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TESIS DOCTORAL

RELATIONAL APPROACHES:

VULNERABILITY AND AUTONOMY IN BIOETHICS

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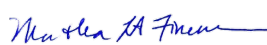
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**RELATIONAL APPROACHES:
 VULNERABILITY AND AUTONOMY IN BIOETHICS**

JANET DELGADO RODRIGUEZ

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CERTIFICADO

María José Guerra Palmero, Doctora en Filosofía y Profesora Titular de Filosofía Moral de la Universidad de La Laguna y Martha A. Fineman, J.D., profesora Robert W. Woodruff de Derecho en la Facultad de Derecho de Emory University.

CERTIFICAN:

Que la Tesis Doctoral presentada por Doña Janet Delgado Rodríguez, Licenciada en Filosofía, con el Título "Relational Approaches: Vulnerability and Autonomy in Bioethics", ha sido realizada bajo su dirección y codirección respectivamente, haciendo constar así mismo que una vez revisado el trabajo lo encuentran apto para su defensa ante el Tribunal.

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CERTIFICATE

María José Guerra Palmero, PhD in Philosophy and Professor of Moral Philosophy at the University of La Laguna and Martha A. Fineman, J.D., Professor Robert W. Woodruff of Law at the Faculty of Law at Emory University.

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That the Doctoral Thesis presented by Doña Janet Delgado Rodríguez, Graduate in Philosophy with the title "Relational Approaches: Vulnerability and Autonomy in Bioethics", has been carried out under her direction and co-direction respectively, noting that once the work is reviewed, they find it fit for your defense before the Court.

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"We all care about life and death, health and illness, medicine and politics. Regardless of choice or preference, we're all invariably engaged in caring about the difficulty of how we set up the world to attend to the profound variability of our bodies and minds lived in community. Care defines us not because we choose to care but because we are claimed by care. If bioethics is care work, we are all bioethicists. Understanding bioethics as care work suggests that the question of care is forever front and center. Because our cares are scattered, it is a struggle to gather the energy they solicit in the service of a more just future for all".

[Joel Michael Reynolds, Bioethics as care work, Hastings Center Report, January 2018, Vol.48(1)]

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ABSTRACT

The concept of vulnerability is central to current Bioethics. In the past several years there has been a great deal of interest generated around the concept of vulnerability in the Bioethics field. Due to this, it is necessary to define and analyse a conceptual framework in which the notion of vulnerability is developed within the scope of bioethics. The purpose of this thesis is to develop an ethics of vulnerability, based on the vulnerability theory. To address this issue, I analyse the reflection that we find in the work of Martha Fineman, emphasizing the main relevant aspects for bioethics. I highlight what are the main implications of an ethics based on a theory on vulnerability on bioethics. First, it is necessary to re-think the concept of autonomy. Theorizing about the concept of vulnerability there is a tension between how to respond to human vulnerability, while also promoting autonomy. A relational perspective on autonomy offers a different way to understand the link between vulnerability and autonomy. This approach maintains the value of autonomy, but avoids the individualism associated with liberal conceptions of it. I consider how rethinking autonomy in its relational sense affects understandings of vulnerability. I explain the meaning of relational autonomy and consider the main implications of this concept in regard to a vulnerability approach. If we are to effectively recognize and respond to ontological vulnerability, we also must the meaning of autonomy. The second implication of a reflection on vulnerability theory in bioethics is the fact that it can foster better relationships between healthcare professionals and patients, through the recognition of our shared vulnerability. Mainstream literature about vulnerability in healthcare field has been developed attending to patient's vulnerability as a consequence of illness. In addition to patients and their families, it is necessary to take into account vulnerability from the perspective of health professionals: these professionals also face day-by-day suffering. Vulnerability theory can guide professionalism to incorporate an ethics of vulnerability in healthcare field, focusing on fostering resilience in patients and families, but also, and less considered in Professionalism literature, in healthcare professionals and healthcare institutions. Vulnerability Theory can offer an important contribution to the studies in professionalism in healthcare. The third implication is a reflection about the concept of "asymmetrical responsibility" in the context of healthcare. The encounter between a healthcare professional and a patient is a professional

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relationship based on care. This means that the responsibility to provide all the necessary tools and strategies to foster relational autonomy in patients correspond to professionals. Fostering relational autonomy and increasing resilience are the main objectives pursued by a relationship based on care. These achievements can be acquired through the understanding of our shared vulnerability as *the* human condition. At the same time, we cannot think about relations between professionals and patients without considering the institutional framework that can provide support or not. It is important to define and think about what is the role of the institutions of healthcare in this effort to promote an ethics of asymmetrical responsibility towards patients and healthcare professionals. In the attempt to improve the face to face relationships in healthcare it is essential the institutional commitment to address the care of those who care for others.

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RESUMEN

El concepto de vulnerabilidad es fundamental para la bioética actual. En los últimos años se ha generado un gran interés en torno al concepto de vulnerabilidad en el campo de la bioética. Debido a esto, es necesario definir y analizar un marco conceptual en el cual la noción de vulnerabilidad se desarrolle dentro del alcance de la bioética. El objetivo de esta tesis es desarrollar una ética de vulnerabilidad, basada en la teoría de la vulnerabilidad. Para abordar este tema, analizo la reflexión que encontramos en el trabajo de Martha Fineman, enfatizando los principales aspectos relevantes para la bioética. Destaco cuáles son las principales implicaciones de una teoría sobre la vulnerabilidad en bioética. Primero, es necesario repensar el concepto de autonomía. Al analizar el concepto de vulnerabilidad, existe una tensión entre cómo responder a la vulnerabilidad humana y, al mismo tiempo, promover la autonomía. Una perspectiva relacional sobre la autonomía ofrece una forma diferente de entender la vulnerabilidad. Este enfoque mantiene el valor de la autonomía, pero evita el individualismo asociado con las concepciones liberales de la misma. Como repensar la autonomía en su sentido relacional afecta la comprensión de la vulnerabilidad. Explico el significado de la autonomía relacional y considero las principales implicaciones de este concepto con respecto a un enfoque de vulnerabilidad. Si queremos reconocer de manera efectiva y responder a la vulnerabilidad ontológica, también debemos entender el significado de la autonomía. La segunda implicación de una reflexión sobre la teoría de la vulnerabilidad en bioética es el hecho de que puede fomentar mejores relaciones entre los profesionales de la salud y los pacientes, a través del reconocimiento de nuestra vulnerabilidad compartida. La literatura principal sobre la vulnerabilidad en el campo de la salud se ha desarrollado atendiendo a la vulnerabilidad del paciente como consecuencia de la enfermedad. Además de los pacientes y sus familias, es necesario tener en cuenta la vulnerabilidad desde la perspectiva de los profesionales de la salud: estos profesionales también enfrentan el sufrimiento día a día. La teoría de la vulnerabilidad puede guiar el profesionalismo para incorporar una ética de vulnerabilidad en el campo de la salud, enfocándose en fomentar la resiliencia en pacientes y familias, pero también, y menos considerado en la literatura de profesionalismo, en profesionales de la salud e instituciones de atención médica. La teoría de la vulnerabilidad puede ofrecer una contribución importante a los estudios sobre

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profesionalismo en el ámbito sanitario. La tercera implicación es una reflexión sobre el concepto de "responsabilidad asimétrica" en el contexto de la asistencia sanitaria. El encuentro entre un profesional de la salud y un paciente es una relación profesional basada en la atención. Esto significa que la responsabilidad de proporcionar todas las herramientas y estrategias necesarias para fomentar la autonomía relacional y aumentar la resiliencia en los pacientes corresponde a los profesionales. Fomentar la autonomía relacional y aumentar la resiliencia son los principales objetivos perseguidos por una relación basada en el cuidado. Estos logros se pueden adquirir a través de la comprensión de nuestra vulnerabilidad compartida como la condición humana. Al mismo tiempo, no podemos pensar en las relaciones entre profesionales y pacientes sin considerar el marco institucional que puede brindar apoyo o no. Es importante definir y pensar cuál es el papel de las instituciones de salud en este esfuerzo por promover una ética de responsabilidad asimétrica hacia los pacientes y los profesionales de la salud. En el intento de mejorar las relaciones cara a cara en el cuidado de la salud, es esencial el compromiso institucional para abordar la resiliencia y la atención de quienes cuidan de otros.

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INTRODUCTION

During the last years, a great interest in bioethics has been created around the concept of vulnerability. In the literature, the main researches are related to the concept and definition of vulnerable groups, and to the attempt to develop taxonomies to try to better understand the notion of vulnerability. Trying to identify what it consists of and reflect on categories or taxonomies on vulnerability, there are proposals that apply a classification or taxonomy of multiple forms that adopt vulnerability, as proposed by Dodds, Mackenzie and Rogers (2014), while others opt for a conceptual clarification, such as the distinction proposed by Kottow (2003) between susceptibility and vulnerability. While these are important contributions in the understanding of the concept of vulnerability, the majority of authors consider unworthy the universal approaches to vulnerability concept, since they understand these approaches as non-applicable. Finally, these proposals are confronted with Martha Fineman's theory of Vulnerability, which conceives vulnerability as a human condition, excluding any possible typology of vulnerability from reflection.

In this thesis, the starting point is the recognition of the necessary to deepen the notion of shared or ontological vulnerability within bioethics. I argue that Martha Fineman's theory of vulnerability is an important contribution to bioethics, since it develops a vision about vulnerability based on a shared condition for human beings, focusing on the role of institutions and the role of the state to try to minimize our common vulnerabilities.

Considering the different theoretical and practical approaches, this thesis proposes to show the contributions of Martha Fineman's theory of vulnerability within bioethics. While this approach has been criticized into the field of Bioethics, since it is considered non-applicable, the purpose of this research is to show how this universal approach on Vulnerability concept has an important impact in practical issues within bioethics. Vulnerability theory conceives vulnerability as the human condition: we are all vulnerable. Vulnerability is universal and constant: there are no more and less vulnerability. This theory claims for a more responsive state towards human vulnerability. Vulnerability theory focus on a life course perspective, which means the institutional support claimed is necessary along the person's life. Highlighting vulnerability as the human condition, the focus is not in the individual level, but in the social responsibility. In this regard, in the core of the

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theory, resilience is the way to respond to human vulnerability, and the state and institutions have the duty of foster resilience in individual.

In addition, there is a tension between the response to human vulnerability and the promotion of autonomy. Therefore, I believe it is fundamental to develop this link between autonomy and vulnerability. The rhetoric of individual autonomy and personal responsibility can work by masking social injustices and structural inequalities. The theory of vulnerability proposes resilience as a way to minimize vulnerability. In my analysis, I argue that in Bioethics Autonomy is inalienable. Now, what autonomy? The concept of relational autonomy is a key that allows us to understand autonomy as a capacity developed fundamentally within the framework of interpersonal relationships, which are constitutive of the human being. Now, there are many ways to understand this term, thus, it has been carried out a definition of the main characteristics that define what is relational autonomy. I emphasize that the interconnections that exist between the categories of vulnerability and relational autonomy are fundamental for bioethics. This is the main point of distance between my research and vulnerability theory.

CHAPTER SUMMARIES

Chapter one: Research problem.

In the chapter I explain what is the problem in regard to the concept of vulnerability in bioethics field, and how I address it on this research. In addition, I explain the main hypothesis and objectives. Finally, some methodological questions are exposed.

Chapter two: The relevance of the ethics of Vulnerability in Bioethics.

This chapter provides an overview to some of the different approaches of the concept of vulnerability in bioethics in last decade. The purpose of this chapter is to indicate how the concept of vulnerability in the field of bioethics has been developed and the main problems that arise from some of these different approaches. Tracking the notion of vulnerability in bioethics, the majority of the reflection about vulnerability concept has emerged around the notion of vulnerable populations or vulnerable groups. Particularly, this notion has arose in the context of research ethics. While this

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reflection has led research in a more respectful way, focusing only in research as well as in vulnerable populations ends on a lack of a wider framework for understanding an ethics of vulnerability in the context of bioethics.

Secondly, the chapter analyses some of the main philosophical approaches I consider should be articulated in the expansion of a critical bioethics approach focused on the notion of vulnerability. To address this issue, I analyse the main different approaches, based on the differences between the particular and the universal approach to vulnerability concept. I examine the reflection that we find in the work of Martha Fineman, emphasizing the main relevant aspects for bioethics. Since it is true that this theory arises in the field of Law, I argue that Fineman’s vulnerability theory contains lot of relevant aspects that need to be included in the bioethical debate. Finally, I highlight what are the main implications of a theory on vulnerability on bioethics. The resume of these implications in three big topics are the guide for the follower chapters: each of them correspond to the research and explanation of the implications of an ethics based on vulnerability theory in bioethics. These implications include:

- a) A criticism of autonomy principle and the necessity of re-think the concept of autonomy in bioethics.
- b) An ethics on vulnerability in bioethics can lead to improve relationships between healthcare professionals and patients.
- c) Vulnerability theory can guide a reflection about global justice, since the concept of vulnerability is a normative challenge that claims for a more responsive state and institutions.

To analyse each one of these implications is the purpose of the following chapters.

Chapter three: Vulnerability and relational autonomy: a necessary reflection in Bioethics.

This chapter focuses on the connection between the vulnerability theory in bioethics and the concept of relational autonomy. Theorizing about the concept of vulnerability there is a tension between how to respond to human vulnerability, while also promoting autonomy. In this chapter, I consider a relational perspective on autonomy that offers a different way to understand vulnerability. This approach maintains the value of autonomy, but avoids the individualism

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associated with liberal conceptions of it. I consider how thinking from vulnerability approach affects understandings of autonomy in its relational sense.

I explore what are the main problems about autonomy in bioethics. Subsequently, I introduce different approaches to the concept of relational autonomy. Since some authors have linked relational autonomy to vulnerability concept (Mackenzie and Stoljar, 2000) they have linked it between a particular understanding of vulnerability concept, and not in relation to a universal approach on the concept of vulnerability. My contribution in this chapter consists in link the universal vulnerability approach to a relational concept of autonomy. I explain the meaning of relational autonomy, introducing some differences in how this concept has been understood in literature. I add some characteristics of this notion that precisely arise from the link between vulnerability theory and relational autonomy. I argue that this link between relational autonomy and vulnerability theory is quite important from the perspective of healthcare professional patient relationship. I consider some potential criticisms of the vulnerability and the relational autonomy model within healthcare relationships. To conclude, I reflect about the relationship between care and paternalism, arguing that if resilience is one of the main purposes of care relationships, paternalism is inadequate and non-necessary in relationships based on the notion of relational autonomy.

Chapter four: Vulnerability as a key concept in professionalism.

The main objective of this chapter is to emphasize how through the lens of an ethics of vulnerability in bioethics the relationships between patients and their families, healthcare professionals and healthcare institutions can be improved. Mainstream literature about vulnerability in healthcare field has been developed attending to patient's vulnerability as a consequence of illness. In addition to patients and their families, it is necessary to take into account vulnerability from the perspective of healthcare professionals: these professionals face day-by-day suffering, death, pain, etc. I argue vulnerability theory can guide professionalism to incorporate an ethics of vulnerability in healthcare field, focusing on fostering resilience in patients and families, but also, and less considered in professionalism literature, in healthcare professionals and healthcare institutions. In this chapter, I investigate professionalism commitment in response to the

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vulnerability from three perspectives: patients, healthcare professionals, and the institutions. A broadly analysis on vulnerability can lead us to consider the condition of shared vulnerability between patients and the professionals who care for them, which also include the vulnerability in institutions, as a way to improve relationships and resilience in health care. These relationships can increase trust, empathy and good communication.

Chapter five: Asymmetrical responsibility in healthcare context.

Last chapter is dedicated to introduce the notion of asymmetrical responsibility as a key concept in the attempt to highlight the necessity of reflection about the institutional healthcare commitment in managing a better way to improve professionalism in healthcare. I have maintained in chapter one that some of the implications derived from the ethics of vulnerability in Bioethics is that it implies a normative challenge about social justice in the context of healthcare. Focusing on the concept of asymmetrical responsibility, the emphasis is on the perspective of healthcare professionals in the face to face relationship that take place at the bedside level. However, these relationships are only possible within an institutional framework. Focusing on institutions is necessary to emphasize the institutional or organizational commitment to provide the required resources to improve healthcare environments. In the institutions are not enough supportive towards the professionals, burn out, lack of well-being and moral distress affect all the persons involved in relations of care: patients, families and healthcare professionals. I argue the only way to improve the care of patients and families is improving the conditions in healthcare institutions where professionals perform their work. How to do that is one of the most important challenges of our time. Finally, this chapter develop suitable strategies for institutions to try to improve spaces for care.

Finally, last part of this research summarize the main conclusions that emerge from this thesis.

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CHAPTER ONE:

RESEARCH PROBLEM

STATEMENT OF THE PROBLEM

Concerns about the concept of vulnerability in bioethics, as well as in social sciences and health sciences, have increased notably during the last decade. For long time philosophy has ignored human vulnerability, and mainly feminist philosophy has reflected more broadly on vulnerability as a constitutive and fundamental feature of the human condition. Especially the ethics of care (Gilligan 1982; Noddings 1984; Tronto 1993; Baier 1994; Kittay 1999; Held 2006) has highlighted the importance of human interdependence and links. Apart from the work of Robert Goodin (1985) *Protecting the Vulnerable*, it has not been until the most recent years that a greater interest in this concept has been aroused. Especially during the last two decades, it has extended a broad interest in Bioethics around the concept of vulnerability.

In a broad sense, there are opposing theoretical approaches on the conception of vulnerability in Bioethics, which ends up making it a largely opaque term. To show this huge variety of theoretical and practical frameworks around vulnerability concept in Bioethics, Henk ten Have (2014) has made a great contribution, since he has conducted the most comprehensive study, analyzing the different ways of understanding this concept within Bioethics field. As a result, we have now a better understanding and clarification about the different proposals in the field of Bioethics. However, there are huge controversies in Bioethics about this concept.

Analyzing the literature in Bioethics, the majority of approaches develop a situational or particular understanding on vulnerability. While there are proposals that carry out a classification or taxonomy of the multiple forms that vulnerability takes, as proposed by Dodds, Mackenzie and Rogers (2014), others opt for a conceptual simplification, such as the distinction proposed by Kottow (2003) between susceptibility and vulnerability. Hurst (2008) proposes to define vulnerability in research and healthcare as the increased probability of incurring extra or bigger damage, starting from the kinds of harms likely to occur. Even if it is not an attempt to classify

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different kinds of vulnerability, Florencia Luna (2008) metaphor of layers points out that there are many potential sources of vulnerability, and each of them forms a different, overlapping layer. These proposals, among others, look for a major clarification, emphasizing the pragmatic approach, which means how to apply the concept into particular situations in bioethics.

Since these approaches contribute to the field in the attempt to try to clarify the concept, turning it as operational as possible, I argue it is necessary to deepen face the notion of shared or ontological vulnerability within bioethics. The reflections on the universal notion of vulnerability in Philosophy has been guided by Enmanuel Levinas (1961, 1972), MacIntyre (2001), Nussbaum (2006), Judith Butler (2006, 2010), Ricoeur (2008), Turner (2006) and Martha Fineman (2008, 2010, 2012), among others. The common feature of all these philosophical approaches on the concept of vulnerability is the fact that all of them emphasize that being vulnerable is being fragile, susceptible to damage and suffering, and it is an ontological, inherent, shared condition. Moreover, they link our bodily vulnerability with our inherent sociability, with the way we are dependent on each other.

Considering all the different theoretical and practical approaches, I argue that Martha Fineman's theory of vulnerability is an important contribution to bioethics, since she develops a vulnerability theory based on a shared condition for human beings, as the human condition, focusing on the role of institutions and the role of the state to try to face it. I consider the concept of vulnerability in this framework as a key concept in bioethics field. To analyse and explore the concept of vulnerability in Martha Fineman's theory of vulnerability, besides the contributions and implications that the applicability of this theory has in bioethics is the purpose of this thesis. I strongly believe this framework can provide analytical tools to examine different situations of damage that people suffer or may suffer in the context of healthcare. In addition, the notion of vulnerability is fascinating, and it contains some positive aspects that I consider necessary to explore. For all of these positive and negative aspects, I argue an ethics of vulnerability can illuminate bioethics nowadays. It is a concept with great critical potential, which must be developed to try to reverse the enormous inequalities of our time, offering new knowledge, and new narratives based on what make us connected as humans: we are all vulnerable.

The reflection about vulnerability theory in bioethics implies a required theoretical approach to the concept of autonomy in the field. In the mainstream literature in bioethics, there is a tension

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between the response to human vulnerability and the promotion of autonomy; therefore, I believe it is fundamental to develop this link between autonomy and vulnerability. The rhetoric of individual autonomy and personal responsibility can work by masking social injustices and structural inequalities. Vulnerability theory proposes resilience as a way to face vulnerability, and rejects any notion of autonomy. In my analysis, I argue in bioethics autonomy, relationally understood, is undeniable. What it is essential is to re-define is the meaning of autonomy that we need to advocate in the context of healthcare.

In this sense, the primacy of autonomy in bioethics has been questioned from different theoretical approaches, but mainly from feminist bioethics, arguing that this notion is based on a distorted view of the individual that makes decisions as independent and self-sufficient individual. The concept of relational autonomy is a key notion that allows us to understand autonomy as a capacity developed fundamentally within the framework of interpersonal relationships, which are constitutive of the human being. In bioethical literature, there are many ways to understand this term, so it has been carried out a tracking of the main characteristics that define what relational autonomy is. Besides, I emphasize that the interconnections between the categories of vulnerability and relational autonomy are fundamental in bioethics. On the one hand, if we take into account the implications of the recognition of ontological vulnerability, we will also have to rethink the autonomy model, based on the reconciliation between autonomy and vulnerability. By emphasizing this alliance, the point of view goes beyond the protection of the vulnerable: it seeks to analyse forms of social support to promote relational autonomy and resilience. In addition, if autonomy is understood relationally, the opposition between autonomy and vulnerability disappears. From a relational autonomy perspective, the institutional and social duties to address vulnerability also include fostering autonomy and improve resilience. Certainly, recognizing shared vulnerability, while promoting relational autonomy and resilience in healthcare, is a matter of justice.

Last decade, in our societies, we are experiencing an urgency of thinking in bioethics in response of all the effects of the neoliberal politics in the context of healthcare. As M. José Guerra (2018) highlights, in Spain (as well as in other countries) the increasingly impoverished and aging population, the dismantling of the welfare state and the levels of equality reached since the beginning of its democracy, health neoliberalization can make bioethics end up being a "luxury" for

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the privileged, in which the issues of justice disappear. One of the consequences of these social and political changes is the lack of attention to the institutional responsibility in regard to promote the necessary conditions for provide the best care. Although last decades we have been witness of an increase in the development of new technologies in healthcare field, nowadays it is a global problem the rise in the levels of stress, burnout, anxiety, moral distress, etc., in healthcare professionals.

We have many examples about health care professional vulnerability experienced in the workplace, unfortunately, increasing during last years (Dyrbye et al., 2017; Davidson et al., 2018; Squiers et al., 2017). In this regard, there are some institutional factors that generate impotence, burnout or moral distress: lack of personnel, lack of administrative support, misbalance in power, inadequate organization of work, lack of communication, work overload, etc. (Moreno, 2016). All these problems can generate in the professional's feelings of impotence, fear or frustration. In addition, the perception of unsafety environment for patients, and the fact that professionals cannot challenge these conditions can trigger moral distress (Berlinger, 2016). Most burnout research has focused on its profound prevalence rather than seeking to identify the origin of the burnout epidemic, and these efforts are usually focused on increasing resilience and wellness among participants rather than combating problematic changes in how medicine is practiced by physicians nowadays (Squiers et al., 2017).

There is an increasing recognition that healthcare organizations need to face burnout and foster well-being, as well as help clinicians to provide the best care to patients, through collective action and targeted investment. In the United States, healthcare organizations are implementing committees and supporting groups in an attempt to reduce burnout among their clinicians, nurses and physicians. In fact, The National Academy of Medicine (NAM), in US, has a strong commitment on addressing these problems, and they have designed the vast initiative "Action Collaborative on Clinician Well-Being and Resilience", which is one of the most important initiatives developed in this area. As part of this project, the NAM is promoting a network of organizations of the Action Collaborative on Clinician Well-Being and Resilience. Moreover, in the uploaded version of the Declaration of Geneva adopted by the World Medical Association (WMA General Assembly on October 14, 2017), the concept of physician well-being was included as a reflection about the role physician self-care can play in improving patient care. At the same time the WMA highlight the own

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health, well-being, and abilities of physicians should be promoted in order to provide care of the highest standard (Parsa-Parsi, 2017).

The development of vulnerability theory in bioethics, and particularly concerning professionalism in healthcare field, emphasizes the recognition and need for care and connections that emerges from our vulnerability. “Collectively, institutions play an important role in compensating our shared vulnerability, providing us with the resilience or resources to respond in specific times of crisis or opportunity” (Fineman, 2013, p 22). This framework challenges the particular context of clinical ethics, guiding us to think broadly about the responsibility of the institutions to foster resilience in patients (and their families) and health care professionals too. In general, addressing the problem about lack of well-being in professionals is linked with the patient’s satisfaction (Vahey et al, 2004; Abed-Ali et al, 2016) or the repercussion on patient’s safety (Halbesleben et al, 2008; Kirwan et al., 2013; Ross, 2016). In a systematic review about healthcare staff wellbeing, burnout and patient safety, Hall et al. (2016) found in the majority of studies reviewed poor wellbeing and burnout are associated with poor patient safety outcomes such as medical errors. Nevertheless, there is not a deep reflection about how these inadequate conditions at work also have an impact in the professional-patient relationships. I consider essential to face the “epidemic” situation (Squiers et al., 2017) from the institutional perspective. The necessity of analyze what are the structural problems that arise from the healthcare institutional organization is important. In this sense, it is necessary a collective action between institutions and the state to promote and foster resilience in both, patients and professionals. It is required a stronger ethical commitment and a relational thought, that allows institutional managers to re-think and re-assess the way how care is understood and performed in the workplace.

For these reasons, I consider necessary to stablish connections between ethics of care, ethics of responsibility and the ethics of vulnerability that I develop along these pages. Especially in the field of bioethics, and particularly in professionalism in healthcare, these three theoretical approaches are essential. In this regard, this thesis takes into account the concepts and background on care and responsibility to develop an ethics based on vulnerability as a shared human condition.

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According to Gilson (2014)¹ an ethics of vulnerability requires a more open, ambiguous and ambivalent conception of the vulnerability that is being used -related to violence, harm, suffering and linked to weakness, lack of agency, femininity. A notion of vulnerability as an opening to the constitutive world of the forms of relationship, not only as a situation but as an indefinite, ambiguous possibility.

HYPOTHESIS AND OBJECTIVES

This thesis is focus on the analyses and justification of the relevance of an ethics of vulnerability in bioethics field. For this purpose, this research is based on the vulnerability theory developed by Martha Albertson Fineman during the last decade. This approach has been developed mainly in the field of Law. However, this theoretical framework has been introduced into the bioethical context, but not in a deep way.

The starting point of this research is the assumption that an ethics based on vulnerability concept as *the* human condition has a normative role in bioethics, and particularly, in healthcare context. One of the main problems that I try to face is the misunderstanding about the applicability of a universal concept of vulnerability in bioethics field. In fact, the majority of literature criticize anthropological or universal approaches, since they are considered as inoperable or non-practical (Hurst, 2008; Allotey et al, 2012; Wendler, 2017). According to these premises, the majority of research in last decades about vulnerability concept tries to explain or create taxonomies or different stages or typology of vulnerability. These taxonomies seek to identify different populations or groups of people who are identified as vulnerable groups. Main goal of these classifications is to find the best way to protect these populations in the context of Bioethics (Rodríguez-Arias, et al. 2008).

