

# The Right to Health at the End of Life: Palliative Care in Italy and in Peru<sup>1</sup>

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## Introduction

The international cooperation programme consists of a comparative study on the right to palliative care (PC) in Italy and Peru, as part of the right to health at the end of life, in the context of an exchange programme between Sapienza University of Rome and Piura University of Peru. Recently Maria Laura Malespina, Associate Professor of Civil Law in the Faculty of Law at Piura University (Lima Campus), stayed for three months in Rome (from December 2017 to February 2018) as Visiting Professor at the Department of Law and Economic Studies of Sapienza for a joint study of the topic with Giovanna Razzano, Associate Professor of Public Law in the above mentioned Department. During the same time the Italian Parliament was approving the Law n. 219/2017, on informed consent and advanced healthcare directives, relevant to end of life issues (Razzano, 2019a); during this time in Italy there was a lively debate, both in civil society and among scholars, because of the ethical, legal and clinical problems posed by the reform law.

Thanks to this bilateral agreement between Sapienza and Piura University, it was also possible that Silvia Lazzari, a student of the degree course in Law, enrolled in Sapienza at the School for Advanced Studies, enjoyed a period of internship in Piura University (during the first six months of the 2017/2018 academic year) and, after graduating, carried out a brief study on the Peruvian healthcare system, that is shown below.

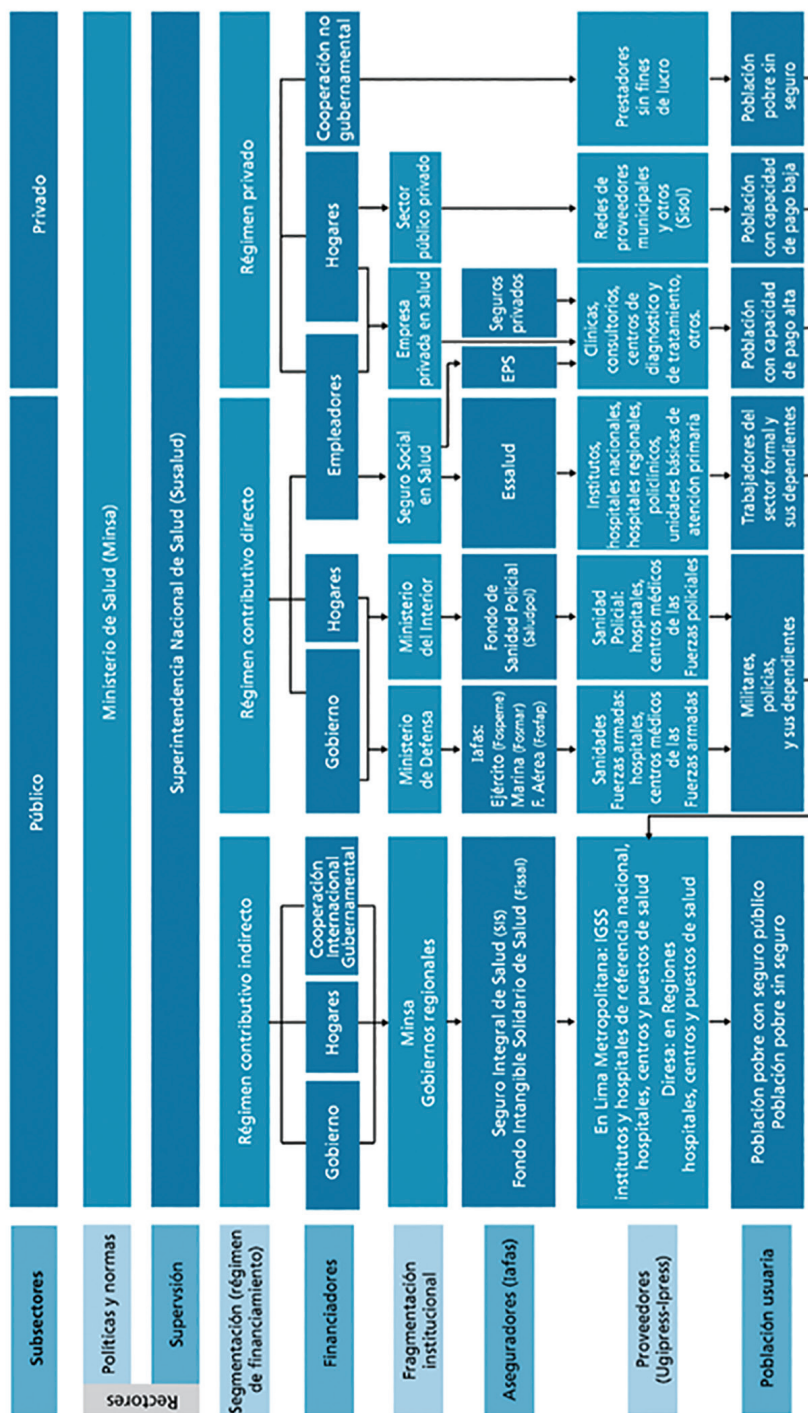
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<sup>1</sup> The work is the result of collaboration between the Authors. However, Prof. G. Razzano wrote paragraphs 1 and 3, while Dr. S. Lazzari wrote paragraph 2.

