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**A method in Clinical Ethics Consultation  
between normative theories and applied ethics**

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To my wife, Mara  
and our two little girls.

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## **Preface**

A few years ago a professor told me that research activity is possible only if it has been desired, contemplated and built upon since youth.

This path started eight years ago during a bioethics course at the University; during those lessons I heard about bioethics for the first time. After that course I began to study bioethics, in particular clinical ethics, in my opinion one of the most interesting and fascinating contemporary research fields. I decided to present my candidacy to a Doctoral Program after two degree theses in bioethics and pursuing a Master's Degree in Bioethics and Education. During the entrance exam I presented a research project regarding method in clinical ethics: I wanted know *how* an ethical issue can be resolved in a clinical setting and learn what type of relationship can exist between daily clinical activity and ethics reasoning.

This dissertation is a step in this research project, conducted as part of the doctoral program I started three years ago.

During this period I attended the Center of Clinical Ethics at the Icahn School of Medicine at Mount Sinai Hospital in New York (January-April 2014), under the tutelage of professor Rosamond Rhodes in order to learn how a Clinical Ethics Service functions in a Hospital and how to conduct ethics consultations in different medical

settings. Furthermore, I attended the Hastings Center in Garrison, NY, directed by Professor Mildred Z. Solomon, during May and June of the same year. My research project was directed to improve a theoretical approach to face ethics consultation.

I also worked as an intern, the Palliative Care Department at the Hospice in the Rehabilitation Center “Domus Salutis” in Brescia for eleven months, during the last year of my doctoral course.

During these three years my research has focused on the figure of the ethics consultant, more specifically about what kind of method he/she should apply to conduct an ethics consultation in concert with patient, family members, medical staff and administrative organs of a medical center.

The work which took place during these three years is described in the following pages. That professor who told me the secret to research activity now is my master. He has given me the possibility to improve my competencies in bioethics and clinical ethics. Many thanks, Professor, for all those times you encouraged me while I was learning.

## Introduction

Why is an ethics consultant called to resolve ethical controversies in a clinical context? What kind of core competences should an ethics consultant have?

These two general questions open a myriad of philosophical and medical considerations to which only a strong relationship between medicine and philosophy can offer virtuous responses.

Often researchers in Bioethics have conflicting ideas in particular about the field of the Clinical Ethics. Some safeguard the theoretical origin of the ethical reflection about daily clinic activity; others defend the medical field as the precise setting in which Clinical Ethics was born and is developing.<sup>1</sup>

A proper attitude might be to recognize that Clinical Ethics arises in both fields. Clinical and bioethics are inseparable, because ethics consultation is impossible without each one of them.

One goal of the following dissertation is to demonstrate how philosophy, in particular ethics, is necessary in medical practice to improve clinical ethics consultations; and, at the same time how medicine is the only *substratum* to improve clinical ethics

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<sup>1</sup> These considerations have been deduced from introductory lectures by Robert Baker, Rosamond Rhodes, George J. Agich and Stella Reiter to the ICCEC meeting occurred in New York, May 19<sup>th</sup>-22<sup>th</sup>, 2015. See also Jonsen AR, *The birth of bioethics*, New York, Oxford University Press, 1998, 6.

consultations. In particular, this research will be geared towards the theorization of a method that finds its epistemological validity and utility in clinical ethics in different socio-cultural fields.

The working hypothesis is to present a method of conducting a clinical ethics consultation, which can be applied in a pluralistic setting, not necessarily following a theoretically rigid form.

This method is called “hermeneutic circle method”, and its theorization – here presented - starts from the analysis and critique of the most important methods already present in clinical ethics.

To achieve this objective, the dissertation is structured in the following way.

The first part presents two reflections about Clinical Ethics Consultation and the history of the Italian working groups of Clinical Ethics Consultation.

The second one is divided into two parts. The first presents two ethics theories: *Principlism*, in particular as presented by Beauchamp and Childress and *Personalism*, as presented by Cardinal Elio Sgreccia.

The third part analyses the role of Hermeneutics and Casuistry, as presented by Gadamer and Jonsen. I then present a method of conducting ethics consultation, which derives from all these ethics theories.

All three ethics theories (Principlism, Personalism and Casuistry) are presented both in their general setting and as applied, with their respective methods, to real clinical cases in which an ethics consultation was required.

The difficulty in identifying one common certainty which can take on the role of general guidance, depends on the fact that the map of moral values in the contemporary world has been defined on one hand by an aspect of the concept of the *defense of life*, which presents the concept of “good”, towards which each individual tends by nature; and on the other hand by the principle of *protection of human dignity*, understood as the right to self-determination by the individual. Each of these two principles, in and of themselves different, must be taken into close consideration in order to analyze the clinical ethics question, because they are values experienced both by the caregiver and by those receiving care.



## **FIRST PART**

## What is Clinical Ethics Consultation?

The distinction between clinical research and clinical practice has dominated our conception of biomedical ethics for the last four decades... a distinction which is no longer tenable.

KIE Scholar Tom Beauchamp

*Healthcare Ethics Consultation* or *Ethics Consultation* is a specific field of bioethics and clinical ethics. The peculiarity of Ethics Consultation is the care of persons; in particular it “involves the identification, analysis and resolution of value conflicts or uncertainties that arise in the provision of health care in clinical setting”<sup>2</sup>. It is related to medicine, life sciences, philosophy, law and religion.

Ethics Consultation, as presented by the American Society for Bioethics and Humanities<sup>3</sup>, is “a set of services provided by an individual or a group in response to questions from patients, families, surrogates, healthcare professionals or other involved

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<sup>2</sup> Jennings B (ed.), *Bioethics*, vol. II, Farmington Hills, MacMillan USA, 2014<sup>4</sup>, 596.

<sup>3</sup> American Society for Bioethics and Humanities is an important scientific society for Bioethics. The ASBH was founded in January 1998 through the consolidation of three existing associations in the field: the Society for Health and Human Values (SHHV), the Society for Bioethics Consultation (SBC), and the American Association of Bioethics (AAB). [<http://asbh.org/>, last seen 8/2/2016].

parties who seek to resolve uncertainty or conflict regarding value-laden concerns that emerge in health care”<sup>4</sup>.

The specific figure who conducts an Ethics Consultation is called the *Healthcare Ethics Consultant* or *Ethics Consultant*. In daily clinical practice all healthcare specialists are calling to respond to ethical issues, the Ethics Consultant “differs from other healthcare professionals in that [he has] been assigned by [his] institutions the distinctive role of responding to specific ethical concerns and questions that arise in the delivery of health care, and therefore require a distinctive set of competences to perform this role effectively”<sup>5</sup>.

The goal of the consultant is to offer help regarding a correct decision, which will be taken by others. The choice must be as much as possible shared between patient, family members and health care team.<sup>6</sup>

Ethics consultation can be requested both by the patient and the family members to find clarification regarding their dilemmas and future choices, and by the physicians, nurses and health care staff as support in making the most appropriate choices and examining all options.<sup>7</sup> The administrative staff may also request the consultation, when it is needed to better explain the specifics of a clinical case or questions concerning health care policy.<sup>8</sup>

The clinical decision has technical and existential values, therefore all protagonists of a clinical case - patients, families, health care professionals - have an opinion to express, but not a refusal to make. This opinion cannot be segmented – the technical aspect regards the doctors and the existential profile regards the patient - and entails a mutual integration.<sup>9</sup>

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<sup>4</sup>American Society for Bioethics and Humanities, Core Competencies Update Task Force, *Core competencies for health care ethics consultation: A report of the American Society for Bioethics and Humanities*, Glenview, American Society for Bioethics and Humanities, 2011<sup>2</sup>, 2.

<sup>5</sup>Ibidem, 2.

<sup>6</sup>Delany C, Galvin J, *Ethics and shared decision making in paediatric occupational therapy practice*, Dev. Neurorehabil, 2013, 1-8.

<sup>7</sup>Weise KL, Daly BJ, *Exploring accountability of clinical ethics consultants: practice and training implications*. The American Journal of Bioethics, 2014,6:34-41; Finder SG, Bliton MJ, *Responsibility after the apparent end: following-up in clinical ethics consultation*. Bioethics, 2011;7:413-424; Hendrick J, *Legal aspects of clinical ethics committees*, Journal of Medical Ethics, 2001, 27:i50-i53.

<sup>8</sup>Godkin MD, Faith K, Upshur REG, MacRae SK, Tracy CS, *Project Examining Effectiveness in Clinical Ethics (PEECE): phase 1 – descriptive analysis of nine clinical ethics services*, J Med Ethics, 2005; 31: 505-512, 508.

<sup>9</sup>Deledda G, Moretti F, Rimondini M, Zimmermann C, *How patients want their doctor to communicate. A literature review on primary care patients' perspectives*, Patient Education and Counseling, 2013; 90: 297-306. Clayton JM, et al., *When and How to Initiate Discussion About Prognosis and End-of-Life*

The consultant acts for the good of those requesting a consultancy. The single clinical case is the starting point of the ethics consultation: the consultation is developed in both a specific setting and a particular relationship, it is inextricably linked to verbal and non-verbal communication skills and it is directly applicable to daily clinical practice.<sup>10</sup> The consultant's point of view must be "interlocutor oriented", helping him/her to consolidate the reasons of his/her positions, but must also underscore the critical issues regarding his/her observations.

In bioethics literature different approaches<sup>11</sup> to Ethics Consultation are described. The attitude of the *Ethics Consultation* can be collocated between two extreme approaches: the "authoritarian approach" and the "pure consensus approach". Both of these approaches present limitations and criticalities and therefore they are not recommended in conducting an ethics consultation.

The "authoritarian approach" emphasizes the figure of the Ethics Consultant "as the primary moral decision maker": "the moral values or perspectives of the consultant are more correct or important than the moral perspectives of other participants in the consultation".<sup>12</sup>

This approach minimizes other protagonists of a clinical case (patient, family, surrogates, the health care team), their values and their abilities to analyze ethics issues. Likewise, the "pure consensus approach" also presents some limits: "the aim of this approach is only to forge agreement among involved parties. It fails to incorporate the importance of ethically justified norms or values".<sup>13</sup>

The latter can be related to other two approaches, used by the Ethics Consultant particularly in relation to the Institution in which he/she works. The first defines the

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*Issues with Terminally Ill Patients*, Journal of Pain and Symptom Management, 2005; 30(2):132-144. Walczak A, et al., *Patient perspectives regarding communication about prognosis and end-of-life issues: How can it be optimised?*, Patient Education and Counseling 2013; 90: 307-314. Steinhäuser KE, et al., *Preparing for the End of Life: Preferences of Patients, Families, Physicians, and Other Care Providers*, Journal of Pain and Symptom Management, 2001; 22(3): 727-737. Parker SM, et al., *A Systematic Review of Prognostic/End-of-Life Communication with Adults in the Advanced Stages of a Life-Limiting Illness: Patient/Caregiver Preferences for the Content, Style, and Timing of Information*, Journal of Pain and Symptom Management, 2007;34(1): 81-93 . Hancock K, et al., *Discrepant Perceptions About End-of-Life Communication: A Systematic Review*, Journal of Pain and Symptom Management, 2007; 34(2): 190-200.

<sup>10</sup> Carrese JA, Sugarman J, *The inescapable relevance of bioethics for the practicing clinician*. Chest Journal, 2006;130:1864-72.

<sup>11</sup> Loughlin M, *Criticizing the data: some concerns about empirical approaches to ethics*, Journal of Evaluation in Clinical Practice, 2011;17: 970-975.

<sup>12</sup> American Society for Bioethics and Humanities, *Core competencies for health care ethics consultation: A report of the American Society for Bioethics and Humanities*, cit., 6.

<sup>13</sup> *Ibidem*, 7.

Ethics Consultant as a “peacemaker”, who tries to correct the mistakes which arise with ethical issues, minimizing the damage, and preventing their return: this type of *Ethics Consultation* “keeps the peace for hospital staff by smoothing over conflicts, he puts patients and families who have to make agonizing choices at peace by easing the burden of that decision making”.<sup>14</sup> The second one defines the *Ethics Consultation* as a “social activist”, it is a more motivated approach than that of the “peacemaker”, but it may create more difficulties: the *Ethics Consultation* identifies “the underlying institutional or structural features that generate ethical problems and change or remove them in a more sweeping effort at prevention”.<sup>15</sup>

Each one of these approaches present limitations and difficulties: the “authoritarian approach” doesn’t pay specific attention to those who are called to take the last decision. It could be considered a “paternalistic approach”, by which the physician unswervingly recommends the best treatment to the patient, who can’t reply, as he/she hasn’t been informed.

The “pure consensus” and the “peacemaker” approaches open a relevant question about the *Ethics Consultation*: must the choices be justified? During an *Ethics Consultation*, it is not sufficient that a choice be shared to make it “good”; it is necessary to justify it. A clinical ethical issue requires reasonable justifications to define a clinical choice as “good”.

Defining the Ethics Consultant as a “social activist” also presents a problem: could the Ethics Consultant be identified as a social reformer? The aim of *Ethics Consultation* is not “doing ethics” or making social and institutional reforms. The Ethics Consultant is attentive to the social and institutional contexts in which he works, but he is a specialist of clinical ethics and his activity is primarily oriented toward the patient.

The “ethics facilitation approach” is considered by international guidelines to be the best criterion to conduct an *Ethics Consultation*: “in this approach, the consultant helps to elucidate issues, aid effective communication, and integrate the perspectives of the relevant stakeholders. The consultant helps the relevant decision makers fashion a plan

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<sup>14</sup> Hoffmaster B, *Anatomy of Clinical Ethics Consultation*, Human Studies, 22:53-68. 1999, in Zaner RM, *Performance, Talk, Reflection, What is Going on in Clinical Ethics Consultation*, Dordrecht, Kluwer, Academic Publisher, 1999, 67.

<sup>15</sup> Idem.

that respects the needs and values of those involved that is within the bounds of ethical and legal standards”.<sup>16</sup>

Specifically the ethics consultant should carry out the following functions: providing consultations about clinical cases (the consultant with knowledge and training should be available to patients and medical staff to review a case, to offer informed and prudent counsel about ethical uncertainties, and to assist in mediating conflict for an ethical solution); supporting the drafting of guidelines of the institutional mission and the allocation criteria; ethical feed-backing about research protocols; systematic collection of ethical deontological documents (journals, books, encyclopedias, commentaries on judgments etc.); communicating with departments and ethicists operating on different levels (institutional, regional, national, international); connecting with the ethics committees (ethics committees and ethics consultants need each other, they are not identical or exchangeable, and their dialectic should be, in all cases, highly productive); planning, organizing and conducting continuous specific ethical training for the clinical équipe, individual health professionals, administrative organs and committees.

In particular, ethics consultation encompasses a variety of purposes<sup>17</sup>:

- guiding clinical practice (clarifying the issues, offering a roadmap for navigating ethical dilemmas, helping clinicians to sort out the relevant issues from those which are more tangential);
- contributing to the education of clinicians (prepare trainees to analyze the ethical dilemmas that arise frequently in clinical practice, development of core competencies – fostering understanding of basic concepts of medical ethics, development of skills in clinical moral reasoning, nurturing the attitudes and virtues that incline medical professionals to do their duty and be good physicians ;
- making academic contributions to medical ethics (highlighting advances in the field, providing insight, clarify issues, challenging accepted views, providing useful guidance for clinicians and researchers, spurring further discussions);
- informing biomedical researchers (laying out the factors that require attention in

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<sup>16</sup>American Society for Bioethics and Humanities, *Core competencies for health care ethics consultation: A report of the American Society for Bioethics and Humanities*, cit., 7.

<sup>17</sup> Considerations deduced from introductory lectures of Rosamond Rhodes at ICCEC meeting occurred in New York, May 19<sup>th</sup>-22<sup>th</sup>, 2015.

animal and subject research, guiding study design by explaining how to answer research questions efficiently, emphasizing the importance of always being humane and respectful);

-giving direction to health policy (being well-informed about issues in moral and political philosophy, and well-informed about the relevant medical facts and health systems concerns that are at issue).

The ethics consultant is called to offer arguments that are measured, fair, presented in the interest of the appropriate stakeholders, his/her contributions should be well-argued, well-organized and well-written.

A good ethics consultation should be: coherent with what we take to be good medical practice, illuminating about the ethical issues which emerge in a specific context, accurate and able to serve as moral compass and not to create confusion, reasonable using simple rules, because knowing the rules seems to make it easier to know how to avoid wrong doing – every simple rule has an exception, but morality requires making difficult judgments and taking responsibility for them, it involves living with the uncertainty of not knowing if you made the right call even if the decision has been shared – consistent with the all other protagonists of a clinical case , informed about the recommendations offered, and measured, paying serious attention to choosing words and avoiding exaggerations.

In a clinical context an ethical issue arises by doubt of a single (e.g. the patient) or two or more persons (e.g. family members, nurses, the medical team, administrators): “The ethics Consultant may listen empathetically [to their] moral distress and help to identify their values or commitments. In this way, [...] values can be discussed and considered openly, which can lead to creative and mutually respectful decisions. The consultant [...] may help him or her point out unrecognized implications of the relevant parties ‘views, allowing the primary decision maker(s) to come to more firmly grounded conclusions.”<sup>18</sup>

Ethics consultation can be requested by the patient and the patient’s family in order to establish clear definitions regarding their present dilemmas and their choices for the future. A consultation can also be requested by physicians, nurses and health care staff

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<sup>18</sup> American Society for Bioethics and Humanities, *Core competencies for health care ethics consultation: A report of the American Society for Bioethics and Humanities*, cit.,7.

as support regarding both what a most appropriate choice may be, and clarification of various available options. This perspective entails two requirements: firstly, the practice of medicine cannot be reduced to mere technique; secondly, the doctor - patient/family relationship must be considered the most convenient setting to make a free and conscious decision about a specific clinical case.<sup>19</sup>

The Ethics Consultant must certainly have specific multidisciplinary training both in ethics and in clinical, deontological, legal, economic and organizational fields in order to face ethics issues in a clinical setting. The clinical ethics consultation requires specific skills to offer help to the applicant about a choice that generally has implications for the patient's life. For these reasons, bioethics and clinical ethics are different, although they are not separate: specific clinical and legal skills could diversify the consultant's educational process from the bioethicist's. The specificity of the consultant's educational process entails attending both academic courses (Masters and Ph.D.) in order to obtain theoretical knowledge (philosophical, medical, legal, theological), and internships in hospital wards in order to acquire specific practical skills and aptitudes.<sup>20</sup> The prominence is given to the skills possessed<sup>21</sup>: teaching bioethics does not automatically mean being able to perform an ethics consultation, just as an ethics consultant might not have the skills to teach bioethics. Another issue revealed during this meeting concerns the affinity between ethics consultation and all

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<sup>19</sup> Nelson C, *The Familiar Foundation and the Fuller Sense: Ethics Consultation and Narrative*, Perm Journal, 2012;16(2): 60-63.

<sup>20</sup> In the international debate, there is not an official shared training program about the preparation of the clinical ethics consultant, but there are a lot of proposals about it. In Europe the Clinical Ethics Consultation has been of increasing interest during the past decade, clinical ethics services are already officially operating in the Healthcare realities of many other European Countries. In Italy there is no academic standard regarding the training of ethics consulting, therefore it seems to be only during postgraduate education that a formal graduate can acquire specific competences to lead an ethics consultation (in particular cases for those persons who do not have graduate training concerning healthcare). Dudzinski DM, Rhodes R, Fiester A, *Pedagogical Goals for Academic Bioethics Programs*, Cambridge Quarterly of Healthcare Ethics Cambridge University Press 2013; 22: 284–296. Hurst SA, Perrier A, Pegoraro R, Reiter-Theil S, Forde R, Slowther AM, Garrett-Mayer E, Danis M, *Ethical difficulties in clinical practice: experiences of European doctors*, J Med Ethics 2007; 33: 51–57. Akabayashi A (ed.), *The Future of Bioethics: International dialogues*, Oxford, Oxford University Press 2014; Gusmano MK, Rodwin VG, Weisz D, *Health Care in World Cities*, Baltimore, The Johns Hopkins University Press, 2010; Pegoraro R, Putoto G, Wray E (eds.), *Hospital based bioethics*, Padova, Piccin, 2007; Widdershoven G, Abma T, Molewijk B, *Empirical ethics as dialogical practice*, Bioethics, 2009; 23:236-248. European Association of Centres of Medical Ethics, *Eacme Newsletter*, 2015,n.4. Pfäfflin M, Kobert K, Theil SR, *Evaluating Clinical Ethics Consultation: A European Perspective*, Cambridge Quarterly of Healthcare Ethics, Cambridge University Press, 2009; 18: 406-409.

<sup>21</sup> Smith ML, *A possible solution, but not the last word*, The Hastings Center Report, 2009;39:3.



other types of medical consultations.<sup>22</sup> Medical advice is generally required when there is a doubt<sup>23</sup>, a dispute or a diversity of approach in relation both to the means and the ends (which can both be subject to judgment) to resolve a specific problem. An essential requisite for the consultant is to clearly and precisely show the different, scientifically documented, treatments which can cure the patient, illustrating his/her personal position, if requested, and leaving at the patient the last word, but not the only one, regarding his/her choice. The ethics consultant applies the same method.<sup>24</sup>

The goal of the consultant seems to be to provide help regarding making a decision which will often involve others. Choices must be, as much as possible, shared among the patient, the family and the health care team. The consultant acts for the good of those requesting a consultancy, with his/her specific skills and abilities.

Advancement of this new kind of healthcare profession is strictly related to train on specific competencies to face a lot of issue in the daily clinical practice<sup>25</sup> to find a good solution on single clinical case. This set of competencies does not concern only good abilities in ethics analysis<sup>26</sup>, but a set of things “including accurate factual information, effective communication skills, and the insights and contributions of a wide variety of professionals”<sup>27</sup>. In fact, patients and physicians could arrive to different choices in similar clinical situation: the possibilities to make different choices<sup>28</sup> are related to the fact that every medical case is original, univocal and the consciences of the protagonists could present different judgments.

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<sup>22</sup> American Society for Bioethics and Humanities, *Improving Competencies in Clinical Ethics Consultation*, Glenview, IL; American Society for Bioethics and Humanities, 2009: 57-58.

<sup>23</sup> Spike JP, *The Birth of Clinical Ethics Consultation as a Profession*, American Journal of Bioethics, 2014; 1:20-22.

<sup>24</sup> Geppert CMA, Shelton WN, *A comparison of general medical and clinical ethics consultation: what can we learn from each other?*, Mayo Clinic Proceedings, 2012; 4: 381-389; Caldjian LC, Weir RF, *A clinician's approach to clinical ethical reasoning*, Journal of General Internal Medicine, 2005; 20: 306-311.

<sup>25</sup> Agich GJ, *Education and the improvement of clinical ethics services*, BMJ Medical Education, 2013; 13:41.

<sup>26</sup> Gligorov N, Sommer TM, Tobin Ballato EC, Frank LE, Rhodes R., *Bridging the Gap between Knowledge and Skill: Integrating Standardized Patients into Bioethics Education*, Hastings Center Report, 2015; 45(5): 25-30.

<sup>27</sup> American Society for Bioethics and Humanities, *Improving Competencies in Clinical Ethics Consultation, An education Guide*, cit., 8.

<sup>28</sup> Niebroj L, *Bioethics of Life Programs: taking seriously moral pluralism in clinical setting*, Eur J Med Res, 2010, 15(Suppl. II): 98-101.

## Tarzian's code

Anita Tarzian presented, along with other authors, "A Code of Ethics and Professional Responsibilities for Health Care Ethics Consultants"; in their opinion the "consultants should regard this statement of responsibilities as authoritative".

Anita Tarzian's code<sup>29</sup> clarifies the Responsibilities of Health Care Ethics Consultants writing the following set of norms:

1. Be Competent. HCE<sup>30</sup> consultants should practice in a competent manner.
2. Avoid Conflicts of Interest. HCE consultants should identify and avoid, when possible, actual and perceived conflicts of interest. If it is not possible to avoid such a conflict, then it should be managed using ethically supportable strategies.
3. Manage Conflicts of Obligation. HCE consultants should clarify and manage potential conflicting obligations when they perform multiple roles within an organization.
4. Protect Confidentiality. HCE consultants should identify information that is confidential and ensure that such information is respected and shared in accordance with standards of ethics, law, and hospital policy.
5. Preserve Integrity. HCE consultants should preserve professional integrity by not engaging in activities that compromise their ability to fulfill the obligations of their role as HCE consultants, and by not accepting terms of employment that will prevent them from performing responsibilities with integrity. HCE consultants should avoid conflating expertise with authority or abusing power.
6. Make Responsible Public Statements. When addressing the lay public about HCE issues, HCE consultants should speak responsibly, and not make public statements outside of their area of expertise.
7. Contribute to the Field. HCE consultants should participate in the advancement of the profession through contributions to practice, education, administration, knowledge, and skill development.
8. Promote Just Health Care. HCE consultants should collaborate with other

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<sup>29</sup> Tarzian A, et al., *A Code of Ethics and Professional Responsibilities for Health Care Ethics Consultants*, American Journal of Bioethics, 2015; 15(5): 38-51.

<sup>30</sup> HCE means "Healthcare Ethics".

professionals and lay persons to promote a more just health care system.

To conclude this section it seems useful to quote a small insert which show U.S. data<sup>31</sup>, as reported in the last document of the American Society for Bioethics and Humanities, regarding which kind of professionals perform Ethics Consultations and how many ethics services are performed in the United States.

physicians 36%; nurses 30%; social workers 11%; chaplains 10%, administrators 10%; lawyers, philosophers, theologians 3%

In 68% of U.S. hospitals ethics consultation were generally performed by small teams (68%), as opposed to full committees (23%) or individual consultants (9%), with only 5% of ethics consultation being conducted by people who had completed a fellowship or graduate program in bioethics, and only 41% by people who had learned to perform ethics consultation with formal, direct supervision by an experienced member of an ethics consultation service.

After a general presentation about ethics consultation features, the next section focuses on the Italian debate about ethics consultation, illustrating the history of the Italian Working Group of Clinical Ethics and Healthcare Ethics Consultation.

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<sup>31</sup> Fox E, Myers S, Pearlman RA, *Ethics consultation in U.S. hospitals: a national survey*, American journal of bioethics, 2007;7(2): W1-3. In American Society for Bioethics and Humanities, *Improving Competencies in Clinical Ethics Consultation, An education Guide*, Chicago, American Society for Bioethics and Humanities, 2015<sup>2</sup>, 2.

## **History of the Working Group of Clinical Ethics Consultation in Italy.**

The Italian debate about the role of clinical ethics and ethics consultation has brought about the need to create a working group of Healthcare Ethics Consultants. The group began to take shape and to be organized in 2010; its activities are largely directed to share experiences, to analyze this field and to develop a professional profile of the clinical ethicist recognized throughout the nation.<sup>32</sup>

The working group of Clinical Ethics and Healthcare Ethics Consultation was the result of some initial meetings, and the group subsequently started to draft a Document about Clinical Ethics Consultation in Healthcare in Rome (June 2013). The Document was approved in Trento at the Kessler Foundation (October 2013) and undersigned by more than two hundred people. The newborn document was called “The Document of Trento”: it is the first Italian document regarding clinical ethics consultation.

Since 2010 the newborn working group of Clinical Ethics and Healthcare Ethics Consultants has organized meetings and conferences to debate about the situation of Clinical Ethics in Italy and the ways to perform Ethics Consultation. The goal that the organizers of the meetings have proposed is to make a contribution to developing clinical ethics services, especially in view of the fact that these services are already

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<sup>32</sup> I would like to thank Professors M. Picozzi and R. Pegoraro for recommendations on writing this section.

officially operating in the Healthcare realities of many other European Countries.<sup>33</sup> The first meeting was organized as a seminar by invitation, for those who were truly involved in the ethics consultation activity.

The preamble to the group works was the meeting “Towards professionalization in the bioethicist” regarding the ethics consultant and clinical ethics consultation, took place in January 2001 in Varese. National and international researchers discussed theoretical issues and practical consequences of the ethics consultation in the Italian health care system. Warren T. Reich wrote about the field of clinical bioethics in the preface of the volume that collects the proceedings of the meeting: “A common experience in today’s medical institutions is the struggle over the proper locus of bioethics as an academic discipline, and an underlying theme in clinical ethical consultations is the power struggle over which discipline should be dominant in shaping, governing, and managing those consultations. Put bluntly, the question is: Who “owns” clinical ethical consultation from academic, disciplinary and professional perspectives? Parochial disputes of this sort are not good for the field of clinical bioethics. We can neutralize those disputes by constantly asking the question: Where should our attention lie? How can we jointly turn our attention to the people, the values, and the issues that call out for our assistance?”<sup>34</sup> In addition, at the end of his speech, by recalling the differences between the American setting, where ethics consultation has been an established tool, and the European scenery, where it has only started to develop, Warren T. Reich warned that “those differences need to be respected; and each culture needs to promote its own investigations of the contours, methods and limits of clinical ethics and clinical consultation”.<sup>35</sup>

A decade later, those words have preserved their originality and significance with regards to the development of ethics consultation in the Italian context. New thinking has developed, different local experiences have been consolidated and others have taken their first steps, even though the profiles of the ethics consultant and the clinical ethics consultant have not been officially established in the Italian health care system.

The first meeting of the working group was organized in April 30<sup>th</sup> 2010 at the Department of Medicine and Public Health at the University of Insubria in Varese

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<sup>33</sup> See note 20.