¹ Gilson's thesis is that vulnerability is fundamental, omnipresent and shared. It is defined by openness and the fact that one is affected in ways that one cannot control. If vulnerability means being susceptible to pain, we have an ethical obligation to reduce vulnerability. The focus of his work is how we think, speak and feel about vulnerability as a characteristic of life that deserves ethical concern. Gilson's discussion of vulnerability is a deep and in-depth analysis of an ethical perspective that has been at the center of many contemporary discussions about ethics. She reviews the recent literature on vulnerability with special attention to feminist contributions.

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However, there is other possibility, and it is to start from the recognition of our shared and inevitable vulnerability as the human condition. From this basis, there are no more or less vulnerability, since it is constant. What is different is the resources we have to deal with vulnerability. Because we cannot be invulnerable, the partial solution to our vulnerability is resilience. The focus, then, is not on the characteristics of a person or a group, but it is in the resilience they have. More importantly, this resilience is not a personal achievement, but it is dependent on how institutions provide us the required resources and strategies to increase our resilience. Consequently, and applied to healthcare context, the main goal must be to increase resilience in healthcare context, which means foster resilience in healthcare professionals as well as in patients and their families, because all of us are vulnerable.

The main objectives of this study include the following:

- Raise and critically analyze the theoretical scenario in relation to the theorization about the concept of vulnerability in bioethics in last decade.
- Establish the main ideas that an ethics of vulnerability based on vulnerability theory implies in bioethics.
- Re-think the conceptualization of vulnerability and the interrelation and interconnection between the notion of vulnerability and relational autonomy from relational approaches.
- Reconsider the clinical relationship from the recognition of the vulnerability of health professionals.
- Formulate an alternative proposal, in a relational way, to better explain and understand different dimensions of professionalism in healthcare.
- Develop an ethics of professionalism in healthcare field centered mainly in the ethics of responsibility from the perspective of institutions.
- Determine the impact of the claims for more responsive institutions and state in the attempt to improve spaces of care in healthcare context.

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METHODOLOGY

This is a theoretical analysis of the vulnerability theory in bioethics, but has an impact on concrete practical issues. From the methodological point of view, this study of vulnerability is proposed from two perspectives:

- Theoretical-conceptual, with the purpose of attending to the basis, the discourses and ethical proposals about how to understand and develop an ethics of vulnerability within bioethics field.

- Practical-moral, in order to know the reality of specific cases, consequences and public policies that increase or diminish conflicts in healthcare context that affect professionals as well as patients and their families.

To carry out this study, bibliographical sources as well as electronic resources and biomedical and philosophical databases have been used. As databases, it has made use of the ISOC, Philosopher's Index, ProQuest, DOAJ, JSTOR, PubMed, BVS, EBSCOHOST, Wiley Online Library, among others. Some of the reference magazines to consult are American Journal of Bioethics, Bioethics, Clinical Ethics, Hasting Center Report, among others.

The other methodological resource in this research are the research stays that I have had the opportunity to perform. Thanks to the research stays carried out abroad, it has been possible to consult the bibliographic collections, as well as discuss broadly my preliminary results with scholars and experts in different universities and research centers.

Throughout the weeks of my first research stay in The Vulnerability and Human Condition Initiative (<http://web.gs.emory.edu/vulnerability>), at Emory University, I had access to the Emory School of Law library, the documentation related to The Feminist and Legal Theory Project and the resources and documentation of the Vulnerability and Human Condition Initiative. Furthermore, I had the opportunity to attend different conferences and workshops, in different Emory University departments: Rollins School of Public Health, Center for Ethics and School of Law. All of these activities allowed me to prepare a draft, which I had the opportunity to discuss extensively with both researchers and teachers who they work in the Vulnerability and Human Condition Initiative, as well as with Professor Martha A. Fineman, founder of the initiative. From the aspects discussed,

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I was able to go modifying some of the concepts worked on in my research. Afterward, I performed a presentation attended by professors and researchers from Vulnerability and Human Condition Initiative, and I received their suggestions to exchange opinions regarding my research.

During my research stay at the Hastings Center, I had access to the resources of the library, as well as meetings with researchers working at the center. From the presentation of my work at the center, I was able to discuss some aspects with the center's research team, incorporating their suggestions and comments to my work. The research I conducted in The Hastings Center has revolved around two main themes: the concept of relational autonomy and the importance of having the theory of vulnerability incorporated to reflection on Professionalism in the health field.

In similar way than in previous occasions, my research stay in Leeds also gave me the opportunity of access to bibliographical sources. In this case, I was working with Professor Martha Fineman and Stu Marvel, from Emory University. As a result of the research stay in Leeds University, I participated in the Workshop on Professionalism and Vulnerability, where I carried out the presentation of the work "Professionalism and vulnerability in Healthcare field".

Finally, last research stay has taken place again in Atlanta, in The Vulnerability and Human Condition Initiative, at Emory University Emory. In this final process, I participated in the Workshop on Autonomy and Vulnerability, with the presentation "Asymmetrical responsibility in healthcare context: relational autonomy, care and paternalism", and I received the suggestions and comments of all the scholars about it. In addition, during this last research stay I had the opportunity to discuss my research with scholars working in vulnerability and bioethics, or working on vulnerability theory in different fields. I also attended to vulnerability theory seminars and classes during the semester, and I had the opportunity to discuss broadly my ideas and research findings with professor Fineman.

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CHAPTER TWO

THE RELEVANCE OF THE ETHICS OF VULNERABILITY IN BIOETHICS

INTRODUCTION

Over recent decades, concern for human vulnerability seems to have been at the centre of reflections in different fields, such as sociology and health care. Despite the fact that traditionally this concept has not been sufficiently addressed, neither in the field of moral philosophy nor in bioethics, remaining under-theorized, in recent years a wide range of scholars have been interested in exploring this concept. One of the first contributions was conducted by Florencia Luna (2006, 2008, 2009, 2013), exploring vulnerability in regard to bioethics, mainly in the research context. In addition, one of the most relevant contributions is the huge analysis that Henk ten Have provides (2016) to comprehend how this concept has been understood in bioethics, through different conceptions of and philosophical approaches to vulnerability. Also, the work of Mackenzie, Rogers, and Dodds (2014) has had an important influence on the endeavour to clarify the concept, as well as the more recent research of different authors collected in Straehle (2017). In spite of this, the vulnerability concept retains some opacity, and there is a controversy about its meaning and the way to understand it in bioethics.

Within bioethics, the concept of vulnerability has been developed mainly in relation to biomedical research ethics and secondarily in the area of public health. In both cases, the focus has been on the categorization of vulnerable groups. Undoubtedly, this approach has been very useful in alerting researchers to the damages associated with biomedical research if the minimal protection principles are not respected, especially under certain circumstances, such as in situations where there is a lack of capability to give informed consent or in situations of potential exploitation. In terms of public health, the issue of vulnerability has generated a vast body of literature concerning how to address social and health problems with regard to different populations. Through classifications of vulnerable populations, political and protection measures have been developed in different contexts. While not neglecting the fact that in clinical ethics there is a tendency to consider disease as a specific form of vulnerability, the main approach in bioethics is to focus on vulnerable

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groups or populations. This discourse on vulnerable groups has had an important impact on practical aspects of bioethics, such as the institution of compulsory research ethics committees², among others. However, this understanding of the vulnerability concept represents the most standard interpretation, reflecting the diverse fields in which it has been developed, which gives rise to some problems.

I argue that vulnerability *is* and *must be* a central and key concept within bioethics. Thus, in the first part of this paper, I examine how the concept of vulnerability has evolved in the field of bioethics and what main difficulties arise as a result of this conception. In my view, the main problem in focusing on the discourse of vulnerable groups is that this perspective excludes other reflections concerning an extended understanding of vulnerability as human condition.

From a philosophical perspective, it is essential to explore the controversy surrounding universality and particularity with regard to vulnerability (Wisner, 2016; Zagorac, 2017). To address this issue, in the second part of this chapter I discuss some of the characteristics of the category of vulnerability in light of the analysis that we find in the work of Martha Fineman. The concept of vulnerability as a human condition has some normative implications that it is necessary to investigate. The main goal of this chapter is to analyse the ontological conception of vulnerability that is in the base of a theory of general vulnerability in bioethics. Finally, I highlight the main implications of a theory of vulnerability in bioethics.

As MacIntyre (2006, p. 23) points out, human vulnerability has generally been neglected throughout the history of philosophy; it has predominantly been feminist philosophy that has highlighted the importance of human interdependence and its links. Other than the work of Robert Goodin (1985)³, it has been only in recent years that a greater interest in this concept has been aroused. According to Hoffmaster (2006), ethics has not paid attention to vulnerability for three reasons:

² It is assumed that these organizations safeguard the integrity of research and the safety of participants involved in research.

³ For a long time, this study was considered the most influential approach to the vulnerable subject in the field of bioethics. Indeed, it was one of the earliest works addressing this issue in bioethics and the social sciences.

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1. Vulnerability is the antithesis of the individualistic ethics predominating in Western societies.
2. Vulnerability is not addressed in ethics because philosophy ignores the body.
3. Ethics has been prominently rationalist and therefore feelings have been displaced or have not been taken into account.

In general terms—and considering that vulnerability has been an under-theorized concept—we can find two principal ways of thinking about vulnerability that have been developed in ethics:

- a) *Ontological or universal vulnerability*⁴. This conception is linked to its Latin origin “*vulnus*” and the possibility of suffering that is inherent to human beings. In the philosophical approaches that address this concept, it is common to think of vulnerability in relation to being fragile, susceptible to damage, and also to suffering. In a broad and general way, these perspectives highlight that it is an ontological, anthropological, inherent, and shared condition. In addition, another shared feature of these perspectives is that they link our vulnerability with our inherent sociability—i.e., with the inevitable fact that we are dependent on one another.
- b) *Contingent or situational vulnerability*. Another type of response to the issue of vulnerability emphasizes different forms of inequality, dependency, basic needs, deprivation of liberties, etc. These social, economic, and political aspects make some people more vulnerable than others. In this regard, this approach is focused on the economic and social inequities that make some people more vulnerable than others.

One of the challenges we have to face in the context of critical bioethics is how to understand the relationship between these two ways of conceptualizing vulnerability, as critical bioethics is concerned about inequalities worldwide.

TRACKING THE VULNERABILITY CONCEPT IN THE CONTEXT OF BIOETHICS AND IDENTIFYING THE MAIN PROBLEMS

When one analyzes the bioethical literature, it is apparent that the notion of vulnerability has developed mainly in the context of the ethics of biomedical research. In this regard, the principal

⁴ I use the terms “ontological vulnerability” and “universal vulnerability” without distinction, since I consider them to have the same meaning.

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approach adopted concerning the concept in bioethics has been marked by different international documents. These documents have been articulated with regard to regulations concerning vulnerable populations. One of the first documents to provide an approach to the concept in this specific area is the Belmont Report (1979)⁵. This text focuses on the respect for persons, on beneficence, and on justice in the context of medical research, and the issue of vulnerability is argued with regard to each principle. Another text, the Declaration of Helsinki⁶, mentioned vulnerability in its fifth revision in 2000, but only in the introduction to principles (Art. 8):

‘Medical research is subject to ethical standards that promote respect for all human beings and protect their health and rights. Some research populations are vulnerable and need special protection. The particular needs of the economically and medically disadvantaged must be recognized. Special attention is also required for those who cannot give or refuse consent for themselves, for those who may be subject to giving consent under duress, for those who will not benefit personally from the research and for those for whom the research is combined with care’.

Five years after this revision of the Declaration of Helsinki, another indispensable document was developed: the Universal Declaration on Bioethics and Human Rights⁷. This text contains the first statement of bioethical principles accepted by governments. Article 8, “Respect for Human Vulnerability and Personal Integrity,” is as follows:

⁵ Today the Belmont Report is considered to be an essential reference for researchers and groups working with human beings in research for ensuring that projects comply with ethical regulations. The report explains and unifies the basic ethical principles of different reports of the National Commission and the regulations that incorporate its recommendations. The three fundamental ethical principles that permit the use of human subjects in research are respect for people, beneficence, and justice.

⁶ The Helsinki Declaration is a document embodying a number of ethical principles related to human experimentation, developed for the medical community by the World Medical Association (WMA). It is widely regarded as the main document on the ethics of human research. It is updated regularly. There is an extended analysis concerning the evolution of the Declaration of Helsinki in Carlson, Boyd, and Webb (2004).

⁷ The Universal Declaration on Bioethics and Human Rights adopted by the United Nations Educational, Scientific, and Cultural Organisation (UNESCO) on October 19, 2005, is important in seeking global minimal standards in biomedical research and clinical practice. It aims to provide a comprehensive framework of principles that should guide biomedical activities to ensure that they conform to international human rights law. It is also interesting to see Evans (2012, pp. 170-173).

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'In applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected.'

Following the recommendations in all these documents, among others, we can find some of the most significant implications of the vulnerability concept with regard to biomedical research⁸:

- (a) An additional justification for involving vulnerable people in research is needed. Although involving vulnerable people in research is a useful tool for trying to avoid exploitation or recruitment without consent, people who are included under the term “vulnerable populations” may then not benefit from progress in research. As a result, these populations may be subject to some forms of discrimination, as the access to scientific advances could be limited for them. For example, pregnant women are excluded systematically from research, when it could be possible to ask them if they want to participate in clinical research or not.
- (b) The second implication is that vulnerable populations need extra protection when involved in research. But we have to consider that all the participants in research need to be protected, regardless of whether they are considered more vulnerable. Due to risks associated with research, it is extremely important to balance the risks and benefits for participants, independently of their potentially greater vulnerability.
- (c) The third implication is that researchers should be more responsive to the needs of vulnerable populations—especially with regard to informed consent—and must be alert to ways of avoiding exploitation. The main problem is that avoiding exploitation leads researchers to limit their consideration of vulnerability to the issue of informed consent and thus to not take into consideration other aspects related to vulnerability.

⁸ To implement this analysis, see Ten Have (2016). In particular, chapter 3 ‘Vulnerability in the context of healthcare and bioethics’ is devoted specifically to showing the importance and impact of the main international documents.

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Undoubtedly, reflections concerning vulnerable groups have been very useful in alerting researchers to the damages associated with biomedical research if the minimal protection principles are not respected, especially under circumstances such as the incapability to give informed consent, or in situations of potential exploitation⁹. The use of minimal protection principles for vulnerable populations exerts a widespread influence of understanding within bioethics. However, there are several criticisms that have been made in recent years with regard to the population-based approach to vulnerability in bioethics.

One of the main criticisms of the concept of vulnerability in research ethics is that the term itself is nonsense because of the “hyper condition of vulnerability.” As Levine et al. (2004, 46-47) argue, it is a concept that is both too broad and too narrow at the same time. On the one hand, it is too broad because there are so many vulnerable groups that it results in a paradox: the term loses its sense of special protection for some populations. The list of vulnerable groups is so extensive that ultimately each of us belongs to such a group (for example, women, the elderly, and so on). On the other hand, the concept is too narrow because it focuses on difficulties only with regard to

⁹ The minimal principles of protection are set out in the Declaration of Helsinki as follows: “a) To promote and safeguard the health, well-being and rights of patients, including those who are involved in medical research; b) Medical progress is based on research that ultimately must include studies involving human subjects; c) The primary purpose of medical research involving human subjects is to understand the causes, development and effects of diseases and improve preventive, diagnostic and therapeutic interventions (methods, procedures and treatments); d) Medical research is subject to ethical standards that promote and ensure respect for all human subjects and protect their health and rights; e) While the primary purpose of medical research is to generate new knowledge, this goal can never take precedence over the rights and interests of individual research subjects; f) It is the duty of physicians who are involved in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects; g) Physicians must consider the ethical, legal and regulatory norms and standards for research involving human subjects in their own countries as well as applicable international norms and standards. No national or international ethical, legal or regulatory requirement should reduce or eliminate any of the protections for research subjects set forth in this Declaration; h) Medical research should be conducted in a manner that minimizes possible harm to the environment; i) Medical research involving human subjects must be conducted only by individuals with the appropriate ethics and scientific education, training and qualifications. Research on patients or healthy volunteers requires the supervision of a competent and appropriately qualified physician or other health care professional; j) Groups that are underrepresented in medical research should be provided appropriate access to participation in research; k) Physicians who combine medical research with medical care should involve their patients in research only to the extent that this is justified by its potential preventive, diagnostic or therapeutic value and if the physician has good reason to believe that participation in the research study will not adversely affect the health of the patients who serve as research subjects; l) Appropriate compensation and treatment for subjects who are harmed as a result of participating in research must be ensured.”

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consent. Attitudes and politics regarding protection are directed almost exclusively towards improving the informed-consent process, which is insufficient to ensure proper protection of vulnerable people. This implies a restrictive conception of vulnerability, which neglects many other factors that are decisive in understanding how a person is located in a position of greater vulnerability, such as in poverty and precarious living conditions. By reducing vulnerability to informed consent, there can be many situations not detected by researchers in which people are vulnerable, thus meaning that these people cannot be adequately protected.

Another criticism regarding the concept is related to “labelling.” The categorization of people into vulnerable groups results in a form of labelling, which can lead to discrimination and stereotyping, as such groups seem to be established as something fixed and static. After an intensive analysis of the principal arguments against the use of the concept of vulnerability within the field of biomedical research, Florencia Luna (2008) addresses the problem of labelling in biomedical research ethics using the metaphor of layers. She points out that there are many potential sources of vulnerability, and each of these constitutes a different, overlapping layer. This metaphor of layers presents a contextual and variable concept of vulnerability, moving away from the fixed and static view. Luna (2008) proposes that if we think about the idea of layers, we can understand that there may be different situations in which sources of vulnerability overlap, all operating on the same person. We all have some unavoidable layers of vulnerability because of our finite condition, arising from the fragility of being human, but if we add different circumstances and conditions, we add more layers. In this way, it is also easier to identify the different elements that locate a person in a situation of special vulnerability; once these elements have been identified, it will be possible to try to modify these circumstances.

In addition, another problem that has been pointed out is that, while protection measures are established based on the analysis of vulnerability, the door is then open to unjustified versions of paternalism. Protections for the vulnerable carry the danger of being paternalistic. There is a tendency in all the approaches that Rogers (2014) analyzes (research-ethics, clinical-ethics, and public-health approaches) to engage in labelling, with its associated risks of discrimination and paternalism. Moreover, there is no complete description of the responsibilities owed to the vulnerable in terms of protection, remedies, compensation, benefits, or aid. From her perspective,

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this points to the need for a better explanation of the theoretical connections between vulnerability and justice. In this regard, the notion of vulnerable populations can undermine individual autonomy and result in potential damage as a consequence of such unjustified forms of paternalism. Mackenzie (2014) also considers that, to counter the risks of objectionable paternalism, we should respond to vulnerability through fostering the value of autonomy.

Finally, from my perspective, the main problem presented by the group-based approach is that it centres all reflection concerning vulnerability in bioethics on research ethics and public health, and restricts reflection only to the concern for vulnerable groups. The consequence is a too-narrow focus in bioethics, which is why this field needs a broader reflection on vulnerability. In addition, as Martha Fineman (2012) has highlighted,

‘...the designation of vulnerable (inferior) populations reinforces and valorizes the ideal liberal subject, who is positioned as the polar opposite of the vulnerable population. This liberal subject is thus constructed as invulnerable, or at least differently vulnerable, and represents the desirable and achievable ideals of autonomy, independence, and self-sufficiency’ (p. 86).

In this regard, the entire discourse of mainstream bioethics has been built around this ideal of autonomy within the liberal perspective. The main problem is the dominance of the rhetoric of the liberal subject, which perpetuates the myth of the independence, self-sufficiency, and autonomy of the subject also within bioethics. Focusing on the vulnerability concept as a core feature in bioethics is a challenge in terms of reversing this dominance of the ‘autonomy myth’¹⁰.

HOW TO UNDERSTAND VULNERABILITY WITHIN BIOETHICS?

Henk Ten Have’s (2016) analysis underlines some of the problems that have to be addressed with regard to the concept of vulnerability within bioethics. First, the fact that there are different kinds of vulnerability is widely accepted within the field. Lange et al. (2013) highlight the fact that

¹⁰ These ideas are also expressed in Luna and Vanderpoel (2013). In this paper, the authors challenge the traditional way of thinking about vulnerabilities in the research field and they develop a layered account of vulnerability. They show the relevance and applicability of an approach to vulnerability that is more nuanced and respectful towards persons.

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the treatment of vulnerability offered by international documents relies on enumeration of vulnerable groups, rather than an analysis of the features that make such groups vulnerable. This is one of the reasons why scholars try to develop a typology of sources of vulnerability. These taxonomies can be understood as an attempt to showing how distinct sources, generate distinct obligations (Lange et al. 2013).

One of the first taxonomies on vulnerability in research ethics was developed by Kipnis (2001, 2003). Based on the establishment of standards can provide researchers with useful guidelines for the responsible development of protocols, he developed six categories of vulnerability. Each of the six types of vulnerability is distinguished by a positive response to a single question (Kipnis, 2001):

-Cognitive vulnerability: Does the individual have the capacity to deliberate and decide whether or not to participate in the study?

-Juridical vulnerability: Is the individual responsible before the authority of others who may have an independent interest in that participation?

-Deferential vulnerability: Is the individual given to patterns of deferent behavior that may mask an underlying lack of will to participate?

-Medical vulnerability: Has the individual been selected, in part, because he or she has a serious health-related condition for which there are no satisfactory remedies?

-Allocation vulnerability: Does the individual seriously lack important social assets that will be provided as a consequence of its participation in the research?

-Infrastructural vulnerability: Does the political, organizational, economic and social context of the research environment possess the integrity and resources necessary to manage the study?

In addition, he turned this taxonomy (Kipnis, 2003) into seven categories when focusing on the varieties of pediatric vulnerability: incapacitacional, juridic, deferential, social, situational, medical and allocational.

In a broader sense, beyond research ethics, some reflections on vulnerability create taxonomies of the multiple forms of vulnerability, such as the contribution of Rogers, Mackenzie, and Dodds (2012, pp. 24-25). These authors structure a distinctive taxonomy of different forms of vulnerability, as well as different states of it. Within their taxonomy of vulnerability, first, there is

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inherent vulnerability, which is intrinsic to human condition. For them, inherent vulnerability is related to our corporeality and our dependence on others. This vulnerability is ever-present, but may vary in degree, depending on factors, such as age, gender, health status, and disability. Second, situational vulnerability refers to features that depend on the specific context of the person. Situational vulnerability is context specific and it is affected by the personal, social, political, economic, and environmental circumstances of individuals or social groups. This kind of vulnerability refers to a sociological notion of the term, since, as Mackenzie et al. emphasize, it refers to how the vulnerability that is initiated—for instance, by an earthquake—is mediated by a social context. They identify another kind of vulnerability—pathogenic—which is generated by a variety of sources, including morally dysfunctional or abusive interpersonal and social relationships and socio-political oppression. Pathogenic vulnerability occurs as a consequence of social-policy inventions that attempt to reduce some other kind of vulnerability, but which have the paradoxical effect of increasing overall vulnerability. Pathogenic vulnerability is generated by social relationships characterized by disrespect and prejudice. Pathogenic vulnerability is more clearly political than other kinds, because it is related to the disparities of power between those who design the rules, for instance, of “protecting the vulnerable humans in a research,” and those who are subjected to those rules. The most interesting aspect of this kind of vulnerability is that it emerges when a response aimed at ameliorating vulnerability in fact generates a new vulnerability and possibly also exacerbates existing ones. In my view, this kind of vulnerability shows how the notion of vulnerable groups or populations could be potentially dangerous, because it can contribute to creating new forms of vulnerability in the attempt to minimize it. This point is especially relevant from the institutional perspective, since, the majority of the time; vulnerability emerges precisely because of the institutional framework.

In addition to this taxonomy of vulnerability, the authors distinguish between different states of vulnerability: dispositional and occurrent. The distinction between dispositional and occurrent refers to states of potential or actual vulnerability, and it serves to separate vulnerabilities that are not yet or not likely to become sources of harm from those that require immediate action to limit harm. These two states of vulnerability will also require different actions to ameliorate vulnerability, depending on whether it is dispositional or occurrent. Through this distinction, the

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authors try to clarify the opacity that usually accompanies the perspectives on vulnerability in bioethics.

However, while taxonomies can provide conceptual clarity and make us think that reality can be organized, as Florencia Luna (2015) remarks, the problem is that not all phenomena are understandable in the same way, and this is the case of vulnerability. Luna (2015) argues three reasons why the taxonomy proposed by Mackenzie, Rogers and Dodds (2012)¹¹. The first problem she find is that there is no clear taxonomy that allows us to locate each layer of vulnerability in a different category, because the categories can overlap. This makes it very difficult to use the taxonomy. The second reason she argues is the difference among the category of pathogenic vulnerability and the other two categories. “Pathogenic is a subtype of the situational category, thus it does not have the same status as the other two “(Luna, 2015, p 3). In addition, she remarks, it is not clear that only situational sources can be intermittent or lasting, because inherent sources of vulnerability may persist for a period of time. Taxonomies presuppose the existence of a clear order, but a clear order is not really done. Finally, Luna maintain that it is not clear how the duties are related to the sources of vulnerability following this taxonomy. Luna argues that the metaphor of the cascade effect is a useful way to characterize some layers of vulnerabilities (Luna 2015).

Other authors consider it better to opt for a conceptual clarification, such as the distinction proposed by Kottow (2003, pp. 470-471) between susceptibility and vulnerability. He recognizes that vulnerability is a common feature of human beings. When individuals become biologically weak or diseased, they are susceptible to increasing their predisposition to additional harm and require social actions to treat their situation. Thus, he considers the problem to be that mislabelling people as vulnerable—a characteristic that all humans share—leads researchers to avoid registering the deprivation that these people suffer and to neglect their ethical obligation to offer them real help. The distinction between vulnerability and susceptibility marks the difference between being intact but fragile (vulnerable) and being injured and predisposed to additional harm (susceptible).

In spite of the potential of these different contributions to clarify the concept of vulnerability, globally the main and most-accepted distinction is expressed as the distinction between universal

¹¹ Florencia Luna refers this taxonomy as a response on Lange, M.M, Rogers, W. and Dodds, S. (2013) Vulnerability in research ethics: a way forward, *Bioethics*, (6), 330-340. In this article, the authors shown the taxonomy they developed in Mackenzie, Rogers and Dodds (2012).

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and particular (or situational) vulnerability. The notion of particular vulnerability is assumed in relation to vulnerable groups. While broadly accepted, there are also many criticisms of the classification of individuals in vulnerable groups, especially because such classification is considered potentially harmful in that it can lead to stigmatization for persons included in some group, as I have considered.

On the other hand, there are two main reasons why it is difficult to accept the universal condition of vulnerability within the mainstream discourse of bioethics. Firstly, because it has been argued as no pragmatic approach, and secondly, because it is difficult to reconcile this conception with the liberal autonomy principle, which is at the centre of mainstream bioethics.

Alison Cole (2016, p 262) argues the project of re-signifying vulnerability by emphasizing shared universality and amplifying its generative capacity, could dilute perceptions of inequality and confuse important distinctions among particular vulnerabilities. She considers vulnerability scholars have yet to elaborate the path from acknowledging constitutive vulnerability to addressing concrete injustices. In addition, she highlights that “promoting an exceedingly expansive conception of vulnerability and, concurrently, rigidly differentiating its numerous manifestations, seems contradictory” (Cole, 2016, p 266). On her analyses, she considers that Fineman’s vulnerability theory reflects a ruse of liberalism attached to the vulnerable/invulnerable binary, since for Fineman, one of the most destructive effect of the segmenting of a general population in a way in which only some of them are designated as vulnerable is that this segmentation suggests that the rest of us are not vulnerable. Consequently, for Cole, in Fineman the concept of vulnerability remains too obscure the needs of specific groups and individuals, and this fact undermines the purpose of develop a conceptual frame to understand and challenge systemic inequalities (Cole, 2016, p 267).