## The right to health in Peru: a general overview

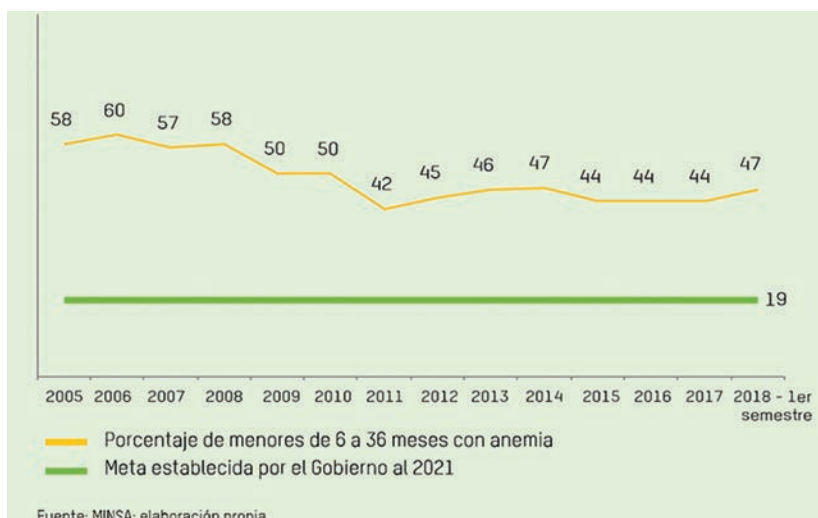
The Peruvian Constitution (the “*Constitución Política del Perú*”), does not encompass the right to health among the fundamental rights protected by the Constitution, whilst among the social and economic rights (*Capítulo II – De los derechos sociales y económicos*). In this respect, article 7 “*Derecho a la salud. Protección al discapacitado*” states that “*todos tienen derecho a la protección de su salud, la del medio familiar y la de la comunidad, así como el deber de contribuir a su promoción y defensa*”. Under the mentioned article, the Peruvian Constitution seems to grant an individual right to health as well as a collective right to health in the family and social dimension (“*la del medio familiar y la de la comunidad*”). Moreover, under article 11, the Peruvian State has the legal obligation to grant everybody’s access to healthcare through public, private or mixed institutions. Therefore, the right to health in Peru seems to have a strong programmatic content rather than a self-executive nature, consequently the positive action of the State is essential to give effect to the constitutional right.

The Peruvian health care system went through several reforms aimed at granting a widespread access to the healthcare. As it emerges from the graphic below (Alcade-Rabanal J., et al., 2016), it is characterized by (i) a strong fragmentation and a division between the public and the private sector, both supervised by the *Superintendencia Nacional de Salud* (“SUSALUD”), an entity under the Ministry of Health, established in the 2009 with Law no. 29344 and reformed in 2013 by Legislative Decree no. 1158; (ii) three different kinds of financing regime: (a) “*indirecto*” or subsidiary, which is dedicated to people in need; (b) “*directo*” which is financed by direct and compulsory contributions from workers; and (c) “*privado*” financed through the direct payment of the healthcare services; (iii) a strong role for the insurance sector with different insurers for each kind of financing regime, the “*Iafas*” (“*Instituciones administradoras de fondos del aseguramiento en salud*”): (a) the “*Seguro Integral de Salud - Sis*” and the “*Fondo Intangible Solidario de Salud - Fissal*”; (b) the “*Fospeme*” (for the military), the “*Fosmar*” (for the marina), the “*Fosfap*” (for the aeronautics), “*Fondo de Sanidad Policial*” (for the police) and “*Essalud*” (for other workers); (c) “*EPS*” and other *seguros privados*.