<sup>34</sup> Reich WT, Preface, IX-XII in: Picozzi M, Tavani M, Cattorini P, *Verso una professionalizzazione del bioeticista. Analisi teoriche e ricadute pratiche*, Milano, Giuffrè, 2003.

<sup>35</sup> Idem.

among those who directly carried out ethics consultation. The goal was to begin drafting a picture of the current experiences of the ethics consultation services in the Italian health care system.<sup>36</sup> During this first meeting every participant was given the opportunity to explain his/her experience in the ethics consultation field, highlighting perspectives and issues. In that context twelve realities were presented. It was noted that consultation was generally conducted in three different ways: by the ethics committee, within the Department of Forensic Medicine, and by autonomous organizations. Two important aspects emerged from the seminar. First, the ethics consultation service was often handled as volunteer work, without an official acknowledgement<sup>37</sup> by the institution in which it was carried out, and without a formalization of the service. Secondly, the Department of Forensic Medicine<sup>38</sup> was the main author of the ethics consultation.

A second meeting took place in October 2010 at the Institute of Bioethics of the Catholic University in Rome. The working group discussed the historical development of ethics consultation. Clinical ethics was recognized as a branch of bioethics, but with its own distinctive aim of research oriented towards clinical cases<sup>39</sup>, and it was always considered in connection with a theoretical reflection about the reasons for the expressed judgments.

The third and fourth meeting took place in 2011, the first in April at the Lanza Foundation in Padua, the second in October at the Center for Clinical Bioethics of the Mediterranean in Cagliari. The main topic of the conferences was the undergraduate and postgraduate training in clinical ethics. Two aspects about the undergraduate courses were highlighted. The first regarded the different names of the academic courses on clinical ethics: it was decided that it could be advantageous to use the same diction as in the medical field (not only formal but substantial characteristic regarding teaching clinical ethics) because this teaching method is different from those of the human sciences and forensic medicine. The second concerned the need to lead the students with

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<sup>36</sup> Pegoraro R, Picozzi M, Spagnolo AG, *La Consulenza di Etica Clinica in Italia. Lineamenti e Prospettive*, Padova, Piccin, 2016.

<sup>37</sup> Miles S, Purtilo RB, *Institutional support for Bioethics Consultation*. In: Ausilio MP, Arnold RM, Youngner SJ, eds. *Ethics consultation. From Theory to practice*, Baltimore, The John Hopkins University Press, 2003:11-128.

<sup>38</sup> Benciolini P, *La medicina legale clinica*. *Rivista Italiana di Medicina Legale* 2005; 3: 451-459.

<sup>39</sup> Carrese JA, et al., *HCEC pearls and pitfalls: suggested do's and don't's for Healthcare Ethics Consultation*. *The Journal of Clinical Ethics*, 2012; 3: 234-240.

focused teaching both during the preclinical phase and in the following experience with the patients.

Postgraduate training in Italy was usually more focused on bioethics than on clinical ethics. A necessary specification about graduate degree training has emerged over the past four years. As has occurred in other Countries, in Italy as well there is no academic standard regarding training on ethics consultation. This issue underscores the importance of defining the professional profile of the clinical ethics consultant.

The fifth meeting occurred in April 2012 at Fatebenefratelli Hospital in Rome. The topic focused on the different models of ethics consultation. The international experience has shown that a single person, a small group, or the ethics committee of an institution can conduct an ethics consultation. Each of these models has its own potentialities and criticalities<sup>40</sup>. In the United States the dominant models are the single consultant and the small group<sup>41</sup>, whereas in Italy there is the experience, although limited, of the “ethics committee for clinical practice” in each single Local Health and Social Care Unit in the Veneto Region. The ethics committee is characterized by multi-tasking and pluralism, but at the same time it seems unsuitable to engage in both emergency situations and a daily relationship with the patient, the family, and the physicians. The ethics committee seems to be the best means to draw up recommendations and ethics guidelines about specific issues, as well as to supervise the consultations conducted by a single consultant or a small group, but it does not seem to be able to conduct daily ethics consultations. The small group seems to guarantee a pluralistic and multidisciplinary approach, as it has the opportunity to work with the patient and caregivers over a brief period. At the same time it presents the same criticisms: three ethicists with different backgrounds - clinical, juridical, ethical – could unduly burden the consultation, generating the suspicion that each ethicist is trying to defend his/her multidisciplinary position, rather than to support the patient in making his/her decision.<sup>42</sup> The single consultant might respond to emergencies and offer his/her space and time to listen to everyone involved. The limits of this model can be both the

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<sup>40</sup> Adams DM, Winslade WJ, *Consensus, clinical decision making and unsettled cases*, The Journal of Clinical Ethics, 2011; 4: 310-327.

<sup>41</sup> Troug RD, et al., *Microethics: the ethics of everyday clinical practice*. The Hastings Center Report 2015; 1: 11-17. Cho MK, et al., *Strangers at the bedside: research ethics consultation*. The American Journal of Bioethics, 2008; 3: 4-13.

<sup>42</sup> Rushton, Youngner, Skeel, cit., 2003: 88-95. Casarett DJ, Daskal F, Lanots J, *Experts in ethics? The authority of the clinical ethicist.*, The Hastings Center Report 1998; 6: 6-11.

difficulty for a single consultant to have the multiple skills required to conduct a consultation, and the risk of taking a directive or paternalistic approach. This issue, given its importance, was re-examined during the sixth meeting which took place in October 2012 in Verona. The working group suggested the model of the single consultant as preferable for practical reasons and also economic sustainability. Therefore the group underlined the importance of verifying the specific clinical ethics consultant's skills and competencies (not only considering his/her background – e.g. medical, philosophical, juridical education).

The considerations presented in the Document of Trento are the result of these above-mentioned meetings.

### **The Document of Trento**

The Document presents the definition of Healthcare Ethics Consultation as stated in the Report of the American Society for Bioethics and Humanities<sup>43</sup>. Clinical Ethics concerns the identification, analysis and resolution of bioethical issues current in ordinary clinical practice.

The Document of Trento is composed by five paragraphs: a) Ethical issues in clinical practice, 2) What is the Healthcare Ethics Consultation, 3) Who is the clinical ethics consultant, 3) Ethics Consultation Service, 5) The presence of Ethics Consultation in Healthcare Institutions.

The Document took two strong stances: it considered Ethics Consultation just as any other “medical” specialized consultation with some special features, and recognized the individual consultant as a more appropriate figure to conduct bedside consultations.

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<sup>43</sup> American Society for Bioethics and Humanities, cit., 2011, 2.



**DOCUMENT OF TRENTO**

(Approved on October 10<sup>th</sup>, 2013)

**1- The ethical issues in clinical practice**

The Mass Media reports almost daily cases that raise bioethical issues. This is also the experience of many health care providers and administrators as well as patients and their families, facing doubts and conflicts regarding clinical practice such as: IVF, the use of stem cells, the allocation of organs for transplantation, informed consent, the request to suspend treatments, the demand of psycho-physical enhancement treatments, the allocation of resources which are more and more limited, the need to ensure appropriate care without neglecting the ethical issues relating to new medical technologies. Bioethical issues do not apply only to exceptional cases, but to ordinary clinical practice as well. One might wonder whether, as a result of rapidly advancing medical technology these exceptional cases might become the rule: an ethical dilemma concerns all subjects involved in health care: what is it best thing to do in such situations? No one is alien to that or exempted from the question: from the patient, to the health care providers as well as the family and the health care institutions. For this reason, ethics is a central part of clinical practice and not auxiliary.

**2-What is Healthcare Ethics Consultation**

Health Care Ethics Consultation is “a service provided by an individual or a group for giving an answer to questions posed by patients, relatives, tutors, health professionals or other people involved in health care, about uncertainties and conflicts between values that can emerge in clinical practice” (A Report of the American Society for Bioethics and Humanities, Core competencies for Healthcare Ethics Consultation, 2a

ed., 2011, 2).

Ethics has a goal, which is to improve the care of the patients, with reference to both methods and results through the identification, analysis and resolution of ethical issues.

The Ethics Consultation is a specialist consultancy comparable to all other health care consultations, but with some special emphases and peculiarities: a more closely and focused approach to relationships, dialogue, and pluralism, both in contents and methods.

### **3-Who is the Clinical Ethics Consultant**

To perform ethics consultation it is necessary to have a specific knowledge of ethical, clinical and legal topics. For this reason, the health care ethics consultant is a new professional figure. Therefore, in the characterization and definition of his/her professionalism, what matters are skills and abilities which regard clinical ethics.

This figure requires specific training. Although there is no *core curriculum*, there are Master's and Ph.D. degrees, which will be targeted to Ethics Consultation. Simple training in bioethics is not sufficient: an adequate and specific education is needed to address issues "by the bedside of the patient", as well as at the decision-making level in healthcare. As an example, it is necessary to train professionals to be able to respond to emergency situations. The ethics consultant isn't an intermediary, a defense attorney, a spiritual consultant or a psychologist; he creates the conditions, he leads and helps subjects in taking an ethically sound and possibly shared decision.

The international experience shows that ethics consultation can be carried out by a single person, a small group, or the ethics committee. Each mode has its own potentials and criticalities.

### **4-Ethics Consultation Service**

It is desirable that the Healthcare Ethics Consultation be integrated in an Ethics Consultation Service with a single ethics consultant or a small team. This service would ensure continuity and sustainability in different fields such as ethics

consultation, the training of all the operators, the support to the work of ethics committee, research in bioethics and the development of ethics in health care institutions. If we consider the Italian situation which is still marked by a lack of experience in institutionalized ethics consultation, we believe that the model of the single ethics consultant is, for reasons of feasibility and sustainability, to be preferred. The ethics committee, when effective, would play a role in the review of consultations and in the discussion about more general topics which often emerge in critical situations while making recommendations and offering ethical guidelines.

### **5-The presence of Ethics Consultation in the Healthcare Institution**

We believe it is crucial that an ethics consultation service be offered in hospitals, in nursing homes, in healthcare institutions, in social care homes and in hospices. Wherever such service is already effective we think that an institutional recognition should be formally given for several reasons: ethical issues in clinical practice are more and more relevant for patients, care-givers, families and administrators; there is finally a consolidated profile of skills and abilities of the ethical consultant along with specific training programs designed specifically for this educational background; ethics consultation is internationally considered not just merely effective, but also efficient; health care institutions need be able to respond to moral issues in order to achieve accreditation (see for example the requirements of the Joint Commission on accreditation of Healthcare Organizations).

The ways to implement Ethics Consultation can be different: the Institution can integrate the Ethics Consultation in its own organization or it can outsource Ethics Consultation as a service. We believe that specific training programs for ethics consultants should be promoted and we strongly recommend that in Italy a bioethical service be introduced and nurtured as soon as possible.

The Document resulted from a choral work of people with different cultural backgrounds who perform clinical ethics consultations in different ways; it was promptly endorsed by more than two hundred people. This Document is an Italian first step towards improving both the role of clinical ethics and healthcare ethics

consultation, and the method of conducting an ethics consultation as a central part of clinical practice to better treat the sick and dying.

The first public presentation of the Document occurred on March 27<sup>th</sup> 2014 in Rome. It generated an interesting debate about the practical need for Ethics Consultation Services and the role of the clinical ethicist in Italian hospitals: this last topic in particular has stimulated discussions between physicians and philosophers.

For these reasons, after exactly one year, on March 27<sup>th</sup> 2015 at Insubria University (Varese) a meeting regarding Clinical Ethics Consultation in the Italian Healthcare System was organized.<sup>44</sup> The working group on Clinical Ethics and Healthcare Ethics Consultation promoted the conference. The debate focused on some important, previously explained, points: the role of the ethics consultant in a pluralistic social context; the ethics consultant's competencies; the functions of the consultant; and the similarities and differences between ethics consultation and all the other types of medical consultation. The meeting was divided into two parts. During the first phase, various theorists, philosophers and bioethicists presented the theoretical and philosophical meaning of ethics consultation in health care system. The second, more clinical phase was oriented towards reflections on the role of the ethics consultant in everyday clinical practice. The lecturers, specialists in different fields of medicine, made the focal point of their speeches, each one from their own specific vantage point, the issue and, indeed, the need to rely on Clinical Ethics Services in order to perform their daily medical tasks.

The considerations presented in the Document of Trento regarding the aims of Ethics Consultation (“improving the care of patients, with reference to both methods and results through the identification, analysis and resolution of ethical issues”<sup>45</sup>) were the core concept and the impetus for all of the reports.

This document was well accepted by all the speakers, with some clarifications, in particular regarding the tasks of the ethics consultant. The following were specifically highlighted: the need to be present near the health care team to engage ethical issues in the daily clinical practice; the need for adequate training to operate in different social

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<sup>44</sup> Cfr. *Medicina e Morale*, 2015,6 (in press).

<sup>45</sup> American Society for Bioethics and Humanities, cit., 2011, 2.

and cultural contexts<sup>46</sup>; and the necessity to improve a methodologically rigorous activity of research, given that ethics consultation is also an integral part of the clinical environment.<sup>47</sup>

After these meetings, the Working group is paying specific attention to the organization and concrete activities of a clinical ethics services. Therefore it is developing three courses of the research. The first topic focuses on the training in clinical ethics both for the specialist consultant, and for the health workers. The second one concerns the organization of the ethics service in a hospital or in other healthcare centers (e.g. private clinic, hospice and nursing home). The third takes on the evaluation about the quality and the efficiency of the clinical ethics service.

This first part has presented peculiar characteristics of the ethics consultant and the Italian situation about ethics consultation. In the second part two ethics theories, *Principlism* and *Personalism* are presented. The second part focuses on the investigation and critiques of these theories and the analysis of clinical cases following the methods originated from them.

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<sup>46</sup> Jonsen AR, Siegler M, Winslade WJ, Clinical Ethics, *A practical approach to ethical decisions in clinical medicine*, New York, McGraw Hill, 2010, 2.

<sup>47</sup> Giannini A, Pessina A, Tacchi E, *End-of-life decisions in intensive care units: attitudes of physicians in an Italian urban setting*. Intensive Care Medicine, 2003; 29: 1902-1910; Bertolini G, et al., *End-of-life decision-making and quality of ICU performance: an observational study in 84 Italian units*. Intensive Care Medicine, 2010; 9: 1495-1504.

## **SECOND PART**

## **Principlism and Kidney Transplant**

### **The AMA Code of Medical Ethics**

The Principles of Medical Ethics are contained in the *Code of Medical Ethics* of the American Medical Association (AMA). The first nine ethics principles presented in the Code are the most important of more than two hundred ethical issues in Medicine: “a single Principle should not be read in isolation from others; the overall intent of nine Principles, read together, guides physicians’ behavior”.<sup>48</sup>

The origins of Ethical Principles regarding the medical profession come from the Oath of Hippocrates (Fifth century BC), one of the most important declarations about medical principles. In the past, this set of principles “protected the rights of the patient and appealed to the inner and finer instincts of the physician without imposing sanctions or penalties on him or her”. It was Christianized between the tenth and the eleventh centuries “to eliminate reference to pagan gods”<sup>49</sup> and after other developments it has

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<sup>48</sup> AMA Council on Ethical and Judicial Affairs, *Code of Medical Ethics*, American Medical Association, 2012, Preface.

<sup>49</sup>AMA Council on Ethical and Judicial Affairs, *Code of Medical Ethics*, American Medical Association, 2012, History. “The most significant contribution to Western medical ethical history subsequent to Hippocrates was made by Thomas Percival, an English physician, philosopher, and writer. In 1803, he published his Code of Medical Ethics”.

lasted as a milestone<sup>50</sup> until now: “at the first official meeting of the American Medical Association (AMA) at Philadelphia in 1847, the two principal items of business were the establishment of a code of ethics and the creation of minimum requirements for medical education and training. The AMA’s first adopted Code of Ethics was based on Percival’s Code”.<sup>51</sup>

In the Preamble it is written, before the first nine Principles that: “The medical profession has long subscribed to a body of ethical statements developed primarily for the benefit of the patient. As a member of this profession, a physician must recognize responsibility to patients first and foremost, as well as to society, to other health professionals, and to self. The following Principles adopted by the American Medical Association are not laws, but standards of conduct which define the essentials of honorable behavior for the physician”.<sup>52</sup>

The first nine Principles are:

- 1- A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights.
- 2- A physician shall uphold the standards of professionalism, be honest in all professional interactions, and strive to report physicians deficient in character or competence, or engaging in fraud or deception, to appropriate entities.
- 3- A physician shall respect the law and also recognize a responsibility to seek changes in those requirements which are contrary to the best interest of the patients.
- 4- A physician shall respect the rights of patients, colleagues, and other health professionals, and shall safeguard patient confidences and privacy within the constraints of the law.
- 5- A physician shall continue to study, apply, and advance scientific knowledge, maintain a commitment to medical education, make relevant information available to patients, colleagues, and the public, obtain consultation, and use the talents of other

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<sup>50</sup> Baker RB, Caplan AL, Emanuel LL, Latham SR (eds.), *The American medical ethics revolution*, Baltimore, The Johns Hopkins University Press, 1999: 159. The single most important figure was the philosopher-physician John Gregory (1724-73). He presented the lectures to the University of Edinburgh medical students that gave rise to the most important volume of the day: *Lectures on the Duties and Qualifications of a Physician* (Gregory 1772). He influenced decisively the work of Thomas Percival (1740-1804).

<sup>51</sup> AMA Council on Ethical and Judicial Affairs, *Code of Medical Ethics*, cit., History.

<sup>52</sup> AMA Council on Ethical and Judicial Affairs, *Code of Medical Ethics*, cit., XV. This Code has been adopted since June 1957; and it has been constantly revisited.



health professionals when indicated.

6- A physician shall, in the provision of appropriate patient care, expect in emergencies, be free to choose whom to serve, with whom to associate, and the environment in which to provide medical care.

7- A physician shall recognize a responsibility to participate in activities contributing to the improvement of the community and the betterment of public health.

8- A physician shall, while caring for a patient, regard responsibility to the patient as paramount.

9- A physician shall support access to medical care for all people.

The *Code of Medical Ethics* also offers a definition of *Ethics Consultation* and it includes guidelines about Clinical Ethics Services.

## **2- AMA Ethics Consultation Guidelines**

The AMA guidelines present some directives regarding the circumstances and modalities that make possible the establishment of an ethics consultation service.

According to the *Code*, ethics consultation could be conducted by an ethics committee, or its subset, by an individual consultant, or by a consultation team. The ethics consultation should be called: “to clarify ethical issues without reference to a particular case, facilitate discussion of an ethical dilemma in a particular case, or resolve an ethical dispute”.<sup>53</sup>

The Code presents guidelines about ethics consultation. They are:<sup>54</sup>

1- All hospitals and other health care institutions should provide access to ethics consultation services. Health care facilities without ethics committees or consultation services should develop flexible, efficient mechanisms of ethics review that share the burden of committee functioning among collaborating health care facilities.

2- Institutions offering ethics consultation services must appreciate the complexity of the task, recognizing the potential for harm as well as benefit, and act responsibly. This includes true institutional support for the service.

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<sup>53</sup> AMA Council on Ethical and Judicial Affairs, *Code of Medical Ethics*, cit., 362.

<sup>54</sup> *Ibidem*, 362-363.

3- Ethics consultation services require a serious investment of time and effort by the individuals involved. Members should include either individuals with extensive formal training and experience in clinical ethics or individuals who have made a substantial commitment over several years to gain sufficient knowledge, skills, and understanding of the complexity of clinical ethics. A wide variety of background training is preferable, including such fields as philosophy, religion, medicine, and law.

4- Explicit structural standards should be developed and consistently followed. These should include developing a clear description of the consultation service's role and determining which types of cases will be addressed, how the cases will be referred to the service, whether the service will provide recommendations or simply function as a forum for discussion, and whether recommendations are binding or advisory.

5- Explicit procedural standards should be developed and consistently followed. These should include establishing who must be involved in the consultation process and how notification, informed consent, confidentiality and case write-ups will be handled.

6- In general, patient and staff informed consent may be presumed for ethics consultation. However, patients and families should be given the opportunity, not to participate in discussions either formally, through the institutional process, or informally.

7- In those cases where the patient or family has chosen not to participate in the consultation process, the final recommendations of the consultant(s) should be tempered.

8- In general, ethics consultation services, like social services, should be financed by the institution.

9- A consultation service should be careful not to take on more than it can handle, i.e., the complexity of the role should correspond to the level of sophistication of the service and the resources it has available. As a result, some services may offer only information and education, others a forum for discussion but not advice, others might serve a mediation role, and some might handle even administrative or organizational ethics issues.

Today this does not seem to be enough to be applied to daily clinical practice, since a general set of values can create various difficulties as regards resolving concrete ethical issues which can arise in specific clinical cases.

Therefore, another set of principles seems to be required, which lies somewhere between general principles and clinical practice.<sup>55</sup> These mid-level principles, as presented by Beauchamp and Childress<sup>56</sup>, can be used to resolve bioethical controversies.<sup>57</sup>

Beauchamp and Childress refer to the single and concrete situation in order to balance these different principles,<sup>58</sup> because they are important<sup>59</sup>:

- 1- To resolve moral controversies between individuals with similar moral sentiments but different theoretical approaches;
- 2- To explore and compare the ways in which different theories reconstruct the same set or similar sets of moral sentiments and intuitions;
- 3- To determine the differences among moral views and their implications for bioethics and health care policy, but not
- 4- To resolve controversies between individuals who do not share the same moral vision or moral sense.

### **Beauchamp and Childress' *principles***

The *four-principle approach*, or *principlism*, attempts to examine ethics aspects of a biomedical question. They derive from “considered judgment”<sup>60</sup> in the common morality and daily activities of healthcare professionals.

They are:

**Respect for autonomy:** respecting the decision-making capacities of autonomous persons; enabling individuals to make reasoned informed choices.

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<sup>55</sup> Post SG (ed.), *Encyclopedia of Bioethics*, 3 ed., vol.2, New York, MacMillan, 2003, 821.

<sup>56</sup> Beauchamp TL, Childress JF, 1979, *Principles of Biomedical Ethics*, New York, Oxford University Press, 2009<sup>6</sup>. Engelhardt HT Jr, *The foundations of Bioethics*, New York, Oxford University Press, 1996<sup>2</sup>, 56.

<sup>57</sup> Some other ethical norms are considered basic moral notions, whose aims are to act as normative guides: “these guides, depending on their level of specificity, can serve either to motivate behavior directly or to justify and make sense out of other, more detailed, action directives”. Meyers C, *A Practical Guide to Clinical Ethics Consulting*, Lanham, Rowman & Littlefield, 2007: 36. These norm will not be presented in this dissertation, because they does not present a method to conduct an ethics consultation.

<sup>58</sup> Mordacci R, *Una introduzione alle teorie morali, confronto con la bioetica*, cit., 84.

<sup>59</sup> Engelhardt HT Jr, *The foundations of Bioethics*, cit., 58.

<sup>60</sup> Beauchamp TL, Childress JF, *Principles of Biomedical Ethics*, cit., 25.

**Non maleficence:** avoiding the causation of harm; the healthcare professional should not harm the patient. All treatment involves some harm, even if minimal, but the harm should not be disproportionate to the benefits of treatment.

**Beneficence:** considers the balancing of benefits of treatment against the risks and costs; the healthcare professional should act in a way that benefits the patient.

**Justice:** distributing benefits, risks and costs fairly; the notion that patients in similar positions should be treated in a similar manner.

### **a- Respect for Autonomy**

The principle of Autonomy of a subject defends the decision-making capacities of autonomous persons. It is used and approved especially in contemporary society, but at the same time, it is the principle that mainly requires many specifications regarding its role and its implications in healthcare settings where there are many individual subjects.

Beauchamp and Childress write “respect of autonomy is not excessively individualistic (thereby neglecting the social nature of individuals and the impact of individual choices and actions on others), not excessively focused on reason (thereby neglecting the emotions), and not unduly legalistic (thereby highlighting legal rights and downplaying social practices and responsibilities)”<sup>61</sup>.

The principle of respect for autonomy does not seem to give the subject full independence regarding his/her own actions. Respect for the individual’s actions primarily entails not harming other persons (negative obligation). It implies a duty to acknowledge some specifics of this principle, like the “right and obligations of liberty, privacy, confidentiality, truthfulness, and informed consent”<sup>62</sup>. Secondly, the respect for autonomy implies a specific dialogue, between caregiver and patient, in order to disclose this information so that the patient is able to take autonomous decisions (positive obligation): “many autonomous actions could not occur without others” material cooperation in making options available; respect for autonomy obligates professionals in healthcare and research involving human subjects to disclose

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<sup>61</sup> Beauchamp TL, Childress JF, *Principles of Biomedical Ethics*, cit., 99.

<sup>62</sup> *Ibidem*, 104.

information, to probe for and ensure understanding and voluntariness, and to foster adequate decision making”<sup>63</sup>.

These two slides of the respect for autonomy are related to other moral rules, like the following<sup>64</sup>:

- Tell the truth;
- Respect the privacy of others;
- Protect confidential information;
- Obtain consent for interventions with patients;
- When asked, help others make important decisions.

The essential basis of the principle of autonomy is the capacity for autonomous choice and as a consequence the consent about the treatment, the care or the medical procedure: “consent should refer to an individual’s actual choices, not to presumptions about the choices the individual would or should make.”<sup>65</sup> It could be expressed or tacit, but an important question seems to be related to the previous step: how does the autonomous patient choose?

Some patients encounter various difficulties in making choices about their present or future medical treatments because they probably do not have a complete set of competencies<sup>66</sup> necessary to make an adequate judgment: competence could vary from hour to hour; sometimes a competent person who can usually select appropriate means to reach his or her goals will act incompetently in a particular circumstance”<sup>67</sup>.

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<sup>63</sup> Idem.

<sup>64</sup> Idem.

<sup>65</sup> Beauchamp TL, Childress JF, *Principles of Biomedical Ethics*, cit., 107.

<sup>66</sup> Culver CM, Gert B, *Philosophy in Medicine*, New York, Oxford University Press, 1982: 123-126, In Beauchamp TL, Childress JF, *Principles of Biomedical Ethics*, cit., 112. The concept of *competence* could be defined as “the ability to perform a task”. This criteria can change by the different contexts in which a person is called to choose and by different abilities owned by the decision-maker.

<sup>67</sup> Beauchamp TL, Childress JF, *Principles of Biomedical Ethics*, cit., 112.

## **b- Non Maleficence**

The second principle presents the obligation to not cause harm and to not impose risks of harm on others<sup>68</sup>: “*primum non nocere*”. This principle can be elaborated using other rules, such as:

- Do not kill;
- Do not cause pain or suffering;
- Do not incapacitate;
- Do not cause offense;
- Do not deprive others of the goods of life.

It is significant that this principle and its specifications are *prima facie*, not absolute<sup>69</sup>: “all general moral norms are justifiably overridden in some circumstances, [...] Principles, duties, and rights are not absolute merely because they are universal”<sup>70</sup>.

Following Beauchamp and Childress’ line of reasoning, the observance of not inflicting harm is related to some other fields of bioethics and clinical ethics, such as the concept of *Proportionality* and the rule of *Double Effect*.

The concept of proportionality is related to the themes regarding *withholding* and the *withdrawing* of Treatments<sup>71</sup>, and the distinction between *ordinary* and *extraordinary* Treatments.

### **The concept of proportionality: an historical development.**

The concept of proportionality is related to the concept of *ordinary* and *extraordinary* means of conserving human life, which has been developing in philosophical and

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<sup>68</sup> Ibidem, 149,153.

<sup>69</sup> Ibidem, 153.

<sup>70</sup> Ibidem, 15. For example, we might justifiably not tell the truth to prevent someone from killing another person; and we might justifiably disclose confidential information about a person to protect the rights of another person.

<sup>71</sup> Terman SA, *Is the principle of Proportionality Sufficient to Guide Physicians Decisions Regarding Withholding/Withdrawing Life-Sustaining Treatment After Suicide Attempts?*, The American Journal of Bioethics, 2013; 13(3): 22-24.

theological moral traditions the since XVI century. Only since 1980 has this set of terms been changed to *proportionate* and *disproportionate* means. This latter set of terms better interprets the relationship with the concept of *person*.<sup>72</sup> Caring for the person is the center of the question regarding whether a clinical choice is “good”. Moral tradition started to look at this question addressing the issue of suicide, thanks to St. Thomas: «a man has the obligation to sustain his body, otherwise he would be a killer of himself [...] by precept, therefore, he is bound to nourish his body and likewise, we are bound to all the other items without which the body cannot live».<sup>73</sup> No theologians immediately following St. Thomas developed a position which differed from his regarding suicide.

In the Catholic moral tradition, after St Thomas, three fields concerning the difference between ordinary and extraordinary means of conserving human life can be identified.<sup>74</sup>

1- In the XVI-XVII centuries the main factors used to explain the difference between ordinary and extraordinary means are related to food and drugs.

During the XVI century the main commentary on *Secunda Secundae* of St. Thomas is the *Relectiones Theologicae* by the Spanish Dominican F. de Vitoria (†1546). Vitoria explains his position on the relationship between a patient’s life and the questions regarding administering food and drugs. He writes in the chapter *Relectio de Temperantia*: «If one uses foods which men commonly use and in the quantity which customarily suffices for the conservation of strength, even though from this his life is shortened, even notably and this is noticed, he would not sin... From this, the corollary follows that one is not held to use medicines to prolong his life even where the danger of death is probable, for example to take for some years a drug to avoid fevers or anything of this sort»<sup>4</sup>. For F. de Vitoria there is no obligation to use all means available to conserve one’s own life: it is morally admissible to use only the proportioned mean designated to this end.<sup>75</sup>

This omission is not equivalent to a suicide, but to living using only the ordinary

<sup>72</sup> Spaemann R, *Persone*, Roma Bari, Laterza, 2007; 31.