My purpose is to demonstrate how this universal approach to vulnerability concept, particularly in the core of Fineman’s vulnerability theory, solve these apparently contradictions in the way how all humans experience vulnerability. For this purpose, I focus my research in the context of Bioethics. To gain a better understanding of vulnerability as a philosophical concept and the important role of the ethics of vulnerability within bioethics, I defend the importance of a notion of universal vulnerability in bioethics. To this end, I start showing some of the universal approach on

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the concept of vulnerability that we find in Levinas and Butler. I consider some of the key elements developed by this two authors can be linked to Fineman's vulnerability theory.

UNIVERSAL VULNERABILITY AS A CRITICAL CONCEPT

All human beings are involved in networks of relationships; our own vulnerability, fragility, and dependence on others lead us to develop links with others (Guerra Palmero 2009, p. 81). Universal vulnerability refers to our own and shared fragility and dependence as an ontological condition of our humanity.

In this part of the chapter, first I analyze some of the theories from which it is possible to develop an ethics of vulnerability for bioethics. To address this issue, I summarize the reflection that we find in the work of Emmanuel Levinas¹² and Judith Butler. After discuss some of the main ideas of these authors that contribute to enrich the current bioethical debate, I argue that in order to develop an ethics of vulnerability in bioethics it is required a robust framework that can be applied into the bioethical context. Following this end, I focus on the work of Martha Fineman. My argument is that her theory of vulnerability is one of the most important contributions in developing an ethics of vulnerability into the field of bioethics.

It can be considered that the most radical approach to universal vulnerability is Emmanuel Levinas' philosophy. His philosophy of alterity inverts the roles of the self and others, putting 'the Other' in first position in the discourse. Levinas' philosophy introduced a new way of thinking completely different from the ethics of subjectivity. For Levinas (1972), philosophy has insisted on neutralizing alterity. However, in his ethics of alterity, the Other appears explicitly and openly. In Levinas' thought, the Other questions my position (that of the self). As the Other comes from the outside, from its transcendence, it opens up for me an exit without return from the self to the other (Levinas, 1977). This otherness shifts the identity of its role to a higher normative category granted by classical philosophy. Levinas' philosophy has the virtue of removing from otherness its marginalization and oppression in relation to the philosophy of the identity. In traditional philosophy, the self has been affirmed by denying the other in alterity, reducing him/her to identification with

¹² In chapter five, I will develop broadly the concept of asymmetrical responsibility that arises from Levinas' Philosophy.

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the self. In Levinas' view, the negation of the self, its subordination to the Other, is a way of confronting the dominant ideology of subjectivity that starts from the self to return to the self-consciousness¹³. In Levinas' philosophy, the self acquires awareness in *the face-to-face encounter* with another human being who is asking for a response. It is the vulnerability expressed in the face of the other that generates ethical responsibility. Moreover, this is not the action of an autonomous subject: it happens despite oneself. In addition, this is a kind of answer that the self cannot omit. In Levinas' ethics the encounter with the 'vulnerable Other' is the origin of ethics. It is not an epistemological relationship, but an ethical one: the Other does not extend my knowledge, but makes me responsible for him.

The philosopher Judith Butler, a follower of Levinas' work, emphasizes the central thesis that life is precarious due to the inevitable dependence on others. We cannot avoid the fact that we, as humans, are necessarily related to others: we are always exposed to others. Butler insists on the recognition of a common vulnerability that starts with the idea of our corporeality. A vulnerable being is one who can be hurt and therefore is not able to survive without others' attention and hospitality. Butler's conception of the subject is a being thrown to the 'other' through language, gaze, social norms, etc. She considers common human vulnerability, but for her this does not imply a common notion of the human, i.e. vulnerability as a human condition. This vulnerability emerges with life itself and thus precedes the formation of the self: it is a precondition. She makes a claim for a new ontology (Ten Have, 2016, p 102):

"I want to argue that if we are to make broader social and political claims about rights of protection and entitlements to persistence and flourishing, we will first have to be supported by a new bodily ontology, one that implies the rethinking of precariousness, vulnerability, insurability, interdependency, exposure, bodily persistence, desire, work and the claims of language and social belonging" (Butler, 2009, p. 2).

¹³ Ulysses represents for Levinas the circle as an expression of the perfect movement from the Greeks to Hegel, a circle that begins and closes on the self. Faced with this image of Western philosophy, Levinas seeks to break the ontological circle that has dominated the whole history of Western thought and propose a complete exit from the self without return: from the self to the Other that never returns to the self. Levinas' thought is situated in the position of otherness, which he identifies with the position of the victims, the oppressed people.

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However, she considers that this does not imply a common notion of the human condition. For her, humanity is not a state of being, but is rather one of ‘becoming’. For her, an approach to vulnerability is indispensable to develop an ethics of non-violence, but she does not want to consider this conception exactly as a new form of humanism:

“By insisting on a common corporeal vulnerability, I may seem to be posting a new basis for humanism. That might be true, but I am prone to consider this differently. (...) If vulnerability is one precondition for humanization, and humanization takes place differently through variable norms of recognition, then it follows the vulnerability is fundamentally dependent on existing norms of recognition if it is to be attributed to any human subject” (Butler, 2006, pp. 42–43).

From Butler’s perspective, vulnerability is not distributed in the same way: some people are more vulnerable than others. Vulnerability is accentuated under certain social and political conditions, especially in forms of life subjected to violence and with limited resources for self-defence (Butler, 2006, p. 29). For her, to recover the sense of human vulnerability implies assuming what she terms collective responsibility for the physical lives of others with regard to the different forms of the distribution of physical vulnerability worldwide. This responsibility should focus not only on the value of life itself, but on the social conditions that sustain life. Social obligations arise to minimize precariousness and vulnerability and their differential distribution. The obligation to conserve life emerges from being dependent on what is outside ourselves: on others, on institutions and on sustained and sustainable environments. Thus, in Butler’s view, our obligations are in regard to the conditions that make life possible: our obligations arise from the idea that there can be no sustaining of life without these supporting conditions (Butler, 2009, p. 46). As she argues, ‘the question is not whether a given being is living or not, nor whether the being in question has the status of a “person”; it is, rather, whether the social conditions of persistence and flourishing are or are not possible’ (Butler, 2009, p. 20). The lack of social and economic support networks is what

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makes populations more vulnerable to harm, violence and death. Our ethical and political obligations are to protect life from these precarious conditions¹⁴.

Despite the fact that there are many ethical contributions in these two authors that can be applied to the field of bioethics¹⁵, by themselves, these approaches do not allow us to fully articulate an ethics of vulnerability to be applicable to the field of bioethics. The reason why I deeply analyze Martha Fineman's theory of vulnerability is because the universal view of vulnerability and the theory she developed around this premise, actually has a normative power, interesting for bioethics and research ethics.

Martha Fineman has developed one of the most influential theories of vulnerability in recent years. She has emphasized that vulnerability is universal and constant: it is a human condition. From her perspective, "the concept of vulnerability reflects the fact that we all are born, live, and die within a fragile materiality that renders all of us constantly susceptible to destructive external forces and internal disintegration" (Fineman 2012, p. 71). Vulnerability defines what it is to be human, and this conception reminds us of our corporeality and fragility. This feature is common to all human beings, and it is because of the universality involved in the vulnerability concept that we must consider it as *the* human condition, on the basis of which it is possible to articulate a series of social-protection and state responsibilities

In *The Autonomy Myth*, Fineman (2004) thoroughly develops a theory of dependency¹⁶.

¹⁴ Butler's goal in *Precarious Life* is to refrain from an aggressive, vengeful and violent response when we have hurt ourselves and become aware of our own vulnerability when one's vulnerability has been exposed. Butler's reflection emerges in the context after September 11. The wars declared by the United States to both Iraq and Afghanistan are presented as an unethical response to the "wound" that has been inflicted on them, an incorrect way of dealing with the damage and pain, to face the realization of our own precariousness. Her thinking is anchored in a psychoanalytic vision of our human responses to violence, the loss (of a loved one) and vulnerability. Butler's second objective is also to highlight the differentiated value we usually attribute to "our dead" (the dead we mourn and commemorate) in the face of the value we attribute to Muslim bodies (the dead we have dehumanized and abhor).

¹⁵ As an example the concept of asymmetric responsibility that will be developed in chapter five.

¹⁶ See Fineman (2015). The myth of autonomy has produced institutional arrangements that do not take into account the dependency inherent in the human condition. As already noted, Fineman points out that all humans are dependent at some point in their lives. This "inevitable dependence," in Fineman's terms, can be found in children, often in old age, and at other stages in most people's lives as a result of physical or mental illness. The inevitable dependence creates the need for care. Fineman stresses that the consequence of this is a secondary form of dependency experienced by caregivers. Due to this, the state has a responsibility to meet dependency needs and to support caretaking.

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She argues that political rhetoric and popular ideology in the United States have become so fixated on the myth that citizens should be autonomous that they fail to recognize the inevitability and normality of dependency. Fineman argues against the prevailing autonomy myth, because dependency is an unavoidable feature of any society and it is not a feature that is taken into account from the liberal perspective. She later expanded on the work that she did in theorizing dependency, focusing on the concept of vulnerability (Fineman 2010, p. 255):

“The concept has evolved from those early articulations, and I now think it has some significant differences as an approach, particularly in that a focus on vulnerability is decidedly focused on exploring the nature of the human part Vulnerability is posited as the characteristic that positions us in relation to each other as human beings and also suggests a relationship of responsibility between state and individual. The nature of human vulnerability forms the basis for a claim that the state must be more responsive to that vulnerability”.

By emphasizing the vulnerability concept as *the* human condition, it takes on a critical dimension as it calls into question the dominant model of the liberal subject. It challenges this dominant model focused exclusively on autonomy and highlights the shortcomings of the model. The autonomous and independent subject is a fiction and through it inequalities are perpetuated. The focus on vulnerability leads us to think about our individual and collection obligations, in order to provide assistance.

Vulnerability theory tries to confront the individualistic autonomy model. The image of the subject in vulnerability theory is built in opposition to the image of the autonomous subject of the liberal model in modern philosophy: that sovereign subject (autonomous, rational, etc.) sets aside the corporeality, fragility, and interdependence that form human life. We can understand our humanity in a broader sense only by recognizing our universal vulnerability and interdependence. This view contrasts radically with the liberal view of the autonomous subject and is a criticism of that perspective.

Martha Fineman’s theory also emphasizes the importance of our bodies and of our dependency. In this regard, her way of understanding vulnerability allows a new ethical perspective,

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which is focused on our corporeality. The tradition of Western philosophy has neglected the importance of considering our bodies within discourse and thought. Human vulnerability and dependency have no place, let alone a central place, in philosophical approaches that equate morality with rationality, and moral agency with rational agency. Vulnerability has little to do with our contemporary morality, as it is antithetical to our emphasis on individualism and rationality. As Fineman highlights, only by recognizing our vulnerability can we understand our humanity.

Another important aspect in Fineman's approximation is the fact that vulnerability is not only a negative condition. For Fineman, vulnerability can provide positive or negative results, but it must be first accepted and not ignored. Indeed, recognizing the positive aspects of vulnerability can improve the experiences of people in terms of isolation and exclusion:

"Properly understood in the context of the human condition, vulnerability is also generative. Importantly, our vulnerability presents opportunities for innovation and growth, creativity and fulfilment. It makes us reach out to others, form relationships, and build institutions" (Fineman 2012, p. 96).

The main aspect that Fineman highlights is that recognizing the inevitability of vulnerability will lead to a better understanding of the concept and will redefine our responsibilities as a society, which means that vulnerability also contains positive aspects. We live in deep networks of radical interdependence that the ideology of individualism denies. The ideal of an autonomous and self-transparent being does not foster ethically responsible behaviour. On the contrary, the liberal self, theorized in terms of the prevailing notion of autonomy—an individualistic and narcissistic self—promotes the ethics of violence. It is in this conception of the subject as vulnerable—in opposition to the idea of the sovereign subject, the owner of oneself, conscious and transparent to oneself—that the possibility of responsible and nonviolent ethical practice opens up. Vulnerability challenges the modern illusion of self-sufficiency and allows us to discover and invent life together.

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PARTICULAR VULNERABILITY: SOCIAL AND POLITICAL ASPECTS CONCERNING VULNERABILITY AND VULNERABLE GROUPS PROBLEMS

The various approaches to the concept of vulnerability agree that we all share a common vulnerability, but this common vulnerability is distributed in different ways. Thus, universal vulnerability becomes exacerbated in certain social, political, and other situations. The notion of particular vulnerability implies that we need to discover the mechanisms of this unequal distribution to try to resolve the inequality. Recognizing that inequality is assigned differently can be directed to developing specific social policies.

Fineman emphasizes that vulnerability is a human feature that can be expressed in different ways. Each individual is positioned differently, and vulnerability is dependent on the different positions we occupy in the social space, or on the ways in which we are supported by social institutions. The result is that human beings are not vulnerable in the same way or to the same degree. This can appear to contradict with our anthropological vulnerability, which is a constant in people's lives. But we do not have to consider these two perspectives to be irreconcilable. As Fineman (2010, p. 31) has argued:

“While human vulnerability is universal, constant, and complex, it is also particular. While all human beings stand in a position of constant vulnerability, we are individually positioned differently. We have different forms of embodiment, and also are differently situated within webs of economic and institutional relationships. As a result, our vulnerabilities range in magnitude and potential at the individual level. Vulnerability, therefore, is both universal and particular; it is experienced uniquely by each of us.”

Our individual experiences of vulnerability vary according to the resources we have to deal with it. It is true that, as Fineman remarks, society cannot eradicate our vulnerability, but what it should do is act as a mediator compensating for our different positions through particular programmes, institutions, and structures. In this regard, Fineman has extensively argued that it is

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vulnerability as the human condition that generates the responsibility to provide support. As Ten Have (2016, p. 107) has stressed, based on Fineman's approach, the argument that links vulnerability and responsibility is that the shared human condition generates moral obligations for others. Indeed, these obligations are not the result of voluntary choice or commitment, but arise from vulnerability. While we are all vulnerable, some people are located in a worse position than others in the social space, because of social inequities and their limited access to resources. Thus, it is not enough to provide equal protection to all, because social conditions are not the same for everyone. The degree of dependence involved in vulnerability can vary, so that some people have more needs than others. Indeed, the universality of the concept does not mean that people are homogeneous. Therefore, as a society we have to promote the necessary resources to face inequalities. As Martha Fineman (2008, p. 4-5) remarks:

“The general tendency under a sameness of treatment equality framework is to focus on individuals and individual actions. The task under this approach is to identify the victims and the perpetrators of discrimination, as well as to define what were the prohibited activities, the individual injury, and the specific intent involved in each occurrence. Unless they are tied to individuals and discrimination, systemic aspects of existing societal arrangements are left out of the picture. It is as though existing material, cultural, and social imbalances are the product of natural forces and beyond the ability of the law to rectify. While it may be beyond the will of the law to alter, existing inequalities certainly are not natural. Inequalities are produced and reproduced by society and its institutions. Because neither inequalities nor the systems that produce them are inevitable, they can also be objects of reform”.

In the bioethics field, as I have shown, the most extensive view of vulnerability is related to vulnerable groups. However, the use of the designation vulnerable also results in their stigmatization, since the term vulnerable population has an air of victimhood, deprivation, dependency, or pathology attached to it (Fineman, 2010, p 27, 28). Consequently, should we avoid using this categorization in bioethics? Even more, should we avoid using this categorization in bioethics? Is that possible? I would like to analyse the most complex aspects concerning the

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possibility of avoiding this designation within the bioethics field and the advantages and disadvantages in such a change of perspective. Some of the advantages of the use of the terminology of vulnerable groups in bioethics are as follows:

1. Researchers must take into account the fact that these people may have certain characteristics that require more protection so that they are not damaged due to their particular circumstances. An example of this is the capability of a soldier to consent when part of a hierarchical structure, which may influence the decision to participate in an investigation.
2. Similar resources can be offered to people who are in similar situations of vulnerability—that is, when their circumstances may require similar responses from institutions. This can lead to the implementation of more operational measures, since, through this categorization, the labelling of people within groups who have similar needs, one can try to provide some formalized or standardized resources.

However, there are two main problems posed by the concept of vulnerable groups. First, there is the risk of stigmatization if we carry out labelling: people can be trapped inside categories that correspond to vulnerable groups. Hence, an association can be made between the categorization of vulnerable groups and victimization, need, loss, lack, etc. In this regard, we must also consider the way in which people viewed as belonging to vulnerable populations within bioethics perceive themselves as belonging to these groups or as being distant from them. The second problem is that categorization and labelling can lead to paternalistic forms of response to vulnerability. A mode of protection of vulnerable people centred on forms of paternalism can be highly harmful because it denies people the capability to decide for themselves, delegating decision-making about what is better or worse for the people involved to others and discounting their views (Rogers, Mackenzie, and Dodds 2012).

Vulnerability theory understands that the designation of universal and constant vulnerability implicitly means that vulnerability should not be used as a variable in degree and comparative concept. One of the main points highlighted by Fineman is that no individual or group should be

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considered more or less vulnerable, uniquely vulnerable, or specifically or especially vulnerable. This aspect is very important: she rejects the categorization of vulnerable groups or populations because this is related directly to stigmatization and victimhood and is needless: “This targeted group approach to the idea of vulnerability ignores its universality and inappropriately constructs relationships of difference and distance between individuals and groups within society” (Fineman 2012, p. 85). What vulnerability theory proposes is that instead of using this designation:

“...we can think about spaces, places, and positions or relationships as indicators of the proximity of, exposure to, or probability for vulnerability to be manifested or realized in the form of dependency. By the same token, we can think of these same spaces, places, and positions as sites for the production of resilience – these are or should be thought of as sites of state responsibility”¹⁷.

Consequently, bioethics has the huge challenge of trying to avoid this denomination. In this regard, vulnerability theory focuses on the inequality of resilience because it directs the attention to society and social institutions. This means that we don’t have to focus on the characteristics of individuals as vulnerable: human beings do not become more or less vulnerable because they have certain features or characteristics, or because they are at a particular stage of their lives, but they do experience the world with different levels of resilience¹⁸. Resilience is the remedy for vulnerability, even if it is an incomplete remedy: “although nothing can completely mitigate vulnerability, resilience is what provides an individual with the means and ability to recover from harm, setbacks, and the misfortunes that affect her or his life” (Fineman, 2015, p 622). It is important to point out that nobody is born resistant. On the contrary, resilience occurs within and through the institutions and relationships. That is why within vulnerability theory, the concept of vulnerability as

¹⁷ The myth of autonomy has produced institutional arrangements that do not take into account the dependency inherent in the human condition. As already note, Fineman points out that all humans are dependent at some point in their lives. This ‘inevitable dependence’, in Fineman’s terms, can be found in children, often in old age and at other stages in most people’s lives as a result of physical or mental illness. The inevitable dependence creates the need for care. Fineman stresses that the consequence of this is a secondary form of dependency experienced by caregivers. Due to this, the state has a responsibility to meet dependency needs and to support caretaking. Fineman, M. Understanding vulnerability theory. See <https://newlegalrealism.wordpress.com/2015/11/30/fineman-on-vulnerability-and-law/>.

¹⁸ In the core of vulnerability theory, assets or resources can take five forms: physical, human, social, ecological or environmental, and existential. For a broader definition of resilience in the context of vulnerability theory, see Fineman, 2015. In addition, in last chapter I develop broadly this concept.

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our shared condition lead us to focusing on the state and institutional responsibility on providing resources for increase or foster resilience.

In addition, one of the most important problems that arise when we use vulnerable groups as a scope of reflection is the fact that this designation can imply an inevitable sense of paternalism. Luna's metaphor of layers is useful for overcoming stigmatization, as it understands particular vulnerability as something flexible, dynamic, and nonstatic. Fineman's proposal that we speak about spaces that generate greater vulnerability, rather than groups, is also useful in trying to avoid the stigmatization associated with the categorization of vulnerable groups. In addition, vulnerability theory accentuates the importance of the role of the state and institutions in trying to improve people's support. Fineman suggests that vulnerability has a creative dimension, and she understands that it can lead to the generation of resilience as a way of overcoming vulnerability.

From my perspective, the only way of avoiding the paternalism that can be associated with interventions made by the state and institutions to try to protect people is to actively reject it. This is why it is necessary to rethink a new way of understanding autonomy as a concept of relational autonomy. Of course, it is true that it is necessary to cultivate resilience. But even when we are working with resilient people in an attempt to provide protection and assistance measures, if we do not focus on actively avoiding paternalism by fostering autonomy rearticulated in a relational sense, actions undertaken for protection may be paternalistic. As Mackenzie and Stoljar (2000) highlight, there is no single way to understand the term "relational autonomy"; it is more like an "umbrella term" that contains different points of view. Following the analysis of Jennifer Nedelsky (1999, 2011), and bringing the concept of relational autonomy into bioethics and the clinical context, we have to consider how this concept can help us to face unjustified paternalism. Firstly, autonomy must be understood as a capability. This means that autonomy is not a "natural" characteristic of a human being. It is a fundamental element of human existence, but it needs to be developed. More specifically, in the field of medical care, it is really important to realize that if the conditions of the possibility for autonomy are not given, the principle of autonomy will be only a myth or an illusion. In this way, we can conclude that autonomy and vulnerability are not incompatible. Far from it—these two terms are strongly related. We cannot think about vulnerability without considering

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autonomy, and, vice versa, we cannot think about autonomy without considering the inevitable and universal vulnerability that we have¹⁹.

SOME CRITICISMS OF VULNERABILITY THEORY

Having analyzed the general conceptual framework on the basis of which it is possible to develop the concept of vulnerability in bioethics, I now wish to highlight what is in my view the basis for an ethics of vulnerability in bioethics. Not only has Fineman's theory of vulnerability had a very significant impact, but it is also indispensable. I would like to summarize briefly the main arguments developed by Fineman and also some of the criticisms of this theory. In brief, the three main arguments in Fineman's vulnerability theory are as follows:

- 1) Vulnerability is *the* universal and inevitable condition of our embodied humanity. Vulnerability is a constant feature of the human condition, which carries with it the imminent or ever-present possibility of harm: "understood as a state of constant possibility of harm, vulnerability cannot be hidden" (Fineman 2008, p. 11). Making vulnerability central in an analysis of equality leads us to redirect focus onto the societal institutions that are created in response to individual vulnerability.
- 2) In addition, vulnerability is a constant in the human lifetime, but it is also context specific, being dependent on social and economic circumstances. Thus, it is experienced differently by each individual, but it is resilience what varies in degrees. At the same time, we don't born with resilience, rather it is accumulative depending on the social institutions and relationships that provide resources over the life course.
- 3) Fineman approaches the subject of vulnerability by focusing on the conception of state responsibility. While the rhetoric of autonomy supports a non-interventionist state, within the

¹⁹ In chapter three, I analyze broadly the concept of Relational autonomy. In addition, and for a broader analyzes, I have developed the concept of relational autonomy in Delgado, J. (2012) La autonomía relacional, un nuevo enfoque para la Bioética, Trabajo fin de master, Facultad de Filosofía, UNED.

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vulnerability-theory approach the role of state institutions is to provide protection from the vicissitudes of fortune, “collectively forming systems that play an important role in reducing, alleviating and compensating for vulnerability” (Fineman 2010, p. 269). In fact, the ultimate objective of a vulnerability analysis is to argue that the state must be more responsive to, and responsible for, vulnerability (Fineman, 2008, p 13). Such systems cannot make us invulnerable, but they do provide us with resources that promote resilience.

In Fineman’s view, “vulnerability raises new issues, poses different questions, and opens up new avenues for critical exploration.” (2008, p. 9) I strongly believe in the potential of the concept of vulnerability to help examine new problems and develop new solutions to the principal issues in the bioethics field. However, before I look more closely at the main implications of vulnerability theory for bioethics, it is necessary to analyze the main criticisms that have been made with regard to Fineman’s theory in relation to this field²⁰.

Catriona Mackenzie (2014) has developed a taxonomy of vulnerability and has extensively analyzed the concept of vulnerability in relation to bioethics. She argues against the three main proposals of Fineman’s theory. Although she considers vulnerability theory to be a good approach and to have many possibilities for development, she distances herself from Fineman’s theory. Her main criticisms are as follows.

First, in Fineman’s analysis of vulnerability the ontological conception is overly salient. For Mackenzie (2014, pp. 37-38), Fineman gives too much importance to the ontological vulnerability emanating from our own corporeality. Although Mackenzie acknowledges that Fineman’s theory includes the different ways in which people experience vulnerability based on their resources, Fineman overemphasizes universal vulnerability. The problem from Mackenzie’s viewpoint is that this attitude does not pay much attention to the social, economic, or political structures that generate greater vulnerability, because in Fineman’s approach vulnerability is a constant.

From my perspective, the emphasis on recognizing ontological vulnerability does not presuppose a deficit in the way of understanding how social and political conditions clearly affect people’s needs. “Undeniably universal, human vulnerability is also particular: it is experienced

²⁰ There is a broad literature of scholars criticizing vulnerability theory of Fineman. In this chapter, I focus on Mackenzie’s criticism because in her analyzes is collected the majority of arguments exposes by other authors. For a broad analyzes on these criticisms, see Straehle (2017) and Cole (2016).

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uniquely by each of us and this experience is greatly influenced by the quality and quantity of resources we possess or can command” (Fineman, 2008, p 10). Indeed, I consider an emphasis on our shared vulnerability a fundamental ethical concept and a normative tool necessary for dealing with dominant discourses that have not taken into account this inherent characteristic of the human condition. In bioethics, the approach to vulnerability as universal concept is fundamental for developing health professional-patient relationships that take into account all the dimensions of the subject, particularly when that subject has to deal with illness. It is also important for political developments concerning public health because the approach to vulnerability is entirely different from the approach to autonomy and the individual responsibilities derived from them. In addition, as I have shown in the previous section, there is no contradiction between the recognition of ontological vulnerability and a close attention to particular vulnerability²¹ in Fineman’s theory. As Fineman (2008, p. 10) points out:

“Because we are positioned differently within a web of economic and institutional relationships, our vulnerabilities range in magnitude and potential at the individual level. Undeniably universal, human vulnerability is also particular: it is experienced uniquely by each of us and this experience is greatly influenced by the quality and quantity of resources we possess or can command”.

The second argument made by Mackenzie concerns the fusion of autonomy with the liberal conception of autonomy. Although Mackenzie agrees with Fineman’s critique of the liberal model of the subject and the understanding of autonomy that derives from this conception, from Mackenzie’s perspective it is a mistake to conceive autonomy only with reference to in the liberal view. According to Mackenzie, we must consider autonomy relationally. The problem for Mackenzie is that Fineman views vulnerability and autonomy as opposing terms. Mackenzie sees this as a mistake, for she argues that autonomy must be reconceptualized in a relational way.¹³

It is true that Fineman initially theorizes the notion of vulnerability in opposition to the liberal discourse of autonomy. However, I think that it is also true that in Bioethics we must challenge the liberal model of autonomy, even when we defend a relational model of autonomy. That is, to

²¹ In fact, Mackenzie agrees with Fineman’s criticism regarding the liberal subject. Moreover, she also acknowledges that Fineman leaves the door open to the possibility of theorizing about the relational notion of autonomy, but does not develop it. See Mackenzie (2014).

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emphasize the importance of a discourse contrary to that developed within the liberal conception of autonomy is fundamental. Another question raised by Mackenzie's critique is whether Fineman's criticism of the liberal notion of autonomy implies a complete rejection of the concept of autonomy. In my view, it is possible to articulate a notion of relational autonomy from Fineman's theory of vulnerability. This is also suggested by Fineman (2010, pp. 260-261) in some way:

"Autonomy is not an inherent human characteristic, but must be cultivated by a society that pays attention to the needs of its members, the operation of its institutions, and the implications of human fragility and vulnerability.... Autonomy understood through a lens of equality would carry social and reciprocal duties to others; it would not be confused with selfishness, self-absorption and egocentric attention to only one's own circumstances".