It is worth nothing that in Peru, as well as in many other Latin American countries, the need for universal healthcare insurance has been debated since the beginning of 2000 as part of the right to health. In Peru, it was affirmed in 2009 by Law no. 29344 "*Ley marco de aseguramiento universal en salud*", notwithstanding the considerable opposition of public opinion and professional colleges. The mentioned law was aimed at granting and regulating the universal health insurance system in order to endow everybody the full and progressive right to social health security. The main principles of this system are settled out in article 4 as follows: (i) universality; (ii) solidarity-based financing system; (iii) unity for the goal; (iv) integrity of the action; (v) fairness; (vi) irreversibility; and (vii) widespread participation. Moreover, based on the mentioned law, a minimum coverage of health services was established in the PEAS, the "*Plan Esencial de Aseguramiento en Salud*". Finally, the Decree no. 008-2010-SA affirmed that the affiliation to an insurance scheme was mandatory and established the different insurance regimes, as described above, based on each individual socioeconomic characteristic (EsSalud, 2013). After the reform, a strong increase in the access to insurance occurred and the *Seguro Integral de Salud – Sis-* founded in the 2002 and mostly dedicated to poor people-emerged as the main Iafas (Alcade-Rabanal J., et al., 2016). Observing the goals reached in the last ten years there is no doubt that the Peruvian healthcare system has been expanding and improving (PAHO, 2017a; PAHO, 2017b).

Without prejudice to the above, Peru (Oxfam 2019a), together with the other Latin American countries (Lusting, 2015), still have to deal with a very hard issue which is intimately linked to the right to health: social inequality (Barreto, 2017; Bascolo et al., 2020). Based on Oxfam's Report (Oxfam 2019b), the years 2017 and 2018 were sadly characterized for a downgrading of the measures taken in the social field, entailing growing inequality and severe impacts on the access to health. A significant evidence of that should be recognized in the increase in childhood anemia, a disease that entails a lower physical and mental development in children. In Peru this kind of disease affects about half of the children under three years of age, more than double of the OCDE's average. For this reason, in the 2017 the "*Plan Nacional para la Reducción y control de la anemia Materno Infantil y la Desnutrición Crónica Infantil en el Peru: 2017-2021*" was formally adopted, but, as showed in the graph below, between the 2017 and the 2018 the cases of childhood



anemia appear to have increased rather than reduced, due to the absence of effective measures.

In conclusion, a social-equality oriented approach seems to be of paramount importance to actually grant everyone's access to health-care. A cornerstone of this kind of approach should be identified in the respect for the dignity of the human person, which, pursuant to article 1 of the Peruvian Constitution, is the ultimate aim of the State and of the society as whole.

## Palliative care in Italy and in Peru

The starting point of the comparative study on the right to PC is the recognition of it as a primary human right by the World Health Organization (WHO) (Brennan, 2007; Connor, Sepulveda Bermedo, 2014). According to WHO's definition (WHO, 1990), PC involves a holistic approach, taking care of the patient's physical, spiritual and psychological wellbeing; it marked a new beginning, not only for the care of the dying but for the practice of medicine to a person as a whole (Saunders, 1990; 1995; 2008). PC is fundamental to improve quality of life, comfort and human dignity for individuals, being an effective person-centred health service that values patients' needs (WHO, 2013) and it is an essential part of the right to health, as well as a fundamental task of the education and training of medical doctors and healthcare personnel (Arias-Casais et al., 2019).

