Salud," *Revista Panamericana de la Salud Publica* 11, nos. 5–6 (2002): 316–326.

Teresa of Calcutta states that poverty has not been created by God but by us because of our selfishness. In today's globalized world, in which diseases that affect poorer or less developed countries can affect the entire planet, we must care about the health of the most vulnerable as a matter of social justice and care for our home, the common home.

It is necessary to consider the cost-effectiveness of preventive programs, given that by investing in health promotion and disease prevention, they reach a large number of the population and fewer resources are spent at the hospital level. For the measures to be effective, they must be carried out with cultural competence. The health professional must consider the beliefs of the community to which he/she has to deliver health care since personal ideas in relation to the disease have a strong impact on adherence to treatment or healthy lifestyle habits.

Interesting is the perspective of Donald Berwick. He proposes that the major investment should be made in correcting the social determinants of health and not in continuing to build and provide care in large and expensive "repair workshops." These do not address low investment in health promotion and so fail to change human well-being.¹⁶ Thus, he proposes to base the motivation to change human well-being in health on what he calls the moral determinants of health, among which the most important is a strong sense of social solidarity in which people understand that they depend on each other to ensure the health of all.

In summary, globalization has allowed us to have a great connection between countries and communities, which has allowed us to know the impact that some diseases like cancer have around the world, and at the same time, has generated international collaboration through research, being able to know different realities, differentiating people according to their culture. However, as there are differences, we can see that not all people have the same access to health care at any level, violating fundamental ethical values. By having a social responsibility in the face of these disparities,

¹⁶ Donald M. Berwick, "The Moral Determinants of Health," *JAMA* 324, no. 3 (2020): 225–226.

we hope to continue contributing through innovation to better health care and the reduction of gaps in access and coverage. Among the countries following this line of action is Chile with the advanced practice nursing initiative.

It is expected that models of care will be created with preventive and intercultural approaches, while considering sociocultural factors. This motivation is aligned with the words of Pope Francis: “It is impossible to be ‘local’ in a healthy way without being sincerely open to the universal, without feeling challenged by what is happening in other places, without openness to enrichment by other cultures, and without solidarity and concern for the tragedies affecting other peoples” (*Fratelli Tutti*, no. 146).

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