Although she does not develop a new conceptualization of autonomy, and in fact the theory rejects the notion of autonomy clearly, I am of the view that there is no contradiction between Fineman's approach and relational theories of autonomy. In my interpretation, is not only possible but also absolutely necessary to develop a new concept of relational autonomy with regard to vulnerability theory. This concept is essential within bioethics.

The last criticism made by Mackenzie is the lack of specificity in Fineman's analysis of justice and equality. She considers Fineman's response to this issue unclear because it sometimes refers to equal access to resources, sometimes to "equality"²² in terms of position, and occasionally to capabilities. She supports the role of capability theory in addressing this issue and demonstrates its conceptual connections with relational approaches to autonomy and its importance for an ethics of vulnerability.

²² The theory of vulnerability goes beyond the normative claim of equality to suggest that we question what can be the right and appropriate mechanisms to structure the terms and practices of inequality. Human beings find themselves dependent and embedded within social relationships and institutions throughout the course of life. While the institutions and relationships on which any individual is based will vary over time and in response to changes in incarnation and social contexts, the claim of social relationships and institutional structure remains constant. Vulnerability approach argues that the state must respond to the realities of human vulnerability, as well as situations that reflect inequality. For broader analyses, see Fineman (2017).

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One of the interesting aspects of Fineman's theory is that it opens up reflection on the responsibilities of both the state and the individual to provide the necessary resources for individuals to try to increase their resilience as a way to face vulnerability. Her approach does not imply a lack of clarity with regard to our real responsibilities and the measures that we should implement, but rather it is a broad discourse that can include different areas of reflection on this issue. In the specific field of bioethics, reflection on vulnerability implies that the institutions responsible for care practices, biomedical research, and public health policies must become aware of the importance of carrying out their obligations towards individuals and take into account the vulnerability of individuals as one of the key elements. Undoubtedly, this will generate particular forms of very diverse institutional responses that it would be impossible to address in all their variety. What is important is to draw attention to how, starting from the reflection on vulnerability, it is possible to think about the responsibilities of the institutions:

The nature of human vulnerability forms the basis for a claim that the state must be more responsive to that vulnerability. It fulfils that responsibility primarily through the establishment and support of societal institutions. Additionally, those institutions are themselves vulnerable to a variety of internal and external corruptions and disruptions and this realization is the basis for the further claim that these institutions must be actively monitored by the state in processes that are both transparent and inclusive (Fineman 2010, pp. 255-256).

I have shown the way in which some of the principal criticism to vulnerability theory can be overcome. I consider some of the reasons why these criticisms arise is due to a misunderstanding on the theory, or a superficial exploration on the premises and implications contains on it. Through this chapter I have illustrated what are some of the key elements that vulnerability theory develops, understanding their value as a radical new approach into the way how we understand and use vulnerability concept in bioethics. To address some of the practical contributions that arise once I have analyzed vulnerability theory in the core of bioethical discourse, I will highlight the main implications that I find derived from this approach.

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IMPLICATIONS OF AN ETHICS OF VULNERABILITY FOR BIOETHICS

The foregoing analysis of the theoretical approach and development of the vulnerability concept is useful for establishing a theoretical framework for the necessary development or implementation of an ethics of vulnerability in bioethics. In particular, Martha Fineman’s theory of vulnerability can be articulated as the theoretical basis from which to develop an ethics of vulnerability in this field. Reflections concerning vulnerability have certain important implications for bioethics, which are detailed in the following paragraphs.

Criticisms of the liberal model of autonomy

The vulnerability concept is developed within a critical theory held up against the liberal conception of the autonomous subject has been extended within ethics and politics and also in bioethics. Indeed, mainstream bioethics is articulated in relation to informed-consent theory as a model for respecting personal autonomy. In some respects, it has been necessary to focus on autonomy because of the dominance of paternalism in the relationship between health-care professionals and patients. The problem is that this considerable emphasis on autonomy leaves out of the bioethical discourse other kinds of principles and concepts that are of great importance for our understanding of our responsibilities and concerns within health care—for instance, vulnerability, dignity, caring, and solidarity. A critical approach to bioethics needs this framework, which focuses on the vulnerable subject rather than on the autonomous subject. In the same way that Fineman indicated the importance of the vulnerability concept as a critical tool, I consider this conception to be essential in bioethics:

“Vulnerability thus freed from its limited and negative associations is a powerful conceptual tool with the potential to define an obligation for the state to ensure a richer and more robust guarantee of equality” (Fineman 2008, pp. 8-9).

As a universal feature of human beings, vulnerability should be located at the centre of our ethical reflections. These reflections face the challenge of changing the relationships between professionals and patients, focusing on what patients think and on what is really important to give

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them better care²³. However, at the same time, it is important to highlight that patients are both vulnerable and autonomous; moreover, the same is true for health-care professionals. The shared vulnerability in patients and health-care professionals should be recognized instead of hidden (Carel, 2009).

Rethinking autonomy in bioethics

In my view, the recognition of universal vulnerability suggests that we will also have to rethink the autonomy model. This consideration involves the need to link autonomy and vulnerability instead of setting them in opposition to one another. For this purpose, it is fundamental to develop the notion of relational autonomy. Autonomy is not to be understood only as a feature of an individualistic, self-sufficient being. We are all vulnerable and we are all socially constituted beings requiring social support and relationships to exercise and develop our capabilities, among which is the capability of autonomy. The development of autonomy requires certain conditions in terms of opportunity; these conditions can be provided only in the context of social relationships, which are what makes autonomy possible. In addition, recognizing this relational element also implies the recognition that, on many occasions, the exercise of autonomy can be frustrated or blocked by different relationships.

By highlighting the alliance between vulnerability and relational autonomy, this approach goes beyond the mere protection of vulnerable people: it is about seeking social support to promote autonomy and empowerment for the people. Finally, ethical reflection about vulnerability should be guided by the value of relational autonomy for two reasons:

- To counter the sense of loss of control associated with vulnerability,
- To avoid the risk of unjustified paternalism that may result from the practices and policies to “protect the vulnerable.”

Recognizing vulnerability reveals that there are obligations and duties toward patients that need to be assumed by institutions and the state. These obligations include the creation of the

²³ Patient-centred care is a model of relationships that has been developed in recent years. For a better explanation, see Stewart et al. (2003), Epstein and Street (2011) and Fix et al. (2018).

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conditions for fostering and promoting patients' autonomy, relationally understood. To this end, we need to incorporate the vulnerability theory into bioethical reflection.

Vulnerability as a normative challenge

Vulnerability theory offers different conceptual tools for developing a more complex approach to issues in bioethics. For example, thinking about dependency, about a more complete understanding of disability, and about ways to better respond to people's needs in this regard changes substantially when we start by recognizing that we are all vulnerable. Vulnerability is the expression of human relationality and dependency. Being vulnerable challenges us to become human. Anthropological vulnerability affirms that human existence always begins in a normative context" (Ten Have 2016, p. 115).

Usually, vulnerability is used as a descriptive tool, with a pragmatic aim of trying to fix a particular situation, but not as a normative element. Thinking about vulnerability as a common feature of the human condition has a normative force because it demands a response, generating responsibility and implied obligations. These obligations are especially important from the perspective of the institutions and the state. It is also necessary to call attention to the fact that state already responds to vulnerability and remains normative, but the claim of the theory is focus not only in an initial response that the state provide in some particular circumstances: it is focus on the perspective of life course, since vulnerability is constant in human life.

Once we have redefined the concept of vulnerability and placed it at the centre of our reflections, many possibilities open up in terms of implementing measures to improve relationships—for instance, those that arise predominantly in the clinical context. Understanding it in this way, vulnerability could be used not only as a descriptive tool, as it is usually employed in research and consequently in bioethics, but above all as a normative tool, which urges us to action.

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Vulnerability as a way of improving professionalism and relationships between professionals and patients

In bioethics, the notion of professionalism has an important role, since the content of principles of professional responsibility that shape institutions in healthcare, such as medicine, nursing or healthcare systems. In bioethics, the notion of professionalism has an important role, since it defines the content of principles of professional responsibility that shape institutions in healthcare, such as medicine, nursing or healthcare systems. In the core of professionalism in healthcare, there is a necessity to rethink what is the role of professions in society, and attending particularly to the notion of responsibility. One of the aspects implied on understanding vulnerability theory in regard to professionalism is being alert to the manner in which relationships are enacted in the health-care system. I maintain that relying on vulnerability theory especially, we can develop greater empathy, as well as skills and strategies aimed at improving communication and relationships between health professionals and patients²⁴. Becoming aware that all humans are vulnerable is important for health professionals. Facing disease, disability, suffering, and death accentuates the experience of vulnerability both in patients and their families and friends, as well as among health professionals. Vulnerability as a shared condition in health care and has an impact on the way of understanding vulnerability in regard to the relationships among patients, health-care professionals, and institutions. Vulnerability can lead us to better understand our shared condition and the effect this condition has on relationships in health care.

Kirsti Malterud and co-authors (2005a, 2005b and 2009) have explored vulnerability extensively in regard to healthcare professionals. In particular, their studies analyze by way of qualitative research how vulnerability can be a strength in the context of health care. They describe two kinds of situations that compel physicians to expose their vulnerability: their identification with the patients' circumstances and their experiencing of feelings of uncertainty. Vulnerability experienced by doctors in one of these two situations and revealed to patients can increase the

²⁴ I prefer to use the term "patient," even if usually, in a "critical approach to bioethics," the word "patient" is avoided, specifically because of the passiveness and powerlessness that it suggests, and because of the hierarchy between this person and his or her health practitioner that it reinforces. However, the term "patients" also contains the idea of "those seeking professional help," while other words, such as "clients" or "users" do not reflect this position whence people look for professional help. See Pellegrino (2012).

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doctors' responsiveness to sensitive matters. In addition, as Carolyn Ells (2012, pp. 180-185) has stressed, expressing vulnerability can help people engage with one another and care for one another in a more meaningful way, as well as help others cope with difficult situations. It can trigger feelings of empathy and consequently motivate action. Recognizing everyone as vulnerable can contribute to improving human warmth, respect, and care within health relationships, in all directions, including care for professionals.

Reflection on social justice

The vulnerability approach can play an important role in global bioethics because it can provide a new way of thinking about the state's and international institutions' responsibilities for global problems. Global bioethics has among its most urgent and complex concerns the enormous inequalities in health worldwide. The right to health, defined within the framework of human rights, implies that everyone has the right to an adequate standard of living assured to him or her and to his or her family. An adequate standard of living refers to both health and well-being, and factors in especially food, clothing, housing, health care, and social services. As the General Observation on the Right to Health of the United Nations noted in 2000²⁵, the right to health encompasses not only timely health care, but also health determinants, such as access to drinking water and adequate sanitary conditions, adequate provision of healthy food, adequate nutrition, adequate housing, healthy working and environmental conditions, and access to education and to information on health-related issues, including sexual and reproductive health care.

With regard to global access to health care, there is an urgent need to direct attention towards social justice in connection to vulnerability. Concerning this approach, Henk ten Have (2016) conducts an important analysis of the impact of globalization and neoliberal policies on increasing vulnerability around the world. Using this framework, he makes some arguments that show why social justice should be considered to be among the main concerns for bioethics (Henk ten

²⁵ See United Nations High Commissioner for Human Rights, The Right to Health. World Health Organization. <http://www.ohchr.org/Documents/Publications/Factsheet31.pdf>

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Have, p. 173). His first argument is that, in general, justice in healthcare is centred on access to healthcare systems and distribution of resources for those who are damaged. In this regard, justice should consider how those needs arose. The second argument is related to globalization: neoliberal policies benefit the private health-care sector, while public health services have become weak and less accessible. The third argument is if we interpret vulnerability not as individual weakness but as the consequence of an exploitative order produced by neoliberal globalism, it will focus attention on structural injustice. This concern about the structural injustice is common to vulnerability theory, whose major claim concerns the obligations and responsibilities of both the state and institutions. This is an essential concern also in relation to the right to health, as a fundamental subject for global bioethics.

CONCLUSIONS

The starting point on this chapter was the recognition of the importance that the reflection about the concept of vulnerability has into current developments in bioethics. The centrality of vulnerability approach on bioethics are due to not only because of its analytic nature, but also due to its capacity for criticism. While there some scholars on vulnerability have addressed different studies focusing on particular conception of the concept, or on how to make a more pragmatic approach to analyze social context, I have shown the lack of a broader and deeper reflection about the universal approach on vulnerability in bioethics. Due to that, I argue it is necessary to define and analyze a universal conceptual framework in which the notion of vulnerability is developed within the scope of bioethics. Thus, the purpose of this chapter has been to indicate how the vulnerability theory developed by Martha Fineman can contribute to an ethics of vulnerability in bioethics. I consider necessary to open a broad reflection in the field about the studies addressing the universal approach on vulnerability. On this chapter, I have emphasized the main relevant aspects for bioethics that vulnerability theory contains. In addition, I have shown what are the main difficulties and criticism that arise from this approach. Finally, I highlight what are the main implications that I find on this approach that can contribute to improve the reflection about some issues within bioethics.

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CHAPTER THREE

VULNERABILITY AND RELATIONAL AUTONOMY: A NECESSARY REFLECTION IN BIOETHICS

INTRODUCTION

Vulnerability and autonomy have been thought in terms of opposition: vulnerability as a lack of autonomy, and autonomy as a way to avoid vulnerability. This way of understand the relationship between these two concepts is due to the misunderstanding of both. Vulnerability theory understands that vulnerability is a human condition, inherent and shared condition of human beings, and it is not a “lack”: is the primary condition of human beings. We all shared the same vulnerability, and we are all dependent on others, we are embedded in social relationships.

In addition, in general terms, and especially in bioethics, the concept of autonomy has been developed exclusively in the liberal sense, which means the supreme value of a self-sufficient, independent, individualistic self. The concept of autonomy has been highly criticized by Feminist Theory (Dryden, 2008) and in this context, the term of relational autonomy has emerged as a critical term to better understand the meaning of autonomy. Understood on this way, we can realize that human beings are always involved in a network of social relations, and it is not possible to be autonomous if there are not relationships and social conditions that allows autonomy to emerge. As a capacity, autonomy needs to be developed, and this is only possible in the core of supportive social relationships. The relational approaches can provide the possibility of correcting the excessive atomism that many individualistic perspectives have in bioethics (Jennings, 2016). For this purpose, the relational perspective (Downie and Llewellyn, 2012) can offer a different approach not only to the autonomy concept or to the vulnerability issue, but also to the relation between two concepts.

I argue that vulnerability and relational autonomy are two intimately related terms: it is the same human being that is vulnerable and that can be autonomous at the same time, but it is required to understand vulnerability and autonomy as relational terms. There has been a huge literature in Bioethics last years about the links between these two concepts (Rogers, Mackenzie and Dodds, 2012; Mackenzie in Mackenzie, Rogers and Dodds, 2014, Dodds, Donchin, MacLeod and Sherwin in

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Mackenzie and Stoljar 2000, Straehle, 2017). However, all of these proposals are focus on the link between a pragmatic concept of vulnerability, a particular o contextual vulnerability approach, and the concept of relational autonomy. I argue that it is also necessary to think about the links between the universal vulnerability approach and the notion of relational autonomy. In this regard, the concept of relational autonomy can be enriched from the link to universal approach with a series of characteristics that broaden knowledge about the same term, and that until now have not been sufficiently developed in bioethics.

Ricoeur (2008) points out that autonomy presents itself paradoxically and fundamentally as an "idea-project": "because the human being is by hypothesis, autonomous, it must become so". Ricoeur reveals the paradox of autonomy and vulnerability:

"It is the same human being who is one and the other from two different points of view. And what is more, not satisfied with opposing, the two terms are composed of each other: autonomy is that of a fragile, vulnerable being" (Ricoeur, 2008, p 71)²⁶.

In other words, we must become autonomous precisely because we are vulnerable, and our horizon or goal is the pursuit of that autonomy. Starting from that recognition, not only of autonomy, but also of vulnerability, we can re-conceptualize the way we understand the nature and function of autonomy.

Recognizing that at that point there is a distance with vulnerability theory, since the theory reject the notion of autonomy, I argue in bioethics it is not possible to renounce to the concept of autonomy. I consider the way to transform the problems related to the liberal autonomy, as self-sufficient, individualistic being, it is necessary to re-formulate what autonomy is necessary to foster in bioethics field. I maintain the link between shared vulnerability and relational autonomy has important implications in Bioethics field. One of these implications is to re-think about paternalism. Bioethics has been built against paternalism in health care relationships. In plural societies, nobody can decide for other, in substitution to other, what is best for him or her. Nevertheless, at the same time, as citizens, we need social support from the state and institutions to flourish. This relationship

²⁶ As mentioned before, Ricoeur maintains the idea of autonomy as liberal idea, and he does not use the term of relational autonomy, neither it meaning. In any case, I find this paradox suggestive, because it shows the deep connection that exists between these two terms.

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between the responsibilities of the state and institutions to provide resources to face vulnerability through increasing resilience and the paternalism in healthcare context is problematic. Understanding autonomy as a relational autonomy, the focus is on the responsibility of the healthcare professionals to try to create all the necessary conditions for develop the best environment to empower patient. Foster autonomy and increasing resilience will be possible through the comprehension of our shared vulnerability as *the* human condition.

My purpose on this chapter is develop the concept of relational autonomy, and the connections I find between this concept and the concept of vulnerability in the core of Fineman's vulnerability theory. It is true that the theory does not develop a concept of autonomy, even disagree with the notion of autonomy in any kind of version, including a relational understanding. Likely, the more approximate concept that can reflect any kind of decision making process for vulnerability theory is independence or independent act. However, from my view, in the particular field of bioethics we cannot change or turn all the building around the notion of autonomy towards the notion of independence. From a pragmatic, but also from a philosophical position, I strongly consider the concept of relational autonomy can contribute to bioethics to transform the drawbacks and problems that arise from a liberal and individual understanding of autonomy. One of the great differences between the liberal and the relational conceptions of autonomy is that while in the liberal conception is the degree of competence to decide the most important aspect, in the relational autonomy, the vulnerability of the person is that impels her or him to seek help in healthcare context. Which means that autonomy is always related to vulnerability. The most important aspects are not only focus on informing the person, but also about creating spaces and contexts where respect for the person and their life is possible (Busquets, 2017, p 65). The ethics of care recognizes the human being as being vulnerable and autonomous. Within bioethics, I consider fundamental to face and solve the problems arising from the conception of liberal autonomy re-signifying what is the difference that relational autonomy, thinking from the vulnerability approach, can provide. For this end, firstly I start with a brief approach of some of the main ideas about vulnerability theory, then I summarize how the concept of autonomy is generally understood in bioethics, and what are the main problems that emerge from this understanding. In the second part

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of the chapter, I develop broadly the main characteristics of the concept of relational autonomy. Finally, I will finish with some reflections about the concept of paternalism.

A BRIEF APPROACH TO THE CONCEPT OF VULNERABILITY BEYOND RESEARCH ETHICS

As I have shown in chapter two, within bioethics, the concept of vulnerability has been developed mainly in the field of biomedical research ethics. Undoubtedly, it has been very useful in alerting researchers to the damages associated with biomedical research if minimum protection principles are not respected, particularly under certain circumstances, such as the incapacity to give informed consent or potential situations of exploitation. This way of understanding vulnerability in terms of vulnerable groups represents the most extended influence in the development of the concept of vulnerability. However, this emphasis on the category of vulnerable population has some problems. In this sense, vulnerability is a dangerous concept in Bioethics, since it may stereotype those deemed vulnerable as passive, weak, and in need of protection, encouraging unwarranted paternalism and even discrimination, as Henk ten Have (2016) and Rogers, Mackenzie and Dodds (2014) have highlighted.

Hurst (2008), Allotey et al. (2012) and Wendler (2017), from a pragmatic analysis of vulnerability, considers that we should stop asking too much of general accounts of vulnerability, because the way to ensure appropriate protections for research subjects is not to undertake an analysis of the concept of vulnerability in a broader sense. However, the concept is essential in bioethics not only for a pragmatic use, in the sense that it is applied to try to understand and solve contingent conditions that create vulnerability. Beyond the pragmatism, it is a crucial concept try to develop a new and different ethics, more sensitive to responsibility for others in society. That is why a theory on vulnerability is important.

A universal conception of vulnerability has been highly criticized in bioethics because it has been considered unhelpful. One of the main reasons why it is difficult to accept the universal condition of vulnerability within mainstream discourse of bioethics is because the conception of vulnerability is difficult to reconcile with the liberal autonomy principle at the center of bioethics. Turner (2006) has developed the idea of vulnerability as common ontology shared for human beings.

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Rendtorff (2008) states that vulnerability must be considered as a universal expression of the human condition; as an expression of our finitude and fragile humanity.

Martha Albertson Fineman has established one of the most influential vulnerability theory in recent years. She has emphasized that vulnerability is universal and constant, it is *the* human condition (Fineman, 2008). Vulnerability defines what means to be human, and this formulation reminds us our corporeality and fragility. As a common and shared condition for all human beings, vulnerability is not something that happens only to specific populations groups (Timer, 2013). Fineman also emphasizes that while all human beings stand in a position of constant vulnerability, we are individually positioned differently. We have different forms of embodiment, and people are differently situated within webs of economic and institutional relationships (Fineman, 2008, p 269). However, it does not mean that there are different kinds of vulnerability. There are no more or less vulnerable people.

One of the main aspects that Fineman emphasizes is that through the recognition of the inevitability and societal implications of human vulnerability, we can achieve a better understanding of and redefine our responsibilities as a society. The nature of human vulnerability constitutes the basis for the social justice claim that the state must be responsive to this reality in defining its responsibilities and obligations (Fineman, 2013). The vulnerable self is offered in contrast to the liberal self, which is theorized in terms of prevailing notions of autonomy and independence – an individualistic and narcissistic projection of the self, which promotes the ethics of individualism.

At this point, while vulnerability theory maintains an opposition towards the concept of autonomy, even in other re-formulations, I consider it is highly important to rethink autonomy concept in bioethics field from the perspective of vulnerability approach. The concept of autonomy has had a huge impact in bioethics. It serves as a crucial concept, its importance highlighting why it must now be reconsidered and redefined in relational terms. In bioethics as it is currently construed, there is a tension between responding to human vulnerability and promoting autonomy. Unmodified, the rhetoric of individual autonomy and personal responsibility can mask social injustices and structural inequalities. The relational perspective linked with vulnerability theory can maintain the value of autonomy and, at the same time, avoid the individualism and mandate of self-

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sufficiency associated with the liberal conceptions of autonomy. In order to address this problem, I proceed to consider some of the main problems with the liberal idea of autonomy in bioethics field.

WHAT ARE THE MAIN PROBLEMS IN REGARD TO AUTONOMY?

The autonomy principle, and the concept of autonomous choice, is central in bioethics. In fact, most of the literature and debates have revolved around the notion of autonomy, particularly in relation to informed consent. This fact has led to the medical ethics mostly being associated with the principle of autonomy (Puyol, 2012; Varelius, 2006). Undoubtedly, this model of individualized autonomy was necessary in an historical moment when paternalism was the main approach in clinical healthcare. The principle of autonomy has transformed the relationships between physicians or healthcare professionals and patients and this change has had positive aspects: more respect for patient's opinions and more limits to the doctors and healthcare professional's activity without the consent of the patients. In addition, advocacy for autonomy has achieved awareness in people about their rights in the field of clinical practice or research. Recognizing the achievements that the autonomy principle has attained in bioethics and for society, however, does not negate the reality that it is now necessary to rethink autonomy as a concept, as well as reflecting on what is the best way to foster actual productive autonomy for people and societies that are also vulnerable.

According to Diego Gracia (2012), throughout Western history, autonomy has had four different meanings:

- a) Political: the capacity of old cities and modern states to give themselves their own laws.
- b) Metaphysical: it is understood as an intrinsic characteristic of all rational beings.
- c) Legal: in which actions are called autonomous when performed with due information and competency and without coercion.
- d) Moral: when acts are postconventional (Kohlberg, 1958, 1981), inner-directed (Riesman, Denney and Glazer, 1950), and responsible (Arendt, 1963, 2003).

From his view, is the legal meaning the most frequently used in bioethics, instead of moral.

In general terms, although main use is legal, the foundation of this conception is directly related with the metaphysical meaning that Gracia explains.

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Following mainly the philosophy of Kant and Mill, the autonomy principle has been related to the freedom of the individual and the possibility of the development of the human person according to personal choices and desires²⁷. Camps (2005, p 110-111) points out that for Kant, autonomy should not only be understood as the possibility of choosing between one or the other option, but also as the capacity and even the obligation to know for ourselves what we should do. García Gómez Heras (2005) exposes some of main limitations that Kant's autonomy presents. In the first place, it emphasizes the abstract formalism, which focuses on universalizability of norms, but lacks concrete material contents. Second, Kant's moral autonomy moves in idealistic speculation, and is an individualistic view, since many contradictions are generated when trying to link the autonomy of the subject with general interests. In addition, it can be considered to be excessively rationalist, since it completely excludes the scope of the affects and emotions that come with any decision. Finally, it excludes any procedure of intersubjective dialogue and deliberation.

The principle of autonomy in a modern pluralistic society is presented as the right to choose one's own way or version of the good life and is considered a supreme value (Charlesworth, 1993). The traditional idea of autonomy includes liberty and the active choices of the individual. Rendtorff (2008) emphasizes five important aspects of autonomy: the capacity for the creation of ideas and goals for life; the capacity of moral insight, "self-legislation" and privacy; the capacity of rational decision and action without coercion; the capacity of political involvement and personal responsibility, and the capacity of informed consent to medical experiments, etc.

In bioethics field, the principle of autonomy is expressed mainly in relation to the requirement of informed consent. Informed consent represents the assurance of complete self-determination for the patient undergoing medical treatment, signifying that the patient had a significant freedom of choice in relation to the medical treatment process. The essential element of informed consent is the provision of enough adequate information to ensure understanding, the exercise of the patient's own free will if he or she is considered competent. However, the excessive of emphasis on informed consent has turned relationships in healthcare in terms of transactions, as a mere contract between two parties. This fact has also turned in a fragmentation of the role that

²⁷ For a broader and acute analyzes of Kant and Mill Philosophy and their influence in Bioethics, see Tauber, A. (2005) *Patient Autonomy and the Ethics of responsibility*. Cambridge, Mass., MIT Press.

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professions represent for society, instead of attend to the social good for society these professions mean.

The main problem in regard to this conception of autonomy is that it perpetuates the myth about the existence of an independent, self-sufficient, and autonomous subject (Fineman, 2004). Within mainstream bioethics, as well as in political discourse, autonomy is structured by the liberal framework, which excessively emphasizes an individualistic, rational, and self-sufficient construction of the human being. Focusing only on autonomy renders invisible the fragility and vulnerability of the human condition, which means we all require care and respect. For that reason, a more complex concept of autonomy of the human person is necessary, one that incorporates human vulnerability (Rendtorff, 2008). In addition, it is important to realize that the focus on an unmodified principle of autonomy generates an individualistic and self-referential manner of understanding relations with others, which is especially problematic in the clinical context. Due to all this controversy, the primacy of autonomy has been questioned arguing that it is based on a distorted view of the individual who makes decisions as independent and self-sufficient, when the reality is that he decides in a context of personal and social relationships (Camps, 2001).

Some of the problems in relation to a narrow or poorly conceived principle of respect for autonomy can encourage contractual relationships between patients and health professionals (Tauber, 2005). In addition, it can lead patients or their families to feelings of isolation with the responsibility to make decisions, sometimes with the sensation of lack of support for that purpose, and it can block conversation about different possible courses of action. Occasionally, respect for autonomy can force health professionals to act against their professional judgment. Some of these concerns can frustrate the potential of health professionals to build a successful therapeutic relationship with patients (Ells et al. 2011, p 84-85).