<sup>73</sup> Thomas S. *Super Epistolas S. Pauli*. Taurini-Romae, Marietti, 1953; II thess, lec. 11, n. 77.

<sup>74</sup> Smith RE, *Conserving Human Life*, Massachusetts, Pope John XXIII Medical-Moral Research and Educational Center, 1989: 32-76.

<sup>75</sup> Vitoria F, *Relectiones Theologicae*, Lugduni, Relectio de Temperantia, 1587: n.1.

means possible to put off imminent death. In general only food is recognized as an ordinary means, but not in every instance – a sick person is excused from taking food only when there is limited or no hope of life.<sup>76</sup>

2- In the XVII-XX centuries another study-question emerged: can the mutilation of a limb or an essential part of the body be evaluated as an extraordinary means to conserve a human life?

The Jesuit Francisco Suarez (†1617) in his *Opera Omnia* asserts that the mutilation of «a principal member is almost equivalent to death, for this reason a man is not bound to undergo it in order to save his life»<sup>77</sup>.

Regarding amputation, Suarez explains that the reasons for differentiating ordinary means from extraordinary means are related to pain: no one has the duty to conserve his life if suffering is tremendous and the result is uncertain. The exception, as Cardinal De Lugo (†1660) writes, concerns a person *whose life is very necessary for the public good*<sup>78</sup>. A person can accept the order to be operated (mutilated) but only on the condition that the outcome will be safe and certain.

N. Mazzotta (†1746) in his *Theologia Moralis* explains the features of the extraordinary means (therefore not mandatory): 1- there is no hope of recovery, 2- great horror or torment, 3- extraordinary expenditure. These would excuse a person from employing these means.<sup>79</sup>

3- The moral reflection changes with the introduction of the modern use of the *anesthesia* (from the XIX century to 1957).

The physician C. Capellmann applies traditional moral theological principles to modern medical science. In his opus *De Operationibus Vitae Periculum Afferentibus* he mentions the obligation of conserving one's life and the duty to submit to treatment, now considered safer, if one's life is at risk. Pain is no longer the criterion which justifies the withholding of a surgical operation. But anesthesia doesn't necessarily remove the concept of extraordinary means regarding a difficult surgical

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<sup>76</sup> Sayrus G, *Clavis Regia Casuum Conscientiae*, Lib. VII, Cap. IX, n.38.

<sup>77</sup> Suarez F, *Opera Omnia*, Paris, Berton, Vives, 1858; tom. XII, disp. 9, sect. 3, concl. 5.

<sup>78</sup> De Lugo J, *De Justitia et Jure*, disp. 10, Sect. I, n. 21.

<sup>79</sup> Mazzotta N, *Theologia Moralis*, Venetiis, 1760, tom I, tract. II, disp. II, quaest. I, cap.I.



operation. This clinical data made a significant impact on choices of treatment, given the new, more readily available resources. As A. Lanza and P. Palazzini write in their *Theologia Moralis* (1955), extraordinary means should be decided in individual cases, in which no one has the duty to undergo a *grave incommodum* – serious disadvantages – to conserve his life.<sup>80</sup>

4- Since 1957 there have been some important pronouncements by the Catholic Church, in which the notion of proportionality is related to the criteria regarding the terminally ill and to end-of-life issues. In a famous document, entitled *An address of Pope Pius XII to an International Congress of Anesthesiologists*, published in *Osservatore Romano*, November 25-26, 1957, the *Pope* considers objective ethical aspects (clinical condition) related to subjective ethical patient and familial aspects (existential condition).<sup>81</sup> The difference between “right” and “obligation” opens up the question of the relationship between two free wills: those of the patient or his family and those of the physician; who together must arrive, as closely as possible, at a mutually consensual therapeutic choice.

Only in 1980 do the terms “ordinary” and “extraordinary” come to signify change in “proportionate” and “disproportionate” means of conserving life. The new terminology is mentioned in the document *Iura et Bona* (1980) published by the Sacred Congregation for the Doctrine of the Faith.<sup>82</sup>

Pope John Paul II, in the Encyclical *Evangelium Vitae*, explains the difference between killing and allowing someone to die, referring to the notion of the proportionality of care<sup>83</sup>.

From an historical point of view, it can be deduced that the notion of proportionality is relevant in every clinical choice – also today – regarding patient care and freedom of choice.<sup>84</sup>

A sound medical approach considers how both clinical and living conditions affect the patient’s quality of life. Proportioned treatment originates from a precise evaluation of

<sup>80</sup> Lanza A, Palazzini P, *Theologia Moralis II*, Taurini-Romae, Marietti, 1955: n.125.

<sup>81</sup> Smith RE, *Conserving Human Life*, cit.,1989, 316.

<sup>82</sup> *Iura et Bona*, 1980, IV.

<sup>83</sup> *Evangelium Vitae*, 1995, 65.

<sup>84</sup> Jansen LA, Sulmasy DP, *Proportionality, terminal suffering and the restorative goals of medicine*, *Theoretical Medicine*, 2002; 23: 321–337.

both clinical conditions and personal history, and is developed through the specific relationship between patient and physician (the so called “therapeutic alliance”) in which the significance of every choice is identified.<sup>85</sup>

Proportionality must be evaluated for each single patient, considering his/her particular clinical history, objective state of health, needs, psychological resources, and personal values (ascertained through careful listening, open dialogue, and with sufficient time).<sup>86</sup>

### **The Rule of Double Effect (RDE)**

Another important question related to the principle of non-maleficence is the Rule of Double Effect (RDE). RDE is related with the principle of Non Maleficence because it helps to recognize a good action even if this good action implies a harmful effect, a minimally foreseeable effect.

There are four conditions which justify an act with a double effect<sup>87</sup>:

1 *The nature of the act.* The act must be good, or at least morally neutral, independent of its consequences;

2 *The agent’s intention.* The agent’s intent is only the good effect, not the bad effect. The bad effect can be foreseen, tolerated, and permitted, but it must not be intended.

3 *The distinction between means and effects.* The bad effect must not be a means to the good effect. Even if the good effect were the causal result of the bad effect, the agent should not produce the bad effect in pursuit of the good effect.

4 *The proportionality between the good effect and the bad effect.* The good effect must outweigh the bad effect. That is, the bad effect is permissible only if a proportionate reason compensates for permitting the foreseen bad effect.

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<sup>85</sup> Clayton JM et al., *When and How to Initiate Discussion About Prognosis and End-of-Life Issues with Terminally Ill Patients*, *Journal of Pain and Symptom Management*, 2005; 30(2): 132-144.

Walczak A et al., *Patient perspectives regarding communication about prognosis and end-of-life issues: How can it be optimised?*, *Patient Education and Counseling*, 2013; 90: 307–314.

<sup>86</sup> Giannini A, et al., *End-of-life decisions in pediatric intensive care. Recommendations of the Italian Society of Neonatal and Pediatric Anesthesia and Intensive Care (SARNePI)*, *Pediatric Anesthesia* 2008; 18:1089-1095.

<sup>87</sup> Beauchamp TL, Childress JF, *Principles of Biomedical Ethics*, cit., 162.

## **The distinction between Non maleficence and Beneficence**

The Principles of Non Maleficence and Beneficence may be interpreted as similar, and considered two different aspects of the same phenomenon as well<sup>88</sup>.

It seems to be better to distinguish them, as the second principle focuses on one single medical treatment for one specific patient and its implications regarding his/her pain; instead the principle of Beneficence highlights operative actions used to improve the patient's clinical condition.

The principle of Beneficence is different from that of Non-maleficence because: “the rules of Non-maleficence are 1- negative prohibitions of action, 2- must be followed impartially, and 3- provide moral reasons for legal prohibitions of certain forms of conduct. Furthermore, the rules of Beneficence 1-present positive requirements for action, 2- need not always be followed impartially, and 3- generally do not provide reasons for legal punishment when agents fail to abide by them”<sup>89</sup>.

### **c- Beneficence**

The Principle of Beneficence involves helping people with an active contribution, acting for the benefit of others, not only avoiding damaging acts.

Beauchamp and Childress present two principles of beneficence: positive beneficence and utility. Positive beneficence “requires agents to provide benefits to others. Utility requires that agents balance benefits, risks, and costs to produce the best overall results”<sup>90</sup>.

The principle of positive beneficence can include different kinds of moral rules. Some examples are<sup>91</sup>:

- 1- Protecting and defending the rights of others;
- 2- Preventing harm from occurring to others;
- 3- Removing conditions that will cause harm to others;

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<sup>88</sup> Cattorini PM, *Bioetica*, Milano, Elsevier, 2011<sup>4</sup>: 16.

<sup>89</sup> Beauchamp TL, Childress JF, *Principles of Biomedical Ethics*, cit., 199.

<sup>90</sup> *Ibidem*, 197.

<sup>91</sup> *Ibidem*, 199.

4- Helping person with disabilities;

5- Rescuing persons in danger.

Moreover, Beauchamp and Childress explain that the principle of utility, in their analysis, is not identical to the principle of utility as presented in the moral theory called utilitarianism<sup>92</sup>. Classical Utilitarianism has had two important exponents: Jeremy Bentham and John Stuart Mill. Bentham describes the principle of utility as the most important principle useful to clarify every action: “Nature has placed mankind under the governance of two sovereign masters, pain and pleasure. It is for them alone to point out what we ought to do... By the principle of utility is meant that principle which approves or disapproves of every action whatsoever according to the tendency it appears to have to augment or diminish the happiness of the party whose interest is in question: or, what is the same thing in other words to promote or to oppose that happiness. I say of every action whatsoever”<sup>93</sup>. Beauchamp and Childress distance themselves from this position: the principle of utility is “one among a number of prima facie principles, and it does not determine the overall balance of moral obligations”<sup>94</sup>.

In general the principle of beneficence “refers to a statement of moral obligation to act for the benefit of others”<sup>95</sup>. The principle of beneficence responds to the most important aim of medicine: to provide benefits to others. In particular, as expressed in the Hippocratic Oath: “to help, or at least to do no harm”.

In the last decades this principle is often presented in contrast with the patient’s right to choose autonomously about our treatments: “the principle of respect for autonomy has grounded several rights for patients, including rights to receive information, to consent to and refuse procedures, and to have confidentiality and privacy maintained. Others

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<sup>92</sup> Maclean A, *The Elimination of Morality. Reflections on Utilitarianism and Bioethics*, London, Routledge, 1993. Laing JA, *Critical Essays in Consequentialist Bioethics*, London, Macmillan Press, 1997.

<sup>93</sup> Bentham J, *An Introduction to the Principles of Morals and Legislation*, 1789, I, § 2-3; tr. It. Di Pietro S, *Introduzione ai principi della morale e della legislazione*, Torino, Utet, 1998: 90-91, in R. Mordacci, *Una introduzione alle teorie morali, confronto con la bioetica*, Milano, Feltrinelli, 2003: 94.

<sup>94</sup> Beauchamp TL, Childress JF, *Principles of Biomedical Ethics*, cit., 199.

<sup>95</sup> Beauchamp TL, Childress JF, *Principles of Biomedical Ethics*, cit., 197. A significant example of beneficent behavior is that of the Good Samaritan in the New Testament. The Good Samaritan is not the only one inclined to take care of the sick man. The publican also accepts taking care of a stranger, without requesting money, based only on a promise from the Samaritan. Luke 10, 25-37. The parable of the Good Samaritan.

ground such obligations on the health care professional's primary obligation of beneficence, which is to act for the patient's medical benefit"<sup>96</sup>.

Thus an important problem arises in clinical ethics: the relationship between the principle of Autonomy and the principle of Beneficence.

This argument finds its origins in the *Paternalism*, attitude under which the physician is compared to a father and the patients to his children. Paternalism is "the intentional overriding of one person's preferences or actions by another person, where the person who overrides justifies this action by appeal to the goal of benefiting or of preventing or mitigating harm to the person whose preferences or actions are overridden"<sup>97</sup>.

This paternal position of the physician has two features: "beneficence, and that he makes all or at least some of the decisions relating to his children's welfare, rather than letting them make those decisions"<sup>98</sup>.

The distinction between soft and hard paternalism could better balance the principles of autonomy and beneficence.

Hard paternalism seems not to consider the patient's opinion about his/her own choices, and the physician is considered the only well-informed individual able to perform care planning for the patient's good: "the hard paternalist will restrict forms of information available to the person or will otherwise override the person's informed and voluntary choices"<sup>99</sup>.

Hard paternalism is morally justified if the following conditions are satisfied:

- 1- A patient is at risk of a significant, preventable harm;
- 2- The paternalistic actions will probably prevent the harm;
- 3- The projected benefits to the patient of the paternalistic actions outweigh their risks to the patient;
- 4- There is no reasonable alternative to the limitation of autonomy;
- 5- The least autonomy-restrictive alternative that will secure the benefits and reduce the risks is adopted.

Soft paternalism seems resolve the conflict between the principle of beneficence and the principle of autonomy: it reflects "the intended beneficiary's own conception of his or her best interest, even if the intended beneficiary fails to fully understand or recognize

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<sup>96</sup> Beauchamp TL, Childress JF, *Principles of Biomedical Ethics*, cit., 207.

<sup>97</sup> *Ibidem*, 208.

<sup>98</sup> *Idem*.

<sup>99</sup> *Ibidem*, 210.

those interests or to fully pursue them because of inadequate willfulness, commitment, or self-control”<sup>100</sup>. This conception of soft paternalism seems to be able to respect the autonomy of the patient, because it is oriented to offer support in order that the patient can choose the better things for itself. In fact there are three positions on the justification of paternalism in literature<sup>101</sup>: Anti-paternalism; Paternalism that appeals to the principle of respect for autonomy; Paternalism that appeals to principles of beneficence. In general, all these three forms accept and justify soft paternalism.

### Paternalism and the Pasteur’s case

To better explain the theme of paternalism, a clinical episode of euthanasia in XIX century France is presented below. This case presents paternalistic behavior on the part of one of the most famous scientist of XIX century, Louis Pasteur, the father of biochemistry.

Louis Pasteur and the case of the *six Russian peasants*.<sup>102</sup>

The young Dr. Munthe observed the suffering of many patients in a famous hospital in Paris during the second half of nineteenth-century and left moving written descriptions of his initial wonder about the desolation of the death that struck most of those poor souls: «How could He be so cruel, He who could be so gentle? How could He take away so much of youth and life with one hand, when He could give so much peace and happiness with the other?”<sup>103</sup>

Axel Munthe immediately developed a significant relationship with death, despite the

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<sup>100</sup> Ibidem, 211.

<sup>101</sup> Ibidem, 213.

<sup>102</sup> This is a clinical case of euthanasia which occurred at the end of the Nineteenth Century. Regarding the practice of euthanasia in the nineteenth century, was there an undisputed or conditioned acceptance? Following we will present a few pages which clarify the thought processes, but at the same time underscore a surprising aspect of cruelty involved in a particular case: they were obtained from the reflections of the fascinating autobiographical narrative by Axel Munthe, *The Story of San Michele*, a masterpiece by the great Swedish physician and writer. They describe a nineteenth-century clinical case of euthanasia, which was forgotten or eluded medical history and bioethical reflections: this case is not described in works of scientific literature, but it is part of the cultural baggage of narrative doctrine and the memorandums of the well-known author. I would like to thank Professors G. Armocida and M. Picozzi for recommendations on writing this case.

<sup>103</sup> Munthe A, *The Story of San Michele*, kindle version, New York, E.P. Dutton & Co.,1945: 492.

fact that his medical career was just beginning. He worked in that old hospital in the hopes of authenticating his approach and he believed that his mission had inevitably obliged him to combat the arrival of the implacable enemy.

Later on, however, experience caused him to change his mind regarding the idea of death; it subsequently became so familiar that he was able to call it “colleague” and “friend”, believing that: «He had his share in the work, as well as I had mine, His mission to fulfill just as I had mine [...] that when the wrestling over a life was over and He had won, it was far better to look each other fearlessly in the face and be friends»<sup>104</sup>.

The doctor felt “defeated”, but not “disarmed” when confronted by death. Death had its eternal narcotic, but the young doctor had his as well: «When he was slow in dealing out His remedy, why should not I deal out mine with its merciful power to change anguish into peace, agony into sleep? Was it not my mission to help those to die I could not help to live?»<sup>105</sup>.

Basing his reflections on the “relationship” which developed resulting from his experiences regarding death, Axel Munthe recounts a significant episode which regarded two of the biggest names in the history of medicine and science: Pasteur and Tillaux.

Six Russian peasants (moujiks), who had been attacked by a pack of mad wolves, had been sent to Paris at the expense of the Tsar to be cared for in the famous Pasteur Institute: «They were all horribly mauled in the face and hands and their chances from the outset were almost nil”.

They had been hospitalized in a separate ward at the Hôtel Dieu, under the care of the surgeon Tillaux, friend and collaborator of Pasteur. Axel Munthe writes: «Pasteur knew this better than anybody, and hadn’t he been the man he was, he would no doubt have declined to take them in hand. Pasteur came himself every morning with Tillaux to inoculate them, watching them anxiously from day to day. Nobody could understand a word they said».

Munthe said that no one wanted to get close to the ward where the six moujiks were, not even the courageous sisters: «Their screams and howls could be heard all over the

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<sup>104</sup> Ibidem, 486.

<sup>105</sup> Ibidem., 506.

Hotel Dieu, people said even below in Place Notre Dame. The whole hospital was flooded with emotion. Nobody wanted to go near the ward, not even the courageous Nuns fled in terror. I can see now the white face of Pasteur as he passed in silence from bed to bed, looking at the doomed men with infinite compassion in his eyes». The young doctor describes a sequence of difficult situations in which he found himself having to take care of the six patients: «One afternoon, it was on the ninth day, I was trying to pour a drop of milk down the lacerated throat of one of the moujiks, a giant whose whole face had almost been torn away, when suddenly something wild and uncanny flashed in his eyes, the muscles of the jaws contracted and opened spasmodically with a snapping sound, and a ghastly cry I had never heard before either from man or animal rang out from his foaming mouth. He made a violent effort to spring out of bed and nearly knocked me down, as I tried to hold him back. His arms, strong as the paws of a bear, closed on me in a clasp, holding me tightly as if in a vice. I felt the foul breath from his foaming mouth close to mine and the poisonous saliva dripping down my face. I grasped at his throat, the bandage slipped off his ghastly wound, and as I drew back my hands from his snapping jaws, they were red with blood. A convulsive trembling passed over his whole body, and his arms relaxed their grasp and fell back inert at his side. I staggered to the door in search of the strongest disinfectant I could get hold of. [...] In the evening the moujik, tied hand and foot to the iron bars of the bed, was carried to a separate pavilion, isolated from the others. I went to see him the next morning with Sœur Marthe. The room was semi-dark. The bandage covered his whole face and I could see nothing but his eyes; they haunted me for years afterwards. His breathing was short and irregular, with intervals similar to Cheyne-Stokes respiration – the well-known precursory symptom of death. He talked with vertiginous rapidity in a hoarse voice, now and then interrupted by a wild cry of distress or a hooting moan which made me shudder. I listened for a while to the rush of unknown words half-drowned in the flow of saliva, and soon I thought I distinguished one same word repeated incessantly, with an almost desperate accent: “Crestitsa! Crestitsa! Crestitsa! [Crucifix]”. I looked attentively into his eyes, his kind, humble, imploring eyes. “He is conscious,” I whispered to Sœur Marthe, “and he wants something, I wish I knew what it was. Listen!” “Crestitsa! Crestitsa! Crestitsa!” he called out incessantly. “Run and fetch a



crucifix,” I said to the nun. We laid the crucifix on the bed. The flow of words ceased instantly. He lay there quite silent, his eyes fixed on the crucifix. His breathing grew fainter and fainter. Suddenly the muscles of his giant body stiffened in a last violent contraction and his heart stood still. The next day another moujik showed unmistakable signs of hydrophobia, and soon another, and three days later they were all raving mad».

Munthe remembers the white face of Pasteur as he passed quietly from bed to bed, watching the condemned men, with infinite compassion: «He sank down on a chair, his head between his hands. Accustomed as I was to seeing him every day I had not noticed till then how ill and worn he looked, though I realized from an almost imperceptible hesitation in his speech and a slight hesitation in the grip of his hand that he had already received the first warning of the fate that was to overcome him soon after».

Tillaux was called while he was working; he arrived with his coat still stained with blood, approached Pasteur, and put his hand on his shoulder: “The two men looked at each other in silence. The kind blue eyes of the great surgeon, who had seen so much horror and suffering, glanced round the ward and his face grew white as a sheet. “I cannot stand it,” he said in a broken voice and sprang out of the room». The surgeon and chemist looked into each other’s eyes: «The same evening a consultation took place between these two men. Few people know of the decision they ultimately arrived at, but it was the only just one, and did them both honor. The next morning all was silent in the ward. During the night the doomed men had been helped to a painless death”.

For several days in Paris there was talk of nothing else but the case of the six moujiks. The clinical case exposes choices which could be interpreted as the only practicable ones, but which at the same time could be defined as acts of disarming cruelty.

This case makes one think that even the greatest scientific minds, when confronted with the limits of modern medicine, cannot help but to take into consideration equally objective factors such as excruciating pain and suffering. The case reported presents several ethical questions. For us the most significant question is: What to do when you have no alternatives?

This issue, initially presented in the nineteenth century, is no less urgent today. Pasteur and the great surgeon Tillaux agreed to put an end to the suffering of the six Russian peasants, and so to their lives, after attempting every possible therapeutic means of conserving their lives. But is this choice ethically justifiable? According to the Kantian perspective, putting an end to the existence of a human life is always to be condemned. This concept can be inferred from the second formulation of the categorical imperative (The Principle of Respect for Persons), described in the *Critique of Practical Reason*: “Act in such a way that you treat humanity, whether in your own person or in any other person, always at the same time as an end, never merely as a means”<sup>106</sup>. In Kantian ethics man is always recognized as the end of any human action.<sup>107</sup>

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<sup>106</sup> Cfr. Kant I., *Critique of Practical Reason*, kindle version, New York, Dover Publications, 2004: 2104-2112.

<sup>107</sup> The first moral theory originated from Kant’s reflections and is therefore called *Kantian theory*. It is a theory based on the principle of duty and today it is also called *deontological theory* (“i.e. a theory that some features of actions other than or in addition to consequences make actions obligatory”, Beauchamp T, Le Roy W, Jeffrey PK, Mastroianni AC (eds.), *Contemporary Issues in Bioethics*, cit., 15.). Kant, unlike Mill, believed that certain types of actions (including murder, theft, and lying) were absolutely prohibited, even in cases where the action would bring about more happiness than the alternative. For Kantians, there are two questions that we must ask ourselves whenever we decide to act: Can I rationally will that *everyone* acts as I propose to act? If the answer is no, then we must not perform the action. Does my action respect the goals of human beings rather than merely using them for my own purposes? Again, if the answer is no, then we must not perform the action - Kant believed that these questions were equivalent. In the *Metaphysics of Morals* (1797) Kant (1725- 1804) analyzes the duties of the human being especially towards himself: the human being is considered both as a reasonable being and a being capable of obligations (in particular towards himself). This double characteristic allows the human being to recognize a duty towards himself: “Man as a moral being (*homo noumenon*) cannot use himself as a natural being (*homo phaenomenon*) i.e. as a mere means (a speaking machine), as if his natural being were not bound to the inner end (of communicating thoughts), but is bound to the condition of using himself as a natural being in agreement with the declaration of his moral being and is under obligation to himself to truthfulness” (Kant I, *Metaphysics of Morals*, Mary Gregor M (ed.), Cambridge, Cambridge University Press, 2003, 183). Kant believes that pure reason is the ultimate basis of moral rules: “the moral worth of an agent’s action depends exclusively on the moral acceptability of the rule on the basis of which the person is acting; the person’s motive for acting must be recognition of the act as resting on duty” (Beauchamp T, Le Roy W, Jeffrey PK, Mastroianni AC (eds.), *Contemporary Issues in Bioethics*, cit., 15). With this idea of the agent’s action Kant develops a supreme principle, *the categorical imperative*, called *the moral law*. The formulations of the categorical principle are different (Cattorini P, *Bioetica*, cit., 19). Kant’s formulation of the Categorical Imperative could be interpreted as: “Act only according to that maxim whereby you can, at the same time, will that it should become a universal law”. And the Second formulation of the Categorical Imperative, highly influential in bioethics, might be: “Act in such a way that you treat humanity... never merely as a means to an end, but always at the same time as an end”. The Categorical Imperative is a completely formal law, it needs to be respected as pure intention, following its formulation and nourishing it as an internal and personal duty. Kant’s imperative underscores that each person in such a situation must be treated with the same respect as all other human beings: “to treat persons merely as a means, strictly speaking, is to disregard their personhood by exploiting or otherwise using them without regard to their own thoughts, interest and needs” (Beauchamp T, Le Roy W, Jeffrey PK, Mastroianni AC (eds.), *Contemporary Issues in Bioethics*, cit., 17). Every person has equal worth and dignity and no one can be used as a means (but considered only as end) towards utilitarian or egoistic behavior, or for any other reasons.

According to this perspective, Pasteur and Tillaux would seem to have no ethical justification to support their final choice: the intentional killing of six Russian peasants also clashes with a basic principle of medical ethics “Primum non nocere”.

However, according to the Kantian perspective one practical question, anything but minor, remains unresolved: should keeping a patient alive always be the only criterion which is used to justify a medical strategy, when there are no alternatives in the extreme fight against pain, and there is no reasonable expectation of recovery?

Therefore the aim of therapeutic action becomes making every kind of effort to reduce or eliminate pain, given that there are apparently no other possibilities. In this case, given that the aim of therapeutic action is restricted to providing relief from pain, does the patient become nothing more than a means to an end? In addition, in the clinical case presented, another useful aspect which supports the two scientists’ final choice can be observed: the option of ending life may also have been indirectly recognized, and taken into consideration given the request of the farmer to have a crucifix placed in front of him. It would seem to be an acknowledgment by the patient of the imminent end of his/her own life.

Therefore, could the two expert scientists’ choice be justifiable? For the previously mentioned reasons, it may be said that the shared choice of the two scientists presents reasonable justifications, given both the lack of means of controlling pain, and a physician’s moral obligation to alleviate suffering, where there are no therapeutic alternatives.

#### **d- Justice**

As for the principle of beneficence, there is not one single principle of Justice. There is one formal principle and different material principles of Justice.

The principle of formal equality is traditionally attributed to Aristotle: “Equals must be treated equally, and the unequal must be treated unequally”<sup>108</sup>.

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<sup>108</sup> Aristotele, *Metafisica*, G. Reale (a cura di), Rusconi Libri, Milano, 1993, V, 9, 1018 a 7.

In its contemporary form, this principle is sometimes expressed as follows: “Individuals should be treated in the same manner, unless they differ in ways that are relevant to the situation in which they are involved”<sup>109</sup>.

As regards the formal principle, there are material principles of distributive Justice. They are<sup>110</sup>:

- 1- To each person an equal share;
- 2- To each person according to need;
- 3- To each person according to effort;
- 4- To each person according to contribution;
- 5- To each person according to merit;
- 6- To each person according to free-market exchanges.

The material principles could be considered as normative and practical criteria to be used to decide about a “good” distribution of resources and obligations. These principles can be deduced from common-sense: “No obvious barrier prevents acceptance of more than one of these principles, and some theories of justice accept all six as valid”<sup>111</sup>. Beauchamp and Childress do not recognize any specific ethics theory (i.e. utilitarian theories, libertarian theories, communitarian theories, egalitarian theories, cosmopolitan theories<sup>112</sup>) under which it would be possible to include all of the

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<sup>109</sup> Velasquez M, et al., *Justice and Fairness*, Issues in Ethics, Spring, 1990; 3: 2.

<sup>110</sup> Beauchamp TL, Childress JF, *Principles of Biomedical Ethics*, cit., 243-265-266

<sup>111</sup> Idem.

<sup>112</sup> Ibidem, 244. The liberal tradition found its origins in the jusnaturalistic tradition (Locke, Rousseau, Kant). The idea of safeguarding individual liberties found in utilitarianism (Mill) a fertile ground in which to analyze various socio-political problems. During the XX century the Rawls’ Theory of Justice was recognized as a valid foundation for liberal justice and was recognized as being different from the utilitarian moral theory, especially regarding some paradoxical utilitarian conclusions that seem to violate the rights of the subject (Mordacci R, *Una introduzione alle teorie morali, confronto con la bioetica*, cit., 131-132). Rawls’ position about liberalism is called *necontractualism* (Mordacci R, *Una introduzione alle teorie morali, confronto con la bioetica*, cit., 131-132). From this *thoughtful judgment*, guaranteed by the common sense of the members of the society, Rawls deduces many principles which are useful in order to found an orderly society. It is important for our discourse to underscore Rawls’ position about the relationship between moral subjects and the principles deduced from the idea of Justice: “the best principles will be represented by the reflection on those moral subjects that will be disinterested, neutral about specific situations and will be provided with a sense of justice (Mordacci R, *Una introduzione alle teorie morali, confronto con la bioetica*, cit., 131-132). Rawls defines the relationship between thoughtful judgments and the *reflexive equilibrium* principles. This type of reflection made by the moral subjects develops the idea of a *contract* between people called to decide about the validity of the principles, not about a specific situation in which the principles could be used to determine a good action. There is a significant difference between the idea of reflexive equilibrium of Beauchamp and Childress and that of Rawls. In Principlism the *reflexive equilibrium* is used to balance different principles in order to resolve a specific situation ( a clinical case or ethics dilemma). In the Rawls’ idea of justice the *reflexive equilibrium* is utilized to identify and adjust its own principles in their original definition, not to determine which principle should be used in a specific situation (Mordacci R, *Una introduzione alle*

characteristics of a coherent theory of Justice.<sup>113</sup> Instead they refer to each single and concrete situation in order to balance different principles, so as to recognize the importance of the right to health and health care. In particular Beauchamp and Childress recognize certain difficulties concerning the principle of justice regarding *allocating*, *rationing* and *setting priorities*.<sup>114</sup>

Beauchamp and Childress present four types of allocation (partitioning the comprehensive social budget; allocating within the general budget; allocating within the health care budget; allocating scarce treatments for patients) and three meanings of rationing (the first is related to “denial from lack of resources”; the second derives from social policy limits; the third sense is related to an allowance that is distributed equitably, but “those who can afford additional goods are not denied access beyond the allotted amount”).