Recently the European Association of Palliative Care (EAPC) pointed out as 20-25% of all the patients need palliative care; that inappropriate hospitalization for people who need palliative care in the last six months of life impacts 70% of healthcare costs; that 35-45% of hospital beds are occupied by patients who need palliative care (EAPC, 2018). Lastly, on November 2018, the Parliamentary Assembly of Council of Europe adopted resolution 2249/2018, *The provision of palliative care in Europe*. The document is based on two main considerations: the first points out that hundreds of thousands of people in Europe still do not have access to adequate palliative care services and remain in a deep suffering condition for months or years, when this could be avoided with adequate treatment; the second one, on the other hand, concerns the issue of rationalizing the expenses of the health system, which is often used in an improperly way aggravating the costs. The main reason for the last is the lack of a prompt identification of the PC needs, with consequent difficulty to find services that offer good PC assistance. The resolution also recognizes the silent but essential role that is played by millions of informal caregivers who take care of the sick people for emotional reasons; figures who are destined to grow in the future, and who deserve all kinds of support from the institutions. Consequently, the resolution asks the acceding States to invest adequate resources in PC as it is a fundamental human right; also calls for integration at all levels of PC, especially where there are chronic patients and people resorting to life-saving treatments. States are then invited to remove bureaucratic and legal obstacles for the appropriate use of analgesics, including opioid drugs; to eliminate barriers that hinder informal caregivers from taking care of their loved ones and taking into account their needs; to invest in professional training in PC, both by qualifying it as a medical discipline, and by including it in the basic and daily training of medical doctors and nurses. The resolution also calls for increasing awareness of PC with media tools and information campaigns and for increasing collaboration between civil society and public institutions in structuring dedicated services. Finally, it invites governments to consult patients who resort to life-support treatments or live in addictive situations, with their families and associations, on issues pertaining to correct development policies in PC.

Furthermore, there is a negative relationship between poverty and the development of PC (Barbera L. et al., 2010; Cotogni P. et al., 2017; SIAARTI, 2013; Cohen J. et al., 2008; Brumley R. et al., 2007; Starks

H. et al., 2013). In Latin America, in particular, the main problem is still insufficient PC coverage, so that international support is necessary (Pastrana T. et al., 2012).

From a legal point of view the current Italian Law N. 38/2010 «Disposizioni per garantire l'accesso alle cure palliative e alla terapia del dolore» on the right to palliative care and pain therapy represents an interesting model, also useful for those legal systems, such as the Peruvian one, which are starting to introduce PC into its healthcare. According to the Italian law, PC assistance is qualified as «essential level of assistance and a priority objective of the national health system» and offers an interdisciplinary approach, according to WHO definition (treatment of pain and other physical, psychosocial and spiritual suffering). PC are also provided for children and their families and the right of access to pain drugs therapy is recognized too. At the moment Italy is trying to include PC in the basic training of medical doctors and other PC professionals, through specific Master Courses. Another challenge is to guarantee the PC throughout the whole national territory, since there are still gaps and shortcomings in many Regions. It is also necessary to implement early home PC. Italian pediatric hospices are still too few and the entire pediatric network is still lacking. As revealed by a survey conducted by the Social Affairs Committee of the Chamber of Deputies, only 10% of children who need PC have a chance to actually get it (Razzano, 2019b).

On the other hand, Peru has recently approved the Law N. 30846, “Ley que crea el Plan Nacional de cuidados paliativos para enfermedades oncológicas y no oncológicas” (19 Sep 2018), which authorizes to create a national PC plan. According to the law, the Ministry of Health is responsible for implementing the plan and convening specialized public and private companies and scientific societies. PC are therefore included in the National Health System, in order to achieve the improvement of the quality of life for the patients and for their families with an interdisciplinary approach (Art. 3). For having already passed these stages, the Italian legislation and the studies of the changes that took place in Italy are very useful to contribute in the discussion raised in the current Peruvian context. The cooperation program helped to form a new awareness. As advisor of the Instituto Nacional de Salud del Niño (the largest public children's hospital in the country), Prof. Maria Laura Malespina is now involved in issues like the dignity of the patient who is under-age, informed consent for minors, ethics and legislation and the interdisciplinary approach in PC (which has been part

of the hospital care since 2014). In addition to the interest of the Faculty of Law in the related legal and social issues, the Faculty of Medicine of Piura has also created the “Department of Basic Sciences and Bioethics”, which is focusing on situations such as those described.

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