Other problem in regard to the manner how the concept of Autonomy has been extended within bioethical context is that this term, understood in liberal sense, exclude other aspects of human condition, as vulnerability. In fact, vulnerability and autonomy have been thought in terms of opposition: vulnerability as a lack of autonomy, and autonomy as a way to avoid vulnerability. This way of understand the relationship between these two concepts is due to the misunderstanding of both. We all shared the same vulnerability, and we are all dependent on others, we are embedded

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in social relationships, “human beings need each other, and we must structure our institutions in response to this fundamental human reality” (Fineman, 2008, p12). I claim that vulnerability and relational autonomy are two terms intimately related: is the same human being who is vulnerable and who can be autonomous at the same time, but it is required to understand vulnerability and autonomy as relational terms²⁸.

Autonomy principle offers rules to guide the discussion of information between patient and healthcare professionals. This interpretation of autonomy is based on an idealized image of the rational patient, self-sufficient, independent, etc., who analyzes different options in regard to the health or treatment, and chooses freely among them. The kind of doctor-patient encounter as one in which the doctor and the patient find themselves as independent contractors is implicit in this model, and their relationship is structured around the need to decide on a course of treatment. Once the decision is made and applied and the patient recovers, he or she becomes independent. Their relationship is structured around the need to decide on a treatment, while other decision-making considerations can be ignored. This means that the context within which the care is provided disappears in the background. The control of the patient over the conditions of care and the effects of the decision for the patient's life projects, the impact of the patient's illness on the life plans and projects of the family members, the capacity or possibilities for the family members to provide care until the patient can restart normal activities again are not considered (Donchin, 2001, p 368).

Other problem about autonomy principle, as Heidenreich et al. (2017) maintain, is the differences between the theory and the practice: “In theory, promoting respect for a patient’s autonomy is quite uncontroversial, but, to deal with autonomy in everyday care is far more complicated”. To describe the content of healthcare professionals’ moral reasoning, Heidenreich et al. (2017) have conducted a qualitative study. In this research, the content of the moral reasoning

²⁸ Paul Ricoeur (2008, pp. 70-71) has pointed out the recognition that we are not only autonomous, but also vulnerable. For him, autonomy is presented in a paradoxical way and fundamentally as an "idea-project": *"because the human being is by autonomous hypothesis, it must become so Ricoeur highlights the paradox of autonomy and vulnerability: "it is the same human being who is the one and the other under two different points of view. And what's more, not happy with opposing, the two terms are composed of each other: autonomy is that of a fragile, vulnerable being "*. We must become autonomous, precisely because we are vulnerable and our horizon, our goal is the search for that autonomy. But he does not renounce the Kantian consideration of the human being as autonomous, while only the ability to give himself rationally the law enables him to act in a truly moral. At that point, I consider necessary the turn to a relational understanding of autonomy.

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was caught in two main categories: a) how to balance convictions of what is good care and the discordant preferences for care assumed by the patient; and b) how to establish a responsible relationship with the vulnerable person. They found that the moral reasoning was infused with discussions about patient autonomy, and these findings led them to clarify the professionals' perceptions of patient autonomy in the clinical practice through the framework of relational autonomy. In this study, the professionals described their patients as being severely ill and in distress, all of which affected their decision-making capacity. They advocated that they could not leave the patient with their apparent deficient and inappropriate decisions which they thought would lead to harm because of lack of care. They were also morally troubled by the use of power to try to influence the patient and the risk of violating the patient's dignity and integrity. Contrary to autonomy interpreted in the traditional sense, relational autonomy could help as a better interpretative tool to understand the professionals' struggles in their findings. Relational autonomy implies commitment from professionals to support and promote patient's capacity for make judgements that are right to their own wishes and values. Abandonment by the professionals, not because of interference, in the decision-making process are the main threats to patient autonomy. This means that the professionals in this study would not leave their patients to make decisions which they judge as not being in the patients' best interests. (Heidenreich et al., 2017).

In addition, they found that responsibility emerged as an important subject during the discussions. Healthcare professionals expressed a responsibility to fulfil the patients' care needs. One the one hand, one of the concerns that healthcare professionals discussed was to what extent it was legitimate to try to influence the patient. On the other hand, they discussed about what was the extent to which the general responsibility of the professional healthcare system reached. Health care professionals expressed determination to help and support patients in difficult situations, but also they expressed a need to stop in situations where they failed to achieve better care for the patients, due to situations where the healthcare system had defective opportunities to benefit patients (Heidenreich et al., 2017).

Due to these concerns, among others, the concept of autonomy has been highly criticized by Feminist Theory, and in this context, the term of relational autonomy has emerged as a critical term to better understand the meaning of autonomy (Mackenzie and Stojlar, 2000). Although there

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is not only one definition or way to understand relational autonomy, this term extends the scope of patient autonomy that health professionals must address, in addition to respecting the patient's right to make informed decisions, since health professionals must pay attention to the patient's preferences, values and network of relationships (Ells et al 2011, p 86). Human beings are always involved in a network of social relations, and it is not possible to be autonomous if there are not relationships and social conditions that allows it. As a capacity, relational autonomy needs to be develop, and this is only possible in the core of supportive social relationships. In the context of healthcare, relational autonomy implies more emphasis on the way how healthcare professionals create conditions to facilitate and support the patient's (and sometimes family) decision making process, instead of the right of patient to decide, without consider the role of the health care professional patient relationship on this decision making.

The concept of relational autonomy has been fundamentally theorized in bioethics linked to particular or contextual notion of vulnerability. My proposal is to reflect about how the concept of relational autonomy can be implemented through the lens of vulnerability theory, focusing on our shared vulnerability. This means to link relational autonomy concept with a universal approach on vulnerability. At the same time, I argue that the concept of relational autonomy can be linked with vulnerability notion within vulnerability theory, coherently.

HOW TO UNDERSTAND RELATIONAL AUTONOMY

Halliburton (2014, p. 6) maintains that in bioethics “any perspective which takes a substantive approach to questions of human good, which describes autonomy in relational rather than individualistic terms, which centers in virtues rather than principles, which makes issues of social and economic justice central rather than beyond peripheral to its analysis, or which draws on theoretical resources which go beyond the bounds of an analytic and procedural method of conceptualizing the issues, is marginalized and dismissed”. In spite of this marginalization, “the relational turn in bioethics” (Jennings, 2016) is not only totally necessary, but also a challenge.

Feminist theorists have questioned the assertion of universal and gender-neutral categories and values, arguing whether they can really apply to all human beings (Marsico, 2006). As traditionally conceived, autonomy is one of the so called neutral values that has been investigated.

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A number of feminist scholars have claimed the concept of relational autonomy in an attempt to rethink autonomy along feminist lines (Mackenzie and Stoljar, 2000; Nedelsky, 1993, 2011). This discussion of autonomy reflects the need to address the concept modified by a relational frame. However, while scholars working in this area agree that both relationality and autonomy are significant aspects of human subjectivity that need to be understood together, there is a wide range of conceptions of how this interaction might be reconciled (Dryden, 2008). The term relational autonomy, as Catriona Mackenzie and Stoljar (2000) present it, does not refer to a single unified conception of autonomy but is rather an umbrella term, designating a range of related perspectives. The common conviction around which the term is built is that human beings are socially embedded and, consequently, people must be understood as involved in the context of social relationships²⁹.

Although there are some variations on the way to define and understand the meaning of relational autonomy, this critical term emerges on understanding that people are not independent individuals: we are relational beings who need connections to others for our existence. In this sense, relational autonomy highlights social surroundings and relationships as crucial for developing autonomy. In addition, in bioethics, and particularly in the clinical context, the term is central. Moser et al (2010) argue that autonomy can be fostered in responsive relationships when patients, nurses, healthcare team professionals and family members carry out care activities supported by a relational care attitude³⁰. As Dove et al (2017, p 153) maintains, “relationships (with family, community and society), responsibility, care and interdependence are key attributes of relational autonomy: people develop their sense of self and form capacities and life plans through the relationships they forge on a daily and long-term basis”. In addition, we can consider this term intrinsically related to an ethic of care. Particularly, relational autonomy constitutes a higher analytic and normative value than individualistic autonomy by inspiring a broader conception of human life, socially embedded. “Such an account of autonomy promotes decision-making guided by an ethic of

²⁹ In regard to relational autonomy, different conceptions of autonomy do not require the creation of different understandings of vulnerability, as Mackenzie and co-authors develop in Mackenzie, C., Rogers, W. & Dodds, S. (eds.) *Vulnerability: New essays in ethics and feminist philosophy (studies in feminist philosophy)*. Oxford, New York, Oxford University Press.

³⁰ In this regard, the relational care attitude is in the core of the reflection about the professional values. We can also think what happens with the autonomy of those professionals who are taken care of the patient. The relational turn on autonomy also implies a new way to think about the professional responsibility, as I will show later.

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care and moral responsibility – whereby the person is respected as an individual but also is encouraged, at levels of legal architecture and clinical practice, to take account of her social situation such that she promotes her own flourishing as well as the flourishing of her social and natural environment” (Dove et al. 2017, p 161-162).

From relational approaches (Downie and Llewellyn2012) we can analyze in what ways autonomy is associated and intertwined with relationships in both positive and negative aspects. The relational approach to autonomy asserts that people are principally social beings who develop the competency for autonomy through social interaction with other persons. As Marilyn Friedman (2000) highlights, autonomy takes place in a context of values, meanings, and modes of self-reflection that cannot exist except as constituted by social practices. Each of us grow as a person in social contexts, located in social networks such as family, community and nation. People make their lives through involvement in social relationships and communities and at some point, they define their identities and constitute their values. Relational approaches emphasis the role that social norms and institutions play in shaping the decision making process for individuals. In addition, it is also important that individuals try to improve the development of skills that are necessary for fostering autonomy. These skills are related to the ability to achieve autonomy, which can be impeded not only by restrictions on freedom, but also by social norms, institutions, and practices that limit the nature and range of options in which autonomy or choice can be exercised.

Capability theories, as Bruce Jennings (2016) synthesizes, stress the background social conditions that empower each individual to effectually employ resources to promote his or her human flourishing and development. Sen’s capability theory (1999) understands that freedom is based not on what we have but on our capability to use the resources and our social position to realize these components in life that are favorable to one’s flourishing as a human being. This means that it is not the lack of external intervention that makes one free, but the occurrence of relationships of social connection. “Liberty is not so much a situation of freedom from interference by others, as a situation of freedom through capability-enhancing relationships with others” (Jennings, 2016, pp 12-13). In addition, the idea of justice of Martha Nussbaum (2006) is based on the question of the social environmental conditions necessary for individuals to develop their potential capabilities and to enact various concrete types of functioning in relational forms of life.

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Justice is not about the distribution of resources; it is about the relationally mediated use of resources to achieve the human good.

Jennifer Nedelsky's relational theory of rights (2011) is founded on the idea of recognition. This theory holds that the conditions of individual freedom are constituted by the relations generated by intersubjective recognition, not by the absolute affirmation of each individual separately. This is the basis of the relational alternative that Nedelsky (1993) proposes as a substitute for conceiving subjective rights as individual and abstract exclusive demands. Traditionally, rights are considered barriers that protect the individuals from the intrusion of others or from the state: rights define boundaries that others should not cross because it would violate our freedom and autonomy. This vision of rights ties in very well with the idea of autonomy as independence. Nedelsky argues this view of autonomy is wrong. What really makes autonomy possible is not separation from others, but relationships with others. Further, autonomy is not a quality that we possess at birth. Rather, the development of this capacity, or right, requires an environment that makes it possible. Collectivity can be both a source of autonomy and a threat to it. Nedelsky maintains that autonomy, as well as other values and rights, has to be seen in terms of relationships, since this view provides a broader understanding than simply conflict resolution. Without the network of relationships that constitutes us, our essential humanity is not comprehensible. It does not only mean that people live in groups and have to interact with each other. Liberal rights' theory specifies the rights of people when they conflict with each other because persons have to interact with others. But we are literally constituted by the relations of which we are part. Conventional liberal rights theories do not make the relationship fundamental to their understanding of the human subject, instead, mediating conflict is the focus, and not the mutual creation and sustenance (Nedelsky, 1993, pp12-13). Rather, the development of the capacity of autonomy requires an environment that makes it possible. This relational approach, the turn to understand rights as relational, also moves the attention from the protection in front of the others towards the construction of relations that foster autonomy. For her, we must become autonomous, and this capacity can only be nurtured in relationship with others. In addition, autonomy is not seen as a static attribute, but is a capacity that is developing throughout our lives. "Autonomy is a capacity that exists only in the context of social relations that support it and only in conjunction with the internal sense of being autonomous" (1989, p 25).

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Jonathan Herring (2014), who is also writing in law, points out four important aspects to consider in regard to Relational Autonomy. First, autonomy must be thought of in the context of the broader social relations. Traditional autonomy plays its part in promoting individualism, which ignores the complexity of the relationships and connections that constitute people's lives. The values of inter-dependence and connection, rather than self-sufficiency and independence, reflect a more precise reality for human beings. As his second point, he states relational autonomy is very sensitive to the way in which our relationships constitute the identity. Our relationships are the field upon which our goals are formed. This means that the individual capacity for autonomy can only be realized within the context of relationships. Relational autonomy does not reject the notion of the self, but reflects how an individual with the support of the family and friends is able to make a decision. A third point to consider is how relationships can impair or damage autonomy. If decisions are reached within a relational context, we need to be alert to the difficulties in determining the extent to which someone's decision may be result of oppression or manipulation of others. Some relationships are destructive of a personal autonomy and the challenge is to define which relationships promote autonomy and which are destructive. Herring considers that there is an inevitable tension: "The more our relational nature is emphasized, the harder it is to define where the boundary between being oppressed within a relationship to such an extent that one loses autonomy and where one is simply deeply embedded in relationship" (Herring, 2014, p 23). Finally, relational autonomy implies some kind of responsibility or commitments to others. We can understand that it could be helpful or good for people to be able to assume committed relationships. Due to that, it is necessary to think about the way to enforce those commitments and obligations.

Joel Anderson and Alex Honneth (2005) understand autonomy as "an acquired set of capacities to lead one's own life, these commitments suggest that liberal societies should be especially concerned to address vulnerabilities of individuals regarding the development and maintenance of their autonomy". For Noddings (2003), vulnerability and the needs of other people forces us to take care of them. This happens when we can't remain indifferent to the suffering of others and we decide to take charge, to care for the people who need us. An encounter with other human beings appeals to our responsibility for them. The practice of care arises from the recognition

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of the vulnerability of the other, not from obedience to moral principles. Ultimately, for the ethics of care, the needs of other people become ethical appeals.

Rendtorff (2008)³¹ has highlighted that in order to fully understand the significance of autonomy we have to expand this concept by other principles. These other principles or ideas are the principles of dignity, integrity and vulnerability, which together with autonomy, help to define the necessary concern for the human person in bioethics. For Rendtorff (2008), while autonomy helps us to focus on human rights and respect for people, it is not sufficient to provide the protection required in many health care limit situations. At this point, vulnerability theory focus is not at the individual level, but at the collective responsibility. This means that the values and the logic of the thought is in regard to community, cooperation, trust, reliance, connection. From my analyzes, this focus on the collectivity can also be reconciled with the relational way of understand autonomy, since the capacity for decision making emerge only in the core of the community.

NEW PERSPECTIVES ON RELATIONAL AUTONOMY THROUGH THE LINK WITH VULNERABILITY THEORY

Based on these analyses, and incorporating vulnerability theory, relational autonomy is a capacity to make decisions, not as an individual, self-sufficient person, but as a person constituted and embedded in social relationships. I want to propose what are the five main characteristics of relational autonomy are important to consider in regard to bioethics and the clinical context:

1.- Relationships. People are social beings who develop the competency for decision making through social interaction with other persons. Autonomy is not a characteristic of the human beings that we have by the mere fact of being born. It is a fundamental element of human existence, but it has to be developed. Development, requires a favorable environment. More specifically, in the field of healthcare, it is important to realize that as long as the healthcare professional does not make possible this "construction of autonomy", the idea of autonomy will be only a myth or an illusion.

³¹ Some of these ideas have been previously analyzed by the author in analyzed in Rendtorff J. (2002) Basic ethical principles in European bioethics and biolaw: Autonomy, dignity, integrity and vulnerability – Towards a foundation of bioethics and biolaw. *Med Health Care Phil* ; 5: 235-244. This article summarize some of the results to the report to the European Commission of the Bio-Med-II Project Basic Ethical Principles in Bioethics and Biolaw. The aim of this Project was to identify these four principles for European Bioethics and Biolaw.

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Similarly to vulnerability concept, relational autonomy contains or reflects both positive and negative aspects. On the one hand, it is through the links with other persons that it is possible to make our own decisions. On the other hand, this means that autonomy can be totally undermined or curtailed if the necessary conditions are missing. Sometimes, this happen because of oppressive relationships, while in other cases from neglect or inattention, such as when people with power (such healthcare providers) don't create the needed conditions for autonomy. As Dodds (2000, p 231-232) has stressed, "assisting patients to make choices through active understanding of their wants and expressed preferences may well better protect autonomy than detailing risk probabilities, especially when the alternatives are limited, and one or another of the alternatives is clearly preferable in the circumstances". We need a social support to exercise and develop our autonomy skills, which means that autonomy requires the recognition of and respect from others. Also, a negative effect can be that it deflects or obscures a needed (but unequal) sense of responsibility – such as the responsibility of a healthcare provided to use their superior knowledge and access to resources in the best interest of the patient.

2.- Capacity for decision making process. Relational autonomy is a capacity, and it is required an environment that makes it possible. This relational approach transfers the attention from the protection in front of the others towards the construction of relations that foster capacity for decision making. It is a claim to respect the right of patients to make their own decision, not deciding under pressure, not being oppressed. But at the same time, in the core of healthcare, relational autonomy emphasizes the capacity for make decisions, and not only the legal right for respect the patient's decisions, regardless how these decisions occur. The emphasis in how the process take place is much important than the final decision in itself. Regarding to this point, relational autonomy is well reflected on the practice of shared decision-making.

3.- Process along the life course. Relational autonomy is not a static attribute, but is a capacity that is developing throughout our lives, not only refers to a specific moment; it represents a life course process to be able to make decisions in the context of healthcare. Vulnerability is constant along life course. Consequently, social and institutional support claimed to manage your vulnerability is

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necessary along the life course, and not just in particular or specific moments (Fineman, 2017, p 10). One of the main aspects highlighted by the concept of relational autonomy is the importance of the relationship between the patient (or the patient and his or her family) and the healthcare professional. As a capacity that needs to be developed, relational autonomy is not only refers to a specific moment; far from that, it represents a life course process to be able to make the best decisions. This represents also a difference in regard to principle of autonomy or informed consent model. While autonomy principle is understood as a punctual moment that occur when patient needs to consent or accept a health care treatment or practice, relational autonomy is the result of a process in which the patient and their family is involved when he or she need to be care. This capacity need to be fostered by professionals in each one of the encounters with the patient, in different moments of their course life, and it will require not only information, but also education for health and tools for deliberation. Relational autonomy should be understood in the center of a process that make it possible.

4.- Professional Commitment. Focusing on relational autonomy, the responsibility for decision making process is shared between the patient and the healthcare professionals, but more accent is now in the professional commitment to allow this process. It is required a supportive relationship, based on care, that allow to flourish all the conditions for make decisions. These decisions emerge from communication, dialogue, and a process of shared decision-making between healthcare professionals and patients and/or relatives. The recognition of inevitable human vulnerability, along with the recognition of suffering, generates responsibilities for the care of the others. This recognition forms the origin of the ethics of care. In this sense, we must consider the importance of this ethical dimension within the field of healthcare relationships. The health care professional-patient relationship is not contractual; it is fundamentally a help relationship.³² This important element is frequently forgotten into the healthcare environment when we exclusively focus on liberal autonomy principle. If healthcare professionals want to respect what people desire, they have to begin by forming the kind of professional relationship that will allow the patient to develop

³² I develop broadly this concept on chapter five.

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autonomy. This focus on the professional responsibility is an essential part of relational autonomy concept as I conceive it.

5.- Collectivity. Relational Autonomy also highlights the network of relationships where all of us are involved. One important aspect that has not been enough considered when theorizing about relational autonomy is the aspect of collectivity that emerge around this concept. This means that relational autonomy is not an individual attribute or capacity, it is only possible in the core of a community. In the context of healthcare, this community is conformed for patient, the family, health care professionals, and the institution. It also includes the role of the professions of healthcare in the society, what is expected from these professionals from the society point of view. While autonomy principle promotes individualistic social values, relational autonomy highlights the importance of collective commitment, collective actions, and the idea of how personal decisions are not individualistic, but they are crossed by the relationships we maintain throughout our lives. As Fineman (2017, pp 10-11) shows, “developing a collective or social justice approach requires that we understand the nature of those who compose the collective”.

Finally, we can realize that autonomy and vulnerability are not incompatible. Far from it, these are aspects of the human condition are strongly related. We can't think fully about vulnerability without taking into account autonomy (relationally understood). Nor can we think about autonomy without considering the inevitable and universal vulnerability that constitutes us. As I have maintained, vulnerability theory and relational autonomy has an important impact in the way how relationships of care between health care professionals and patients are performed. I am interested on exploring how the introduction of these two related concepts affects the professional relationships that occur in healthcare context.

A practical example about the changes that introduces the concept of relational autonomy is as follows:

Sara is a pregnant woman. During the course of the pregnancy, she is informed about the possibility of fill a birth plan. The design of “birth plans” represents a “previous informed consent” in which the woman expresses her preferences in regard to position, natural techniques for managing labor discomfort. She fills the form, and she expects that all what is included in this form

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will be respected. However, what sometimes happen is that it is not possible to follow all the preferences, because delivery is a much-unexpected process sometimes, and lot of problems can appear. Consequently, if these preferences are not respected, Sara can feel dissatisfaction.

A model based on relational autonomy recognizes the role of women in decision-making together with professionals as a key element in improving maternal satisfaction, enhancing the professional's responsibility. Decision making process is more complex than offer birth plans, it is about achieving an appropriate balance between the recognition of vulnerability in this context while respecting the woman's capacity and agency to make decisions (sometimes with other people). To make these decisions, it is necessary to take into account that this should be based on those practices supported by scientific evidence, and those practices will be performed by professionals (midwives), and all of this happen in an institution, with the constrictions or possibilities that this institution offers.

The differences with the informed consent model of relationship lies in the fact that the result is not the sum of independent tasks, ("I don't want episiotomy, or anesthesia") but is a joint, collaborative work, in which dialogue plays a central role. Healthcare professionals can make recommendations and orient the woman decision through the professional knowledge, their experience, but also on the basis of an adequate understanding of the values and objectives of each person. It also requires a relationship between health care professional and woman stablished along time, not just in the moment of delivery. It can include, for instance, to plan visit to the delivery room, to anticipate possible complications, to explain the normal material that it is use in delivery, etc. And of course, this model can only be implemented if there is a commitment from the health organization itself.

CRITICISMS OF THE VULNERABILITY AND THE RELATIONAL AUTONOMY MODEL WITHIN HEALTHCARE RELATIONSHIPS

Can an approach that combines vulnerability theory with the concept of relational autonomy also result in covert ways of diminishing personal agency? It could be argued that if we emphasize the aspects related to vulnerability and dependence, adding to that the exaltation of the relational dimension of autonomy, we are essentially undermining the "true" autonomy of the individual. The

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assertion would be that this concept of relational autonomy involves a new form of paternalism in healthcare ethics. From the liberal perspective, it may seem that relational autonomy will set the stage for excessive intrusions into personal decisions. However, the main objective is to re-define the relation between autonomy and vulnerability to both protect autonomy, but also encourage and increase the best practices of professional responsibility. It is only through the creation of a relationship that includes and encourages dialogue, good communication, mutual trust, and shared responsibility that the patient is able to truly exercise autonomy.

In the field of bioethics, paternalism refers to those situations in which it is the physician or the healthcare professional decides what happens instead of the patient. In doing so they generally appeal to the idea that expert knowledge belongs to physicians and not to patients, as well as the assumptions that the particular circumstances that accompany the disease, the general commitment of health professionals to the well-being of patients, and the principle of beneficence. In response, I would argue that linking vulnerability and relational autonomy, far from justifying any return to paternalism, affirms that autonomy cannot be possible without recognizing and addressing patient vulnerability and dependency. Understanding their vulnerability can empower patients, allowing them to manage the situation by claiming the support they need from institutions and healthcare professionals.

Healthcare professionals should not be afraid of the label "paternalism." Actions labelled paternalistic can reflect a caring about and caring for impulse that should be encouraged in professionals. Cass Sunstein (2014) has argued that there are some forms of state paternalism that can be useful in his book on paternalism. Addressing those who reject the idea of paternalism of any kind, Sunstein shows that there are some government-imposed structures that do not only affect our choices ("choice architecture"), but are inevitable and cannot be avoided³³. He urges, given that inevitability, that there are profoundly moral reasons for those with greater responsibility to ensure that choice architecture is helpful, rather than harmful to those it is designed to help, making their lives better. Accepting that some forms of paternalism are useful, does not preclude

³³ As an example, in some cases, public policies for tobacco control or to control and prevent overweight and obesity can be paternalistic, but these policies are developed to try to guarantee a better health on the population.

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being careful with the idea of applying paternalism in the field of Bioethics, particularly in Clinical Ethics.

Gaia Marsico (2003) has argued that the clinical relationship is an opportunity for empowerment, in which the subjects involved can be helped to make a journey in order to achieve real decision-making capacity. There is no legitimate way to justify that health professionals should decide for the patient. In a plural, multicultural and democratic society, no one can or should be given the power to decide what is best for another person. But it is necessary to give support, and provide tools to help people decide what is best for them and what their options are, instead of leaving them "alone," abandoned and without the resources necessary to make decisions.

Both the paternalistic model of clinical relationship and the contractual autonomist model are contrary to developing real relational autonomy for the patient. In the case of paternalism, there are few reasons that will justify healthcare professionals making decisions and not considering what the patient thinks or wants. Even when a patient is not competent, family members or legal guardians should be involved in making health care decisions concerning them. At the opposite extreme, in the contractual or liberal autonomous model of the healthcare relationship, the autonomy of the individual cannot be exercised when the patient is isolated and uninformed, abandoned to a decision-making process that fails to provide essential support. A contractual model of clinical relationship operates to permits a "misunderstood" informed consent to be secured, not as a guarantee of respect for individual autonomy, but as a legal safeguard for the professionals. The model of relational autonomy empowers the patient. It establishes a clinical relationship in which informed consent is seen as emerging from communication, dialogue, and a process of shared decision-making. I argue that relational autonomy, developed in the link to vulnerability theory, does not involve necessarily some kind of paternalism, because these two concepts implies a claim to increase resilience. This claim for increasing resilience must take into account the perspective of patients and healthcare professionals too. If the main goal of developing relational autonomy in the context of relations of care is to foster resilience, it seems that paternalism does not take place. Nevertheless, it is necessary to better explore this relationship between care and paternalism.

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THE RELATIONSHIP BETWEEN CARE AND PATERNALISM

In general terms, paternalistic actions are those in which one person interferes with the autonomy of other against their will, but for their own good. Paternalism refers to actions aims at the welfare of a person for whom the decision is denied. It can either be targeted to benefit or safeguard the person’s well-being, or it can be to stave off an existing harm or to prevent the threat of harm “for the person’s welfare.” A caring motivation for action is not a sufficient description of paternalism, since one can indeed treat a person beneficently without conflicting with the person’s own will (Schöne-Seifert, 2015, p 146-147)³⁴

In regard to relationships of care, Roxanna Lynch (2015) examines the compatibility of paternalism and care. She explores the compatibility of paternalism and care, considering whether acts of paternalism could be acts of care and what effect paternalism might have on the quality of care. She concludes that paternalism and care are not necessarily incompatible. Nevertheless, paternalism can pose a potential threat to care by threatening the success of caring relationships and by directly opposing the aims of care. “It is argued that though care givers may sometimes have to act paternalistically in order to give care, acts of care that are paternalistic nevertheless represent more ‘risky’ (in terms of their likelihood of success) acts of care” (Lynch, 2015). Caring relations are formed by care givers and recipients of care. A good caring relationship will be one in which one party successfully promotes some conditions necessary for the flourishing of the other party. “Assuming that a reasonable level of communication is in principle possible between givers and recipients of care, e.g. there is a common language between the care giver and the recipient of care, the most significant threats to adequate communication between them are argued to be epistemic injustices and imbalances of power” (Lynch, 2015).³⁵ A risk to the caring relationship happens as

³⁴ She explains some examples of strong paternalism in legal policy like compulsory insurances or the enforcement of helmet laws for motorcyclists, insofar that they are justified by reference to the welfare of the affected individual. An example of strong paternalism in medicine is lying out of compassion to a terminally ill patient about his or her prognosis, although the patient had made an explicit and well-considered request for truthful information.