A third aspect, the setting of priorities, is in particular related to costs, especially for insurance, new technology, deteriorating health conditions and longer life expectancy: “the question in setting priorities is how to determine what ought to be done when resources are inadequate to provide all of the health benefits that it is technically possible to provide”.

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*teorie morali, confronto con la bioetica*, cit., 140). This position is also called coherentism. Relating to this idea of Justice, Hugo Tristram Engelhardt develops his skeptical position about the possibility of finding a shared rational agreement regarding the substantial moral question that pervades society: the “failure to recognize the depth of the moral diversity that characterizes our context is understandable. The presumption that there is a concrete morality available to all through rational reflection has deep roots in Western History”(Engelhardt Jr HT, *The foundations of Bioethics*, cit., 3). His position is called *proceduralism*, because what we can only aim for is the respect of a neutral procedure, which allows us to provide a tolerant and peaceful choice, despite geographical and moral diversities (Cattorini P, *Bioetica*, cit., 20). Engelhardt does not believe that public cohesion about some substantial principles could be arrived at through human reasoning. Human beings are moral strangers, and the rational argument is not able to bridge the differences. Therefore the principle of autonomy is called the principle of permission, the only one valid, because this principle defines the absolute limits of any relationship between individuals, without any moral judgment about their respective moral visions (Mordacci R, *Una introduzione alle teorie morali, confronto con la bioetica*, cit., 140).

<sup>113</sup> Mordacci R, *Una introduzione alle teorie morali, confronto con la bioetica*, cit., 84.

<sup>114</sup> Beauchamp TL, Childress JF, *Principles of Biomedical Ethics*, cit., 267-275.

## **Clinical Case: Jehovah's Witnesses and Organ Transplants.**

Jehovah's Witness patient legitimately could present a request of admission in an organ transplant list. This application is generally related to the prohibition to accept whole blood and some blood constituents for religious reasons.<sup>115</sup>

These two requirements open ethical issues for the patient, the physician and the healthcare system. On the one hand the principle of autonomy remembers the duty to respect the decision-making capacities of autonomous patient, and on the other hand the principle of justice implicates an analysis of fair allocation – non-discrimination – of the resources and the obligations. The aim of the analysis of the following clinical case is to offer an ethical analysis of the possible care for Jehovah's Witness patients who request admission to an organ transplant list but who refuse whole blood transfusions, and the reasons why physicians might accept this religious clause.

### Clinical Case

Our case is about a 61-year-old woman with kidney failure due to high blood pressure and diabetes and complicated by coronary artery disease and Hepatitis C infection, acquired from a blood transfusion after during childbirth. In late 2013 she was referred to the Mount Sinai Hospital's Recanati/Miller Transplantation Institute (RMTI) because our institution's transplant program includes kidney transplants from cadaver donors with Hepatitis C infection to patients with Hepatitis C. The patient was receiving dialysis, but she did not tolerate it well primarily because she experienced persistent Dialyzer Reaction type B, a condition characterized by onset 15-30 minutes into dialysis with symptoms of chest/back pain, nausea, and mild hypotension. In addition, she no longer had dialysis access in her arms, and was being dialyzed through a thigh graft. The medical team was unsure how long they could maintain access for the patient's dialysis treatment. Our patient could not find a living kidney donor, so the transplant team had to decide if the patient was a candidate to register for kidney transplant with the Organ Procurement and Transplantation Network (OPTN). (At one point in the course of the patient, she did find a living

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<sup>115</sup> I would like to thank dr. Paul Cummins. We have presented this work at ICCEC 2015 in New York.

kidney donor, but the transplant team judged the donor not to be a suitable match due to age and ill health.) The decision to register our patient on OPTN was made more complex because the patient informed the team that she would not accept blood transfusion or blood products because she was a Jehovah's Witness. The patient expressed a strong desire to undergo kidney transplant because she wished to live to see her grandchild learn to walk and talk, her adult sons settle down, and spend quality time with her husband without being a burden on him. She was certain, though, she would not accept blood transfusion or blood products, and expressed frustration with prior "ugly experiences" at other institutions, in which her commitment was "ridiculed," and physicians told her they would transfuse when she was unconscious. The patient explained that she understood that her health was precarious, but "it would be silly to make a decision that would displease Jehovah, when my life is at risk, especially if there are alternatives to transfusion."

## **Case Analysis**

### **Biblical Foundations**

It is well known that Jehovah's Witnesses patients refuse whole blood transfusion and some blood constituents; should these refusals disqualify Jehovah's Witnesses from being listed for organ transplant?

Jehovah's Witnesses base their refusal of blood transfusion and blood constituents on a textual interpretation of Scripture. There are no clear references to blood transfusion in Scripture, but some verses forbid the consumption of blood as food because the life of a being is found in blood; e.g. Genesis 9:3-4 says, "Every moving animal that is alive may serve as food for you. Just as I gave you the green vegetation, I give them all to you. Only flesh with its life —its blood —you must not eat," Leviticus 17:14 says, "You must not eat the blood of any sort of flesh because the life of every sort of flesh is its blood. Anyone eating it will be cut off," and Acts 15:28-29 says, "It seemed good to the Holy Spirit and to us not to burden you with anything beyond the following

requirements: You are to abstain from food sacrificed to idols, from blood, from the meat of strangled animals and from sexual immorality”<sup>116</sup>.

The Jehovah’s Witness religion was founded in 1872 in Pittsburgh, Pennsylvania, is administered by the Watch Tower Bible and Tract Society of Pennsylvania (WTS), which itself is under the supervision of the Governing Body of Jehovah’s Witnesses. The WTS has been headquartered in Brooklyn New York since 1969. Since 1945 the WTS has promulgated a doctrine that “Blood transfusions and blood products are officially banned as ‘pagan and God-dishonoring,’”<sup>117</sup> effectively forbidding Witnesses to accept them. The WTS bans these medical therapies because it believes blood is a nutrient, and blood transfusion is “eating” blood, which is forbidden by Scripture. And, from 1967 to 1980 the WTS also rejected the organ transplant: “When men of science [...] suggest removing the organ and replacing it directly with an organ from another human, this is simply a shortcut. Those who submit to such operations are thus living off the flesh of another human. That is cannibalistic. However, in allowing man to eat animal flesh Jehovah God did not grant permission for humans to try to perpetuate their lives by cannibalistically taking into their bodies human flesh, whether chewed or in the form of whole organs or body parts taken from others”<sup>118</sup>.

From the late 1980s and 2000, the WTS revised its guidance to Jehovah’s Witnesses on blood transfusion and organ transplant.<sup>119</sup> Jehovah’s Witnesses are to continue to reject transfusion of whole blood, red blood cells, platelets, plasma, hemoglobin solution, stored autologous blood, and blood donation. However, Witnesses should consult their personal consciences to decide whether to accept hemodilution, intraoperative blood salvage, and blood fractions like albumin, immune globulins, or clotting factors.<sup>120</sup>

The WTS also made the choice for organ transplant a matter of personal conscience when it reversed its previous guidance: “Some Christians might feel that taking into their bodies any tissue or body part from another human is cannibalistic. [...] Other sincere Christians today may feel that the Bible does not definitely rule out medical transplants of human organs. It may be argued, too, that organ transplants are different

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<sup>116</sup> New World Translation of the Holy Scriptures (2013 version), [[www.jw.org](http://www.jw.org), last seen 27/12/2015].

<sup>117</sup> The Watchtower, July 7<sup>th</sup>, 1945, 198-201, [<http://ajwrb.org/watchtower/blood-vaccines-and-organ-transplants>, last seen 27/12/2015].

<sup>118</sup> The Watchtower, November 15<sup>th</sup>, 1967, 702.

<sup>119</sup> The Watchtower March 1<sup>st</sup>, 1989.

<sup>120</sup> The Watchtower, June 15<sup>th</sup>, 2000, 29-31.



from cannibalism since the ‘donor’ is not killed to supply food. [...] There is no Biblical command pointedly forbidding the taking in of other human tissue”<sup>121</sup>.

Is the blood transfusion a real prohibition?

The WTS’s ban on blood transfusion had presented a dilemma for Witnesses whose condition is optimally treated by organ transplant: disqualify oneself from organ transplant by refusing blood transfusion or disobey the religion’s principles, risking exclusion from the congregation. The medical and scientific community responded to this dilemma by developing protocols for “bloodless” surgery and peri-operative management to preclude the necessity of blood transfusion. Today bloodless organ transplants are possible, though they are more complex and raise the possibility of post-operative complications.

Because the WTS has ruled that the choice to receive some blood components and undergo organ transplant are matters of personal conscience some physicians may be puzzled when Witnesses continue to refuse blood transfusion. And while “to be sure, honoring patient values in health care decision making and respecting patient self-determination are of the utmost importance,” other physician may worry that Witnesses are psychologically manipulated to refuse blood transfusion.<sup>122</sup> Formerly, a Witness who accepted a blood transfusion was disfellowed, a finding imposed by a judicial committee when a Witness is found to violate the religion’s standards without repenting. A disfellowed believer “has been spiritually cut off from the congregation; the former spiritual ties have been completely severed.”<sup>123</sup> Today, a Witness who accepts a blood transfusion is disassociated from the religion by his own action. Disfellowed or disassociated Witnesses are subject to communal shunning, the Biblical justification for this is found in the apostle Paul’s claim that Christians should “quit mixing in company” with persons who unrepentantly reject certain Scriptural standards.<sup>124</sup>

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<sup>121</sup> The Watchtower, March 15<sup>th</sup>, 1980, 31, [<http://www.4jehovah.org/jehovahs-witnesses-and-blood-transfusions/> last seen 27/12/2015].

<sup>122</sup> Ridley DT, *Jehovah’s Witnesses’ refusal of blood: obedience to scripture and religious conscience*, Journal of Medical Ethics, 1999; 25: 469-472, 470.

<sup>123</sup> Idem.

<sup>124</sup> The Watchtower, March 15<sup>th</sup>, 1980, p. 31, [<http://www.4jehovah.org/jehovahs-witnesses-and-blood-transfusions/> last seen 27/12/2015].

The practice of shunning pressures Witnesses to adhere to the WTS's ban on blood transfusion, but this should not be interpreted as compromising the autonomy of patients. The elders of a Jehovah's Witness congregation are not authorized to make health-care decisions for a Witness "even if he asks what to do. [...] They can, of course, call attention to what Jehovah has said that may have a bearing on the decision. For example, a Christian needs to remember the Biblical command "to keep abstaining from...blood." (Acts 15:29). [...] This knowledge could even influence a Christian's conscience when he makes a personal decision regarding minor fractions derived from one of those four components."<sup>125</sup> The WTS counsels "it may be that [they] need to examine [their] own conscience, which may need further training in line with divine principles. On matters like health care, each of [them] should be willing to make a personal decision and accept the responsibility that comes with it."<sup>126</sup>

Though physicians may be tempted to judge that a Witness' refusal of blood transfusion is coerced, this would be a mistake. The faithful Witness must choose between selecting the optimal surgical protocols for organ transplant, and adhering to his religious convictions. While medical professionals are ethically permitted to withhold or withdraw treatments both when the patients fail to adhere to treatment plans and when the risk of a surgery is too much high, a Witness' refusal of blood transfusion should not be interpreted as a failure to adhere to treatment requirements. When a Witness refuses blood transfusion, he is autonomously choosing to follow his religion's guidance and observe rigid Biblical norms.

#### The Principles of Bioethics and the role of the medical community

Witnesses desire medical care that is compatible with their religious commitment to refuse blood transfusion. The medical community's development of surgical protocols for performing "bloodless" surgery reflects its collective commitment to the principle of beneficence, which Beauchamp and Childress define as "obligations to provide benefits and to balance benefits against risks."<sup>127</sup> Dr. Denton Cooley

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<sup>125</sup> The Watchtower, September 2015, [<http://www.jw.org/en/publications/magazines/w20150915/bible-trained-conscience-guide/> last seen 27/12/2015].

<sup>126</sup> The Watchtower, September, 2015, point 10.

<sup>127</sup> Beauchamp TL, *Methods and principles in biomedical ethics*, J Med Ethics, 2003; 29: 269–274. Beauchamp TL., *The 'four principles' Approach to Health Care Ethics*, in Ashcroft RE, Dawson A, Draper H, McMillan J (eds.), *Principles of Health Care Ethics*, Chichester, John Wiley & Sons, 2007: 3-11. Beauchamp TL, Childress J, *Principles of biomedical ethics*, New York, Oxford University Press,

pioneered bloodless open-heart surgery, and other surgeons have continued to push the boundaries of bloodless surgery, so that now bloodless organ transplant is possible.<sup>128</sup>

The same techniques that reflect the medical community's devotion to the good of Jehovah's Witnesses also generate autonomy<sup>129</sup> – “the obligation to respect the decision-making capacities of autonomous persons” – and justice – “obligations of fairness in the distribution of benefits and risks”. On the one hand the principle of respect for autonomy supports that if the patient has decisional capacity, then physicians should accept the patient's choice, which in the case of a Jehovah's Witness is that the best treatment for her is to be listed as a transplant candidate and undergo bloodless transplant when she is allocated an organ. On the other hand the provision of medical care sometimes requires medical professionals to make decisions about how to allocate scarce medical resources.<sup>130</sup> The Jehovah's Witness' physician may be reluctant to accept the her decision because the physician may think that refusal of blood transfusion during the perioperative course of organ transplant jeopardizes the success of transplant: “blood transfusion is directly related to preoperative hematocrit level and intraoperative blood loss, both can and should be controlled by better perioperative strategy, higher technical skills, and optimal use of available new drugs and technologies.”<sup>131</sup> Because there is a shortage of organs for transplant, this may unfairly deny an organ to a patient who is willing to accept treatments to optimize success of the transplant.

The principles of autonomy and justice come into because the principle of autonomy is patient-centric value that safeguards the patient's self-determination. Conversely, the principle of justice is a socially oriented value that compels physicians to evaluate the practical social consequences of clinical choices. The patient is the ultimate arbiter of

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<sup>128</sup> It is important to note that Jehovah's Witnesses would not be the only beneficiaries of these advances: reducing the reliance on blood transfusion in surgery reduces the risk of immunological reaction or infection, and it reduces surgical costs.

<sup>129</sup> To see also: Beauchamp, Tom L., *History and Theory in "Applied Ethics"*, Kennedy Institute of Ethics Journal, 2007; 17(1): 61-62. If a person makes a decision from passion or from religious conviction or from a desire to complete personal projects, this decision is not autonomous on Kant's account. Any principle not based on autonomy of the will cannot form the will's law, and thus acting from desire, impulse, interest, personal commitment, or habit is no less heteronomous than actions manipulated or coerced by others.

<sup>130</sup> Silva DS et al., *Clinical Ethicists Perspectives on Organisational Ethics in Healthcare Organisations Source*, Journal of Medical Ethics, 2008; 34(5): 320-323.

<sup>131</sup> Jabbour N et al., *Transfusion free surgery: single institution experience of 27 consecutive liver transplants in Jehovah's Witnesses*, Journal of the American College of Surgeons, 2005; 201(3): 412–417.

the procedures she is willing undergo, but in the contemporary transplant environment the physician must determine whether to recommend her as a transplant candidate.

The medical community's commitment to beneficence toward Jehovah's Witnesses is demonstrated by its development of techniques that do not require blood transfusion to transplant heart<sup>132</sup>, liver<sup>133</sup>, lungs<sup>134</sup>, pancreas, kidneys<sup>135</sup>, stem cells<sup>136</sup>; and techniques to perform "bloodless" surgeries compatible with Jehovah's Witness patients' faith.<sup>137</sup> Since 1986 (first reported successful cardiac transplant in a JW)<sup>138</sup> the advancement of own surgical techniques has entailing good results with a risk always more acceptable to engage operations without blood transfusions: "special consideration to surgical detail [...] and improved methods of perioperative management can result in a successful outcome at tolerable risk levels for this group of patients".<sup>139</sup>

Justifications for refusing a Jehovah's Witness patient as a transplant candidate.

Because a physician's personal conscious alone should not guide the provision of medical care, the reluctance of the surgeon to list this patient as a transplant candidate cannot be decisive. The surgeon's ambivalence about whether or not to list this patient for transplant reflects uncertainty about how the principle of justice applies in this case. Aristotle thought that justice was a question of fair distribution of goods, and in medicine the concept requires the fair allocation of scarce resources.<sup>140</sup> Thus, the

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<sup>132</sup> Elmistekawy E et al., *Should Jehovah's Witness patients be listed for heart transplantation?*, Interactive Cardiovascular and Thoracic Surgery, 2012; 15(4):716–719; Burnett C. et al., *Heart Transplantation in Jehovah's Witnesses: An Initial Experience and Follow-up*, Archives of Surgery, 1990; 125(11): 1430-1433.

<sup>133</sup> Jabbour, N et al., *Transfusion free surgery: single institution experience of 27 consecutive liver transplants in Jehovah's Witnesses*, cit., 412-417.

<sup>134</sup> Partovi S et al., *Bloodless lung transplantation in Jehovah's Witnesses: impact on perioperative parameters and outcome compared with a matched control group*, Transplantation Proceedings, 2013; 45(1): 335–341.

<sup>135</sup> Figueiro, J et al., *Simultaneous pancreas-kidney transplantation in Jehovah's Witness patients.*, Clinical Transplantation, 2003; 17(2): 140-143.

<sup>136</sup> Sloan JM et al., *SCT in Jehovah's Witnesses: the bloodless transplant*, Bone Marrow Transplantation, 2008; 41(10): 837–844.

<sup>137</sup> Ott DA, Cooley DA, *Cardiovascular surgery in Jehovah's Witnesses. Report of 542 operations without blood transfusion*, Journal of the American Medical Association, 1977; 238(12): 1256–1258; Magner D et al., *Pancreaticoduodenectomy after neoadjuvant therapy in a Jehovah's witness with locally advanced pancreatic cancer: case report and approach to avoid transfusion*, The American Surgeon, 2006; 72(5): 435-437; Vaislic CD et al., *Outcomes in cardiac surgery in 500 consecutive Jehovah's Witness patients: 21 year Experience*, Journal of Cardiothoracic Surgery, 2012; 7(95).

<sup>138</sup> Corno AF et al., *Heart transplantation in a Jehovah's Witness*, J Heart Transplant, 1986; 5:175-177.

<sup>139</sup> Burnett C et al., *Heart Transplantation in Jehovah's Witnesses: An Initial Experience and Follow-up*, Archives of Surgery, 1990; 125(11):1430-1433.

<sup>140</sup> Aristotele, *Etica Nicomachea*, trad.it. Natali C, Roma, Laterza, 1999; 15-19.

surgeon's ambivalence is a product of his uncertainty about whether allocating an organ to a patient who refuses blood transfusion is fair; the dilemma the surgeon faces can be put as follows: is it just to allocate an organ to a patient whose autonomous refusal of blood transfusion will be honored?

In order to begin to answer that question it is important to consider the validity of the justification for excluding the Jehovah's Witness patient from being a transplant candidate. Two plausible rationales that the medical community could offer for this decision are triage-type and non-adherence justifications.

The principle of triage guides the allocation of scarce medical resources, including medical professional's time and attention, in emergencies, and it aims to minimize the worst outcomes.<sup>141</sup> A triage-type principle for the allocation of scarce resources may permit the surgeon to choose not to list the patient to allocate the organ to a patient for whom the loss of the organ is less likely because he will accept blood transfusion. Boggi et al note that, "most Jehovah's Witnesses can safely receive a kidney and/or a pancreas transplant without transfusions. However, in a low, though not negligible, proportion of recipients, blood transfusions cannot be avoided without the risk of recipient death."<sup>142</sup> Since the patient's death and the loss of the organ are the worst possible outcome, a triage-type justification would support not listing the Jehovah's Witness patient as a transplant candidate to avoid it.

While the triage-type justification for not listing this patient for transplant is *prima facie* ethically defensible, it should be rejected for three reasons: First, while it is undeniable that there is a severe shortage of organs for patients awaiting transplant, we doubt that this qualifies as an emergency; organ transplants are a matter of urgency for patients, but rarely is it an emergency (in such cases the patient who emergently needs the transplant would be prioritized on the transplant list). A triage-type principle of allocation is only appropriate in cases of emergency. Second, at the time, UNOS' standards for organ allocation, did not factor survival benefit into its kidney matching criteria. Until this factor was formally adopted as part of the criteria, relying on it in the case of Jehovah's Witnesses is unacceptably *ad hoc* (in 2013 the Board of Directors of OPTN/UNOS approved changes to its kidney allocation criteria that take survival

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<sup>141</sup> Rhodes R, *Justice Pluralism: Resource Allocation in Medicine and Public Health*. In Rhodes R, Battin M, Silvers A (eds.), *Medicine and Social Justice*, New York, Oxford, 2012: 66.

<sup>142</sup> Boggi U et al., *Kidney and pancreas transplants in Jehovah's witnesses: ethical and practical implications*, *Transplantation Proceedings*, 2004; 36(3): 601–602.

benefit into account, going into effect in late 2014<sup>143</sup>). Third, applying this triage-type standard to Jehovah's Witnesses may violate medicine's value of non-judgmental regard since they will be made ineligible for transplant in virtue of their commitment to their religious values rather than by medical factors alone, as in triage.

An alternative justification to triage-type one just reviewed is that refusal of blood transfusion constitutes non-adherence to a treatment plan. Medical professionals are ethically permitted to withhold or withdraw treatment when patients fail to adhere to treatment plans. Complications are not uncommon in the operative and postoperative course of transplant, and they may require blood transfusion; when transfusion is viewed as part of the standard medical practice for transplant, then refusal of transfusion is failure to adhere to a treatment plan. Bramstedt suggests that considerations of non-adherence can justify refusal of transplant to Jehovah's Witnesses because "if a patient refuses [peri] operative rescue transfusion, this puts the survival of the graft at risk."<sup>144</sup>

Support for requiring acceptance of blood transfusion as a condition for transplant candidacy is based on a comparison to the conditions imposed on liver transplant candidates whose disease is the product of alcoholism. Bramstedt makes this exact analogy when patients who are recovering from alcoholism and Jehovah's Witnesses. She notes that patients whose liver disease is a product of alcohol abuse must sign alcohol abstinence contracts in order to be considered for transplant since continued alcohol use may compromise the transplant. Patients that relapse are not listed for transplant for failure to adhere to the treatment plan.

Like the triage-type justification, non-adherence is *prima facie ethically plausible*, but we think it should be rejected for three reasons also. First, the analogy is not apt because the organ is not put in jeopardy by the same factor in the case of an alcoholic and a Jehovah's Witness. The behavior of a recovering alcoholic is a factor in the disease, while a Jehovah Witness's convictions are not factors. Behavior contributes to possibility of disease relapse, which may generate future need for re-transplant and future demand for another share in organ allocation. A Jehovah's Witness patient who refuses transfusion if needed after transplant poses no risk of future need of re-

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<sup>143</sup> Board approves significant revisions to deceased donor kidney allocation policy. <https://optn.transplant.hrsa.gov/news/board-approves-significant-revisions-to-deceased-donor-kidney-allocation-policy/> [last seen 27/12/2015].

<sup>144</sup> Bramstedt KA, *Transfusion contracts for Jehovah's Witnesses receiving organ transplants: ethical necessity or coercive pact?*, Journal of Medical Ethics, 2006; 32(4): 193-194.

transplant. Second, as Bramstedt notes, attempts to impose transfusions would be unethical because patients are free to withdraw consent to transfusions at any time. To transfuse the Jehovah's Witness despite his/her refusal would constitute unjustified paternalism, because interventions against a patient's will must be for the good of the patient and this would aim at the good of other patients who will accept transplant and transfusion. Third, this justification appears to assume that the behavior of the person who abuses alcohol and the Jehovah's Witness' refusal of blood transfusion represent equivalent risk to the viability of the transplant. There is reason to doubt this assumption since reports indicate that with proper perioperative care and careful selection of transplant candidates for health, the outcomes for Jehovah's Witnesses receiving transplant but no blood transfusion are comparable to transplant patients who receive transfusions.<sup>145</sup>

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<sup>145</sup> Good medical ethics must reflect sound medical science. We review the medical literature reporting transplant surgeons' experience with kidney and liver transplants in Jehovah's Witness patients. In 1988, Kaufman et al. published the results of their positive experience with kidney transplant for Jehovah's Witnesses; they found comparable success rates from Jehovah's Witnesses and non-Jehovah's Witnesses. And, in 1996, Seu et al. made the first published report of successful liver transplant in a Jehovah's Witness, and they discussed the techniques they employed in this procedure. Since this article appeared, other transplant specialists have reported their experiences in kidney and liver transplant with their Jehovah's Witness patients; the consensus in the literature is that Jehovah's Witnesses refusal of blood transfusion should not bar them from receiving a transplant.

Kandaswamy et al. found no statistically significant difference in the one to ten-year survival rates in a comparison of 50 kidney and kidney-pancreas transplant cases of Jehovah's Witnesses and non-Jehovah's Witnesses. Figueiro et al. also reported on pancreas-kidney transplant in Jehovah's Witnesses, and they found similar graft survival rates between Jehovah's Witnesses and patients who accepted blood transfusion. Boggi et al. also report that Jehovah's Witnesses may safely undergo pancreas-kidney transplant (though they argue that Jehovah's Witnesses should be obliged to agree to rescue transfusion). Hernández-Navarrete et al. reported on three kidney transplant patients who were Jehovah's Witnesses, and they found an acceptable graft function and survival from three to twenty-four months.

The literature on liver transplant in Jehovah's Witnesses is more extensive than for kidney transplant. In a series of articles starting in 1999, Oliver Detry and colleagues discussed their experience with liver transplant in Jehovah's Witnesses; they reported successful transplants without transfusion, and they suggested that their techniques could benefit non-Jehovah's Witnesses by reducing the need for transfusion in transplants overall. Nicolas Jabbour and colleagues also published multiple papers on their experience with transfusion-free transplants, and found comparable outcomes among Jehovah's Witnesses and non-Jehovah's Witnesses. Like Detry et al., Jabbour et al. also found that the techniques developed for Jehovah's Witnesses would have a positive effect on care for non-Jehovah's Witnesses by decreasing the need for transfusion. Other published cases of successful liver transplant in Jehovah's Witnesses come from Nebraska (Stoye et al.), Brazil (Garcia et al.) and Australasia (Jeffrey et al.).

The reports of successful transplant treatment in Jehovah's Witnesses are encouraging, and they should expand access to treatment for them. It is important to note that these reports emphasize the role of perioperative care in the success of the transplants; it is important to manage the patient prior to the transplant to reduce the risks associated with bloodless surgery: optimizing medical conditions (particularly anemia), optimizing blood volume, prevent unnecessary hemoglobin reduction, minimizing post-operative blood drawing and optimizing Red Blood Cells (RBCs) synthesis with erythropoietin, iron, folic acid, and vitamin B12 (Figuero, et al.). Two of Jabbour and colleagues' eight Jehovah's Witness patients who received deceased donor livers died – one intraoperatively and the other on the second postoperative

## Conclusions and Clinical Case Resolution

Contrary to the claims of Bramstedt and Boggi et al., a Jehovah's Witness's willingness to undergo blood transfusion should not be a precondition for kidney or liver transplant, nor should it bar listing a Jehovah's Witness to receive a deceased donor organ. Neither the ethical arguments nor the biomedical literature support the exclusion of Jehovah's Witnesses as transplant candidates. And, non-Jehovah's Witnesses may also benefit from surgical techniques that reduce the need for blood transfusion. At Mount Sinai Medical Center, the transplant program assesses each case on its own merits, and frequently agrees to list and transplant Jehovah's Witnesses. The most common obstacles to listing Jehovah's Witnesses are medical, e.g., a patient with a history of clotting cannot stop his blood thinner. As one transplant surgeon said to us, "It seems unfair to focus on refusal of blood transfusion as a reason not to transplant. There is a reason to reconsider the wisdom of transplant for everybody – nobody's a perfect candidate".

The transplant surgeons at the Recanati/Miller Transplant Institute believed that they could take perioperative and operative steps to transplant the patient successfully, and because the patient was likely to die without a kidney transplant, she should be registered with OPTN for a kidney from either a Hepatitis C positive or negative donor. The patient was listed for transplant in January 2014. The patient nearly received a kidney after three to four months on the OPTN registry, but another patient was a better match for the kidney. The patient also was notified of a possible match while visiting her daughter out of state, but was not able to come to Mount Sinai Hospital due to inclement weather. Finally, a little over a year after registering with OPTN, the patient was matched to a kidney from a Hepatitis C positive donor, and underwent transplant. The patient continues to be monitored by the transplant team at RMTI, and she is doing well, soon to begin the new treatments for Hepatitis C. When the patient reflects on her time waiting to be matched, she said, she was preparing to die, but Jehovah orchestrated the circumstances that allowed her to receive a kidney. "It would be devastating to have been denied the extra days free of dialysis to spend with my family."