³⁵ Lynch bases her analyses of the relationship between care and paternalism in the idea of epistemic injustice developed by Fricker (2007). Epistemic injustice refers to ‘testimonial injustice’ and ‘hermeneutical injustice’: “Testimonial injustice occurs when prejudice causes a hearer to give a deflated level of credibility to a speaker’s word;

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consequence of potential imbalances of power, like strength or knowledge, since they can serve to facilitate exploitation or manipulation, contrary to the aims of care, as Lynch (2015) claims. Paternalistic actions can infringe the desires of patients, but would claim to do so in the patient's best interests. Given this understanding of paternalism, paternalistic acts could threaten the success of care in two different ways (I refer her arguments to the healthcare professionals-patient's relationships).

Firstly, paternalistic acts could be clearly at odds with the aims of care. Acts of care that are not compatible with the patient's personalized notion of flourishing, even if they are performed in harmony with the goods of the patient, will not be beneficial to care because they will fail to promote the necessary conditions for the flourishing. Following Lynch argument, she understands choice as the ability of people to control their lives, bodies and surroundings in a way that is compatible with their accessing other goods. Choice is a good in itself and is moreover instrumentally valuable to individuals being able to access other goods. Lynch (2015, p 120-122) argues that at that point, it has been only claimed that care givers must successfully promote some or all of the necessary conditions for the flourishing of the patient, attending at the welfare of this person. Additionally, she claims that in order to consider as successful care, healthcare professionals must only promote some of the necessary conditions for flourishing. For her, ideally, individuals themselves should determine the extent to which they access each of the goods, but sometimes it will be more consistent with the broader aims of care for such decisions to be made by someone else, and not only focusing on choice.³⁶ However, choice is argued constitutive of human flourishing. Due to that, if someone is always treated paternalistically and, subsequently, there are no opportunity for choice in his or her lives, to flourish won't be possible. That is why, Lynch argues, continuous paternalistic intervention by caregivers, or paternalistic actions that inhibit a patient's future ability to choose, would not be compatible with care. Care and paternalism can be compatible (despite acts of paternalism represents a danger to the choice) if the act of paternalism only provisionally overrides an individual ability to choose and in a manner that not compromise

hermeneutical injustice occurs at a prior stage, when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences" (Fricker, 2007, p 1).

³⁶ The same argument is sustained by Marzano in regard to informed consent as the only justification for actions considered free. See Marzano, M. (2009).

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the other goods.

Secondly, acts of paternalism could pose a hazard to caring relationships. Caregiver could behave paternalistically, and this behavior may damage caring relationships, because these acts have the potential to adversely affect all the aspects of good communication. After analyzing different aspects of good communication such honesty, transparency and the absence of epistemic injustices and imbalances of power, Lynch (2015, p 122-123) concludes that the kind of threats posed by paternalism to care is not clearly particular to acts of paternalism, since they can be produced for other reasons. Though paternalism possibly poses a significant threat to the success of care, all that can be claimed is that paternalistic acts imply a more 'risky' approach to care giving. Finally, her conclusion is that once assumed the risk that paternalistic acts pose to the realization of care, if paternalism could be avoided in care relationships, then it should be. If a paternalistic act must be performed, then this act would account more substantial justification than other acts that aim at care.

I consider that in the theoretical framework of relationships that I have argued, based on vulnerability and relational autonomy, this kind of threats are diminished, which means that paternalistic actions are not necessary. The first reason, is because one of the main goals of care is to increase resilience. Resilience is measured only in part by an individual's ability to survive or recover from harm or setbacks that inevitably occur over the life-course. Resilient persons can form relationships, take advantage of opportunities and take risks in life, confident that if they fail the challenge or meet unexpected obstacles, they are likely to have the means and ability to recover. Considering that vulnerability analysis shows the conceptual faults inserted in the ideas of "personal responsibility" and "free choice" (Fineman, 2014, p 122), it is important to recognize that resilience is also generative: "when individuals have resilience it allows them to take advantage of opportunities knowing that if they take a risk and something fails, they have the means to recover" (Fineman, 2014, p 113- 114). In this sense, resilience implies some choices that individuals can make, but it is important to highlight that they can be able to make these choices once the institutions have provided individuals adequate resources to increase their resilience. The degree of resilience an individual has is dependent on the quality and quantity of resources that he or she has at their disposal (Fineman, 2014, p 114). Therefore, the goal of institutions, also in regard to healthcare,

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should be to increase resilience. This means not acting paternalistic because the wills or values of the person who receive these resources that allow him or her to be resilient are maintain and never denied. This notion of choices is not the notion of individual “free choice”, is more adequate thought in terms of deliberation, which in the case of health care system refers to shared decision-making process.

The second reason, as I have argued, an important aspect of this ethical approach is to point out the necessity of understand autonomy in a relational way. This is an important aspect in regard to paternalism. Relational autonomy means that we are all socially constituted, and as such, we need the support of other persons to ground the best conditions for the flourishing of autonomy. In this sense, relational autonomy, understood as a capacity more than a right needs also a process to emerge in the clinical context. At that point, the concept of autonomy, understood in the liberal way, reflect an idea of autonomy that is binary: totally autonomous or totally lack of autonomy. In this regard, it reflects an idea of inclusion and exclusion, which is in, part overcome by the concept of relational autonomy, which is open to understand and integrate different levels of capacity to consent. Therefore, relational autonomy better reflects some kind of situations in which decisions are made together by healthcare professionals and patients and their families, which mean no broad space for paternalism. One of the goals of the kind of relationships described is to foster relational autonomy, and consequently, the capacity of the persons to make decisions, but ensuring the necessary conditions for a better decision-making process.

CONCLUSIONS

The bioethics’ field has mistakenly conceived of autonomy and vulnerability as polar opposites: as human beings, we are constantly and universally both vulnerable and autonomous. Relational approaches maintain the value of autonomy, but avoid the excessive individualism often associated with it. Based on this approach, we can resolve the apparent tension between autonomy and vulnerability. That’s why it is necessary to turn from liberal autonomy concept towards relational autonomy in bioethics. Recognizing vulnerability reveals that there are obligations and duties towards patients that need to be assumed by institutions and the state. These obligations

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include not only protection, but also creation of the conditions for the development and promotion of patient autonomy. Understanding autonomy as a capacity that we need to develop, not as a right or principle, should change our perception of the responsibility of institutions, including the responsibility to recognize protection against the cases where the application of autonomy can be frustrated by oppressive relations.

Through the link between vulnerability and relational autonomy, it is possible to go beyond viewing bioethics as the mere protection of designated vulnerable people. The responsibility should be to provide the expert and social support to promote patient autonomy and empowerment. Ethical reflection about vulnerability should be guided by the value of relational autonomy, while countering the sense of loss of control associated with the dependency the patient experiences and avoiding unjustified paternalism. Just as in truly understanding the human condition, we must recognize there are no more or less vulnerable persons, only those who are more or less resilient. Therefore, healthcare professionals must use their professional knowledge and expertise to foster patient resilience.

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CHAPTER FOUR

VULNERABILITY AS A KEY CONCEPT IN PROFESSIONALISM

INTRODUCTION

This chapter pursues the goal of showing how through the lens of vulnerability theory and the ethics of vulnerability in bioethics that I have explored in chapter two, relationships between patients and families, healthcare professionals and health institutions can be improved. For this purpose, I address the vulnerability in the core of healthcare relationships from three perspectives: patients, healthcare professionals, and the institutions. I argue that professionalism must be sensitive to the complexity of the “nature of everyday practice” (Milliken and Grace, 2015). I maintain that vulnerability theory can contribute to the development of studies on professionalism in healthcare, focusing on paying attention to the environments and systems in which healthcare workers care for patients (Ulrich and Grady, 2018). A broad analysis on vulnerability can lead us to consider the condition of shared vulnerability between patients and the professionals who care for them, which also include the vulnerability in institutions, as a way to improve relationships in healthcare. Vulnerability theory can guide professionalism to incorporate an ethics of vulnerability in healthcare field, focusing on fostering resilience in patients and families, but and less considered in professionalism literature, in healthcare professionals and healthcare institutions. Within bioethical theories and studies about professionalism, the mainstream discourse in literature about vulnerability has been mainly developed attending to patient’s vulnerability as a consequence of illness and suffering. In addition to patients and their families, it is necessary to take into account vulnerability from the perspective of health professionals.

In this chapter, I analyze from an ethical perspective, the professionalism commitment in response to the vulnerability from three perspectives: those seeking professional help, healthcare professionals working inside institutional framework, and the institutions of healthcare. I claim that a broad analysis on vulnerability can lead us to consider the condition of shared vulnerability between patients and the professionals who care for them, which also include the vulnerability in institutions, as a way to improve relationships in healthcare.

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In the framework of vulnerability theory, this chapter focuses on analyzing different faces of healthcare professionalism, emphasizing two main sides. The first one is a relational approach, which means that the main interest is located in understand and explain the way how relationships in this field are shaped by vulnerability. The second aspect to consider is an approach grounded on “patient-centered care”³⁷, that is to say a care motivated for the patient's particular situation. Our response of shared vulnerability is essential in “patient-centered professionalism” in healthcare, and how to introduce this knowledge in healthcare formation and studies is a big challenge that we need to confront.

After a brief approach to vulnerability theory and professionalism in healthcare profession, I start with an analysis of relationships between patients and healthcare professionals from the perspective of patients. Then, I develop some ideas in regard to these relationships from the perspective of professionals. Finally, I will move to the impact that the relationships with the institution has on both patients and healthcare professionals. I focus on both aspects of vulnerability, negative and positive aspects, trying to find some strategies to increase the positive aspects that are involved in vulnerability notion.

VULNERABILITY IN THE CONTEXT OF HEALTHCARE.

Vulnerability is a fundamental aspect in health care (Gjengedal et al, 2013, 128). The recognition of our corporeality, dependence and fragility is everywhere in hospitals and health institutions. In this context, people do suffer or witness suffering on a regular basis, they confront death and fragility in a more noticeable way than in daily life. Acquiring a deeper understanding of vulnerability will be of crucial importance for health care providers.

Vulnerability defines what is to be human, is universal and constant, inherent the human condition (Fineman 2008, 1), and this notion reminds us our corporeality and fragility. This condition is common and shared for all human beings. We all are embodied beings embedded in social

³⁷ Patient-centered care has been defined for IOM as “providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions”. The focus is on the practice of care for patients and their families in manners that are meaningful and valuable from the patient perspective. See Institute of Medicine Committee on Quality of Health Care in American. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academy Press; 2001. There are a huge literature on this term.

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relationships and institutions, inevitably. We have different forms of embodiment, and people are differently situated within social relationships. As Fineman maintains, “while all human beings stand in a position of constant vulnerability, we are individually positioned differently” (2010, 31). But it does not mean that there are different kinds of vulnerability. As it has been shown, Fineman objects to applying the term vulnerability only to specific groups. As she argues, “this targeted group approach to the idea of vulnerability ignores its universality and inappropriately constructs relationships of difference and distance between individuals and groups within society” (Fineman, 2012, p 85). We are all inevitably dependent on the cooperation of others. As Luna (2009, p 129) maintains, vulnerability is inherently a “relational” term: “it concerns the relation between the person or a group of persons and the circumstances or the context (...) It is not a category or a label we can just put on”.

Vulnerability contains an inherent paradox: it can be used both to diagnose the “is” and the “ought”, and that is one of the reasons why using vulnerability as a critical tool involves exploring how societal or institutional arrangements originate, sustain, and reinforce vulnerabilities (Peroni and Timmer, 2013, p 1059). In this regard, vulnerability is not only a negative condition; on the contrary, vulnerability can provide positive or negative results (Gilson, 2011; Fineman, 2012; Zagorac, 2017). In fact, recognizing the positive aspects of it can improve experiences of people isolation and exclusion. Vulnerability is also generative, because presents opportunities for innovation and growth in the core of relationships (Fineman 2012, 71). In this sense, in the core of vulnerability theory, resilience is the response to face vulnerability. From the perspective of healthcare work, this generative character of vulnerability should be deeper explored, because it contains a very huge potential to improve relationships in this field. On the one hand, some personal experiences of patients show how in the core of illness people sometimes develop a huge resilience, which also can encourage other patients facing similar situations. In addition, the kind of circumstances that healthcare professionals have to face in everyday practice also can be an opportunity for them to develop resilience, which will be useful in both their work and personal life. The shared vulnerability at the workplace can provide the opportunity “to design and implement inter-professional approaches that can improve resilience among teams of co-workers” (Haramati and Weissinger, 2015). This must be a commitment for educators, administrators, and academic

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health leaders.

Moreover, resilience is not a personal choice, and it is directly linked with the capacity of the state and institutions to foster it. Fineman has highlighted that the understanding of inevitability of vulnerability leads us to better understand and redefine our responsibilities as a society. The nature of human vulnerability constitutes the basis for claim that the state must be more responsive: “the ultimate objective of a vulnerability analysis is to argue that the state must be more responsive to, and responsible for, vulnerability” (Fineman 2008, 13). The institutional responsibility to foster resilience in individuals and communities is one of the main challenges of the vulnerability theory. How professionals and institutions can build resilience? In this regard, and focusing on healthcare, it is important to analyze what are some of the strategies that healthcare institutions and healthcare faculties can implement to try to improve resilience in professionals and also, patients and their families.

PROFESSIONALISM IN HEALTHCARE CONTEXT

In general, professionalism refers to the set of values and skills that characterize the essence of a professional work. A healthcare professionals’ ability and willingness to act according to accepted moral norms and values is one key component of professional behavior (Carrese et al. 2015, 744). In brief, professionalism involves practical, ethical and legal aspects. Following Vivanco and Delgado-Bolton (2015) analyses of the term, it is difficult to find only one definition of professionalism. There is certain general agreement of the principal elements of healthcare professionalism. However, having a definition offers important problems due to the interdisciplinary framework around the term and also because of the social inequalities and cultural differences involved in the healthcare practice in a global context. The conceptual framework of professionalism includes professional qualities and skills that have been accepted to constitute what is consider professional work, and is a kind of knowledge reached from three essential bases: clinical skills, communicative skills, and correct understanding of ethical and legal framework of the professional behavior (Vivanco and Delgado-Bolton, 2015, p 4). Based on these three elements, the main characteristics and core values of medical and healthcare professionalism are built: excellence, humanism, accountability, and altruism, as Stern (2016) sustains. This definition understands

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professionalism as a set of virtues to which professionals aspire and it constitute the horizon where to go.

Defining medical Professionalism, The Medical Professionalism Project³⁸ resulted in a professionalism charter consisting of virtue-based personal attributes: altruism, trust, honesty, patient empowerment and commitment to social justice. In addition, some projects have been conducted, especially about how to educate new residents and students on these professional values. The traditional approach and definitions of professionalism lead to understand professionalism as an individual competency, acquired in the core of the professional framework of values, duties and practical abilities. In this sense, one of the problems about this way to understand professionalism is the fracture between the theoretical and practical issues. As Shapiro et al. (2015, p 2) argue, the focus on the personal skills, and particularly on abstract virtues and attributes have proved difficult to translate into daily actions. In addition, the majority of approaches to teach professionalism rooted on the competency model have not reported significant success (Shapiro et al, 2015, p 2). Due to that, in recent years, there is a call to move from abstraction to practice. For instance, one fundamental argument of the PRIME (The Project to Rebalance and Integrate Medical Education Investigators) project is that professionalism must include the application of virtues to the practice of Medicine. The proposal of Shapiro et al. (2015) is to promote the study of Literature as a way to learn in an emotionally and critically engage way, to learn how characters face moral dilemmas, solve them and the consequences of those resolutions. They found literature as an essential element of medical education.

PRIME scholars have defined professionalism based on three main ideas: “professionalism as (1) becoming scientifically and clinically competent; (2) using clinical knowledge and skills primarily for the protection and promotion of the patient’s health-related interests, keeping self-interest systematically secondary; and (3) sustaining medicine as a public trust, rather than as a guild primarily concerned with protecting the economic, political, and social power of its members” (Carrese et al. 2015, Doukas et al. 2013).

³⁸ This project was initiated by the American Board of Internal Medicine Foundation, the American College of Physicians Foundation, and the European Federation of Internal Medicine.

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However, I argue that professionalism nowadays needs to include the complexity of professional work in healthcare systems, which has a very huge impact in the way how those professionals deal with these skills and values are performed that conform the profession. In fact, as I maintain, professionalism in healthcare is shaped by patient-centered care claim, by the complexity of institutions and systems of healthcare where professionals work, and also shaped by society and their expectancies and trust on healthcare professions.

In the introduction of the book *Patient Care and professionalism*³⁹, DeAngelis (ed) (2014) highlights that “the question that has occupied much often recent literature on professionalism is the extent to which the ideal conception of professionalism has survived and can survive in health systems whose services are increasingly being commoditized, whose modus operandum is increasingly being commercialized, and in which patients increasingly are viewed not only as objects of compassion, but as biological structures yielding cash flows that can be traded in the market” (DeAngelis (ed), 2014). One of the ideas that underlies in this criticism is the problem about the fragmentation that the professions of healthcare have to face nowadays. This fragmentation is also in the core of healthcare systems and professions nowadays. As Mildred Z. Solomon has pointed out in an interviewed I had the privileged to conduct:

“Right now, American patients confront a Health Care system that is very compartmentalized, very fragmented and if you have an advanced illness you are likely to be cared for very different specialist. And no one, very often, not always, but very often, nobody feels responsible to help organize and to sit down all the specialists, with the family and come up with a plan that meets families and the patient desires. Everybody just mainly focuses on their specialty...But nobody really says “What is your prognosis, how would you like to spend the last phase of your life?”. Nobody is really articulating what the actual situation is in the person’s life, and helping them navigate that. So, I think it is a responsibility of hospital system arrange for

³⁹ This book is a broad analyses of professionalism in medicine from different perspectives: the patients, nursing, medicine, public health, the role of the law and legal systems and politics. Particularly interesting, the first chapter discusses medical professionalism from the patient’s perspective. It addresses whether increasing team- working in ‘patient-centred care’ and ‘multidisciplinary’ teams has altered physicians’ concept of their own professionalism.

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conversations like that and to have someone responsible for bringing all of them together for family consultations. The other question is what are the society obligations. We have focused so much of our attention and so much about financial resources on acute care in hospitals, and so much less on the social needs that the elderly experience and social and logistical needs.

Even recognizing the positive aspects of professionalism, some authors, as Pellegrino (2012), criticize the current movement towards "professionalism", considering that professionalism weakens the morally binding language of traditional medical ethics "by emphasizing attitudes, behaviors and affects rather than professed duties" (Pellegrino, 2012, p 22). He considers, teaching professionalism emphasizes nurturing medical student instead of the unavoidable duties of truly professing to serve the patient. For him, professionalism does not have the moral force of the vast demands made by those who "profess" healers. Against this criticism, I argue that professionalism has a very powerful normative force, but that it is necessary to develop new lines of research that reinforce it. That is the purpose of this chapter, as well as chapter five, in which I develop the concept of asymmetrical responsibility as a key concept to develop a more sensitive professionalism, likely more connected with Pellegrino's claim⁴⁰.

I argue that the majority of explanations and definitions of professionalism does not consider seriously the ethical demands of the relationships involved in healthcare field from the perspective of the effect that care has in healthcare professionals. In which manner the difficult situations that professionals face can have an impact on their integrity, self-confidence or well-being? Is it not a question directly related to professional values, since it has a deep impact in the quality of care that patients received? I consider that this set of concerns, which is referred to how daily work can undermine the personality, the mood and well-being of professionals should be necessarily took into account in the center of professionalism reflections. In this sense, I consider the importance to introduce a relational approach in the studies on professionalism in healthcare regard to the role of vulnerability in the core of these relationships in healthcare.

⁴⁰ Pellegrino (2012) maintains that medical ethics is primarily about caring for the good of the patients, which means each patient, and society as a whole, depends upon the physician's formation of a good character, i.e., on the acquisition of the virtues that make for a good physician. He claims that virtue is an unavoidable element in any system of medical ethics.

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I claim the necessity of a relational turn in the way to think and progress professionalism in healthcare field. Vulnerability theory along with relational theories can contribute to this turn, since the way how relationships are created, in the particular health care institutional environment, can lead to fostering resilience or the contrary. At the heart of these relationships between patients and families, healthcare professionals and institutions is where it is possible to foster resilience. Considering this, the analyses about professionalism involve not only the professional's responsibility, but also the institutional responsibility concerning how to improve tools and strategies to benefit both patients and professionals, as well as the relationship between them and with the institution. To address this turn, I propose the term relational patient-centered professionalism. In the next section, I consider the main characteristic of this concept.

A RELATIONAL PATIENT-CENTERED PROFESSIONALISM.

Vulnerability theory provides a necessary framework to analyze professionalism in healthcare field. Focusing on the relationships between patients, health care workers and leaders and institutional policies, this approach can contribute to a deeper reflection about how to improve the capacity of all these actors to face vulnerability, emphasizing the responsibility of the healthcare institutions on address it. This way of understand professionalism is what I call "relational patient-centered professionalism". One of the main problems of professionalism in healthcare is the fracture between the normative reflection about moral values, skills and abilities that professionals need to develop and incorporate in healthcare systems and the reality of the complexity and stressful environment of healthcare systems. If this gap between the real and difficult situations that healthcare professionals need to face and the moral values and skills involved on this kind of work is not adequately address, taking into account the context, healthcare professionals cannot face the challenges that day by day work requires (Ulrich et al, 2010; Milliken and Grace, 2015). Healthcare systems need courage and leadership to cultivate open, reflective moral communities that interrogate the disconnect between ideals and the realities of healthcare practice in ways that can relieve individual moral distress as well as transform healthcare culture more broadly (Perni, 2017). Nancy Berlinger (2016, 176) has analyzed these disruptions between ideals and reality broadly:

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“There are limits to thinking of professional ethics in terms of virtues- being caring, being compassionate, being respectful- if healthcare professionals see few ways to put these virtues into practice. Framing professional ethics in terms of an idealized physician -patient relationship is insufficient, as this is closed off from the reality of the complex system professionals and patients have to contend with. Similarly, describing the duties of health care professionals is insufficient without acknowledging the conditions of complexity and how flawed systems can impede individual or team efforts to do good and prevent harm (...) Thinking about the complex systems as a "moral space" that must always be open to the discussion of questions of right and wrong action, of justice and injustice, may help us grapple with the continuing challenge of creating and sustaining health care systems that are safe, effective, compassionate and just”.

In this regard, my proposal of a relational patient-centered professionalism is aligned with the patient-centered care and the relationship-centered care (Beach et al, 2006; Nundy and Oswald, 2014). While patient-centered care is an important innovation developed in the past two decades, and which is now a component of the Triple Aim (Berwick et al, 2008)⁴¹, relationship-centered care has been proposed as a new paradigm for population health management. Relationship-centered care is an important framework for conceptualizing healthcare, focusing on the central role of relationships in healthcare and the broader healthcare delivery system. Beach et al (2006) define relationship-centered care as “care in which all participants appreciate the importance of their relationships with one another”. In addition, they found relationship-centered care in four principles (Beach et al, 2006, 4):

- 1.- Relationships in healthcare ought to include dimensions of personhood as well as roles.
- 2.- Affect and emotion are important components of relationships in healthcare.
- 3.- All healthcare relationships occur in the context of reciprocal influence.
- 4.- Relationship-centered care has a moral foundation.

⁴¹ Triple aim refers a series of goals that the United States must follow to achieve high-value healthcare. Those goals are called the “Triple Aim”: improving the individual experience of care; improving the health of populations; and reducing the per capita costs of care for populations. See Berwick et al (2008).

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In addition, Nundy and Oswald (2014) maintain that "relationship-centered care and patient-centered care are fully compatible and synergistic with each other". Moving toward value-based care, they propose the combination of both as a foundational base to healthcare delivery innovation, especially when these kinds of innovations are closely tied to population health management. One of the important aspects to consider about relationship centered-care is the centrality of relationships between patients and clinicians, but also this model emphasizes the relationships of clinicians with themselves, with each other and with community (Beach et al, p 3). In this regard, I propose to include a relational patient-centered professionalism as a way to improve professionalism studies, beyond individualistic view on skills and values that clinicians must cultivate. As I have maintained, a relational turn in professionalism is required.

How to create or understand this turn towards a relational patient-centered professionalism? I argue it is essential to recognize the importance of vulnerability approach⁴² as a key element in healthcare context, and in the attempt to improving professional values. As I have maintained, vulnerability is also a relational term (Luna, 2009, p129). I consider a more responsive and sensitive professionalism, more connected with day-by-day practice, can be improved through the focus on vulnerability as a shared condition. At the same time, I maintain the importance of deeply analyze how relationships in healthcare context are affected by a range of circumstances, some of them can benefit relationships, while other obstructer them. As Pellegrino (2012, p 22) argues, every healthcare system and policy has its collective pathway in an interpersonal relationship. Accentuating the notion of relations based on care, I analyze the contributions that an introduction of vulnerability approach in professional studies can reached.

For address this turn to a relational centered-care professionalism, in this chapter I suggest a triple approximation. First, we have to attend to the perspective of the patient and their families. A patient centered care need to take firstly into consideration "the patient's perception of the good" (Pellegrino, 2001, p 569)⁴³. This focus also needs to be complemented by studies that show how

⁴² In this regard, vulnerability theory focus on the concept of vulnerability, as well as in the concept of dependency and inequality. All of these concepts are relevant in regard to professionalism. I address the issue about inequalities in the next chapter, focusing on the structure of relationships base on care.

⁴³ Pellegrino defines the good of the patient in tangible terms connected to the phenomenology of the clinical encounter. The good of the patients is explained as a quadripartite good, a complex relationship between medical, personal, human, and spiritual good. This concept creates the duties of the clinician. As he concludes, a theory of the

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some models of relationship can be oppressive relationships. Moreover, these oppressive relationships may go unnoticed by the professionals themselves, therefore, it is necessary to develop strategies to detect and stop this type of relationship (Thensen, 2005). Secondly, in health field, vulnerability of professionals must be recognized and studied broadly. In addition, from the recognition of professional's own vulnerability, positive situations can be generated that give rise to closer relationships of trust and help between professionals and patients, since vulnerability is also generative (Fineman, 2012, p. 96)⁴⁴. In this way, she argues "human vulnerability should be understood as providing the compelling impetus for the creation of social relationships and institutions" (Fineman, 2015, p 614). Finally, professionalism must be nurtured by an institutional analyzes. Fineman (2015, p 615) maintains that our social roles, relationships, and institutions are also inherently vulnerable because they are human constructions. In this regard, institutions can evolve in both negative and positive ways. Negative, for instance, refers to a decline and decay or corruption and capture; positive means enhancement and augmentation or development and enrichment. Especially, I consider crucial to analyze the role of institutions regarding the kind of circumstances that can trigger adverse situations, such moral distress. In this sense, it is essential to generate an institutional culture with a strong ethical commitment that is attentive to the demands and needs of both patients and professionals. Without this institutional support, no change is possible. This is the greatest challenge of health care professionalism in our days.

good of the patient has applicability for the ethics of the other healing and helping professions and the virtues and principles pertinent to their practitioners as well. See Pellegrino (2001).

⁴⁴Alyson Cole (2016) analyzes a series of concerns about vulnerability as an alternative language to conceptualize injustice and politicize the injuries that accompany it. She finds problematic theories about vulnerability emphasizing its universality and amplifying its generation capacity, like Martha Fineman's theory. She states that these theories dilute perceptions of inequality and confuse important distinctions between specific vulnerabilities, as well as the differences between the wounded and those who are already injured. From her point of view, vulnerability specialists have not yet traced the path from the recognition of constitutive vulnerability to the treatment of concrete injustices. However, following Fineman's theory of vulnerability, "the most significant aspect of making vulnerability central to discussions about responsibility and policy is that attention is necessarily called to the individual's location within webs of social, economic, political, and institutional relationships that structure opportunities and options" (Fineman, 2012, p 99).

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VULNERABILITY FROM THE PERSPECTIVE OF THOSE SEEKING PROFESSIONAL HELP

Mainstream discourse in bioethics focuses on vulnerability as a particular feature of patients because of the illness, death proximity, dependence, uncertainty, etc. In her analyses of vulnerability in bioethics, L. Feito (2007, 19) explains how the experience of disease imply all human existence, the reality of the human as such:

- The disease makes patent the bodily condition of human existence, that is, the body determination of identity. The disease condition shows the limitations that we can suffer.
- It reveals "coexistence", the constitutive opening of existence human being to the "other", who is characterized on necessity and helpful assistance.
- Vulnerability is manifested as a permanent susceptibility of existence to destruction.
- Pain is constitutive susceptibility of human existence.

Feito (2007, 20) also highlights that the relationship between health professional and patient is based on interpersonal aspects of care, in the ability to perceive the needs and understand the situation of vulnerability in which the patient is. The patient can be suffering, he or she may feel fear or anguish, may have uncertainty and doubts, is in a situation where probably needs support and understanding, in which he or she perceives him/herself as fragile or dependent, and in which the professional health care provider becomes someone who can give help, advice, and relief. Consequently, the patient relies on that professional of whom he or she expects at least respect and reliability, technical knowledge, professional competence, prudent knowledge, good relationship and care. In this context, and also from the perspective of care ethics, professionals understand the vulnerability of patients in terms of expressing their needs and demands, sometimes derived from dependency.

Along with these features that highlight the negative aspects of disease, disease's experience is also the capacity of appropriation: the fact that the person can do and personally makes his or her own experience, even when it is painful (Feito, 2007, p 19). Appropriation is understood as an act of creation and an act of interpretation. All this, in the final analysis, refers to

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the valuable condition of human existence. As vulnerability theory stands, the capacity of growth is in the core of vulnerability (Fineman 2012, 96). In a synthesis of the literature (Molina et al. 2014) about resilience in different stages of cancer, with a patient-centered care focus, the review provided important information to consider at each stage of the continuum and offered healthcare providers and researcher different forms of resilience to incorporate in the patient care process. The authors concluded that promoting resilience is a critical element of patient-centered psychosocial care, and multidisciplinary healthcare teams can foster resilience by recognizing and improving features of resilience through the cancer continuum. A strong commitment from healthcare teams is needed in order to develop programs and interventions oriented to foster resilience in patients. But this is not only a concern of multidisciplinary teams. It should be a responsible and one of the priorities of policies in healthcare institutions. There is a need in healthcare institutions for training to improve resilience among patients through educational programs (Ghanei Gheshlagh et al., 2016, 8).

The focus on the patients and their families' view is one of the main achievements of a patient-centered care approach in healthcare. Spiers (2000) shows a perspective of vulnerability in healthcare field (in Nursing studies) based on distinguishing between the concepts of risk and experience. From her perspective, "risk consists of assumptions from etic or external evaluation of relative danger while lived experience informs an emic or personal interpretation" (Spiers 2000, 715)⁴⁵. An etic view includes normative social values as well as social support for intervention. An emic view of vulnerability is founded on perception of challenge to personal integrity and the universal and mutual nature of the phenomenon. Regarding vulnerability, emic approaches to vulnerability are experiential and qualitative, while etic descriptions involve the identification of individuals or groups that are at particular risk according to normative standards derived from the general population.

⁴⁵ These terms were originally developed in anthropology. The *etic* perspective refers to the descriptions that are used to explain the existing external schema, whereas the *emic* perspective designates the structure of a language or culture in terms of its internal elements and their function. In ethnographic research, the *etic* perspective is used to describe phenomena seen by someone outside the experience, while the *emic* perspective refers to a description of phenomena as understood by the person.

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Healthcare practice that focuses on risk factors can overlook the essential elements of vulnerability, while from an emic perspective vulnerability is not defined by a pre-established dimension (age, sex or education, among others) (Spiers 2000, 719). Vulnerability refers to whole experience rather than a priori determinants based on population norms. The emic view provides a framework for understanding how people integrate and handle multiple challenges in their daily experience.⁴⁶ The emic method can be addressed from different approaches. Some of them, the most helpful in health care field in order to try to catch the personal experience of illness as well as the professionals, are qualitative research and narrative medicine. In general, a narrative approach in daily healthcare encounters consists mainly on a specific openness towards patients and their stories in the practice of medicine and nursing, using narrative skills (Kalitzkus and Matthiessen 2009)⁴⁷. Health care professionals, as well as patients and their families, can learn about different ways how people experience and face vulnerability.

In regard to professionalism, Barnard (2016) develops an approach based on the professional's commitment to trustworthiness in response to the vulnerability, focusing on the perspective of those seeking professional help. Barnard suggests three conceptions to an analysis of vulnerability and trustworthiness in the context of professionalism:

- 1.- Significance of individualized dialogue in regard to the gain a patient's or family's justified trust.
- 2.- Notion of social determinants of trust.
- 3.- Idea of shared vulnerability between patients and the professionals who care for them.

For my purpose, I focus on the third aspect. His starting point is the recognition of shared vulnerability between patients and professionals. But, at the same time, the relationship between

⁴⁶ In her article, one of the best contributions is that Spiers invite us to think about more broad questions: "Do challenges perceived to be within one's sphere of control result in different experiences of vulnerability than those experienced as outside one's control? What prevents people from acknowledging themselves as vulnerable? What are the health consequences when a person sees him/herself as vulnerable but others do not? What challenges to integrity are stigmatized and how does this influence both acknowledgement and experience of vulnerability?" Spiers, J (2000), p 720.

⁴⁷ Some of these skills are: a) sensitivity for consider the context of the person and his or her illness' experience from his or her own perspective, b) highlight the importance of the individual context, and not only in the context of a systematic description of the disease and its etiology, c) narrative communication skills: exploring differences and connections, hypothesizing, strategizing, sharing power, reflection active listening, and circular questioning and d) self-reflection.

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health professionals and patients is not a relation between equal actors⁴⁸. When patients trust professionals, they expect not being exploit for the professionals own self-interested ends, not increase their vulnerability through paternalistic or degrading forms of help that perpetuate dependency or undermine self-esteem, and finally, they expect that professionals can diminish their vulnerability by alleviating sources of vulnerability related to disease, alleviate sources of health-related vulnerability aggravated by social, political, or economic arrangements and enhancing their capacity for self-determination (Barnard, 2016, 294). Barnard proposes a principle to generate the healthcare professional's commitment to trustworthiness in response to the vulnerability of those seeking professional help. He grounds these elements in a broad understanding of vulnerability, what also include the modes in which healthcare professionals can intensify the experience of vulnerability as a function of a particular professional's dehumanizing manner of providing help.

Sometimes healthcare professionals appear in front of patients as oppressors, and the culture of medicine and healthcare need to admit and counteract the experiences of humiliation reported by patients. In this regard, self-awareness has an important role as the key to improve the healthcare professionals- patient relationship. A broad reflection about oppression in health care field is needed. Specially, considering it as a structural oppression following Young (1990) philosophy.⁴⁹ Thesen (2005)⁵⁰ has developed a model to explain how some doctors (and it can be extended to other health care professionals) can adopt the role of oppressors in medical encounter.

⁴⁸ I develop the concept of relations of care as relations of inequality in the next chapter.

⁴⁹ According to Iris Marion Young, there are "five faces of oppression": violence, exploitation, marginalization, powerlessness, and cultural imperialism. In these five categories, she conveys how the social constructs affect and shape the individual. Each of these forms of oppression overlaps with the other. This framework focuses on the ways in which people experience oppressive conditions in their daily lives. See: Young IM. (1990) Justice and the politics of difference. Princeton, NJ: Princeton University Press.

⁵⁰ Thesen explains in her article that she started thinking about the problem of oppression after conducting a study of the experience of users of psychiatric services (in this article called "Study of experience"). Users described dehumanizing experiences of being reclassified as the stigmatized "other". She explains that they presented convincing and harsh experiences of oppression, lack of love and lack of life of their own, mainly in their encounter with people from their local community, but also in health and social services. Her findings leaded her to think that the dominant person in a human encounter sometimes stigmatizes and harasses the other, and that doctors are no exception. After this research, she asked herself why do doctors like her assume the role of oppressor in medical encounters. She also asked herself if the reason for that is due to personal deficiencies, or if there is a more structural reason. She decided to try to explain how could the oppressive process be described. Other concern she expresses arose from this previous study is that if she recognizes that sometimes she acted as an oppressor of her patients, how could this behavior change? And finally, why all of this behavior is invisible for the clinicians.

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Furthermore, she tries to know if this behavior responds to more structural reasons and not only is an issue of personal character. To face this problem, she proposes an “Oppression Model” in order to improve and better understand the role of oppressors in healthcare systems. She bases her approach on the premise that every physician can act as an oppressor without being aware of it. She uses a staircase as metaphor to illustrate the “Oppression Model” (See Figure 1), the progressive temporal and structural relationship between objectifying stereotypes and institutional oppression. On the basis of objectification, the different stages, which can be overlaid are stereotypes, prejudices, discrimination and oppression. She also offers a way to try to change this behavior, what she designates the “Empowerment Track” (See Figure 2). In this case, on the basis of acknowledge, different steps are constituted by diversity, positive regard, solidarity and empowerment. Self-criticism and self-reflection are essential in the understanding of professional behavior. This tool can be used in the training of healthcare professionals trying to avoid oppression.

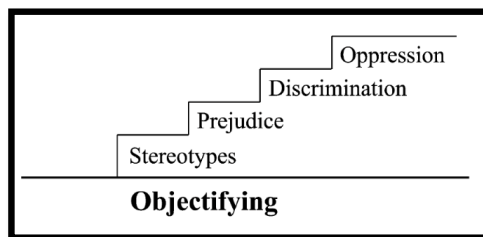


Figure 1.
 The Oppression Model.
 Source: Thensen, 2005.

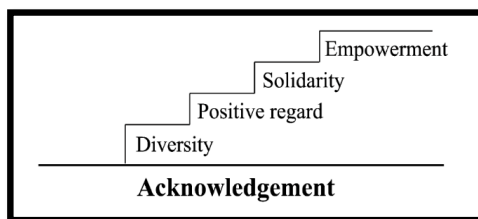


Figure 2.
 The Empowerment Track.
 Source: Thensen, 2005.

This reflection also leads me to re-think the role of healthcare professionals as providers of resilience to patients who are in a situation of dependence. As mentioned before, the relationship

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between healthcare professionals and patient is not a “transaction”, is a relationship of care. At the same time, the oppressive behavior can be grounded on a structural process. As a consequence, it is necessary to call for a more responsive involvement from the institutions in the attempt to design guidelines of professionalism to understand first, and then, to counteract this problem.

To summarize, I have analyzed the importance of recognizing shared vulnerability in healthcare context, but highlighting the perspective of patients. On the one hand, it is important to understand the experience of disease affecting all human existence, the reality of the human as such. On the other hand, exploring and analyzing the idea of shared vulnerability between patients and the professionals who care for them can lead a professionalism to turn in a more responsive way. Since relationships in healthcare are unequal, it is important to paying particular attention at the different ways how professionals can create dehumanizing relationships and oppression, and develop ways to overcome it.

THE HEALTHCARE PROFESSIONAL’S VULNERABILITY

Professionals bring their own vulnerabilities to their encounters with patients. And also, professionals’ vulnerability arise from their everyday practice, from the fact to confront suffer, pain, death day by day. Carel (2009) analyzes in an extraordinary article what she names vulnerability in the face of vulnerability: the vulnerability nursing staff experience in the face of their patients’ *more-than-ordinary vulnerability*. According to her, this type of vulnerability is linked to the view that ordinary vulnerability and *more-than-ordinary vulnerability* are on a continuum, using Sellman (2005) terminology⁵¹.

Healthcare professionals repeatedly witness suffering and they are involved in the attempt to limit it by offering treatment or care. To be witness of all of this has an impact in their own lives, and it constitutes a form of vulnerability. Carel (2009) stands that nursing staff may themselves be

⁵¹ The article published by Carel is written as a response to Sellman’s article, confronting some of their arguments. That is why she uses the same terminology that Sellman. Sellman distinguish between ordinarily vulnerable people and more-than-ordinarily vulnerable people. While all people are vulnerable, all patients are more-than-ordinarily vulnerable and this restricts their potential to flourish. For him, nurses are well placed to contribute to the flourishing of more-than-ordinarily vulnerable persons and he claims that this ‘protective’ function is a legitimate and fundamental part of the role of nurses.

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prone to *more-than-ordinary vulnerability*, since they are routinely exposed to stressors that are not ordinarily encountered by most people in their everyday life. They may witness pain, death, illness, loss, anger, anxiety and grief. These situations cut deeply into the most existential aspects of human life: birth and death, love and loss, suffering and recognizing our limitations. These circumstances put the professionals in a unique position of vulnerability. In this regard, vulnerability is experienced by professionals because of their profession, is a part of their work. Not recognizing our vulnerability may come at a cost for both nursing staff and patients and their families. As Ulrich and Grady (2018, p 2) argue, each day clinicians interact with human health and illness: “While caring for patients and their families, healthcare professionals share and reflect on the joys and sorrows that accompany these interactions. In many ways, they are suffering too”

Kimberly Manning⁵² tell one story that recreates one example about this experience of vulnerability:

“Heavy on My Soul”

- “You okay, doc?”

- “Who me?” I pointed at my chest.

- “Yeah, you.”

I turned my head away from the television and back toward him. I poked out my lip and furrowed my brow.

- “Look like you got something heavy on your soul.”

Heavy on my soul. I didn’t say anything. Instead I just stared at him, surprised at how warm my face was becoming and how my eyes were stinging with tears.

- “I’m okay,” I finally said, speaking quietly. “But yes. That’s a good way to put it.”

⁵² Kimberly Manning is a hospitalist at Grady Memorial Hospital in Atlanta, an associate professor of medicine at Emory, and an adviser in the Semmelweis Society. Her interests include humanism in medicine and the use of reflective writing. She practices what she preaches by writing a blog about her experiences at Grady. “I write to share the human aspects of medicine and teaching and work-life balance,” Manning says, “and to honor the public hospital and her patients, but never at the expense of patient privacy or dignity.” She also writes about her frustrations and ways that she stays energized and optimistic in the face of daunting amounts of human tragedy. Usually, she copes very well, finding joy in the job on most days. This is not a story about one of those days.

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I wanted to tell him. I wanted to tell my patient all about what was weighing me down.

But I was his doctor. So when he asked, I just stayed silent. As soon as I got out of there, I turned my forehead into the nearest wall and let myself cry. I could feel the people looking at me as they walked by, their feet slowing down and wondering what could be going on with this doctor and the muffled, guttural sounds she was making. No one said anything.

Maybe my actions spoke enough. I mean, whatever it was had to be awful.

A doctor facing a wall with shoulders shaking and body heaving in a stiff white coat said plenty.

—Dr. Kimberly Manning’s blog, “Reflections of a Grady Doctor”⁵³

Carel (2009) argues that there is "a vulnerability that arises out of the experience of others' vulnerability, and this type of vulnerability may require more recognition by the profession. Working as a nurse brings with it an almost daily reminder of the fallibility of human flesh and spirit and the fragility of human life and goods. This, in turn, is a lesson in vulnerability"(Carel, 2009, 218). This learning can't be explicitly addressed in training, supervision or practice, but is one of the deepest learning a human could assimilate. I emphasize that there is a distinction between the individual and the professional role on experiencing vulnerability. As progressive-caught with the professional structures, the professionals confine mandate actions in the core of their professional role. The institutional framework of the profession is ever present.

On the other hand, Carel also maintains that the lesson of vulnerability is not a pessimistic one: vulnerability also suggests a relationship of openness to the world. In order to flourish we must let ourselves be vulnerable: this vulnerability is also the gate to creativity and flourishing (Carel, 2009, 218). According to vulnerability theory, vulnerability is not only a negative condition, but it must be first accepted and not ignored. Indeed, recognizing the positive aspects of vulnerability can improve the experiences of people in terms of isolation and exclusion, because vulnerability is also generative. "Importantly, our vulnerability presents opportunities for innovation and growth, creativity and fulfilment" (Fineman, 2012, 96). Some of these positive aspects of vulnerability can improve the relationships in health care field. In addition, I argue that vulnerability can promote

⁵³ To read the whole story, visit <http://www.gradydoctor.com/2017/07/heavy-on-my-soul.html>.

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empathy and solidarity in healthcare relationships and it should be esteemed rather than avoided. But “the ability to translate shared vulnerability into therapeutic relationships requires continuing self-awareness and self-care” (Barnard 2016, 297).

However, it is not easy to explore or research how this recognition of shared vulnerability influence positively the relationships in healthcare. Kirsti Malterud and co-authors (2005a, 2005b and 2009) have explored extensively vulnerability in regard to healthcare professionals. Especially, their studies analyze, through a qualitative research, how vulnerability can be a strength for healthcare professionals. The starting point is the idea that vulnerability is or could be a potential strength in healthcare relationships (2005a). They explore clinical events during which vulnerability had been perceived and exposed in a way appreciated by the patient (2009). In one of the researches, they describe two kind of situations that conduct physicians to expose their vulnerability: the identification with the patients’ circumstances or situation and the feelings of uncertainty. The data suggest that vulnerability experienced for doctors and exposed to patients in one of these two manners can increase the doctor’s responsiveness of sensitive matters (Maltreud et al. 2009, 88).

The authors also highlight that while vulnerability gives strength, it also must be used prudently. On the one side, it can help professionals to build trust and the patient can feel more taken care of. On the other hand, when the doctor’s emotions are exposed primarily in the service of the doctor, it can give the patient a feeling of not being taken care of. According to this aspect, Eva Gjengedal et al. (2013) finds two principal strategies in the professionals’ interactions with patients which are relevant from patient-centered cared perspective. They sustain that if the main purposes at understanding the patients or families is from the professional’s own personal perspective, it ends in excess attention to the professional’s own reactions, which impair the help relationship. But if the professionals try to understand the patients or families from the patients’ or families’ own perspective, this strategy make vulnerability bearable and also turn it into strength. Focusing on the interaction between health professionals and patients, existential, contextual, and relational dimensions of vulnerability, the authors consider that “being sensitive to the vulnerability of the other may be a key to acting ethically” (Gjengedal et al. 2013, 127).

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In other research, Kirsti Malterud and Hollnagel (2005b) have conducted a qualitative study based on memory work, a structured approach to transform memories into written texts. On this occasion, they were also looking for clinical events during which vulnerability was perceived in a positive way from the patient perspective. They identified two kinds of disclosure of vulnerability: spontaneously appearing emotions and moments when professionals considered sharing their own experiences. This study illuminates how vulnerability is a human feature, and the doctor does not always have the option of balancing the benefits and damages of expressing emotions. Into the clinical context, “the doctor’s perception and exposure of emotions are essential to understand patients and their problems and to recognize the distinctive relational character of general practice” (Malterud and Hollnagel 2005b, 352). These experiences can help the patient to face their own situation and may lead to constructive interaction in health care relationships. Finally, they argue that the clinician’s training should include reflexivity, especially about the spontaneous emotions of health care professionals. It is necessary to learn more about how responsible and responsive emotional knowing can be enacted, admitting our own vulnerability when recognizing the patient’s needs. These studies illustrate the important role of understand relationships in healthcare as an opportunity to turn professional’s own vulnerability into strengths that improve the relation of trust and help with patients.

To sum up, I have shown how understanding vulnerability as an unavoidable shared condition, can be a value and not a weakness. In this regard, this framework can increase trust and empathy in healthcare relationships. Recognizing the fact that vulnerability can be a strength in the context of healthcare professionals can lead professionalism to a deeper understanding of the impact of relationships in healthcare professionals. It can be a contribution in the attempt to overcome the fracture between professionalism theory and everyday practice.

THE ROLE OF INSTITUTIONS OF HEALTHCARE

Susan Dorr (2001) argues the contractual model of individual-institutional relationships is completely inadequate for healthcare institutions because the relationships are not between equals. Even more, this relationship between patients and institutions is crucial: “the basis for an adequate

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moral theory of healthcare organizations is thus more appropriately grounded in their relations” (Dorr, 2001, 28). She explores what conditions could influence trust in healthcare institutions, and contrast them with conditions that influence trustworthiness. From her view, a trust-based relationship presupposes the vulnerability, reliance, and dependence. In healthcare she considers that vulnerability arises from the experience of illness, from the imbalance between physicians' and patients' knowledge, from patients' lack of power within healthcare institutions, and from the importance of health and well-being. Health, well-being, and private information are the “trust objects”. She focuses on patients’ vulnerability in regard to illness. Patients are vulnerable to both healthcare professionals and institutions. Inequities of power, particularly of knowledge, are inevitable in both types of relationships. For Dorr, trust in an organization depends on the actions of individuals in it, and trust in individuals depends on trust in their organization which implies multiple levels of analyzes in the interaction. Organizations desiring the highest levels of trust, based on shared values, they have to go beyond minimum standards of openness and honesty and incorporate the voices of those whose trust they seek (Dorr 2001, 32)

While the relationship between patients and institutions has not been enough developed, and it should be, the relationship between the institution and healthcare professionals has been broadly studied, attending particularly to how this relationship affects workers’ health and well-being. Healthcare leaders has the important role to create and sustain an organizational environment that optimizes high-quality, safe and effective patient-centered care. It is not only necessary to ensure the best possible physical environment, rather extends to providing an organizational culture that supports healthcare team members in the often stressful work of care provision (Pipe et al, 2011). An organizational responsibility is to empower healthcare staff with effective skills and techniques to help them transform stressful situations into more therapeutic and efficient scenarios. Through the personal stress management techniques professionals can acquire a better awareness of self and others and more effective communication. This improvement has a direct impact into a safer and satisfactory patient care environment (Pipe et al 2011, 11).

In healthcare environment, resilience plays an important role for workers. A way to foster workplace well-being and engagement is training resilience, developing mental health and subjective well-being. Resilience training has a number of wider benefits that include enhanced

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psychosocial functioning and improved performance (Robertson et al. 2005). All professions in healthcare experience similar effects in relation to the stressful conditions of work. This common aspect offers an opportunity to design and implement inter-professional approaches that can enhance the capacity for resilience among teams of coworkers. For this purpose, it is necessary an institutional culture that prioritizes training and cultivating specific skills and attitudes for promoting resilience to all members of the health care team, which also include students (Haramati and Weissinger 2015).

Resilience has been studied mainly in regard to stress. But what about ethical conflicts and problems that workers have to deal with? Vulnerability in healthcare professionals is also related to moral distress.⁵⁴ Moral distress⁵⁵ was originally described by Andrew Jameton (1984), and occurs when a healthcare professional makes a moral judgment about a case in which he or she is involved and an external constraint makes it difficult or impossible to act on that judgment, and he or she experiences painful feelings and/or psychological disequilibrium. He developed the term in the context of the explanation of the manners through institutional policies and practices can lead professionals to act in a way that they consider morally wrong. In this relation between organization and staff, moral distress can arise when the workers cannot perform their duties in a manner according to their moral values. In many cases, the reasons may be directly related to the institution.

Cristina Moreno (2016) finds different factors related to institutions that can lead to moral distress in professionals. Some of them are lack of staff and resources, lack of administrative support, misbalance in power, some styles of leadership, poor organization of work, poor relations between members of the interdisciplinary group, lack of communication, work overload and the precariousness of personnel, among others. All these problems can generate in the professional feelings of impotence, fear or frustration. There are also some institutional policies or legislation that can generate moral stress. In addition, it is necessary to refer to the ethical dimension of work

⁵⁴ There are some other concepts that arise from the literature: moral blindness, moral numbness and moral distress. For my purpose, moral distress reflects the tension that emerge if institutions do not support enough the workers.

⁵⁵ See Ulrich and Grady (eds.) 2018 to have an uploaded and broad view on moral distress in healthcare. After analyzing current knowledge on moral distress in healthcare, the book address different topics, as building compassionate work environment, research agenda, international perspectives or the term of moral success. In addition, Moreno (2016) analyzes ethical conflicts and resistance actions in in primary healthcare professionals.

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environment. In this regard, some institutions promote a quality professional practice, while others inhibit it. The ethical climate in the institutions is related to moral stress from the professionals (Moreno 2016, 53-56). Furthermore, the perception that the healthcare environment is unsafe for patients, and the fact that professionals cannot challenge these conditions can trigger moral distress (Berlinger 2016, 113). In addition, the precariousness of personnel, together with the need to control spending, has repercussions on not only in the quality of the care provided but also in the vulnerability of the professionals who have to attend to these patients (Burguete et al. 2017). In the latest revised version of the Declaration of Geneva adopted by the World Medical Association (WMA) General Assembly on October 14, 2017, a reevaluation of how the professional obligations of physicians are represented in the Declaration of Geneva should

(Parsa-Parsi, 2017). Due to this, in the newest version the concept of physician well-being was included as follows to reflect the role physician self-care can play in improving patient care: “I will attend to my own health, well-being, and abilities in order to provide care of the highest standard.”

The term of “moral courage”⁵⁶ and more recently the term of “moral success”⁵⁷ and “moral resilience”⁵⁸ are ethical response of moral distress, proposed by some scholars and professional societies. Initially, Lachman (2007) defines moral courage as the “capacity to overcome fear and stand up for his or her core values; the willingness to speak out and do what is right in the face of forces that would lead a person to act in some other way; it puts principles into action”. In her latest work, she also develops the concept of moral resilience, defining it as “the ability to deal with an ethically adverse situation without lasting effects of moral distress and moral residue” (Lachman, 2016). She adds that this requires morally courageous action, activating needed supports and doing the right thing. In addition, she argues “the virtue of moral courage is necessary to meet the ethical obligations of the profession” (Lachman, 2016). Rushton (2016)⁵⁹ highlight that moral resilience “is

⁵⁶ The origin and different definitions of the term has been broadly developed in Moreno, 2016, 44-45. In addition, she argues that moral courage and (micro) -resistance are ethical competencies of health professionals in the current Spanish public healthcare system. See Moreno (2018).

⁵⁷ For a broader reflection on moral success, see Grady et al (2018). They also provide examples of moral success.

⁵⁸ For a broader analyzes on this term, see Lachman (2016) and Rushton (2016).

⁵⁹ Rushton (2016, p 112) shows that there are some similarities between psychological resilience and moral resilience. The main differences from her view are: moral resilience focus on the moral aspects of human experience, the moral

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a concept under construction”, and it is a way to transform the deep despair and impotence associated with morally distressing situations. More recently, the term moral success is also evolving. Caplan (Grady et al, 2018) describes it as an action, which represents not just perceiving a problem, “but finding ways to resolve it that are actionable and practical, rather than idealistic and grandiose”. I agree on the necessity of turning the reflection about moral success, resilience or courage, in a more practical and realistic way to face moral distress.