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day (Jabbour-2005). Jabbour et al. do not attribute the deaths to failure to transfuse. They cite the advanced disease of the patients; they received livers because they were at the top of the transplant list.



## **The necessities and the limits of Principlism.**

Tom Tomlinson presents some arguments in defense of Principles. The arguments for the necessity of principles in ethical reasoning are<sup>146</sup>:

- 1- Principles or rules are what we end up with when we demand reasons; a demand that is, at least up to a point, always legitimate when dealing with ethical matters.
- 2- The principles reply to the requirement of universalizability; if my ethical judgments are not merely arbitrary or ad hoc, I will concede that at least I must be consistent.
- 3- Moral principles can serve to unify or systematize our more specific moral judgments.
- 4- Principles allow us to maintain moral reasoning within a more general and well-understood deductive model (its logical structure is no different from Socrates' famous syllogism).
- 5- Principles seem to form the content of our moral sensibility. They serve to identify morally relevant features in the environment, alerting us to the possibility that we are entering morally risky territory that many require us to make a moral judgment.
- 6- Principles don't tell us what we should do. Rather, they direct our attention to the sorts of things that must be taken into account in deciding on an ethically appropriate course of action.
- 7- Principles play an essential role in the beginning of deliberation, not only towards its end.

On the other hand, one question proffers some reflections about the limits of Principles: Are principles alone adequate to explain and justify our moral judgments, in particular in a clinical ethics consultation?

Following Tomlinson's reasoning, there are some limits to the Principlism Theory<sup>147</sup>:

- 1- The theoretical validation of principles could be offered in order to justify every moral or ethical conclusion;
- 2- In many clinic situations no single principle can resolve an ethical problem;
- 3- It is often very difficult to balance two or more principles involved in a clinical case;

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<sup>146</sup> Tomlinson T, *Methods in Medical Ethics*, New York, Oxford University Press, 2012: 4-6.

<sup>147</sup> Tomlinson T, *Methods in Medical Ethics*, cit., 23-27.

- 4- Principlism refers to the “common morality” as a starting point to justify our considerations;
- 5- “Principles, rules, and rights require balancing as well as specification. We need both methods, because each addresses a dimension of moral principles and rules: range and scope, in the case of specification, and weight or strength, in the case of balancing”<sup>148</sup>;
- 6- There must be balancing among competing principles in a pluralistic system.

Balancing competing goods means, as Beauchamp and Childress wrote, to make “unavoidable intuitive and subjective weightings”. Balancing judgments and justifying acts refers to presenting good reasons, inter-subjectively shared (and in this sense “objective”): “balancing would not then be a mode or method of justification; it would instead mark the end of reasoned justification as a tool of moral reflection”<sup>149</sup>.

Beauchamp and Childress’ balancing principles set forth “six minimal conditions that must be met to justify infringing one prima facie norm to adhere to another”<sup>150</sup>.

The conditions are<sup>151</sup>:

- 1- Good reasons can be offered to act on the overriding norm rather than on the infringed norm;
- 2- The moral objective justifying the infringement has a realistic prospect of achievement;
- 3- No morally preferable alternative actions are available;
- 4- The lowest level of infringement, commensurate with achieving the primary goal of the action, has been selected.
- 5- Any negative effects of the infringement have been minimized;
- 6- All affected parties have been treated impartially.

Principlism has the merit of guiding ethics reflections using four principles as cardinal points. Otherwise it would be difficult for these four principles to summarize all the aspects of the ethics issues involved in daily clinical practice.

Referring to the method to conduct an ethics consultation explained by Beauchamp and Childress, it seems important to underline some critics inherent to two interrelated main

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<sup>148</sup> Ibidem, 50.

<sup>149</sup> Ibidem, 53.

<sup>150</sup> Ibidem, 55.

<sup>151</sup> Idem.

aspects: firstly, if the four principles guarantee an equal opportunities to everyone - is it possible to build a global bioethics (only) with a common words?-, secondly, if the principles are *a priori* characterized by the idea to be *good* - is one man's autonomy another man's prison?-.<sup>152</sup>

Creating a common moral language useful to all stakeholders of a case could be recognize as an significant outcome: "we all think that autonomy is good, that justice is good, that it is good to do good, and that it is good not to inflict harm, in short, [...] we think that good is good"<sup>153</sup>. But the good is characterized in different ways in various circumstances and for this reason a lot of questions could open, ad example: could we [a priori] recognize that common words are sufficient to build global ethics? Are *good* and *bad* objective or subjective? Is the patient to be understood as an individual, as family member, or as a citizen?<sup>154</sup>

Beyond the principles there is a person, i.e. a suffering patient who asks to be cared for. The moral theory called "Personalism" tries to pay specific attention to the person, as its special goal in medical care. This will be the object of the next chapter.

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<sup>152</sup> Takala T, *What is wrong with Global Bioethics? On the Limitations of the Four Principles Approach*, Cambridge Quarterly of Healthcare Ethics, 2001; 10: 72-77.

<sup>153</sup> Ibidem.

<sup>154</sup> Ibidem. "If objective, who is to be trusted to know what the objective truth it? Is subjective, who is the one whose opinion we should listen to? The patient, the customer, the doctor, the ethics committee, family members, or who?".

## Personalism and Palliative Sedation Therapy

Personalist bioethics recognizes the body-soul unit as the foundation of the subjectivity of every human being, also identified by the term *person*. This position is defended in particular by the Catholic Church. The notion of *person* indicates the *homo sapiens* species as the only one able to recognize the right to life for itself: “the human being is structurally a *person*, this condition does not depend on his will, but on his origins”<sup>155</sup>.

Cardinal Elio Sgreccia<sup>156</sup> wrote that respect for the truth about man is the foundation of ethics. Respect for man from the beginning of life to the end of life means in the first case, to respect a God who creates, and in the second case to respect the encounter between man and God: “respected man in the final phase of his life means to respect [...] his return to the Creator, excluding any other power on the part of man, both excluding the power to anticipate this death (euthanasia), and excluding the power to prevent this meeting with a form of biological tyranny (aggressive treatment). It is in this light that the line between “euthanasia” and “death with dignity” is drawn<sup>157</sup>.

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<sup>155</sup> Sgreccia E, *Manuale di Bioetica, Fondamenti ed etica biomedica*, vol. 1, Roma, Vita e Pensiero, 2007<sup>4</sup>, 159-169. The term *person* or human being can be applied to everybody irrespective of the color of the skin, sex or race.

<sup>156</sup> Sgreccia E, *Manuale di bioetica*, cit., 893.

<sup>157</sup> Ibidem.

In this chapter, after a brief presentation of the term *person* and its intimate relationship with the term *identity* according to the teachings of the Catholic Church, a clinical case, which occurred in a hospice, will be presented. The analysis of the clinical ethics questions will be offered after the presentation of the method of analyzing this clinical case, following the principles of this moral theory.

The last paragraph is dedicated to presenting a criticism of a method of conducting an ethics consultation which has its roots in personalist moral theory and the concept of the “sanctity of life”.

### **The human being as a *person*.**

We will try to answer, in the light of the personalist theory, to one of the most important theological and anthropological question, *who is a human being?*

The notion of *person*, as presented by the Christian Church in order to resolve questions regarding Christological and Trinitarian nature, was used to identify the human being with the particular purpose of presenting the spiritual characteristics of human nature. The result was a way of interpreting man as related to the image of the Creator: “not enough - writes Karol Wojtyła -to define a man as an individual of the species Homo (not even Homo-Sapiens). The term *person* was chosen to emphasize that man cannot be locked up in the notion of ‘an individual of the human species’; that there is in him something more, a fullness and perfection of being special, that you cannot do more than define him/her with the term *person*”<sup>158</sup>

In bioethics this ethics theory shows the set of rules to be referred to in defense of the human person seen in its totality. The acknowledgement of the other human being in front of me allows me to say something about myself. So the same question can be worded in two different manners: *Who is the person?* Or, *Who is the other human being who is in front of me?*

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<sup>158</sup> Wojtyła K, *Amore e responsabilità*, Genova, Marietti, 1978, 12.

Personalism identifies all human beings with the term *person*. The idea that all human beings are persons entails the concept that “people are in a relationship based on mutual acknowledgement, but this acknowledgement does not come before of the human being, as our condition, but it responds to a need that comes from someone else”<sup>159</sup>.

By the fact that we always identify a specific human being in a relationship, we must firstly know that the subject in front of us is a human being and therefore a person.

On the subject, Robert Spaemann affirms that “we should before know if this is a man [...] in order to know if he/she is a person”<sup>160</sup>.

It is very difficult to offer a definition of *person* because every categorization is insufficient to encompass all of the facets which are implied in the term.

The term *person* in its original Greek meaning (in Greek: *prosopon*; in Latin: *persona*) indicates a theatrical mask, therefore signifies a character who plays a certain role during a performance.

With the term *person* it is customary to indicate the mask used by actors during theatrical performances “to hide the face and resonate the voice loudly (per-sound: playing in all directions)”<sup>161</sup>.

The purpose of the mask is to represent the transcendence of the actor to highlight the essential being of the character who he represents, and the words he speaks: “it was later, in this sense, that the term *person* lost the ancient meaning of “mask”, to be identified –in theological disputes- with the Greek word *ipostasis* (in Latin: sub-stantia, in English: substratum, foundation)”<sup>162</sup>.

In Dogmatic Theology the noblest use of *person* is represented by the three *hypostases* of God - Father, Son and Holy Spirit -.

In Theology and Philosophy the different interpretations of this word are numerous. It is possible to find specifics regarding the term by referring to the concepts of consciousness (Locke), rationality (St. Thomas) and of dignity and autonomy (Kant)<sup>163</sup>.

In particular, the term *person*, for Christian theology, marks the opening to the transcendent because the single human being is a son, and therefore has a relationship

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<sup>159</sup> Spaemann R, *Persone*, Roma, Laterza, 2007<sup>2</sup>, 5.

<sup>160</sup> Spaemann R, *Persone*, cit., 8.

<sup>161</sup> Idem.

<sup>162</sup> Idem.

<sup>163</sup> Aa.Vv., *Enciclopedia garzanti di filosofia*, Milano, Garzanti, 1993, 855-856.

with the Father. Thus being a human being signifies a relationship, because the *person* is in communion with God and his neighbor.

Thus Boethius' definition of *person* is significant for theology: "Persona est naturae rationalis individua substantia"<sup>164</sup>.

Robert Spaemann, recouping the Boethius' definition, says: "The rational nature may require a certain kind of attention. But primarily, in Boethius, the sense of the definition is ontological. *Naturae Rationalis* exists as being-itself. [...] But it means that the individual who exists in this way cannot be adequately described by any possible description"<sup>165</sup>.

*Person* cannot be described as *something* that can be only outlined by a set of characteristics. The *person* is *someone*<sup>166</sup>: mentioning it oversteps any possible qualitative description.

Karol Wojtyła speaks about the *person* reflecting on the subject – object relationship. He expressed his position in this way: "Now the subject is [...] a being, being that exists and acts in one way or another. Thus it can be said that the world in which we live it is made up of a large number of subjects. [...] The human being is objectively *someone* and this is what distinguishes him from other beings of the visible world that, for their part, objectively are always only *something*"<sup>167</sup>.

So an evolution of the meaning of the word *person* can be seen during historical development: the term which was originally identified as an important object for the work of the actors, now identifies the essence of a human being.

Regarding the concept of *person*, another important related term is *identity*.

The word *identity* has its origins in Aristotle's *Metaphysics*; the Stagirite philosopher writes: "Identity is somehow a unit, whether that the unit refers to several things, or refers to one single thing, taken as two: as when it is said that the thing is the same as itself"<sup>168</sup>.

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<sup>164</sup> Boezio AMS, *Contra Eutychen et Nestorium*, in Spaemann R, *Persone*, cit., 30.

<sup>165</sup> Spaemann R, *Persone*, cit., 30-31.

<sup>166</sup> Cfr. Spaemann R, *Persone*, cit., 31.

<sup>167</sup> Wojtyła K, *Amore e responsabilità*, cit., 15.

<sup>168</sup> Aristotele, *Metafisica*, cit., V, 9, 1018 a 7.

A second definition, important for our discussion, is: “It is impossible for the same thing, at the same time be inherent and not be inherent to the same thing in the same respect”<sup>169</sup>.

Therefore it can be said that composed units, such as the living, are inclined to have an identity coherent with the totality (spiritual, somatic, psychological) of their own kind, which is not only characterized by the simple sum of its parts, but by the harmony of the parts with the personal entirety.

Thus, personal identity does not develop from a pure solipsistic reasoning. Through the definition of the term *person*, the idea of a man as an individual can be surpassed, “the identification of ourselves necessarily includes the existence of others”<sup>170</sup>.

Other persons perform gestures and develop practices of life by which we learn, and to which we belong. The practice of the practices of life is the alphabetic practice. The word, the Logos, is what allows us to communicate and to recognize another person in front of us, as similar to us. This is the substrate for personal identity: “solipsism is incompatible with the concept of person”<sup>171</sup>.

The identity of a person exists and it is only formed in an intrapersonal relationship, in which the presence of a multitude of persons gives meaning to the personal existence and to the identity of the individual.

### **The sanctity of life**

The philosophical and theological paradigm which refers the concept of the sanctity of life<sup>172</sup> is supported by Catholic Bioethics, which is based on faith and the Scriptures; this philosophical paradigm is composed as follows: “from that particular ethical-metaphysical teaching, originated by a Greek-scholastics conceptual matrix and

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<sup>169</sup> Ibidem, IV, 2, 1005 B 20.

<sup>170</sup> Spaemann R, *Personae*, cit., p. 36.

<sup>171</sup> Ibidem, p. 40.

<sup>172</sup> Before presenting the critique of the theory of the sanctity of life defended by the Catholic Church, it is better to define its peculiar characteristics.



a finalistic-providential vision of the world, sees in human life [...] an ontological-axiological reality worthy of “absolute respect”<sup>173</sup>.

Throughout history the influence of this theory was enormous, even though it presents itself with a very precise orderliness. The ideological construction is articulated around three interconnected concepts, related to the first asset for a person, which is his/her life<sup>174</sup>.

- 1) the characteristic of being a creature intrinsic to man;
- 2) the total non-availability of the human life;
- 3) the inviolability of the human life in all of its aspects.

The theory of the Sanctity of life is rooted in the idea of life as a gift from God. In the encyclical of John Paul II, *Evangelium Vitae*, the Pope wrote<sup>175</sup>: “Man is no longer able to see himself as “mysteriously different” from other earthly creatures; he regards himself merely as one more living being, as an organism which, at most, has reached a very high stage of perfection. Enclosed in the narrow horizon of his physical nature, he is somehow reduced to being “a thing”, and no longer grasps the “transcendent” character of his “existence as man”. He no longer considers life as a splendid gift of God, something “sacred” entrusted to his responsibility and thus also to his loving care and “veneration”. Life itself becomes a mere “thing”, which man claims as his exclusive property, completely subject to his control and manipulation”.

In this position it should be noted that the individual does not have an arbitrary hold on his life. The conception of human life as a gift is put into close relation to the principle of the absolute inviolability of life<sup>176</sup>: the principle of inviolability implies, therefore, positively, the norm of acceptance and respect and, in the negative, the rejection of its disability or suppression.

In Catholic Bioethics there is no difference between life and the human person: life is always characterized as human. It is sacred, because it inherently possesses the ability to relate to God. Theological tradition says that life is not in man’s possession, but is

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<sup>173</sup> Fornero G, *Bioetica cattolica e bioetica laica*, Milano, Mondadori, 2005, 27.

<sup>174</sup> Ibidem, 28.

<sup>175</sup> *Evangelium Vitae*, 22.

<sup>176</sup> Fornero G, *Bioetica cattolica e bioetica laica*, cit., 30. See also in this dissertation § *The concept of proportionality: an historical development*, 38.

entrusted to him, and he will be accountable to the Creator<sup>177</sup>: what God commanded, and that man should respect and not coincide in any way with the determinism of biological processes. It coincides with what in those processes presents good reasons for a will which has a human heart. In this sense, the maturity with which modern man looks at his life can be appreciated, when he demands a higher quality and he considers his life increasingly as his responsibility, rather than a blind mechanical succession of natural events.

For the Catholic religion life finds its deepest meaning in faith in God, who through an act of love, gave it to man. The goal of the creature is to live a good life and accept its conditions.<sup>178</sup>

The Roman Catholic doctrine of the sanctity of life is presented as a rigorous deontologism, focused on some absolute prohibitions that apply regardless of the circumstances.

In the Catechism of the Catholic Church we read<sup>179</sup>: “There are acts which, in and of themselves, independently of circumstances and intentions, are always gravely illicit by reason of their object; such as blasphemy and perjury, murder and adultery. One may not do evil so that good may result from it”.

There are three important pronouncements, which definitively clarify the position of Catholic Church about the beginning and end of life<sup>180</sup>:

1-Therefore, by the authority which Christ conferred upon Peter and his Successors, and in communion with the Bishops of the Catholic Church, I confirm that the direct and voluntary killing of an innocent human being is always gravely immoral. This doctrine, based upon that unwritten law which man, in the light of reason, finds in his own heart (cf. Rom 2:14-15), is reaffirmed by Sacred Scripture, transmitted by the Tradition of the Church and taught by the ordinary and universal Magisterium.

2- The Church makes clear that abortion is a most serious and dangerous crime, thereby encouraging those who commit it to seek without delay the path of conversion.

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<sup>177</sup> Cattorini P, *Sotto scacco. Bioetica di fine vita*, Napoli, Liviana Medicina, 1993, 36.

<sup>178</sup> Ibidem, 38.

<sup>179</sup> Chiesa Cattolica, *Catechismo della Chiesa Cattolica*, Città del Vaticano, Libreria Editrice Vaticana, 1999, §1756.

<sup>180</sup> *Evangelium Vitae*, 57, 62, 65.

3- Euthanasia is a grave violation of the law of God, since it is the deliberate and morally unacceptable killing of a human person.

Bioethics Catholic echoes a personalism ontologically based on rational metaphysical scholastics. This metaphysical concept founded Catholic philosophical anthropology, and proceeded to outline the precise vision of man that emerged.

Based on rational metaphysics, Catholic bioethics means that the theory of the sanctity of life has the following characteristics:

- the primacy of being (*agere sequitur esse*);
- the existence (and knowledge) of a universal human nature, from which to draw moral rules that apply to all and forever;
- the normativity of natural structures, in which God's project for life is embodied.

In the encyclical *Veritatis Splendor*, which concerns the moral teachings of the Church on the freedom of man, it is asserted that<sup>181</sup>: “Freedom which claims to be absolute ends up treating the human body as raw datum, devoid of any meaning and moral values until freedom has shaped it in accordance with its design. Consequently, human nature and the body appear as presuppositions or preambles, materially necessary for its freedom to make its choices, yet extrinsic to the person, the subject and the human act. Their functions would not be able to constitute reference points for moral decisions, because the finalities of these inclinations would be merely “physical” goods, called by some “pre-moral”. To refer to them, in order to find in them rational indications with regard to the order of morality, would be to expose oneself to the accusation of physicalism or biologism. In this way of thinking, the tension between freedom and a nature conceived of in a reductive way is resolved by a division within man himself”.

Starting from this position and expanding upon it, it can be said that the relationship that man must have with nature is not neutral: nature, in fact, reflects the wisdom that created it.

The human body is the visible dimension of the person's life, and therefore must be defended<sup>182</sup>; it is significant, because only through it the morality of human actions is realized.

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<sup>181</sup> *Veritatis splendor*, 48.

<sup>182</sup> Cfr. Fornero G, *Bioetica cattolica e bioetica laica*, cit., 50.

According to the Magisterium, only the appeal to natural moral law would have the prerogative to provide clear and safe ethical answers. Following the official Bioethics of the Catholic Church, personalism without strong anthropological and metaphysical anchors, that is, without consideration for the objective ontological structure of the human person and of his roots in a natural order established by God, would risk falling into a form of subjectivism unsuitable to safeguard instances of sound doctrine<sup>183</sup>.

About the particular vision of euthanasia that the Church of Rome defends, it is fair to mention one last time the *Evangelium vitae*<sup>184</sup>: “Today, [...] the experience of dying is marked by new features. When the prevailing tendency is to value life only to the extent that it brings pleasure and well-being, suffering seems like an unbearable setback, something from which one must be freed at all costs. Death is considered "senseless" if it suddenly interrupts a life still open to a future of new and interesting experiences. But it becomes a “rightful liberation” once life is held to be no longer meaningful because it is filled with pain and inexorably doomed to even greater suffering.

Furthermore, when he denies or neglects his fundamental relationship to God, man thinks he is his own rule and measure, with the right to demand that society should guarantee him the ways and means of deciding what to do with his life in full and complete autonomy.

After a presentation of the concept of *person* from a Catholic point of view, below a clinical case which occurred in a Hospice<sup>185</sup> is presented, in which different points of views about suffering, pain, judgments about palliative sedation and the patient-physician relationship are highlighted.

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<sup>183</sup> Cfr. Fornero G, *Bioetica cattolica e bioetica laica*, cit., 58.

<sup>184</sup> Cfr. *Evangelium Vitae*, 64.

<sup>185</sup> Drane JF, *A liberal Catholic Bioethics*, Berlin, LIT, 2010, 192. The focus of the palliative medicine is “switched away from aggressive attack on body parts and defeat of the enemy death”. The specific place where the palliative medicine has a diriment role is the Hospice. The focus of the Hospice is “on the whole person and on the quality of a dying patient’s life. Their background medical theory or vision is more holistic. Their objective is to create a more humane medicine”. Objectives of palliative care are: effective focus on a management of pain and suffering; concern for both the bodily condition and for the inner life of the patient and decision-making which respects patient autonomy and the role of legal surrogates.

## **Clinical case: Why not palliative sedation?**

Mr. G. Rossi, 65 years old, medical doctor, not married, cohabitant. He stayed in Hospice from July 25<sup>th</sup> to September 1<sup>st</sup> (date of death), total days of stay - 39.<sup>186</sup>

Diagnosis upon acceptance: neuroendocrine carcinoma. Main diagnosis: pulmonary infiltrate cancer. Complementary diagnosis: atrial fibrillation, heart failure, anemia.

The patient is always alone during the night. He was conscious and responsive until August 31<sup>st</sup>. The evening of the 31<sup>st</sup> of August a therapy with midazolam 5mg to aid in sleeping was initiated. He then rested until 7:00 a.m.

He had two sisters and a partner. They regularly came to visit him in the Hospice. He also had a couple of friends (husband and wife). They were medically competent, as one is a dentist and the other a general practitioner, but without experience in palliative care. For them, palliative care meant keeping the patient in the Hospice, letting him do whatever he wanted, and allowing him to make decisions regarding his condition and quality of life.

The two sisters and partner were never questioned by the patient's friends. They came to the hospice when the friends were not there. The partner agreed to a symptoms therapy, to appease the patient, and she approved of the use of morphine so the patient could breathe easier and so reducing dyspnea.

Friends came to halt any medical procedures, and to persuade the patient do nothing after their initial visit to the facility. The patient was well-disposed to the palliative care to reduce the pain symptoms, but his friends persuaded him to change the therapy after every visit.

For them he was to live to the end of his life in full command of his own situation. He was completely conscious although suffering and dyspnoic, and underestimated the symptoms which were masked by morphine. Friends attributed his pain to a cardiological problem (cardiopathy), even though they knew that he would die from lung cancer. Another friend, a lawyer, was favorable to the palliative care, but the other two competent friends silenced him. There was much coming and going in the room and in general the patient willingly seemed to accept all these visits.

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<sup>186</sup> I would like to thank dr. G. Zaninetta and dr. E. Faggiani (Hospice, Domus Salutis, Brescia) for recommendations on writing the clinical case.

For 38 days the doctors and the nurses offered their time to the friends to help them get used to the idea of death, of the end of life, and the need to use morphine. They brought vitamins from home. Vitamins were given to him orally or intravenously (glucosate).

The staff did not prevent the administration of vitamins because it was not contraindicated. On August 27<sup>th</sup>, there was an acute event, it was treated with Dilzene and the symptoms passed immediately.

On August 24<sup>th</sup> the catheter was applied. On August 27<sup>th</sup> only a sister visited the patient. The patient was no longer able to stand up. For the four nights before August 31<sup>st</sup> the patient slept in an orthostatic position in order to breathe more easily.

During the evening of the August 31<sup>st</sup> the physician decided to start night therapy with Midazolam as the patient was suffering intensely, although the patient's doctor friend, present in his room, was puzzled about the usefulness for the patient of breathing better. After the patient's consent, the nurses put him to bed.

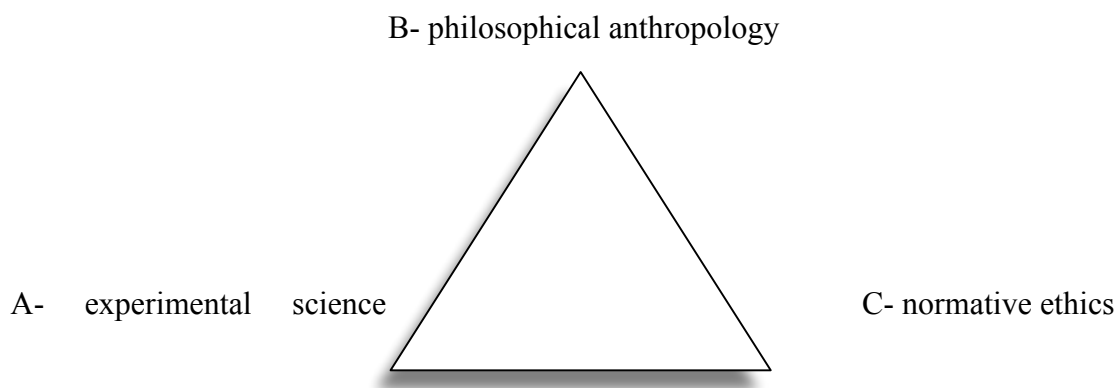
The patient slept until 7 o'clock am. During the morning the patient's condition worsened and he died at midday. During the patient's last ten days only the doctor friend came to visit him, and stayed with him for only a few minutes. In those days the couple of friends banned the partner from seeing the patient. The doctor friend arrived at 10 a.m. with her husband, and she began brightly to discuss use of the palliative therapy since the patient only had 2 or 3 days to live. She did not say that the patient was well, but in her opinion the patient could continue to draw breath and not to sleep during these days, thus prolonging the patient's suffering before his imminent death.

Why should the doctor always convince everyone? If the patient agrees to the treatment, why must the doctor convince his friends?

If the doctor and patient agree about the treatments, it seems too difficult to listen to and be influenced by other opinions, especially if they are inadequate and not supported by experience. Friends were always disagreeing on therapies. They accused the doctor and nurses of wanting to free up the room.

### The *triangular method* and case analysis.

The ethics judgment about different bioethics questions is related to an epistemological and methodological configuration founded on the *triangular method* between experimental science, philosophical anthropology and normative ethics. Fundamental philosophical configuration is guided by *ontological personalism*, which gives credit to human reason and remains open to revelation and dialogue with actuality.<sup>187</sup>



The starting point is the biomedical data (point A). After the scientific analysis (e.g. diagnosis, prognosis, therapy) the second is the anthropological point: it is useful to understand which values are present in the connection between life, dignity, and the integrity of the human person. The last one concerns the resolution of the ethics question: decisions regarding ethics issues in a clinical setting should take into consideration the values explained by anthropological reflections on specific clinical conditions.<sup>188</sup>

In relation to our case the most important issue is palliative sedation: the point A concerning philosophical anthropology has already been treated in the previous paragraph. Now it is useful to concentrate on clinical and ethics questions in order to offer a solution.

The clinical case presented regards many ethics issues. Some of them are:

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<sup>187</sup> Sgreccia E, *Manuale di bioetica*, cit., XVI.

<sup>188</sup> Sgreccia E, *Manuale di bioetica*, cit., 74-75.

What kinds of implications are there for a dying patient consenting to palliative sedation during the last moments of own life? What kind of ethical issues are present in this kind of decision? And, how can an ethics consultant take them on? Could you kill the patient with palliative sedation therapy? What is the role of the family members or friends in choosing a palliative sedation therapy? Is the palliative sedation therapy understood as a sort of soft euthanasia? Is the palliative sedation therapy a proportionate treatment?

Continuous Sedation until Death (CSD) is the act of reducing or removing the consciousness of an incurably ill patient until death. *Terminal Sedation* and *Palliative Sedation* are the most frequently used terms to describe CSD.<sup>189</sup>

In the last twenty years a terminological development occurred: from 1998 to 1999 all studies referred to the procedure as ‘terminal sedation’. Enck R.E. first introduced the concept of “terminal sedation” in the palliative care literature in 1991: “Since then, sedation practices for patients who are terminally ill or in the final stages of dying have rapidly expanded. At the same time, there has been an extensive and growing debate about the ethical assessment of these practices. Almost from the start, the practices were considered controversial. Critics claimed that it was “slow euthanasia” or mercy killing in disguise. They argued that the adjective “terminal” was not simply an indicator of time, reflecting the final phase of a patient’s life when such sedation was typically administered; instead, it revealed the real purpose of the intervention, that is, to terminate the patient’s life. Because the concept of terminal sedation was deemed confusing, ambiguous, and open to different interpretations, it was argued that it should be abandoned altogether.”<sup>190</sup>

In 2006-2008 83% of studies were using the term ‘palliative sedation’ to indicate: the use of sedative medications to relieve intolerable suffering from refractory symptoms by a reduction in patient consciousness.<sup>191</sup>

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<sup>189</sup> Rys S et al., *Continuous sedation until death: moral justifications of physicians and nurses – a content analysis of opinion pieces*, *Med Health Care and Philos*, 2013; 16:533-542.

<sup>190</sup> Henk t.H, et al., *Palliative Sedation Versus Euthanasia: An Ethical Assessment*, *Journal of Pain and Symptom Management*, 2014; 47(1): 123-136. Enck RE, *Drug-induced terminal sedation for symptom control*, *Am J Hosp Palliat Care*, 1991; 8: 3-5.

<sup>191</sup> Maltoni M et al., *Palliative sedation in end-of-life-care*, *Current opinion in oncology*, 2013; 25(4): 360-367. Hasselaar JG et al., *When cancer symptoms cannot be controlled: the role of palliative sedation*, *Curr Opin Support Palliat Care*, 2009; 3: 14-23.



Today it seems better to use the term “palliative sedation” to specify the goal of this end-of- life practice.

Palliative Sedation Therapy (PST)<sup>192</sup>:

- 1- It is a clinical procedure that is an integral part of the palliative care continuum.
- 2- Its ‘mission’ is to find a solution for a refractory symptom by reducing the level of consciousness only as much as needed.
- 3- PST has no detrimental effect on survival.
- 4- Life expectancy is referred to imminently dying patients with an expected survival equal to or less than 2 weeks.
- 5- PST is an important clinical ethics issue in a physician’s daily practice.
- 6- In many countries, PST is considered as clinically and ethically distinct from Physician Assisted Suicide (PAS).

Palliative sedation therapy is different from both euthanasia and from Physician Assisted Suicide. Euthanasia is generally defined as the act, undertaken only by a physician who intentionally ends the life of a person at his or her request. The physician therefore administers a lethal substance. In physician-assisted suicide (PAS) on the other hand, a person self-administers a lethal substance prescribed by a physician.<sup>193</sup>

Two examples:

1- PAS in Oregon

Physician-assisted suicide has been legal in Oregon since November 1997. The *Death with Dignity Act* requires that a patient must be:

- An adult (18 years of age or older),
- A resident of Oregon,
- Capable (defined as able to make and communicate health care decisions),
- Diagnosed with a terminal illness that will lead to death within six months
- Self-administered lethal medications

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<sup>192</sup> Idem.

<sup>193</sup> Pereira J, *Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls*, Current Oncology, 2011; 18(2): e38-e45. “To date, the Netherlands, Belgium, and Luxembourg have legalized euthanasia. The laws in the Netherlands and Luxembourg also allow pas. In the United States, the states of Oregon and Washington legalized PAS in 1997 and 1999 respectively, but euthanasia remains illegal”.

## 2- PAS in Netherlands:

The Netherlands, Belgium, and Luxembourg have legalized euthanasia. The laws in the Netherlands and Luxembourg also allow PAS.

The physician must fulfill these criteria:

- to be satisfied that it is a spontaneous and well-considered request of the patient;
- to be satisfied that the patient's suffering is unbearable with no prospect of improvement;
- to have informed the patient of the situation in which it is located and the prospects arising;
- to be sure, together with the patient, that no other solution is reasonable for his status;
- to have asked the opinion of at least one other independent doctor who has examined the patient and have then formulated an opinion on the existence of written policies;
- to have scrupulously executed all the steps of life's interruption or of PAS.

It is not necessary that the patient is terminally ill.

A PAS involves someone who has suicidal motives, intends to die, wants to do something to cause his or her death, and is not coerced into deciding to kill himself or herself. In contrast to “normal” suicide, a PAS requires aid from a relative or friend, a physician, or some other person who carries out the role of “enabler”.<sup>194</sup>

## 5- PST- PAS: ethical differences

The points of difference revolve around the intention, the act (or intervention) itself, and the outcomes of the act.

General description of the setting (PST-PAS):

- 1- the subject consciously chooses;
- 2- the choice involves the conscious interruption of all the rapports: the leaving of loved ones takes place in a specific time and place (determined by the patient);

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<sup>194</sup> Weir RF (ed.), *Physician-Assisted Suicide*, Bloomington, Indiana University Press, 1997.

- 3- the need for direct action by a health care worker (physician) is recognized;
- 4- the patient loses consciousness;
- 5- the patient dies.

	PST	PAS
INTENTION	To relieve symptoms	To alleviate suffering?
ACT	sedation of the patient	Cooperation with the patient’s desires regarding death
OUTCOMES	Allowing the patient to die during sleep	Death of the patient

**“Allowing to die” or killing?**

There are five kinds of actions that, under specific circumstances, can define the distinction between allowing someone to die and killing<sup>195</sup>:

1- *Withholding Life-Sustaining Treatment*. Deciding not to use certain medical treatments that would prolong life (the ventilator for terminally ill patients or DNR for patients afflicted by severe illness) is not killing a patient; it is allowing the patient to die. It is not always morally right, but it is sometimes, indeed it is often, morally right if the means are ‘morally extraordinary’; i.e. not using that particular means is generally accepted as morally licit.

2- *Withdrawing Life-Sustaining Treatment*. Deciding to stop the use of a means that has already been initiated (to turn off the ventilator) is considered by Catholic moral tradition as the equivalent of withholding life-sustaining treatment. If it is morally right and legal to withhold treatment X in circumstances ABC, it is also morally and legal right to withdraw treatment X in the same circumstances. The circumstance may

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<sup>195</sup> Kelly DF, *Medical care at the End of Life. A Catholic Perspective*, Washington D.C., Georgetown University Press, 2006, 13-20.

change, as when patients or surrogates state that they would have withheld treatment but are now unwilling to withdraw it.

Is it only a question of who decides? Allowing the patient to die and deciding to withhold or to withdraw a treatment considered 'extraordinary' is not a means to actualize a 'passive euthanasia' or an 'indirect euthanasia'.

3- *Pain Relief that Hastens Death*. Relieving pain is a moral right act. Is it possible even if the drugs administered to relieve the patient's suffering can hasten death? This question can be analyzed with the principle of double effect (PDE). Pain relief that hastens death meets the first condition of the PDE (the act-in-itself must not be morally wrong) because the act itself is not a killing but an administration of medication that relieves pain. It meets the second (the bad effect must not cause the good effect) because the bad effect, death, is not caused by the good effect, pain relief. Rather, the medication causes both with equal causal immediacy. Third (the agent must not intend the bad effect), the intention of the agent is not that the patient die, but that the patient be free of pain. And fourth (the bad effect must not outweigh the good effect), in the case of a dying patient, the bad effect, a slightly earlier death, is outweighed by the good effect, the relief of pain. Thus this action, like the first two, may well be morally right according to Catholic moral tradition.

The three most commonly cited arguments for why elimination of pain in a dying patient is not always possible are related to use and abuse of drugs and to the relationship with the family members.

First, there is fear of addiction. Addiction is an important problem for those whose unwarranted use of drugs causes harm to their lives (heroin, cocaine, alcohol, nicotine and morphine used improperly by doctors for pain relief). But, in this context the term addiction has an opposite meaning. It indicates both a description of a physical condition (withdrawal causes physical symptoms) and a social condition (the need for rehabilitation): none of these are present in the imminently dying patient. Dying patients need pain relief as they die.

The second concerns the increase in the use of drugs in dying patients. The standard of medical care clearly permits using enough drugs to eliminate pain in these patients. But families may feel guilty about withholding or withdrawing treatment or about pain relief

when this may hasten death. For them these acts could be understood as a lack of respect for their loved one's death.

The third reason opens the question about the consciousness of the dying person. The increase in drugs can render the person unconscious as he/she dies. This is called "palliative sedation". If the patient decides it is better to stop the pain than to be conscious and in constant agony, surely that wish must be granted. There are cases in which dying people themselves choose to suffer pain rather than lose their capacity to complete tasks they wish to do before dying. In these cases the wishes of competent people should be followed.

4- *Physician-Assisted Suicide*. It is a direct self-killing with the support of a practitioner. This practice is ethically and legal wrong both in Catholic tradition and in US and Italian jurisprudence.

5- *Active Euthanasia*. The health care practitioner may take action that directly causes the patient's death. It is a direct killing.

The document "Declaration on euthanasia"<sup>196</sup>, approved by Pope John Paul II and originating from the Congregation for the Doctrine of the Faith, explains the official position of the Catholic Church about euthanasia and voluntary suicide. In particular the passage n. 371 explains that "when death is imminent and cannot be prevented by the remedies used, it is licit in conscience to decide to renounce treatments that can yield only a precarious and painful prolongation of life, but without interrupting in any way the ordinary care which is due to the sick person in such cases".

Therefore, on the one hand there is no moral obligation to prolong a life when "there is no longer any reasonable basis for such a hopeful prognosis"<sup>197</sup> and on the other hand the ordinary care refers "to the obligation, common to all members of the human race, to conserve and sustain patient's life."

We can reread these norms into the logic of the polarity of resistance/surrender. Resistance implies the recognition that the other person (the patient) is a "good for me"; and surrender entails no obligation to do the impossible.

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<sup>196</sup> *Enchiridion Vaticanum*, VII, 1980; 332-351 (nn. 346-373).

<sup>197</sup> *Conserving Human life*, p. 154.

The resistance towards pain in order to protect the patient's life validates the "right and duty in case of serious illness to take the necessary treatment for the preservation of life and health"<sup>198</sup>.

And when the treatment cannot benefit the patient, and so it can be identified as "extraordinary", it may be interrupted: "if treatment is of no benefit to the patient, it may be interrupted while continuing with the care of the patient"<sup>199</sup>.

The surrender of active care opens up the possibility of directing palliative care towards the development of a type of care which improves the patient's quality of life during his/her remaining time.

## **Open issues**

### **Abuse and inappropriate use of the PST**

Inappropriate use of sedation occurs when doctors sedate the patients approaching the end of life with the primary objective of accelerating death.

This practice has been called "slow euthanasia": some doctors, in fact, administer medication, apparently to relieve symptoms, but with the hidden intention to hasten death.<sup>200</sup>

This can happen in the case of deliberate use of heavy sedation in patients who have refractory symptoms, or deliberate use of doses that far exceed what is needed to provide adequate comfort. These doses in excess may impair physiological functions such as spontaneous breathing and hemodynamic stability.

These ambiguous practices represent an unacceptable and often illegal deviation from the rules of ethical practice.<sup>201</sup>

Inappropriate use of palliative sedation occurs when sedation is practiced with the intent to relieve symptoms, but in clinical circumstances that are not appropriate. In such cases sedation is practiced with the intent to relieve symptoms which are considered untreatable and is carefully titrated to this effect, but the evidence is inadequate to justify such a radical intervention.

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<sup>198</sup> Pope Pius XII, *The Prolongation of life*, 1957, in Smith RE, *Conserving Human Life*, cit., 157.

<sup>199</sup> Enchiridion Vaticanum, IX, 1727, n. 1768, in Smith RE, *Conserving Human Life*, cit., 174.

<sup>200</sup> Cherny NI, Radbruch L., The Board of the European Association for Palliative Care, *European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care*, *Palliative Medicine*, 2009; 23(7): 581–593.

<sup>201</sup> Idem.

Representative examples of injudicious use<sup>202</sup>:

- 1) Cases in which, for inadequate assessment of the patient, potentially reversible causes of discomfort are overestimated
- 2) Situations where before resorting to sedation, you avoid engaging physicians who are experts in the relief of symptoms, despite their availability
- 3) Use of sedation by a doctor who is tired and frustrated by a patient's complex care in symptomatic terms
- 4) Situations in which the request is made for sedation of the patient by the family and not by the patient.<sup>203</sup>

### **Irrational refusal of sedation**

Irrational rejection of sedation in the management of refractory symptoms occurs when doctors refer excessively to the use of sedation, while at the same time insisting on other therapeutic options that do not provide adequate relief.

Given the subjectivity of the refractory evaluation and the profound inter-individual variability of the responses to palliative interventions, these evaluations are often very difficult to make.

Physicians should be aware of the possibility of a “determination which is counter-productive to dealing”, where the anxiety of having to deal with all of the difficult discussions on sedation and treatment of end of life issues leads to avoidant behaviors and treatment efforts that are futile, resulting in increased patient anxiety or resistance based on exaggerated concerns of hastening death.

### **Inadequacy of palliative sedation in clinical practice**

This occurs in situations where sedation is used in appropriate circumstances, but without the proper attention to one or more processes essential for good clinical practice.

Examples of inadequate clinical practice are the following<sup>204</sup>:

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<sup>202</sup> Idem.

<sup>203</sup> In our opinion this request should not always be considered incorrect.

<sup>204</sup> Idem. Indications for palliative sedation: weighted average: Delirium = 65%; Dyspnea = 26%; Pain = 14%; Other = 5% [emergencies: bleeding; Individual complex situations for which the answer cannot be reduced to just the domain of medicine: existential distress, psychological distress], Sykes N, Thorns A, *The use of opioids and sedatives at the end of life*, *Lancet Oncology*, 2003; 4(5): 312-318.

- 1) The improper consultation with the patient (if possible), family members, or other staff members to ensure their understanding of the indications for surgery, the objectives of the treatment plan, expected results and potential risks.
- 2) Inadequate monitoring of symptom distress or adequacy of relief.
- 3) The inadequate assessment of the psychological, spiritual and social factors can contribute to the patient's suffering.
- 4) Inadequate monitoring of physiological parameters that may indicate a risk of overdose (when clinically relevant).
- 5) The increase in hasty doses without the titration of sedative effects and without respecting the minimum effective dose.
- 6) The use of inappropriate drugs to achieve adequate sedation (for example opioids).
- 7) Inadequate care of the patient's family.
- 8) Inadequate attention to the emotional and spiritual well-being of staff members in distress.

### **The Critique of the Sanctity of Life.**

The critique of the Catholic thesis derives from the fact that it does not consent to addressing all of the issues that a lay person might consider important. A lay person generally maintains an anti-dogmatic and critical attitude, thinking in a manner independent from the hypothesis of a God.

From this secular vision of life, made possible by the safeguards of secularity in many States, it is possible to configure a bioethics concept focused on the quality of life<sup>205</sup>:

It is not life as such, or life as an expression of one particular religious or metaphysical value, to have value, but the quality (or well-being) of life, which constitutes a life that seems “worthy to be lived”.<sup>206</sup>

Opposing the value of the sanctity of life and the nature of man, which is imbued with culture, means placing a higher value on the personal choices that the individual is called to make. These choices are based on freedom and the self-determination of

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<sup>205</sup> Fornero G, *Bioetica cattolica e bioetica laica*, cit., 74.

<sup>206</sup> The most critical theory of the sanctity of life is utilitarianism: in it the secular paradigm differs from the sacred one, because it puts human nature in a rational metaphysical context.



individuals. This position is characterized by some conditions which characterize the concept of “quality of life”<sup>207</sup>:

- *Maximizing the good (the principle of Utility)*: For example, we ought to maximize the public benefits of scientific research, clinical medicine, public health measures.

- *A Theory of Value: The Standard of Goodness*. There are various theories of the good (or of value) used by Utilitarians to specify the core of goodness: 1- happiness, 2- satisfaction of desires and aims, 3- the attainment of such conditions or states of affairs as autonomy, understanding, various kinds of functioning, achievement and deep personal relationships.<sup>208</sup>

- *Consequentialism*. Any Utilitarian theory decides which actions are right entirely by reference to the consequences of the actions. A Utilitarian demands that we take account of what can reasonably be expected to produce the greatest balance of good or least balance of harm.

- *Impartiality (Universalism)*. A moral point of view is impartial in the sense that a moral judgment is formed without regard to either personal preference or interest (opposite to the egoism) and the particular advantages or disadvantages of persons such as special talents or handicaps, because these properties are morally arbitrary. Therefore, all parties affected by an action must receive *impartial consideration*.

The concept of “quality of life” has been elaborated using these parameters (minimum pain and often minimum total cost).<sup>209</sup>

From this, the respect for the autonomous choices that each person is called to make, the idea of respect, which can be interpreted in two ways arises<sup>210</sup>:

- 1- As the right to be left free to choose, without outside interference by governing authorities, who presume to tell people what they can or cannot do;
- 2- As the duty of everyone to preserve as much as possible the spaces and the possibilities of choice (one’s own or those of others).

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<sup>207</sup> Fornero G, *Bioetica cattolica e bioetica laica*, cit., 13-14.

<sup>208</sup> Cfr. Cattorini P, *Bioetica*, Milano, Elsevier, 2011<sup>4</sup>, 18-19. Mill and Bentham are hedonistic: they believe that only pleasure or happiness (synonymous terms in this conditions) can be intrinsically good. Other Utilitarian philosophers, with specific attention to pluralism, believe that no single aim constitutes the good and that many other values besides happiness possess intrinsic worth – the value of friendship, knowledge, love, culture, freedom might all qualify in a Utilitarian theory .

<sup>209</sup> Sgreccia E, *Manuale di bioetica*, cit., 96. This principle cannot be used in an ultimate and founding, balancing uneven goods, as comparing costs in money with the value of a human life.

<sup>210</sup> Fornero G, *Bioetica cattolica e bioetica laica*, cit., 81.

Secular bioethics focuses its critique on developing the concept of autonomy. In medicine the patient has a responsibility regarding the different possible treatment options. The patient decides what he considers to be most suitable in itself, in line with his value system.

Starting from the concept of individual autonomy, secular bioethics recognizes the sovereign power of each person over his/her body. There is a kind of self-awareness with regards to the individual's being.

Secular bioethics subordinates the value of life to the value of quality: a relationship that implies a possible differentiation between types of human lives. Peter Singer, pointing out the extreme consequences of this position, says<sup>211</sup>: "It is highly unlikely that a person really believes that all human lives have equal value. The rhetoric, which is full of speeches and writings of Popes, theologians, ethicists, and sometimes doctors, is belied in practice every time these same people indulge in opposite admissions: when they deny that everyone must work to save a child with severe birth defects, when they recognize that we can let an elderly man suffering from an advanced form of Alzheimer's disease die of pneumonia, without treating it with antibiotics".

The Utilitarian position, based on the principle of self-determination, states that in the patient who decides to die, it is not the will to live, which is his determination to stay alive. It is precisely for this reason that secular bioethics' voluntary euthanasia is certainly legitimate, and allows a dignified death in respect of the patient<sup>212</sup>.

Hans Küng has a very particular position in favor of euthanasia, because it is aimed to respect both the secular view and that of Christianity. Küng deserves particular attention, because his thinking is aimed at a kind of democratic vision of euthanasia, in accordance with all of the views under consideration. He says<sup>213</sup> believers should not contest the fact that even non-believers can bravely die. And, vice versa, the non-believers should not deny that believers strong in their faith in God as the ultimate reality can have a different relationship with death.

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<sup>211</sup> Singer P, *Ripensare la vita. La vecchia morale non serve più*, Milano, CDE, 1997, 193-194.

<sup>212</sup> Cfr. Reichlin M, *L'etica e la buona morte*, Torino, Edizioni di Comunità, 2002, 71.

<sup>213</sup> Küng H, *La dignità della morte. Tesi sull'eutanasia*, 2007, trad. it. di A. Corsi e F. Leitner, Roma, DataneWS, 31.

The struggle for life is presented as valid only if it makes sense to have a hope of recovery. The fight against dying - believes the author - tends to see death as an enemy to fight. Actually for terminal patients the care of body and soul together with a minimum of therapy is the best way to assist them<sup>214</sup>:

Today we can care in a largely optimum manner body aches, but the suffering of the soul is not helped in any way. Patiently donating time to terminally ill is perhaps the last best gift that we can do: to give him the time to listen to his insecurities, anxieties, anxieties, to give him a little comfort, and also to say a prayer for him. Today, we know that even a terminally ill patient who is unable to speak can still listen; we know that bodily contact can communicate spiritual comfort even when he/she is no longer able to move.

After careful analysis of the care that is described by the theologian in a simple but exemplary manner, in some places I will now expose his thinking in favor of euthanasia. The feature of this argument is that, despite Christian assumptions, both accept active and passive euthanasia<sup>215</sup>:

1- According to Christian belief, human life is a gift from God, that man himself does not deserve it. But at the same time life, according to the will of God, is also the duty of man. And it is so given to our (not alien!) responsibility. This also applies to the last stage of life; death. Euthanasia should be understood as a definitive support for the living.

2- As man who continues to remain in a terminally ill condition (i.e. death is expected in the foreseeable future) or is dying (death is expected in the short term), he has the right not only to a humanly dignified life, but also to take leave from life and to die with dignity, as a human being.

3- In the case of patients with a disease in course or irreversible lesions with poor prognosis, as in the case of infants with severe deformities incompatible with life, one can accept a “shortening of life”, which results in an alleviation of suffering.

The different positions presented here lead us to draw a conclusion as well as a question: is there a right or a duty to die? Given that every man would like to recognize

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<sup>214</sup> Ibidem, 33.

<sup>215</sup> Ibidem, 76.

the dignity of death without agony, it is legitimate to decide the when and how of his own death?

After clarifying the opposing views of Catholic and secular bioethics and attempting along with Küng to join them, the legal and medical implications in any case present a dilemma about death, as difficult to solve as it is impossible for humans to relate precisely to that “event”.

Beyond any valid hope of relieving pain, to treat the patient, to act according to the principle of being, or remain consistent with Catholic doctrine, death for man is the only certainty. Although it is an appointment which no one can put off, fear arises mainly because of the impossibility of defining the moment of its arrival.

Modern man claims to be able to decide the moment of encounter with death, but this attitude poses the moral question on the validity or otherwise of the relevance of such a claim. Death is still waiting for the inevitable.

Physician Assisted Suicide seems to be a shared choice about surrender to the patient’s disease; in Palliative Sedation Therapy there is not a direct choice regarding death, but we recognize a patient’s minimal resistance versus his/her imminent death. In conclusion Palliative Sedation Therapy may be ethically preferable to Physician Assisted Suicide.

The personalist model is structured by a triple underlining of meaning: the relational personalism, the ontological personalism and the hermeneutical personalism.

If the criticisms of the method proposed by Principlism are directed to relevant questions about the acceptability or not of the same principles as a common language regarding global bioethics, the criticisms of the personalist method are geared towards the theme of the sharing or not “a priori” of a specific idea of the *person* which derives from this irreducible notion, ultimately referring back to the concept of the sanctity of life, on which the method bases its critical dialectic structure. The relationship with the transcendent seems to be a foundational criterion in order to understand the human being as a person. But this concept does not seem to be an irreducible a priori criterion shared by all.

In the next and last chapter the hermeneutical position will be analyzed in order to structure our proposal of a method in clinical ethics consultation.

## **THIRD PART**

## Between Hermeneutics and Casuistry

The paradox is that  
while medicine seems to offer  
infinite possibilities,  
the practice of medicine  
is governed by limits.  
K.W. Wildes, 1995

### From *how* to *why*

In this last chapter I will try to present a method of conducting an ethics consultation having as reference points both a specific methodology of interpretation – the philosophical theory called *hermeneutics* – and an example of an empirical method of conducting an ethics consultation – as presented by Jonsen, Siegler and Winslade in their book “Clinical Ethics: A practical approach to ethical decisions in Clinical Medicine”<sup>216</sup>.

The main objectives of this method are resolving the principal criticalities of Principlism and Personalism, presenting a hermeneutic circle method in order to carry out a clinical ethics consultation.

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<sup>216</sup> Jonsen AR, Siegler M, Winslade WJ, *Clinical Ethics, a practical approach to ethical decisions in clinical medicine*, New York, Mc. Graw Hill, 2010<sup>7</sup>.

The Hermeneutic philosophical position and the role of casuistry – the theoretical background from which this method was developed – seem to be the basis to develop a good and sharable method in order to carry out a clinical ethics consultation.<sup>217</sup>

Principlism and Personalism theories were upon presented as important bioethics theories, underlying their critical aspects. In this section those theories are mentioned, but in different ways compared with their official definitions: the four principles open a lot of questions which are useful to analyze not only what kind of values are presented in a specific clinical case, but also a series of questions that seem to better help the consultant to resolve a clinical case. Personalism is here presented only with a double meaning – hermeneutical and relational -. The ontological foundation of the *person* presented in Personalism theory, as penned by the Catholic Church, is present as a position among other different ideas of *person*, but, especially in a plural socio-cultural context, it does not seem to be the only one position a priori which is fully shared.

The following paragraphs present the structure of a method that would be attentive to both the empirical clinical aspect and the ethics theoretical aspects. The core of this method is the relationship, in which all stakeholders - patients, family members, health care professionals - have a word to say about a justified resolution of a specific ethics issue present in a clinical case. This word – about *why* – cannot be segmented (techniques by doctors, or existential profile by the patient) but involves mutual integration: in a good relationship the patient (or another person on his behalf) will be able to make a “good” choice.

The following reflections attempt to formalize a way to help both patients and health care professionals to resolve an ethical dilemma, while trying to stay true to their own values and deontology.

### **Hermeneutics’ Foundations**

Hermeneutics is the science of interpreting literary documents; it means the theory of interpretation, i.e. the theory of achieving an understanding of texts, utterances, and so on (it is not related to a certain twentieth-century philosophical

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<sup>217</sup> Porz R, Landeweer E, Widdershoven G, *Theory and Practice of Clinical Ethics Support Services: Narrative and Hermeneutical Perspectives*, Bioethics, 2011; 25(7): 354-360.

movement). Hermeneutics in this sense has a long history, reaching back at least as far as ancient Greece.<sup>218</sup>

This focus on hermeneutics began in particular in Germany, with Martin Heidegger and Hans-Georg Gadamer in the twentieth century (“hermeneutics” is today often treated as synonymous to “Gadamer's philosophy”).

Presenting Heidegger's idea of *care* between persons seems useful to understand Gadamer's position about its idea of the relation between truth and scientific method in a pluralistic context.

Martin Heidegger defines the term “cure” as an “essential ontological-existential phenomenon”<sup>219</sup>. According to Heidegger, the ontological structure of care is based on the fact that the human condition is to be in a world, therefore a human being is of the world and he has the ability to relate with his own fellow beings,, and is open to that world.

The German philosopher, in his *Logic*, says: “the fundamental way of being of a being, [...] we call it as *cure*. Cure is the fundamental way of being present, and as such it determines every way of being that follows from the constitution of the being and its being present”<sup>220</sup>

Cure is, therefore, the predecessor to every situation, because it is the fundamental characteristic of being a person. Moreover, it is from the kind of caring relationship which we have experienced, that we derive our being. Cure is the basilar relationship between persons starting from birth.

Heidegger defines “cure” as the fundamental trait of what it means *to live*. In the current terminology regarding well-being all of the aspects of the person are involved: affectivity, rationality, emotionality, and physicality. This necessarily makes it a social matter which develops into a dyadic relationship, but it also requires that substratum of interpretation which determines the non-neutrality of the speakers.

From this idea of non-neutrality it can be explained that the objectivity of a story always passes through the subjectivity of who tells it: “is understanding the sole and sufficient access to the reality of history? Obviously there is a danger that the actual reality of the event, [...] will be weakened and misperceived by being seen in terms of the experience

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<sup>218</sup> On the history of hermeneutics in general, see Dilthey W, *Hermeneutics and the Study of History*, Princeton, Princeton University Press, 1996.

<sup>219</sup> Heidegger M, *Essere e tempo*, traduz. di Chiodi P, Milano, Longanesi, 1976, 245.

<sup>220</sup> Heidegger M, *Logica. Il problema della verità*, trad. Ugazio UM, Milano, Mursia, 1986, 146.



of meaning”<sup>221</sup>. Therefore it can be difficult to recognize a neutral approach to ethics questions because beyond who will decide, the choice affects the history of all those who are involved: “When our historical consciousness transposes itself into historical horizons, this does not entail passing into alien worlds unconnected in any way with our own; instead, together they constitute the one great horizon that moves from within and that, beyond the frontiers of the present, embraces the historical depths of our self-consciousness. Everything contained in historical consciousness is in fact embraced by a single historical horizon. Our own past and that other past towards which our historical consciousness is directed help to shape this moving horizon out of which human life always lives, and which determines it as heritage and tradition”<sup>222</sup>.

After having considered some important characteristics of *care* as a constitutive practice of human beings, it is important to share some reflections about the human activity of interpretation, not only considered as mere theoretical activity, but as a reflection on difficulties often present in an empirical and real context, in which *care* is a human activity oriented to the care of the whole person and not just to a disease. For this reason Gadamer’s position about the relationship between *truth* and *scientific method* is important and herewith examined.

Hans-Georg Gadamer presents in his *Truth and Method* his own position about the difficulties in understanding the concept of truth using only the scientific method.

His reflections are useful to us to better understand that an ethics problem cannot be resolved by only using a scientific method, but by opening up to the human experience, which includes the scientific approach, but not only. Gadamer, in his introduction, affirms that: “The following investigations start with the resistance in modern science itself to the universal claim of scientific method. They are concerned to seek the experience of truth which transcends the domain of scientific method wherever that experience is to be found, and to inquire into its legitimacy. Hence the human sciences are connected to modes of experience that lie outside science: with the experiences of philosophy, of art, and of history itself. These are all modes of experience in which a

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<sup>221</sup> Gadamer H-G, *Truth and Method*, 2nd rev. ed., trans. Weinsheimer J and Marshall DG, New York, Continuum, 2006, XXXI. See also Vilhauer M, *Gadamer’s Ethics of play. Hermeneutics and others*, Lanham, Lexington Books, 2010, 26.

<sup>222</sup> Gadamer H-G, *Truth and Method*, cit., 303.

truth is communicated that cannot be verified by the methodological means proper to science”<sup>223</sup>.

Gadamer presents the hermeneutic experience as an open process to new experiences: “The truth of experience always implies an orientation toward new experience [...] The dialectic of experience has its proper fulfillment not in definitive knowledge but in the openness to experience that is made possible by experience of itself”<sup>224</sup>.

For our discourse it is important to present Gadamer’s approach as described in *Truth and Method*: “Fundamentally I am not proposing a method, but I am describing what is the case”<sup>225</sup>. This concept can be further explained by referring to other quotations: “The finite nature of one’s own understanding is the manner in which reality, resistance, the absurd, and the unintelligible assert themselves. If one takes this finiteness seriously, one must take the reality of history seriously as well. [...] The experience of the Thou throws light on the concept of historically effected experience. The experience of the Thou also manifests the paradox that something standing over against me asserts its own rights and requires absolute recognition; and in that very process is “understood”<sup>226</sup>.

Andrzej Wiercinski, in his paper *Hans-Georg Gadamer and the Truth of Hermeneutic Experience*<sup>227</sup>, explains Gadamer’s idea of communication in the following way. “Understanding is not a mysterious communion of minds; it is an event. We want to grasp the character of the process of understanding, to comprehend what happens when we understand something. Convincing and successful interpretation brings us to understanding.”<sup>228</sup> Understanding is a participation in meaning. As an historical event it is embedded in language. The true meaning of language transcends the limits of methodological interpretation. Language as the medium for history is itself a place of mediation. Human understanding is always interpretive. Hermeneutic truth acquires a unique density and fullness of meaning. Hermeneutic understanding is not a process of construing a self-identical meaning of a text, but a continuous dialogue in which a

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<sup>223</sup> Gadamer H-G, *Truth and Method*, cit., xx–xxi.

<sup>224</sup> Ibidem, 350.

<sup>225</sup> Ibidem, 512.

<sup>226</sup> Gadamer H-G, *Truth and Method*, cit., xx–xxi.

<sup>227</sup> Wiercinski A, *Hans-Georg Gadamer and the Truth of Hermeneutic Experience*, in <http://journals.library.mun.ca/ojs/index.php/analecta/article/viewFile/2/1> [last seen 20/2/2016]

<sup>228</sup> Gadamer H-G, *Reason in the Age of Science*, trans. Lawrence FG, Cambridge, MIT Press, 1981, 111. Cit. in Wiercinski A, *Hans-Georg Gadamer and the Truth of Hermeneutic Experience*, cit.

mediation of meaning takes place. Dialogue is the model of hermeneutic understanding. A meaning cannot be determined from the perspective of propositional logic”.<sup>229</sup>

Gadamer’s reflections offer us the possibility of better understanding the importance of posing the correct question, in a dialectic relationship in which the truth can be unveiled only by sharing meanings.

Before presenting a method structured on a different type of question, it is significant to briefly describe the ethics theory – the casuistry – by which this method found its origins. Casuistry discusses the necessity to connect a specific case with other already resolved cases, in order to make the best decision concerning questions of ethics in clinical practice.

### **Casuistry and the *four boxes***

Casuistry is an empirical way of analyzing and resolving clinical ethics issues using particular cases “where the judgments reached rely on judgments reached in prior case”<sup>230</sup>.

Casuistry focuses our attention “on practical decision making, in particular cases and on the implication of those cases for other cases”<sup>231</sup>. It does not consider that the principles and other general moral theories can resolve specific ethics questions in particular clinical cases. It prefers to appeal to narrative medicine, paradigmatic cases and cases beforehand resolved: “many individual factors, including the patient’s medical history, the physician’s success with other similar patients, paradigms of expected outcomes, and the like will play a role in formulating a judgment and recommendation to this patient, which may be very different from the recommendation made to the next patient with the same malady. The casuist views moral judgment and recommendations similarly”<sup>232</sup>.

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<sup>229</sup> Wiercinski A, *Hans-Georg Gadamer and the Truth of Hermeneutic Experience*, cit., 9.

<sup>230</sup> Beauchamp T, Le Roy W, Jeffrey PK, Mastroianni AC (eds.), *Contemporary Issues in Bioethics*, cit., 20.

<sup>231</sup> Idem.

<sup>232</sup> Idem.

Casuistry seems to be a valid alternative to the principle-based ethics approaches because there are two questions that it tries to avoid<sup>233</sup>:

- One is the lack of consensus on any all-encompassing ethical theory or principle. By relying instead on what seem to be firmer and more common agreements about particular paradigm cases of right and wrong, casuistry hopes to sidestep this difficulty with foundational approaches;
- The second is the problem of interpretation of general principles that plagues their application to particular cases – one cannot defend a specification of a general principle in its application to particular circumstances without relying on some intuitive balancing judgment. The casuist argues primarily from other cases rather than primarily from principles, therefore the problem of interpretation would seem not to arise.

Jonsen and Toulmin are two casuists. They wrote about the relationship between the principles and their application in specific cases that “good casuistry ... applies general principles to particular cases with discernment”<sup>234</sup>. Opposite to the Rawls’ moral theory, the casuistry focuses its attention on particular cases and practical judgments: “bioethics, like ethical theory has sometimes unduly minimized this avenue to moral knowledge. Casuists also have rightly pointed out that generalizations are often best learned, accommodated, and implemented by using cases, case discussion, and case methods. These insights can be utilized by connecting them to an appropriate set of concepts, principles, and theories that control the judgments we make about cases”<sup>235</sup>.

An important question about the efficiency of a case-based method concerns the study of medical ethics and the acquisition of core abilities to resolve ethics questions in daily medical practice: “cases are at the hearth of teaching in medical ethics. [...] The problems that are brought to the ethicist to solve are predominantly individual cases”<sup>236</sup>. The effort to argue and to resolve specific clinical cases by analogy with exemplary cases is exemplified in a Jonsen and Toulmin characterization: “it is this feature that draws the important contrast with principle-based approaches, whose idealized mode of

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<sup>233</sup> Tomlinson T, *Methods in Medical Ethics*, cit., 85.

<sup>234</sup> Jonsen AR, Toulmin T, *Abuse of Casuistry*, 16-19, 66-67, in Beauchamp T, Le Roy W, Jeffrey PK, Mastroianni AC (eds.), *Contemporary Issues in Bioethics*, cit., 21.

<sup>235</sup> Beauchamp T, Le Roy W, Jeffrey PK, Mastroianni AC (eds.), *Contemporary Issues in Bioethics*, cit., 21.

<sup>236</sup> Tomlinson T, *Methods in Medical Ethics*, cit., 85.

reasoning is a deductive inference from a well-specified principle to the case at hand”<sup>237</sup>.

The paradigm cases can be understood using a combination of *facts* and *settled values*. The facts can be used to take on other cases – i.e. “The patient refuses the recommended treatments” –; the settled values – i.e. competent patients have a right to refuse treatment – can be in prima facie defined as principles, rules or rights and they must be considered different from the facts present in specific cases. Following the casuistry “rather than keeping values distinct from facts, the two are bound together in the paradigm case; the central values are generalizable and therefore preserved from one case to the next”<sup>238</sup>.

In his “Casuistry as Methodology in Clinical Ethics”<sup>239</sup> Jonsen describes the typical steps taken to conduct a casuistic analysis.

He uses three terms to identify three categories useful to taking a practical approach to ethical decision-making in clinical medicine: 1- morphology; 2- taxonomy; 3- kinetics.

### Morphology

This first step concerns the circumstances – the circumstances, say the casuists “make the case”<sup>240</sup>. In general they are delineated by seven questions: who, what, when, where, why, how and by what means”. The circumstances are the center of the case: “that center is constituted of certain maxims, brief rule-like sayings that give moral identity to the case”<sup>241</sup>.

The circumstances are related to a history (the patient’s history) and to the maxims (e.g. competent persons have the right to determine their fate): “this interplay of circumstances and maxims constitute the structure of a case”<sup>242</sup>.

Another important part of the morphology of the case is the practical discourse: “any argument contains a sample of one or more standard and invariant patterns of discourse, that is an argument about causality, or about sequences, or about priority or about

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<sup>237</sup> Ibidem, 88.

<sup>238</sup> Beauchamp T, Le Roy W, Jeffrey PK, Mastroianni AC (eds.), *Contemporary Issues in Bioethics*, cit., 22.

<sup>239</sup> Jonsen A, *Casuistry as Methodology in Clinical Ethics*, *Theoretical Medicine*, 1991; 12: 295-307.

<sup>240</sup> Ibidem, 298.

<sup>241</sup> Idem.

<sup>242</sup> Ibidem, 299.

contingency, etc. These arguments have invariant patterns that can, and must be used, in any substantive argument”<sup>243</sup>.

Invariant arguments could be also called “special topics”. In clinical medicine and in clinical ethical activity Jonsen Siegler and Winslade had defined these topics, and they are four: medical indications, patient’s preferences, the quality of the patient’s life, social and economic factors external to the patients.

These four topics have an invariant structure in which different contents may be identified: “the morphology of a case reveals the invariant structure of the particular case, whatever its contingent features, and also the invariant forms of argument relevant to any case of this sort. The first task of the casuist is to discern this structure”<sup>244</sup>.

### Taxonomy

The second step concerns the order and the categorization of the case: “the taxonomy of cases is crucially important in casuistry. It puts the case at hand into its moral context and reveals the weight of arguments that might countervail a presumption of rightness or wrongness”<sup>245</sup>.

Taxonomy is significant in clinical ethics because it shows that a specific case is not unique: “the judgment of the case is based, not on a principle or a theory, but upon the way in which circumstances and maxims appear in the morphology of the case itself and in comparison with similar cases.”<sup>246</sup>

### Kinetics

Kinetics is “the way in which one case imparts a kind of moral movement to other cases”<sup>247</sup>. Jonsen recalls the term “kinetics” from classical physics, as he has borrowed the term “morphology” from classical biology and he uses the term “motion” to understand the way in which one case initiates a kind of moral movement onto other cases.: “the motion is a shift in moral judgment between paradigm and analogous cases, so that one might say of the paradigm, ‘this is clearly wrong’ and of an analogous case, ‘but, in this case’ what was done was justified, or excusable’.

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<sup>243</sup> Idem.

<sup>244</sup> Ibidem, 301.

<sup>245</sup> Ibidem, 302.

<sup>246</sup> Ibidem, 303.

<sup>247</sup> Idem.

In the conclusion of this paper, Jonsen writes about the aim of the casuistry and the reasons for its validity: “the casuist will be able to scan or parse the case, revealing its structure of claims, maxims, grounds, rebuttals. Casuistry will be able to collocate the case in a taxonomy of cases, recognize the similarities and differences, and appreciate the shift from moral certainty to moral doubt. Above all, casuistic reasoning is prudential reasoning: appreciation of the relationship between paradigm and analogy, between maxims and circumstances, between the greater and fewer of circumstances as they bear on the claim and the rebuttals”<sup>248</sup>.

Following these considerations, Jonsen, Siegler and Winslade presented their method, called by some users the method of “the four boxes”.

As stated before, Principlism is present in Jonsen’s Siegler’s Winslade’s reflections, but only explained briefly: “we rather direct our reader’s attention to how these general principles interact within the concrete circumstances of a clinical case, and how they serve as guides to action in specific circumstances”.<sup>249</sup>

The three authors propose a method structured in four topics considered as constitutive of the essential structure of a clinical case: Medical Indications, Patient Preferences, Quality of Life and Contextual Features.

Each topic concerns a specificity of a clinical case. They are helpful to identify an ethical problem and, at the same time, they are useful to offer a complete image of the ethical dimensions of the case:<sup>250</sup>

- Medical indications refer to the diagnostic and therapeutic interventions that are being used to evaluate and treat the medical problem in the case;
- Patient preferences state the express choices of the patient about their treatment, or the decisions of those who are authorized to speak for the patient when the patient is incapable of doing so;
- Quality of life describes features of the patient’s life prior to and following treatment, insofar as these features are pertinent to medical decisions;

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<sup>248</sup> Ibidem, 306.

<sup>249</sup> Jonsen AR, Siegler M, Winslade WJ, *Clinical Ethics, a practical approach to ethical decisions in clinical medicine*, cit., 3.

<sup>250</sup> Idem. Under each of these headings, a series of questions are posed to assure that needed information has been gathered.

- Contextual features identify the familial, social, institutional, financial, and legal settings within which the particular case takes place, insofar as they influence medical decisions.

The three authors believe that “these four topics are essential and constant constituents of any clinical case, which is, of course, unique and varying in its own circumstances”.

Jonsen Siegler and Winslade put in relation the four topics with the Beauchamp’s Childress’ principles (as showed in the table). These two positions are in relation, but at the same time different. Following the method of four topics it can be explained that ethical principles are relevant to a clinical case, however it is possible to go beyond: a case “must be compared to similar cases. It is certainly true that in medicine every case is unique, and every patient *a statistic of one*”<sup>251</sup>. Nevertheless a case “at hand will have similarities with other cases”<sup>252</sup>.

Before offering a solution “other cases may have to be thoughtfully considered”. It is true that “such cases are called paradigm cases” because “even similar cases have variable circumstances” but comparing one case to similar other cases can be considered a valid support to guide clinicians in their daily activities: “clinicians and ethicists should be familiar with these paradigm cases, and be able to discern how they differ and how the circumstances bond with principles in [a] current case”<sup>253</sup>

The four topics are:

A practical approach to ethical decision-making in clinical medicine:

#### **MEDICAL INDICATIONS**

##### **The Principles of Beneficence and Non-maleficence**

What is the patient’s medical problem? Is the problem acute? Chronic? Critical?

Reversible? Emergent? Terminal?

What are the goals of treatment?

In what circumstances are medical treatments not indicated?

What are the probabilities of success of various treatment options?

In sum, how can this patient be benefited by medical and nursing care, and how can

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<sup>251</sup> Jonsen AR, Siegler M, Winslade WJ, *Clinical Ethics, a practical approach to ethical decisions in clinical medicine*, cit., 4.

<sup>252</sup> Idem.

<sup>253</sup> Ibidem, 5.



harm be avoided?

#### **PATIENT PREFERENCES**

##### **The Principle of Respect for Autonomy**

Has the patient been informed of benefits and risks, understood this information, and given consent?

Is the patient mentally capable and legally competent, and is there evidence of incapacity?

If mentally capable, what preferences about treatment is the patient stating?

If incapacitated, has the patient expressed prior preferences?

Who is the appropriate surrogate to make decisions for the incapacitated patient?

Is the patient unwilling or unable to cooperate with medical treatment? If so, why?

#### **QUALITY OF LIFE**

##### **The Principles of Beneficence, Non-maleficence, and Respect for Autonomy**

What are the prospects, with or without treatment, for a return to normal life, and what physical, mental, and social deficits might the patient experience even if treatment succeeds?

On what grounds can anyone judge that some quality of life would be undesirable for a patient who cannot make or express such a judgment?

Are there biases that might prejudice the provider's evaluation of the patient's quality of life?

What ethical issues arise concerning improving or enhancing a patient's quality of life?

Do quality-of-life assessments raise any questions regarding changes in treatment plans, such as forgoing life-sustaining treatment?

What are plans and rationale to forgo life-sustaining treatment?

What is the legal and ethical status of suicide?

#### **CONTEXTUAL FEATURES**

##### **The Principles of Justice and Fairness**

Are there professional, inter-professional, or business interests that might create

conflicts of interest in the clinical treatment of patients?

Are there parties other than clinicians and patients, such as family members, who have an interest in clinical decisions?

What are the limits imposed on patient confidentiality by the legitimate interests of third parties?

Are there financial factors that create conflicts of interest in clinical decisions?

Are there problems of allocation of scarce health resources that might affect clinical decisions?

Are there religious issues that might affect clinical decisions?

What are the legal issues that might affect clinical decisions?

Are there considerations of clinical research and education that might affect clinical decisions?

Are there issues of public health and safety that affect clinical decisions?

- Are there conflicts of interest within institutions or organizations (e.g. hospitals) that may affect clinical decisions and patient welfare?

### **Clinical Case in ICU: if should an acute event arise?**

The following case is presented in reply to the question included in the four boxes previously presented.<sup>254</sup>

Mr. M.G. 59 y.o., Belgian, a sportsman, lives with his second wife and their 12 y.o. son. He has a brother who works as a nurse. While cycling wearing a helmet, he has a violent fall, coincidentally near a clinic. Thanks to the intervention of a doctor and to proper resuscitation, cardiac arrest is avoided. He is transferred to the hospital by ambulance. He undergoes a cervical CT scan, which shows a cervical lesion of C1-C2, without any possibility of surgery. An Angio-Rm and Rm examination of the neck is performed in the ICU and shows the following result: complete spinal truncation at the height of the base of the epistropheus dens with the cranial

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<sup>254</sup> It is answered only to those questions appropriate to the clinical case considered. I would like to thank dr. Giulio Minoia that presented us the case.

medullary stump moved forward. Edematous intramedullary alterations above and below the line of truncation. No current evidence of perilesional blood flow. Confirmed fracture both of the anterior and the posterior arch of the atlas, of the dens and of the posterior arch of C2. The dens is displaced anteriorly and to the right. Diffuse degenerative changes with synostosis between C6-C7. Edematous alterations in the laterocervical soft tissues. Complete occlusion of the right vertebral artery at the height of C2. The posterior circulation appears currently totally supported by the vertebral artery. Regular carotid arteries. They also perform brain/chest/abdominal CT. All examinations give negative results. It is assumed that the patient has no neurological injuries. After the event Mr. M. is treated with sedative and hypnotic-inducing drugs. Antibiotics are given for a rise in temperature, probably due to a small infection of the catheter, in the following three days.

### **Medical Indication**

- What is the patient's medical problem? Is the problem acute? Chronic? Critical? Reversible? Emergent? Terminal? What are the goals of treatment?

The first goal of medical care turns out to be the stabilization of the patient. So all interventions are considered owed to and targeted to producing a benefit for the good of the patient. This implies that the tracheotomy, the administration of antibiotics, the possibility of the use of adrenaline and life-saving maneuvers in the case of an acute event would be considered treatment due to the patient. The futility of care must be balanced with the effectiveness of treatment and with the objective to stabilize the patient. This is justified by the objective of preventing unnecessary suffering, and preserving as much as possible the quality of life of Mr. M.

The second objective is the autonomy of Mr. M., which means he awakens and is able to decide on medical treatments. The benefits for Mr. M. cannot be evaluated according to the version of his wife, who was reported "to be against any form of overtreatment, but making Mr. M. capable of discernment and informed properly on his status."

- In what circumstances are medical treatments not indicated?

The use of life-saving maneuvers or the use of antibiotics must be subjected to the non-repetitive criteria, and must be in favor of minimally invasive treatment, which would be disproportionate given the current conditions and the prognosis of the patient.

- What are the probabilities of success of various treatment options?

The treatments are not intended to cure the disease, now ominous, but to be able to bring Mr. M. to a state in which, after being fully and completely advised about his status, he can in a balanced and free manner make an informed decision regarding his future.

- In sum, how can this patient be benefited by medical and nursing care, and how can harm be avoided?

This path to the awakening of Mr. M. should be gradual, accompanied by counseling, and neurological rehabilitation and, not the least, by his family. An optimal route in the recovery of Mr. M. and of his decision-making process should involve a long-term timeframe. The discharge from the intensive care unit and transfer to a place more suitable to his condition would ensure a better quality of life. This step towards rehabilitation also implies that the whole family (his second wife and son) be involved in understanding the condition of Mr. M. and his choices.

### **Patient Preferences**

- Has the patient been informed of benefits and risks, understood this information, and given consent?

The condition of Mr. M. is stable, but he is not alert. His wife visits every day. After the first three days an ethics consultation by doctors is requested.

- If incapacitated, has the patient expressed prior preferences?

His wife explains his preferences.

- Who is the appropriate surrogate to make decisions for the incapacitated patient?

Probably it is his second wife. When the patient arrived in the hospital the physicians contacted his family. His wife immediately declared his opposition to any form of overtreatment, but she signed the consent form for the tracheotomy.

- Is the patient unwilling or unable to cooperate with medical treatment? If so, why?

Yes, he is. Because he is not conscious.

### **Quality of life**

- What are the prospects, with or without treatment, for a return to normal life, and what physical, mental, and social deficits might the patient experience even if treatment succeeds?

Given the gravity of the situation, the wife continues to repeat the patient's wishes about not agreeing to aggressive therapy.

- On what grounds can anyone judge that a certain quality of life would be undesirable for a patient who cannot make or express such a judgment?

The second day, Mr. M. is transferred to the ICU. His wife reports that Mr. M. had talked about refusing a life as a quadriplegic.

- Are there biases that might prejudice the provider's evaluation of the patient's quality of life?

No, there aren't.

- What ethical issues arise concerning improving or enhancing a patient's quality of life?

During the ethics consultation, the questions posed by the clinicians should be about what the right course to take is if an acute event should occur.

- Do quality-of-life assessments raise any questions regarding changes in treatment plans, such as foregoing life-sustaining treatment?

Caregivers, knowing the position of the wife regarding overtreatment, ask whether it is permissible to use antibiotics or perform resuscitation in the case of a new cardiac arrest. Doctors would like to understand the extent to which treatment in this case could be considered proportionate. During the counseling they express their concerns with respect to Mr. M., forced to live connected to an artificial ventilator and under the constant care of health care professionals and their families.

- What are plans and rationale to forgo life-sustaining treatment?

During the ethics consultation, it was decided that the patient would be reanimated if an acute event should arise. It was decided that the resuscitation process would not be repeated many times.

- What is the legal and ethical status of suicide?

There is no status.

### **Contextual Features**

- Are there professional, inter-professional, or business interests that might create conflicts of interest in the clinical treatment of patients?

No there aren't.

- Are there parties other than clinicians and patients, such as family members, who have an interest in clinical decisions?

Yes, there are. His wife.

- What are the limits imposed on patient confidentiality by the legitimate interests of third parties?

There are none.

- Are there financial factors that create conflicts of interest in clinical decisions?

No, there aren't.

- Are there problems of allocation of scarce health resources that might affect clinical decisions?

No, there aren't.

- Are there religious issues that might affect clinical decisions?

No, there aren't.

- What are the legal issues that might affect clinical decisions?

There are none.

- Are there considerations of clinical research and education that might affect clinical decisions?

No, there aren't.

- Are there issues of public health and safety that affect clinical decisions?

No, there aren't.

- Are there conflicts of interest within institutions or organizations (e.g. hospitals) that may affect clinical decisions and patient welfare?

No, there aren't.

The patient woke up after a few weeks, was moved to Belgium and died not too long after. We do not know how he died. It can be assumed for a “not too aggressive medical treatment” at the first complication.

### **A Criticism of Casuistry: Tomlinson's Position**

According to Tomlinson's position, the casuistic model opens up a series of problems regarding its application. Its limitations and objection can be related to these issues using a principle-based approach to analyze a clinical ethics problem.

There are three types of limits on casuistry<sup>255</sup>:

- Regarding selecting the paradigm cases;
- Regarding connecting maxims and paradigm cases;
- Regarding settled convictions on paradigm cases.

Firstly, Tomlinson notes that “any appeal to a set of ‘paradigm cases’ assumes that the proper ones have been selected for comparison”<sup>256</sup>, but “where there are competing ethical considerations or ‘maxims’, there will also be alternative sets of paradigm cases to which analogies can be drawn. It seems to show that casuistry is not the better alternative to a principle-based approach: it too requires a balancing of moral weights between principles, or some alternative way of choosing between competing lines of paradigmatic cases before the analogical, casuistic part of the argument can even begin”<sup>257</sup>.

Secondly, it seems not be clear “how casuistry is any more articulate than a rule-based approach in explaining the connection between rules, principles, or maxims on the one hand, and specific moral judgments on the other”<sup>258</sup>. The risk is that the casuistic method is considered as one which veils intuitionism.<sup>259</sup>

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<sup>255</sup> Tomlinson T, *Methods in Medical Ethics*, cit., 94-99.

<sup>256</sup> Ibidem, 94.

<sup>257</sup> Idem.

<sup>258</sup> Ibidem, 96.

<sup>259</sup> Ibidem, 98.

The third critique concerns the difficulty regarding casuistry about “its reliance on settled convictions about paradigm cases, where it runs the danger of uncritical conventionalism and conservatism. Casuistry seems to “provide no way by which the settled paradigms themselves might be challenged”.

Therefore for Tomlinson the reference to some cases defined as paradigmatic does not offer any avenues for other cases.<sup>260</sup>

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<sup>260</sup> Ibidem, 99.



## Circle Hermeneutic Method

The proposal of a method that can be called circular can be recognized as valid as it responds to the criticalities and at the same time it serves as a synthesis to the ethical theories previously presented.

From Principlism (method of the four principles) by Beauchamp and Childress one can recognize as valid the effort to have a common language structured in order to face ethical issues in daily clinical practice. Such language can also be applied in a multicultural context in which it can also share different positions related to the concept of care.

Personalism (triangle method) can be a useful tool to fully understand *who* the interlocutor is that you have in front of you, be he patient or care-giver. A person cannot be described as *something*, a person is *someone*<sup>261</sup>: Mentioning it defies any possible qualitative description. This concept of the person, as described by Robert Spaemann, allows us to consider each act as a bearer of certain significance both for the person who carries it out, and for those who receive it. The concept of *person* as presented by the Catholic Church, as already mentioned, does not seem to be fully accepted by everyone, but, from that concept of what a human being is, we can presume which type of respect for each one human being should be owed.

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<sup>261</sup> Cfr. Spaemann R, *Persone*, cit., 31.

Casuistry (method of the four boxes) opens up the possibility of linking a specific clinical case with other similar cases – therefore at the same time they can be considered different and equivalent, thus already solved. Moreover, Jonsen, Siegler and Winslade offer us a valuable guide to facing ethics issues in clinical settings.

### ***Anerkennung* and the certainty of not being alone**

Martin Buber in his famous essay *The dialogical principle* says, “I become me telling you”<sup>262</sup>. In today's more and more multicultural society, clinical ethics is called upon not only to develop a *procedural* method<sup>263</sup>, by which we can understand “who” should decide and therefore have the final word (but not necessarily the only one); but also *relational* and *interpretative* processes thanks to which we can arrive at a satisfactory solution for the patient which is, as much as possible, shared by all those who can be a reference to that specific clinical case.

Before presenting a Circle method, I would like to make some reflections about the concept of *acknowledgement* –as expressed by Hegel and taken on by Mead and Habermas – because it seems a useful precondition on which to base a method that could be applied both in a clinical context and in a multicultural society.

It can be said that the notion of *acknowledgement* refers to that specific form of will that obliges the individual to claim the personal desire to be recognized *as himself* by another counterpart in a relationship between individuals.

The concept of *acknowledgement* (in German, *Anerkennung*) refers to the pre-dialogical time in a relationship between two or more people. It simultaneously recalls both the differences and the similarities between individuals. This terminological dichotomy is what characterizes the major difficulties in the social relationships between people.

In the *Self-Consciousness*, the second moment of the *Phenomenology of Spirit*, Hegel presents the relationship Lordship-Bondage, a metaphor that helps us to understand the origin of mutual recognition between individuals. Hegel considers the subject as a self that establishes relations with other selves. The subject has the security to be conscious of himself only in relation to other subjects that give him the certainty to be such. These

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<sup>262</sup> Buber M, *Il principio dialogico ed altri saggi*, Cinisello Balsamo, San Paolo, 1993, 72.

<sup>263</sup> Engelhardt HT Jr, *Manuale di Bioetica*, trad. it. Rini S, Milano, il Saggiatore, 1999.

individuals should be free and thinking like him. Thus a conscious person becomes, in relation to others, self-conscious (conscious of himself). For Hegel, a person is conscious only if he can be recognized by another being like him: “Self-consciousness is in and for itself as and because it is in and for itself for another; that it is only as something recognized”<sup>264</sup>.

On the basis of mutual acknowledgement Jürgen Habermas reflects on the rules that emphasize a tolerant behavior. Habermas explains his own concept of *tolerance* in *Faith and science* taking the Kant’s philosophy of religion.

The concept of acknowledgement, says Habermas, includes in itself some rules for *tolerant* behavior. Habermas recognizes in the condition of equal freedom for everyone the possibility to “take away the sting of intolerance to tolerance”. He affirms that: “People concerned must take into account of the perspectives of those whom they are from time to time faced with, if they want to fix by mutual agreement the conditions under which they want to exercise mutual tolerance, because all people deserve the same respect”.

In light of Kantian thought Habermas introduces the concept of *dissent* and says that “the mutual refusal of practices and beliefs can be recovered in accordance with good subjective reasons, even if there is not a reasonable hope of a cognitive solution for dissent”<sup>265</sup>.

For Habermas, the idea of *dissent*, if it remains in the individuals, should be dropped from the public and social plan, so that interpersonal relationships between citizens of the same community can continue undisturbed.

In order to implement this concept “a commonly accepted basis of impartial reasons that do not neutralize [...] the reasons for the refusal, but [who have] the better of them”<sup>266</sup> is necessary. Later he writes: “In the other we must respect the citizen even when we think it is wrong thinking, and the way of an unhappy life. Tolerance prevents a pluralistic society from being torn, as a political community, by conflicts between world views”<sup>267</sup>.

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<sup>264</sup> Hegel GWF, *Fenomenologia dello Spirito*, trad. it De Negri E, Milano, La Nuova Italia, 2001<sup>2</sup>, 116.

<sup>265</sup> Habermas J, *Tra scienza e fede*, trad. it. Carpitella M, Roma, Laterza, 2008, 157. See also Honneth A, *Lotta per il riconoscimento, Proposte per un’etica del conflitto*, trad. it Sandrelli C, Milano, il Saggiatore, 2002, 92.

<sup>266</sup> Idem.

<sup>267</sup> Idem.

A relationship of mutual acknowledgement provides for the individual both the freedom to assess negatively the behavior of others, and the responsibility for the social consequences related to own conduct.

After presenting the concept of *acknowledgement* and the related ideas of *dissent* and *tolerance*, following I shall try to explain our method of facing an ethics consultation.

I think there are certain irreducible principles under which the ethics consultation seems to be jumbled, both in reference to what the word *ethics* recalls, and as the consultation must be directed supporting people in a difficult time, in which it is right to make a decision. This activity also involves a consistency with itself.

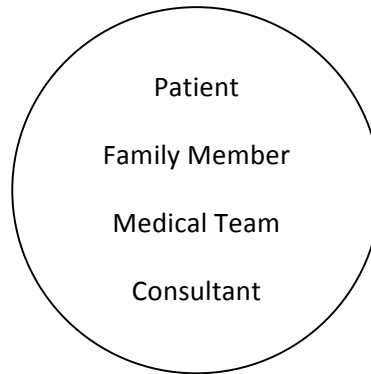
Therefore, following I shall recall some principles that united with the concepts of acknowledgement, tolerance and dissent (presented above) can be of help in the work of the consultant:

- If possible, leave time to those who will decide to consider all hypotheses;
- Be available for all meetings needed and in different ways;
- Recognize that there is not a precise time for counseling;
- In difficult moments, the assignment of the consultant is to accompany, evaluating and helping everyone with due respect;
- Recognize the objectivity of a history through the subjectivity of the storyteller
- Recognize that each case present its own unique aspects.
- Develop a significant research activity
- Do not lie;
- Do not let it favor the death of anyone.

## Circle Method

1: *Who* needs the consultancy? *Why*?

4: **How to offer solution?**



2: **Who is involved?**

3: **Why this problem?**

1: *Who* needs the consultancy?

The first step concerns the way of reception of a request of consultancy.

In this time a consultant should understand:

Who is it that requires consultancy? *Why*?

What is the issue? How urgent is it? Is there a doubt?

Has this doubt been shared by others?

According to the speaker, are there opposing views? If possible, which is patient's position?

2: **Who is involved?**

The second step focuses on the protagonists of the specific clinical case (Personalism)

Regarding the patient: medical indications and patient preferences.

The consultant is called to listen to the patient's history, his/her diagnosis and prognosis.

Are there others involved in this case? What are their roles and ideas?

Have they also expressed a similar doubt? If not, is there another issue?

### 3: **Why this problem?**

The third step addresses the ethical issues related to the clinical and relational condition about the case (contextual features)

What are the difficulties?

What are the possible options? Are there other underlying factors?

What are the principles to balance? Why? (Principlism)

What can be found in the literature? Are there similar cases? (Casuistry)

What are the positions of other people involved?

How and by whom has the path been shared?

### 4: **How to offer a solution?**

The last step is focused on possible solution to ethical dilemma in that specific case.

What are the possible solutions? The pros and cons of each? (Hermeneutical approach, without neutrality)

Have all necessary meetings taken place? (to be always in relationship, allowing the case)

Have all the options been understood by who will decide? If it is asked, it is possible to provide our justified idea).

Look for the biggest share possible, always remembering the good for the patient related with his/her history.

In order to better explain the proposed method, a pediatric clinical case is presented below, and is then analyzed following the Circle Method presented above.

#### **Pediatric Clinical Case: No trach tube!**

This case concerns a young family and its little daughter.

The parents of the new-born child bring her to the Senior pediatrician for the first medical examination.

The doctor observes a light hypotonia; there is suspicion of a slight reduction in muscle tone. This is confirmed during the second visit as well, after having sent the

child to a specialist for a hip ultrasound.

In her third month she has a clear hypotonia, which is also observed by the child neuropsychiatrist. A reduction in body weight is also noted, even though she had eaten in a sufficient manner.

Later, she was taken several times to the Emergency Room for respiratory problems.

During one of these visits an evaluation at the Specialist Centre of III Level was recommended for suspected spinal muscular atrophy type 1 (sma1). The diagnosis would be confirmed by the center a few days later, around the fourth month of the child's life.

The Center decided to take in the child and her family.

After carrying out various exams, the center proposed two options to the parents: an invasive therapy, i.e. tracheostomy, or a non-invasive therapy.

The parents are young, recent residents in Italy. The pediatrician and ASL nurses participated in a series of meetings organized by the Centre aimed at understanding the disease, prognosis, therapy and prescribing home-care for the patient.

All necessary medical devices for the home were provided (catheters, suction, pulse oximeter and all the tools necessary to promote the patency of the airway).

Drug therapy according to protocols was prescribed.

Starting from the first meetings at the specialized center, the parents were adamant about their refusal of any invasive treatment. It was their absolute intention to care for the child as much as possible at home. On this issue the parents never changed their minds, or had any doubts.

The family was constantly supervised at home by the pediatrician, the ASL nurse, and the Center.

For the pediatrician this was a new and very serious case. He was obliged to re-think the management of this patient. After understanding the wishes of parents, and having been instructed by the Centre, the pediatrician went along with the parents' wishes to keep the child at home.

The pediatrician asked me the following question: from an ethical point of view, is it right what we're doing? It is right to keep the child at home when you have another option, i.e. the availability of the hospital?

I agreed with the choice that was made (the analysis of the ethical issues is in the next paragraph). The family had the opportunity to manage their child at home and at the same time to be followed by many specialists. The child died at 11 and a half months, in her own bed.

**Case Analysis: the notion of proportionality and the criteria of “terminal”.**

**1: *Who needs the consultancy?***

Who is it that requests consultancy? Why?

The consultancy was requested by the pediatrician. He was in doubt about what he and the nurses and the Center were doing. The pediatrician asked me the following questions: from an ethical point of view, it is right what we're doing? It is right to keep the child at home when you have another option, i.e. the hospital?

The consultancy was a validation/conflict resolution of the parents' choice, which had been taken earlier after the training offered by the Center of III Level.

What is the issue? How urgent is it?

The problem concerns the withholding of an invasive treatment.

No, it is not urgent.

Is there a doubt? Has this doubt been shared by others?

No, it is not, because the parents have always been very convinced about the refusal of any invasive treatment.

**2: *Who is involved?***

Are there others involved in this case?

Parents, pediatrician, nurses, specialists.

What are their roles and ideas?



All of them shared the parents' decision.

### **3: Why this problem?**

What are the difficulties?

The difficulties are in not intervening with invasive means so as not to bring the child to the Hospital, because the parents do not want the tracheostomy tube for their daughter.

What are the possible options?

The possible options are two: an invasive therapy – with tracheostomy- or a therapy without invasive treatment.

What are the principles to balance?

The principles are: autonomy of the family and beneficence (a balancing of the benefits and the risks of these two different types of treatments.)

How and by whom was the path shared?

The path was shared by all the persons of interest in the case. The parents were recent residents in Italy, the pediatrician and the ASL nurses participated in a series of meetings organized by the Centre aimed at understanding the disease, prognosis, therapy and management of the home-care therapy.

The family was assiduously followed at home by the pediatrician, the ASL nurse, and the Center.

### **4: How to offer solution?**

What are the possible solutions?

The shared solution was to provide total care for the family for eleven months, offering all types of support to the child and her parents.

Have all necessary meetings taken place?

All meetings occurred. The medical team met every day with the family.

Have all the options been understood by who will decide?

Yes, they have. The Center of III Lever offered them every means to understand their possible present and future situations.

In the literature the criterion of “terminal” is at the core of intensive research activity. Given that all that is extraordinary is not obligatory, it would seem that where there is terminal illness the ethical question, i.e. whether treatment should be continued or not, answers itself.

The notion of “terminal” is one of the parameters which make it possible to choose the most appropriate therapy for a better quality of life during the end-of-life process.<sup>268</sup>

The criteria of “terminal” renders ethically legitimate the possibility – but not necessarily the obligation - of withdrawing or withholding a clinically configured treatment as non-proportionate. The patient always has the last word regarding this choice, but, as we shall see later, not the only one. In the literature there is one substantial study on the historical development of the definition of terminally ill: it is a paper by D. Hui, it offers a synchronic elaboration of the different definitions of “terminal” from various sources from 1984 to 2012.<sup>269</sup>

In this paper Mc Cusker’s definition in the matter of the *terminal care period* is cited. He writes: “The period during which there is evidence of progressive malignancy, and in which therapy cannot realistically be expected to prolong survival significantly. Patients enter this period either at time of diagnosis, or following a period of active treatment. The onset of the terminal care period should not be confused with the point at which life-expectation is estimated to be short. A patient might be expected to die within a few months, but have a treatable malignancy. This patient would still be in the active treatment period”<sup>270</sup>. In another paper by D. Hui, the life-span of the *terminally ill*

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<sup>268</sup> Picozzi M et al., *Fino a quando?*, Milano, San Paolo, 2012, 132.

<sup>269</sup> Hui D et al., *Concepts and Definitions for ‘Actively Dying’, ‘End of Life’, ‘Terminally Ill’, ‘Terminal Care’ and ‘Transition of Care’: A Systematic Review*, Journal of Pain and Symptom Management, 2014; 47(1);77-89.

<sup>270</sup> Cusker JM, *The terminal period of cancer: definition and descriptive epidemiology*, Journal of Chronic Disease, 1984; 37: 377-385.

is so defined: “a life expectancy of six months or less”<sup>271</sup>. On the contrary in The Hastings Center Guidelines the term *Terminally Ill* means “having an incurable or irreversible condition that has a high probability of causing death within a relatively short time with or without treatment”<sup>272</sup>.

The definition of the Hastings Center Guidelines underlines the time limit without a precise edge. The term “terminal” can’t be considered univocal in all fields of medicine. In oncology “terminal” is a clinical criterion used to make a prognosis.<sup>273</sup> In neurology (in particular in Alzheimer disease), “terminal” corresponds to the most acute phase of the disease.<sup>274</sup> In all of these definitions an important aspect is the clinical factor, which defines life expectancy. This element may be considered to be more important than the more ample criteria of “terminal”, because it seems to play a relevant role in the patient’s quality of life and in his/her possible future choices.

In general when a patient is terminal each treatment can be evaluated as disproportionate. The criterion of “Terminal” acquires a predominant position in the definition of the principle of proportionality. J. Capasso et al. write: “The goal at this point [terminal phase] is mainly supportive: to ensure the most comfort for the patient and the people providing care. Other goals at this point include symptom management, emotional and spiritual support, help with personal care, transportation assistance, and improving communication with health care providers”<sup>275</sup>. The life expectancy of less than six months results as a sufficiently shared criterion for the approval of the suspension of treatments, including lifesaving ones, save hydration and nutrition. D. F. Kelly writes: “Treatments are morally extraordinary when their burdens outweigh their benefits”<sup>276</sup>.

“Terminal” seems to be a diagnosis (in oncological diseases) that offers certain guarantees; it is often used to define a specific clinical condition (as shown previously

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<sup>271</sup> Hui D et al., *The lack of standard definitions in the supportive and palliative oncology literature*, *Journal of Pain and Symptom Manage*, 2012; 43: 582-592.

<sup>272</sup> Berlinger N, Jennins B, Wolf SM, *The Hastings Center Guidelines for Decision on Life-Sustaining Treatment and Care Near the End of Life*, revisited and expanded 2nd ed., New York, Oxford University Press, 2013, 205.

<sup>273</sup> Hui D, et al., *Concepts and Definitions for ‘Actively Dying’, ‘End of Life’, ‘Terminally Ill’, ‘Terminal Care’ and ‘Transition of Care’: A Systematic Review*, cit.: 86. Mc Cusker mentions the three criteria for a terminal diagnosis: 1) firm evidence of progressive disease, 2) termination of active cancer therapies, and 3) “death is not far off”.

<sup>274</sup> Loeb C, Favale E, *Neurologia*, vol. II, Roma, Società Editrice Universo, 2003, 1047.

<sup>275</sup> Vadivelu N, Kaye AD, Berger JM (eds.), *Essentials of Palliative Care*, New York, Springer, 2013, 58.

<sup>276</sup> Kelly DF, *Medical Care at the end of life*, Washington, DC, Georgetown University Press, 2006, 103.

by the definitions): it seems to offer more security regarding choices about withholding or withdrawing treatment. These choices should be shared as much as possible so as not to violate the patient's right to autonomy.

Where there are no treatments which can cure or block the progression of the disease, the cause of death is strongly (although not exclusively) connected to the disease itself and not to the discontinuation of treatment. According to the principle of double effect, D.F Kelly writes: "the direct killing of an innocent person is never morally right, but allowing a person to die is sometimes morally right"<sup>277</sup>. Noteworthy are the considerations regarding the role of the double effect in end of life decision making by T.E. Quill et al. because they emphasize the clinician's intent. They write: "This principle is often cited to explain why certain forms of care at the end of life that result in death are morally permissible and others are not. [...] The rule of double effect is a conceptually and psychologically complex doctrine that distinguishes between permissible and prohibited actions by relying heavily on the clinician's intent"<sup>278</sup>.

At this point a possible dichotomy arises: the clinical data and consequently the terminal prognosis seem to have a direct influence on the moral question, i.e. *questions of conscience*, inherent in the decision to withdraw or to withhold treatment; withholding treatment may help to provide a higher quality of life during the patient's last moments, although it may accelerate the dying process.

There are three ethically relevant aspects that may help to explain why terminal illness is a key criterion in end of life issues. They are:

1. Is the criterion of terminal illness only clinical data?

In a situation of terminal illness the principle of proportionality seems too biased towards the clinical data, but at the same time, the criterion of terminal represents a sufficient but not necessary clinical condition to determine whether to withdraw or to withhold treatment. There are therefore other factors, which can come into play, which influence decisions regarding good therapeutic choices. R.P. Hamel and J.J. Walter write about the intentions involved in ending treatment: "Life is something more than biological existence. Life is a conditional value which couples biological existence with

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<sup>277</sup> Ibidem, 12.

<sup>278</sup> Quill TE et al., *The Rule of Double Effect – A Critique of Its Role in End-of-Life Decision Making*, The New England Journal of Medicine, 1977, 337(24): 1768-1771.

social, spiritual and human activities such as loving, praying, remembering, forgiving and experiencing. Life is all these things. Consequently, when these activities can no longer be realized, there is no moral obligation to continue medical treatment, unless to relieve suffering. The conclusion that treatment can stop *does not mean that the person is worthless, but that the person has activated all human potential*<sup>279</sup>.

2. Can the criterion of terminal illness influence the policies of rationalizing the use of economic resources in the health care field? J.W. Finn writes: “Patients with inadequate social support, and patients who are impoverished or poorly adherent to prescribed regimens, may have shorter life expectancies. Unresolved relationship issues or existential distress may prolong the dying process<sup>280</sup>. If true, this allows us to underscore both the ethical issues relating to the burdens of health care, and the inherent question of whether terminal patients should have the possibility of obtaining life-sustaining care”<sup>281</sup>.

3. Does the criterion of “terminal” respond to a specific moral issue? If so, which one? It defines the difference between directly causing death and letting someone die. This difference seems to be the most important feature in justifying the substantive meaning of “terminal”: the cause of death is related to the irreversibility of the terminal disease and not to the suspension of treatments. From a Catholic perspective, the difference between letting someone die and killing them also excludes the *immediate and mediate material cooperation* with evil, in reference to the patient’s death.<sup>282</sup>

J.P. Bishop writes about the distinction between killing and allowing a patient to die: “In the traditional formulation, there is thus no distinction between acts of commission and acts of omission, but there is a morally important distinction that remains helpful for the care of the dying; that distinction is between directly and indirectly causing death. Today, directly causing death is often seen as parallel with acts of commission; indirectly causing death is commonly confused with acts of omission. But nothing could

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<sup>279</sup> Hamel RP, Walter JJ, *Artificial Nutrition and Hydration and the Permanently Unconscious Patient, The Catholic Debate*, Washington, D.C., Georgetown University Press, 2007, 151.

<sup>280</sup> Finn JW, *Determining prognoses for patients with terminal illnesses*, American Family Physician, 2006; 73(11): 2062 -2067.

<sup>281</sup> Berlinger N., Jennins B, Wolf SM, *The Hastings Center Guidelines for Decision on Life-Sustaining Treatment and Care Near the End of Life*, cit., 28. In United States, the Patient Protection and Affordable Care Act (2010) «should reduce the number of patients who lack access to health insurance or who are underinsured».

<sup>282</sup> Ashley BM, Deblois J, O’Rourke KD, *Health Care Ethics: A Catholic Theological Analysis*, Washington, D.C., Georgetown University Press, 2006, 56.

be further from the case in the older formulation. Acts of commission and acts of omission are both forms of directly causing death for both entail the direct action of the will”<sup>283</sup>.

Based on the above-mentioned critical analysis one can identify the key factors regarding what is really crucial regarding end-of life decisions in near death situations: a) the relationship between persons (patient, physician, family member), b) the dialectic between resistance to and surrender to a terminal disease.

All three aspects have important ethical implications but the third aspect seems to be the most relevant moral criterion for those who must decide. This last feature turns out to be the most significant, irrespective of who will have the last word (patient, family member or legal guardian).

The criterion of “terminal” maintains its specific ethical and clinical value, given the difference between directly causing death and letting someone die.

But is all that has been said so far enough? Can the difference between killing and allowing someone to die only be understood through the criterion of terminal illness?

The criterion of “terminal” provides guidelines to establish the difference between killing and allowing someone to die, but this difference may not be comprehensible only by using this criterion.

Is this criterion really nullifying? Or do we take it for granted that just because it reassures, it eases the consciences of those who should decide? Perhaps it is useful to take time to think. From the ethical point of view, in the case of a patient with a non-terminal incurable disease the suspension of treatments is in any case a choice: a choice always within a narrow range of possibilities: “there is a grey zone of physician complicity”<sup>284</sup>. On the other hand if the patient is terminal the suspension appears to be “always” more clear and morally licit.

The decision to withdraw treatment is made considering the clinical data, but this may not be the only factor. In a quality care situation, the clinical reality which can best justify the idea of conditioned and shared surrendering to the disease is the irreversibility factor.

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<sup>283</sup> Bishop JP, *Euthanasia, efficiency, and the historical distinction between killing a patient and allowing a patient to die*, *Journal of Medical Ethics*, 2006; 32: 220–224.

<sup>284</sup> Duffy TP, *Physician Assistance in Dying, A Subtler Slippery Slope*, *The Hastings Center Report*, 2014; 44(2): 49.

In the case of non-terminally ill patients with incurable diseases suspension of treatment is debatable from an ethical point of view, while it is “always” licit to withdraw treatment if the patient is a terminally ill.

There are some valid reasons for discussion regarding the suspension of treatment in patients afflicted with incurable but non-terminal diseases. They are at least three: 1. If the criterion of proportionality originates from a dialectic relationship between clinical conditions and the existential status of a specific patient, terminal status leans strongly and inevitably towards the clinic condition; 2. Today “terminal” appears to be too restrictive a clinical criterion; technology prolongs difficult and painful clinical situations indefinitely, and often patients do not have the additional financial resources necessary to continue treatment; 3. It is essential to consider the complicated situations of the patients’ families or loved ones. They are often required to attend to their loved ones for prolonged periods of time.

The criterion of irreversibility has not only a clinical but also an ethical value. Only in a good physician-patient relationship may the criterion of irreversibility help to decide about the suspension of the treatment. And this is true not only when the patient is terminally ill. The act of surrender seems justified when disease is irreversible. This clinical data must be related to both patient’s quality of life and the patient’s therapeutic history.

Why does irreversibility better correspond to the difference between killing and allowing someone to die than the “terminal” factor?

Both irreversible and “terminal” conditions oblige us to recognize what the ultimate limits are to which a sick person must surrender. But the irreversibility factor leaves room for the power of choice of the sick person or of the proxy. The criterion of irreversibility can be fully included in the notion of proportionality, through which it is possible to arrive at a morally “good” choice regarding suspension of treatment.<sup>285</sup>

The elements that make it ethically acceptable to the situation are:

1. if the disease which the subject is afflicted with is irreversible, the prognosis is poor, and their condition is worsening; i.e. there are no scientifically valid therapies and their condition is doomed to continuous deterioration over time;
2. if the subject has manifested forms of resistance to the diseases. From this point of view, having had the

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<sup>285</sup> Picozzi M et al, *Fino a quando?*, cit., 133-134.

experience of the treatment that is to be suspended is a significant aspect (and indirect experience cannot be excluded from the equation, i.e. having witnessed a loved one suffering from the same disease). In some cases this is the only possibility – vegetative states come to mind, of which of course one cannot have direct experience); 3. if suspension is gradual: it is not about “pulling the plug”, but suspending things before more invasive treatments begin, then slowly progressing towards more traditional treatments (this allows time to contemplate mixed solutions); 4. if it acknowledges the value of the underlying symbolic gestures of care: this allows us to focus attention on the methods by which treatments are administered and meaning connected to said methods.<sup>286</sup>

These reasons were explained briefly to the pediatrician during our meeting, and it gave him the possibility to understand another point of view (the ethics point of view), which had great influence on his convincing himself that the chosen path was at the same time the hardest but also the most correct for this child (especially since it had been shared with and promoted by the parents).

## **Clinical Ethics Record**

The last point concerns the Clinical Ethics Record, a database used to analyze the data about Ethics Consultation. The ethics consultation is not only focused on single clinical cases, but is also oriented towards reporting and evaluating a posteriori the consultations carried out. Therefore, every case consultation should be accompanied by the filing of a clinical ethics record.<sup>287</sup> The international literature confirms this practice,

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<sup>286</sup> These factors are not meant to eliminate the criteria regarding terminal states, but to render ethically acceptable both the suspension of treatment (on certain conditions) and also the continuation of treatment for patients in their dying moments (who should Not be obliged to suspend it).

<sup>287</sup> Thomas M et al., *Not just little adults: a review of 102 paediatric ethics consultations*, *Acta Paediatrica*, 2015; 104(5): 529-534. Bramstedt KA et al., 2009, *Optimising the Documentation Practices of an Ethics Consultation Service*, 2009; *Journal of Medical Ethics*, 35(1): 47-50. Pfäfflin M et al., *Evaluating Clinical Ethics Consultation: A European Perspective*, *Cambridge Quarterly of Healthcare Ethics*, 2009; 18: 406–419. Richer G, 2009, *Clinical Ethics as Liaison Service: Concepts and Experiences in Collaboration with Operative Medicine*, *Cambridge Quarterly of Healthcare Ethics*, 2009; 18: 360–370. Romano ME, et al., *Mandatory Ethics Consultation Policy*, *Mayo Clin Proc.*, 2009; 84(7):581-585. Cho MK et al., *Strangers at the bedside: research ethics consultation*, *The American Journal of Bioethics*, 2008; 8(3): 4-13.



but there are only few studies related to the assessment of how the ethics consultation is able to meet the specific needs in a hospital.

The compiling of the clinical ethics record by the consultant should help: to report the data on the consultation; to verify and to improve the consultation service provided by the consultant or the clinical ethics committee; to understand who, when and why an ethics consultation is requested; and to develop guidelines.

The majority of the clinical ethics services take note of ethics consultations to create a database. Compiling a clinical ethics record implies having both a history of the ethics consultations and the possibility of developing an ethics consultation service focused on the specific contexts in which the consultant works. In our experience the clinical ethics record is a valid tool for performing a consultation and in the development of empirical research.

Following I present a clinical ethics record model, in which the consultant reports the information about the patient, the health care team, the ethical questions (identification, analysis, clarification) and the consultant's recommendations about one or more possible solutions which were developed.

### **An example of a Clinical Ethics Record**

n. .../...

Date: .../.../...

Time: .....:.....

Name of the Consultant: .....

#### Regarding the Consultation Requestor:

Name of the Consultation Requestor: .....

Age: .....

Role:	Department:	Field of the Consultation:
MD <input type="checkbox"/> RN <input type="checkbox"/> JD <input type="checkbox"/> Family member <input type="checkbox"/> Clergy <input type="checkbox"/> Doctor of psychology <input type="checkbox"/> Genetic counselor <input type="checkbox"/> Ethics Committee <input type="checkbox"/> Management Team <input type="checkbox"/> Other: .....	Neonatology <input type="checkbox"/> Pediatrics <input type="checkbox"/> Cardiology <input type="checkbox"/> Oncology <input type="checkbox"/> Pediatric ICU <input type="checkbox"/> ICU <input type="checkbox"/> Gastroenterology <input type="checkbox"/> Neurology <input type="checkbox"/> Psychiatry <input type="checkbox"/> Nephrology <input type="checkbox"/> Genetics <input type="checkbox"/> Obs. and Gyn. <input type="checkbox"/> Palliative Care Unit <input type="checkbox"/> Other: .....	End-of-life issues <input type="checkbox"/> Quality of life <input type="checkbox"/> Parental decision-making <input type="checkbox"/> Informed consent <input type="checkbox"/> Professional obligation <input type="checkbox"/> Disagreement among professionals <input type="checkbox"/> Discharge planning <input type="checkbox"/> Professional integrity <input type="checkbox"/> Medical and surgical treatments <input type="checkbox"/> Patient/family behavior <input type="checkbox"/> Professional boundaries <input type="checkbox"/> Resource utilization <input type="checkbox"/> Decisional capacity <input type="checkbox"/> Treatment genetics <input type="checkbox"/> Resource allocation <input type="checkbox"/> Refusal of non-life-threatening treatment <input type="checkbox"/> Decision-making <input type="checkbox"/> Genetics <input type="checkbox"/> Miscommunication/misunderstanding <input type="checkbox"/> Pain control <input type="checkbox"/> Quality of care <input type="checkbox"/> Reproduction <input type="checkbox"/> Non-compliance <input type="checkbox"/> Truth-telling/disclosure <input type="checkbox"/> Treatment innovation <input type="checkbox"/>

		Professional distress <input type="checkbox"/>
		Other: .....

Location of the Consultation: .....

1- Level of urgency:

- earliest
- planned consultancy
- within 1 day
- within 3 days
- within 5 days

2- Reason for the Ethics Consultation:

- Advice
- Validation
- Problem-solving
- Information
- Conflict resolution

About the Patient:

Patient's name: .....

Age: .....

3- Patient's decision making capacity:

.....  
 .....

4- Information about the authorized proxy (if applicable):

.....

.....

5- Medical and Personal History:

.....  
.....

6- Patient's preferences and interests  
(culture, religion, quality of life considerations):

.....  
.....

7- Prognosis:

.....  
.....

8- Ethical dilemma, question, issue, doubt:

.....  
.....

9- The ethical issue or dilemma has been shared:

- with the medical team
- with the medical and nursing teams
- with the medical team and the patient
- with the medical and nursing teams and the patient
- with the medical team and the family members
- with the medical and nursing teams and the family members
- with the medical team, nursing team, the patient and the family members
- other: .....

About the decision:

10- What kind of decision has been made?

.....

.....  
.....

11- Who took the final decision?

- the medical team
- the medical and nursing teams
- the medical team and the patient
- the medical and nursing teams and the patient
- the medical team and the family members
- the medical and nursing teams and the family members
- the medical team, nursing team, the patient and the family members
- other: .....

12- What kind of motivation has been offered?

.....  
.....

13- Is there anybody who disagrees with the final decision?

.....  
.....

Comments:

.....  
.....

## Conclusions

Maybe I was not able to represent thoroughly the thirteen different ways of seeing a blackbird.<sup>288</sup> Many, perhaps too many things have been left unsaid. The work is not complete; perhaps, it is more the parts that are missing, the ones that have yet to be written.

The Ethical theories and methods presented have been used to approach the different cases described during the Doctoral Course. These analyses require further reflection as to their exhaustiveness in approaching different clinical cases in a comprehensive manner.

For this reason the analysis of the virtues and criticalities of these ethical theories and their methods gave me the opportunity to propose a new method, which I hope will bring about shared interest.

Of course, it can be improved upon, but is this not the goal of clinical ethics? That is to create new constructive points of reflection in order to better track that thin red line between different positions, to make a definitive choice which provides the best possible solution?

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<sup>288</sup> Sulmasy D, Sugarman J (eds.), *Methods in Medical Ethics*, Washington DC, Georgetown University Press, 2010<sup>2</sup>.

The mistake that I want to underscore is that the fact that everyone can create their own ethic, ignoring the validity of a concerted effort to share dilemmas, issues or doubts (just as the word “ethics” suggests) which are not resolvable a priori, or by simply applying general logic or common sense.

The effort should begin with reasoning together. Each of us starts from nuances, experiences and different meanings, but the risk is that we live each day in a department as 'moral strangers', at the same time both near and far. Therefore, sharing seems to be an essential aspect.

Sharing does not necessarily mean agreeing, but finding a moment in which to explain one's own contrasting opinions, in a reasonable and tolerant manner, and to seek the possibility of achieving a synthesis in order to come to one final choice.

Through general sharing we can begin to discuss specific cases, the difficulties involved for both the patient and the health care professional, and the reasons why a specific therapeutic strategy should be followed.

The goal is to acknowledge clinical ethics as an integral part of everyday medical practice, recognizing that in all branches of medicine there are numerous ethical issues to take on and resolve.

And it is precisely, given this common goal, that it is desirable that this field of research, between philosophy and medicine, develops and finds a recognized place in healthcare settings.

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