One of the problems that arise in the context of professionalism is how to balance the recognition of the need to foster moral resilience or moral success from healthcare institutions, when it is the same institution that can create problems due to excess of work, not recognition of the team, lack of communication, etc. Within the institution, professionals in defective systems are often encouraged to compensate for the situation with better personal attitudes. Sometimes, moral distress appears when professionals have to do the job in the best possible way, even in inadequate or unsafe working conditions. Healthcare professionals should resist the notion that just suffering moral distress or recognizing moral wrongness is ethically enough in regard to their obligations to patients, even considering imperfect conditions of work (Berlinger 2016, 118). Encouragement for reflecting and discerning when the norms of the workplace are in conflict with the safety of patients is part of health care work, but it should not come from the workplace itself. The institutions responsibilities to face moral courage are not clear: if the institutions are creating with their policies what is perceived for workers as incorrect conditions of work, should these institutions encourage their staff to act with “moral courage”? In this regard, professional societies should encourage their members analyzing these problems, offering professional norms and proposing guidance that can also support organizational changes. Furthermore, it is necessary a collective action. Berlinger (Grady et al. 2018, p 169) claims:

“Moral distress is a collective action problem. It is produced by a system, it is experienced by individuals or groups on the lower status group, so its resolution, including the analysis of upstream problem, depends on more-powerful individuals or groups taking an interest on behalf of

complexity of the decisions, obligations and relationships, and the inevitable moral challenges that trigger conscience, confusion, and moral distress.

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the system and those it includes and those it serves. So moral success- if we're taking this term to be the opposite of or antidote to moral distress- must be more than a moral distress free day at work, or being "ethical". It must also have a systemic dimension, and must involve some effort to get at factors that produce moral distress."⁶⁰

To try to manage ethical or moral problems in the core of healthcare institutions, Berlinger (2016, 163-176) has proposed some recommendations. She suggests that clinical leaders, in consultation with workers at all levels should support efforts to identify realistic ways to solve or manage problems in health care work. These problems are foreseeable, not unexpected, and that's why it is necessary a dialogue between health care professionals who face pressure and leaders who can develop some tools to try to solve them. Clinical leaders should offer health care professionals occasions to talk about the difficulties they face, including the pressures produced by the conditions of complexity, and they should do that in modes that are supportive and constructive. In addition, organizations have also the responsibility to conduct, support and share empirical research about how health care professionals perceive and make judgments concerning all these issues.

To summarize, thinking about vulnerability and professionalism from the perspective of the role of the institutions of healthcare, it is clear that it is required a strong ethical commitment within the institutions to develop and promote actions and strategies to stop moral distress, stress and lack of well-being in clinicians. All of these actions will have an effect in more resilient institutions and professionals, which final purpose is to provide a better care of patients and their family. Otherwise, if the problems that professionals face in the day by day practice are not adequately manage with institutional support, the aim of a patient-centered care is not possible to achieve. In the next chapter, I address some of these problems.

⁶⁰ Berlinger also describes an example of moral success, when morally distressed professionals understand that feeling bad or tortured does not improve conditions for their patients. So further, they agree to take the first step toward collective action: analyzing what exactly triggers moral distress and identifying opportunities for further actions, as report these circumstances (Grady et al, p 169).

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CONCLUSIONS:

In this chapter, I have claimed the development of a relational patient-centered professionalism to overcome the insufficiencies provided for an individualistic way of understand professionalism. Through the lens of vulnerability theory, combined with a relational approach, and taking into account the patient-centered care point of view, I have showed how professionalism nowadays needs to be complemented with studies closer to daily practice in healthcare arena. I have argued that vulnerability theory provides a valuable framework to improve professionalism in healthcare field, since the recognition of shared vulnerability is an essential tool to foster empathy and to improve communication in healthcare. In addition, I maintain that healthcare professionals' vulnerability must be recognized and studied, especially taking into account the institutional circumstances that trigger adverse situations. Pointing out the way how institutions of healthcare can damage well-being of clinicians, with the repercussion of this on patient's safety and satisfaction (Kirwan et al, 2013; Vahey et al, 2004), is a call to generate an institutional culture with a strong ethical commitment and collective actions (Dzau et al, 2018).

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CHAPTER FIVE

ASYMMETRICAL RESPONSIBILITY IN HEALTHCARE CONTEXT

INTRODUCTION.

The purpose of this chapter is to analyze the concept of responsibility as “asymmetrical responsibility” in the context of healthcare. I argue the concept of asymmetrical responsibility is essential in the development of professionalism, attending at the same time the relationships between the institutions and the healthcare professionals and the relationships between those and patients. The premise is that institutions of healthcare should assume and implement the professionalism based on the framework provided for ethics of vulnerability and care.

On one hand, it is necessary to reflect about the kind of professional relationships that take place in the context of healthcare. It has been argued that relationships between patients and professionals should be relationships between equals, as a relationship between a client and a professional, according to the mainstream bioethical discourse, which main focus is on the autonomy principle. Nevertheless, this is not only a myth, but also not desirable. As Pellegrino (2012, p 22) argues: “those we treat are patients, not consumers, clients, customers, insured lives, items on a balance sheet, or centers of profit or loss. Patients are human beings who suffer, who bear the burden of illness”. The encounter between a healthcare worker and a patient is a professional relationship based on care. This means that the responsibility to provide all the necessary tools and strategies not only for cure and care, but also to foster relational autonomy in patients, correspond to professionals. In this regard, as I have shown, understanding autonomy as a relational autonomy, the focus is displaced for the patient to the professional, emphasizing the healthcare professional’s responsibility to try to generate all the necessary conditions for develop the best environment to “empower” patients.

I argue the professional responsibility must be thought as “asymmetrical responsibility” in the context of healthcare. Why asymmetrical? Because the relationship between patients and healthcare professionals is a relation of “inescapable inequality” (Fineman, 2017), and it must be,

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since these relationships take place in the context of care. As Baier⁶¹ (1994, p 29) maintains, “the recognition of the importance for all parties of relations between those who are and cannot but be unequal, and of their effect on personality formation and so on other relationships, goes along with a recognition of the plain fact that not all morally important relationships can or should be freely chosen”. This is the kind of unequal relationships that take place in healthcare arena. Patients looking for care probably desire information and the opportunity to give consent to treatment, but, first and notably, they are asking for help (Snead and Mulder-Westrate, 2014). By understanding the constitutive inequality of these relationships, we must focus on the responsibility of professionals to provide all the necessary tools and strategies for improve the patient care and to enable autonomy, in relational terms, in patients.

On the other hand, we cannot reflect about the encounter and the responsibility of physicians and nurses in the face to face relationship with patients and families regardless the institutional framework in which these relationships occur. Nowadays, we are having more and more reports of staff shortages, lack of capacity and an unmanageable demand that puts at risk the quality of care and patients (Oliver, 2018). These problems are affecting whole specialties: general practice, emergency medicine, psychiatry, pediatrics, intensive care, etc. Doctors and nurses feel unable to provide the level of care for which they were trained or desired by patients. Institutions need to be responsive to these situations, which include being more supportive toward the care of clinicians, as well as design strategies to counteract this epidemic (Squiers et al, 2017). As Ulrich and Grady (2018, p 1) affirm, “addressing moral distress also crucially requires attention to the environments and system in which healthcare workers care for patients”.

In this chapter I reflect about the institutional asymmetrical responsibility in response to healthcare professionals suffering, which includes, moral distress, stress, burn out, etc. It has been called the “Quadruple aim”: care for the patient requires care of the provider”⁶² (Bodenheimer and

⁶¹ Annette Baier’s moral philosophy considers trust as the essential component to fundamental moral conceptions. According to Baier in his book *Moral Prejudices*, morality should not be guide by rules and codes, but by trust: a moral prejudice. From a feminist perspective, her work focuses on addressing the notion of vulnerability and inequalities of vulnerability, and with trust and distrust among equals. She broadly explores the implications of trust and confidence.

⁶² In the article From Triple to Quadruple Aim: Care of the Patient Requires Care of the Provider, the authors propose the care of the healthcare professionals as the fourth aim to optimize health systems performance. The Triple aim broadly accepted is enhancing patient experience, improving population health, and reducing costs. The authors developed the Quadruple aim considering the widespread burnout and dissatisfaction reported by clinicians. They

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Sinsky, 2014). Academic health centers, hospitals, medical schools, clinical practices, and other institutions that train, hire, and rely on healthcare professionals must focus on improving the organization, culture, and system, in terms of create “real spaces of care”, in the very broad sense.

I have argued in chapter two that the ethics of vulnerability challenges bioethics to action, since vulnerability constitutes a normative element: it demands a response, generating responsibility and implying obligations. These obligations arise especially from the perspective of the institutions and the state, in the core of vulnerability theory. Furthermore, I have claimed the imperative necessity to address attention towards social justice in connection to vulnerability in the context of healthcare. Attending to the impact of globalization and neoliberal policies on healthcare field, neoliberal policies benefit the private healthcare sector, while public health services have become weak and less accessible (Ten Have, 2016, p 113; Guerra, 2018, p 359-360). In this context, the role of healthcare institutions to assume “asymmetrical responsibility” in the process of care (which include to take care of professionals) is a challenge. Institutions not always promote the professional commitment to their patients, and sometimes these institutions are obstructing it. How can we improve more supportive healthcare institutions for both, patients and professionals? How can the notion of asymmetrical responsibility help institutions to address these problems?

Alfred Tauber (2005, p 126) formulated main question that I try to face in this chapter more than a decade ago as follows:

“...We should acknowledge that autonomy is a plastic concept exhibiting different <<degrees of freedom>> for in the highly technical arena of contemporary medicine, the power relationship between physician and patient is profoundly unequal. Patients, simply out of deference to superior knowledge and technical expertise, agree to delegate varying degrees of their freedom and entrust their care to others. It is precisely at this point that current medical ethics fails to make the appropriate adjustment of modifying a restrictive definition of autonomy and complementing it with expanded physician responsibility.”

recommend that the Triple Aim should be expanded to a Quadruple Aim, adding the goal of improving the work life of healthcare providers.

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Tauber proposes a reconfiguration of patient autonomy at the bedside and in the clinical context to achieve a balance between patient rights and physician responsibilities. In doing so, for him it is necessary to transform a defensive medicine into a model of healthcare in which autonomy is more properly lined up with beneficence, in order to become more effectively serve the *telos* of care. Some scholars have comprehended that, although Tauber repeats several times that he does not propose a return to old paternalism, it is not clear in his proposal that the consequence of the kind of relational ethics that he advocates do not drive to a new paternalism, much subtler than the old, but paternalistic end of the day (Courseiro, 2012; Triviño, 2012).

I have discussed in chapter three the necessity of a concept of relational autonomy, linked to the vulnerability theory, as well as the main problems regarded to paternalism. In this chapter, to address the ethical question of professional responsibility in healthcare, I explore the notion of “asymmetrical responsibility”. The starting point of this reflection about asymmetrical responsibility in the context of healthcare is to explain why relationships of care are necessarily relations of inequality. From the recognition of the structure of these relationships, I propose the concept of asymmetrical responsibility attending to Levinas’ philosophy as key concept to reflect the kind of professional responsibility that takes place in healthcare relationships. I claim that professionalism in healthcare today must face which I consider the main problem: how to develop strategies to address the improvement of relationships in healthcare, considering the importance of professional responsibility in the face-to-face encounter with patients and their families, but also considering how to solve the critical situation of these professionals, currently facing moral distress, burn out or short staffing, among others. Subsequently, I argue that in order to improve relationships between professionals and patients, we need to focus on the institutional commitment that allows or impedes the flourishing of relations of care. Finally, I focus on the institutional commitment in healthcare institutions to improve the environments and conditions, since these conditions clearly shape in healthcare professionals and patients. The aim institutions must have is looking for a more responsive care as a key element that professionalism need to address.

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NECESSARILY UNEQUAL RELATIONSHIPS

The reflection about how and why people should act toward others in relationships of variable power asymmetry is central in the reflection about professional responsibility. Annette Baier (1994, p 120) maintains that “these relationships of inequality-some of them, such parent-child, of unavoidable inequality- make up much of our lives, and they, as much as our relations to our equals, determine the state of moral health or corruption in which we are content to live”. She explains that unequal power relations, such as healthcare professionals and patients, among others, had been treated with some kind of promotion of the weakest, so that an appearance of virtual equality is achieved. This means that their rights are seen as the rights of the equals. This myth of an equality that is in fact nonexistent can lead to the desirable protection of the weakest or most dependent. However, in doing it, the “idea of equality” does not take into account, and in fact masks, the question as to what our moral relations are with others in these situations in which people occupy positions of *necessarily* unequal power (Baier, 1994, p 28). In addition, a more accurate understanding of our interdependency through the life course might lead us to a more direct approach to questions concerning the design of institutions structuring these relationships between unequal (families, schools, hospitals). Presenting the limited myth of equality among members of a community, and the inappropriateness of trying to pretend that all of them are treated as equals, tends to be in agreement with the accompanying myth that moral obligations arise from associations freely, which ultimate base is the concept of autonomy.

Martha Fineman (2017, p 134) has exposed how the development of vulnerability theory has been based on struggling with the limitations of equality. Though vulnerability is universal and constant, “vulnerability is manifested differently in individuals, often resulting in significant differences in position and circumstance” (Fineman, 2017, 133). She explains that the borders of equality are particularly noticeable in situations that she refers as situations of “*inescapable*” *inequality*. In this regard, some social relationships, as healthcare professionals/patients, “are inherently, even desirably, unequal relationships” (Fineman, 2017, p 133). Vulnerability theory provides a theoretical model that challenge traditional assumptions about individual and state responsibility, as well as let us address social relationships of inevitable inequality in a more appropriate way. Moreover, through these lenses it is possible to address a broader reflection,

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which ends are to explore what are the fair and right instruments to organize the relationships of “inescapable” inequality.

Within bioethics, and more particularly in clinical ethics, great attention has been directed to the relationships between patients and health professionals. Mallia (2013) analyzes different aspects of the patient-doctor relationship, following the recommendation of Pellegrino⁶³ to maintain the principles in bioethics, but complementing them more completely with the ideas of other ethical theories, as well as the fundamental reflection on the doctor-patient relationship.

Autonomy has become the “star” principle or the “default” principle of bioethics and in healthcare context (O’Neill, 2002; Camps, 2011). It has become more an ideology than an ethical principle, that is, a belief whose kindness is always taken for granted, which includes a belief that informed consent is the basic and unquestionable column of all bioethics (Puyol, 2012, p 50). Healthcare practice has changed from a paternalistic model of care to the adoption of a patient-centered practice model (Evans, 2009). In other words, it has gone from a benevolent model that led to the practice of paternalism to a model of autonomy that leads to the practice of informed consent (Feito, 2011, p 2). Following this principle, healthcare relationships have been defined as client- professional one. In this respect, a “more equal” relationship is claimed, and it is considered that this is the main achievement of autonomy principle on bioethics: to respect each person as a person with the complete capacity to make his or her own decisions about his or her body and health.

Without doubts, in bioethics, the informed consent model has become the paradigm of autonomy. Nevertheless, informed consent is not always the best way to ensure autonomy of patients because this way of understand that consent is the enough justification for ensure autonomy, makes us believe we can choose, but the multiple cultural, economic and psychological factors determine us more than we are willing to recognize (Marzano, 2009). Stoljar (2011) argues that informed consent does not secure patient autonomy, and she explains two arguments for that:

⁶³ Mallia expresses that the aim of his book is follow Pellegrino recommendations developed in Pellegrino E.D., “The Four Principles and the Doctor-Patient Relationship.: the Need for a Better Linkage’ in Raanan Gillon, ed. (1994) “Principles of Health Care Ethics”, Chichester, England: John Wiley & Sons, pp 353-366. In this work, Pellegrino retains principles but supplementing them more fully by insights from other ethical theories and importantly ground principlism more fully in the phenomena of the doctor-patient relationship.

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“The first is that informed consent, like negative freedom, is an “opportunity” concept, whereas autonomy, like positive freedom, is an “exercise” concept; the second is that informed consent requires merely weak evaluation and hence is not a sufficient condition for the normative competence that is required for autonomy”.

Autonomy has been promoted as the fundamental principle of clinical ethics, and this fact have leaded bioethics suffers especially from this reductionism ignoring the fundamental role of obligations or professional responsibility (Camps, 2011, p 11). As a consequence of this conception, the responsibility assumed by the patient in the decision making process is higher than before, while it is not also considered in the same mode the importance of responsibility of healthcare professionals in the role of providing enough information for patients. The commitment to autonomy has also made it difficult for bioethics consider, with the same rigor and interest, other ethical issues related to health and life that cannot be addressed properly with greater protection of autonomy (Puyol, 2012, p 47). In fact, autonomy has been a leading idea on bioethics literature, while trust has been marginal (O’Neill, 2002). Moreover, the same situation of marginal idea occurs with other concepts, as the case of responsibility. As Antonio Casado (2009, p 57) points out, there are an increasing gap between patient autonomy and an ethics of responsibility. He analyzes Tauber’s argument (Tauber 2005) that the principle of respect for autonomy cannot be disconnected from the responsibility healthcare professionals assume in the care of the patient, and that patient autonomy often does not give way to other principles present in biomedical ethics, as beneficence.

The emphasis on autonomy principle, connected to the idea of equal relationships in healthcare, has displaced the responsibility from the professionals to the patients. It does not mean that professionals do not have their responsibility in the performance of their work, as it is recognized in Deontology codes of doctors and nurses. Nevertheless, focusing on informed consent model as the translation of autonomy, it has been understood that the decision (and consequently the responsibility for that decision) corresponds to the patient. On the contrary, the assessment of quality of information provided for professionals has not been enough examined in the practical

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context. These circumstances lead me to consider the necessity of highlight professional responsibility.

The ethics of medical care guided by the model of individual autonomy based on the contract leads us not to recognize the profound and structural inequality of the power relationship between doctor and patient (Tauber 2001, p 47; 2005, p 126). Tauber does not renounce the autonomy of the patient, but without returning to paternalism, he believes that it is not possible to think of strict relationships equality between doctor and patient. The professional's responsibility consists to put their knowledge at the service of restoration of the autonomy of the patient who, just for the sake of getting sick, it may already be threatened. That is in his view why the relationship cannot be symmetrical. In this model proposed by Tauber, respecting the values and the perspective of the patient, the burden of responsibility falls on the doctor, because he or she is the one who has the knowledge and tools to be able to help the patient (Feito, 2012, p 48).

From my view, the notion of responsibility in Clinical Ethics has been developed under the paradigm of reciprocity and symmetry, because it has been thought based on the ideology of autonomy. I claim that it is necessary to promote the scope of the clinical relationship, focusing on the interaction between health professionals and patients, and especially in the professional responsibility involved in this relationship of care. I claim that it is necessary to promote the professional responsibility in the core of healthcare relationship. That is why Tauber (2001) proposes a relational approach to medical ethics, which emphasizes personal encounter and trust as keys to a caring relationship. He argues that in these care relationships, professionals should be attentive to what Levinas calls the "face of the other". From my point of view, however, the "face-to-face relationship" in the context of healthcare depends largely on the institutional framework where these relationships occur. For that reason, in the current debate on bioethics, we cannot reflect on the relationship between the health professional and the patient as only a "personal" relationship. We need to define and promote these professional relationships, but considering the profound and significant impact of institutional commitment towards the possibility of improve these relationships, or the contrary, to block and obstructe them.

In the next section, I reflect and explain what is the meaning and relevance of asymmetrical responsibility in healthcare relationships.

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ASYMMETRICAL RESPONSIBILITY

I have argued that relationships in healthcare context between professionals and patients are inherently unequal relationships, because they are based on care. It is important to highlight that, although the clinical relationship must be based on a symmetric dialogue, the inherent responsibility of each of the participants is asymmetric, because the situation in which each of the participants is situated is different, is a situation of an unavoidable inequality, even desirable (Fineman, 2017, p 133). In order to understand the notion of asymmetric responsibility, I want to consider in brief some ideas from the ethics of alterity of Emmanuel Levinas.

Levinas' ethics of alterity places the category of Other in the core of the philosophical discourse. In his thought, the Other is defined for his/her vulnerability, which is condensed in the concept of "the face of the Other". For Levinas (1961), the relationship that arises in the ethical encounter with the Other, who is vulnerable, is given in the face-to-face encounter. It is an asymmetrical relationship because the self must respond to the Other's demands. This implies that one (the self) has to assume an asymmetrical responsibility for the life of the other person that is in front of one. This emphasis on the asymmetry of responsibility towards the Other pays particular attention to vulnerability, because the Other is vulnerable and he/she is placed in a situation of injustice⁶⁴.

Levinas' philosophy introduces a new way of thinking completely different from the ethics of subjectivity. For Levinas (1972), philosophy has insisted on neutralizing alterity. However, in his ethics of alterity, the Other appears explicitly and openly. This otherness shifts the identity of its role to a higher normative category granted by classical philosophy. Levinas' philosophy has the virtue of removing from otherness its marginalization and oppression in relation to the philosophy of the identity. In traditional philosophy, the self has been affirmed by denying the other in alterity, reducing him/her to identification with the self. In Levinas' view, the negation of the self, its subordination to the Other, is a way of confronting the dominant ideology of subjectivity that starts from the self to return to the self-consciousness. In Levinas philosophy, the self not only is defined

⁶⁴ The Other of Levinas is not abstract or hypothetical, but is the other concrete part of the face-to-face relationship. Although he describes the Other in the figure of the foreigner, the widow and the orphan, he extends and identifies the Other with the face of the suffering, of those who are oppressed by the power of the self. In this sense,

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in relation to the Other, but the very nature of its being resides in that intersubjectivity (Arrieta, 2012). For Levinas, communication with the Other is a demand for responsibility, because the Other is in a situation of vulnerability⁶⁵. In addition, responsibility does not appear as a concern for itself and as a recrimination of oneself, but demands openness to an understanding of the ethical relationship with the Other, which does not depend on causal links between an actor and an act, but exceeds them, as Azauagh (2016, p 263) argues.

In his work *Humanisme de l'autre homme* (1972), Levinas treats vulnerability as a philosophical theme, and he defines it as 'subjectivity'. According to Levinas' understanding of subjectivity, the self always comes after otherness (Patrão, 2009, p 157-158). Consequently, the self is in dependence to the Other and hence vulnerable, since the self is vulnerability (Levinas, 1972). Subjectivity is built from the alterity as *being for the Other*, which means that the self builds identity from the responsibility towards the other human being. "Subjectivity is then sensitivity, exposition to the other, vulnerability and responsibility in the proximity to the others" (Gimenez, 2011, p 337-338). Hence, vulnerability appears as an intrinsic feature of the human, the universal condition of humanity, as far as the self only exists in relation to the other (Patrão, 2009, p 158).

The relationship with the Other is asymmetric for Levinas because the Other manifests itself to the self in an imperative way, from his situation of vulnerability, of requesting help. The self is constituted as a moral subject from the moment it is challenged by the Other. The responsibility is thus, for Levinas, prior to freedom: we are not responsible for our freedom, but we are free because we are responsible (with respect to the other). Since the relationship with the Other occurs, the self is responsible for him, because the responsibility in the Levinasian Philosophy is prior to freedom. As Ten Have (2016, p 103) explains, "through the concrete encounter with the face of another we are immediately in an ethical condition, or rather, as Levinas calls it, a <<non-condition>>. Ethics is preliminary, antecedent to ontology".

Rather than claiming for a mutual recognition, Levinas understands the ethical relationship, in legal and political questions, as the relationship between subjects that starts with an asymmetric

⁶⁵ For a broader and deeper analysis of the concept of vulnerability in Levinas, see Ten Have, H. (2016) *Vulnerability: Challenging Bioethics*. Routledge, New York. Particularly, chapter 5. We are all vulnerable. Philosophical perspectives on vulnerability.

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responsibility for the truly embodied person. The position that persons occupy are neither reciprocal to each other: the opening up to the other is a gift, an act of generosity (Macioce, 2017, p 242-243). According to Iris M. Young (1997)⁶⁶, a symmetrical effort to comply with democratic processes and discourse ethics tends to portrait inaccurately the difference and the particularity of the other's position (Macioce, 2017, p 241).

Furthermore, Gabriel Bello (2006, 2010) develops a broad analysis of moral symmetry and moral asymmetry in relation to Levinas philosophy. He maintains that reciprocity as an ethical model is based on recognition, which is always recognition of the other with the one that is exchanged, and the key to recognition is the construction of that other. Hence, the recognition of the other consists in taking the other as another human being as well as the self, which refers to a reiteration of one's own self and humanity, this being the basis of a universalist morality. This is the reason for the symmetry. The other possibility, he argues, consists in a construction of the other as completely another, without the "self" being able to reduce him to his sameness. Thus, the other vulnerable (the foreigner, the widow and the orphan in which Levinas represents the other vulnerable, and in the case at hand we can extrapolate to the patient), *interpellates* the self from his vulnerability. It is a call for the injustice he or she suffers, so that the ego is placed in the position of responsibility, given that you have to respond to such demand. The responsibility, in this situation, is inescapable, since refusing to respond is already a form of answer.⁶⁷

Applying the concept of asymmetrical responsibility to healthcare context lead us to re-think about relationships that take place in this arena. Considering these relationships are relations based on care, we can analyze the link between the concept of asymmetrical responsibility, which is developed within an ethics of response, and ethics of care. Joel M. Reynolds (2016, p 781) maintains,

⁶⁶ She argues that moral respect in dialogical interaction involves taking the other's point of view. It is a political argument, since many contexts of moral interaction and political conflict involve members of socially and culturally differentiated groups. These groups are also involved in specific relations of privilege and oppression among themselves. In these circumstances, the social position of a group is defined by its differentiation from another or others, in such a way that it is constitutive of the definition of those relations of privilege and oppression. See Young (1997)

⁶⁷ Gabriel Bello argues that it could be an objection to Levinas' concept of vulnerability that it is a characteristic of the Other. From the approach based on universal vulnerability it is understood that vulnerability is a human condition, so all of us are vulnerable, which includes the Other and the self who is in the position of response. From Gabriel Bello point of view, the universal vulnerability approach is inadequate in the ethical analysis, because he considers that vulnerability is also asymmetric, and we are not symmetrically vulnerable. To follow this discussion, see Bello, G. (2010)

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“feminist care ethics and levinasian response ethics complement each other in ways that productively illuminate themes of each”. More specifically, he uses a hermeneutic phenomenology of care to demonstrate that the normative concerns of care ethics and the metaethical concerns of response ethics are constitutive factors of the experience of care in dependency work, and consequently, they are not incompatible. He argues that there are three different moments in the interaction of embodied response in dependency work: leveling, attention, and interruption⁶⁸. He bases his analyses on these three moments to argue that care ethics and response ethics mutually complement each other. As he explains, because care ethics is grounded in experience, care ethics also assumes the principle of radical alterity. Response ethics provides a language to explain the compulsory nature of relations of care as a result of the claim the other places on me in their uniqueness. Consequently, “each of the three moments is undergirded, in turn, by what I consider to be the two primary claims of care ethics: (1) I (and others) are responsible to care for others’ needs, and (2) this responsibility for the other is always mediated through socially and historically situated relations with other others, including myself” (Reynolds, 2016, p 785).

Dependency work illustrates the responsibility paradox⁶⁹ as a consequence from a misunderstanding of in what way care is shaped by embodied response, what Reynolds consider a misunderstanding of the complexity of the material dialectics of care in responding to the other. Dependency work is based on "individual" or "particular" care, and goes towards a principle that serves as a basis for conceptualizing more general ethical relationships. However, there is never merely an encounter of “the face to face”, as if response ethics appears out of the relation between oneself and one other. As Reynolds (2016, p 788) argues:

⁶⁸ These three moments of leveling, attention, and interruption, are brilliantly explaining for Reynolds as follows: “If I am attentive, then I prepare, at least provisionally, for the response of the other. A constant shift from leveling to attention is the mark of an exemplary dependency worker, for it is less taxing to instead remain in the comportment of leveling. Yet, whether attentive or not, one will encounter moments of interruption. If I am trying to change the bedpan, and the recipient of care yells out in pain, this interruption is often unwelcome, for, alas, I must change the bedpan. Recall that above I had to balance my grandfather’s interruptive pain with the necessity of getting him to the toilet. Whereas the obligation to alleviate the suffering of the other is a “supreme ethical principle” for Levinas (Levinas 1988, 159), dependency work suggests that there are times I must even make someone suffer in order to care well as any doctor, nurse, or parent would attest. Moments of interruption puncture the leveling of the other and condition the necessity of attention” (Reynolds, 2016, p 785).

⁶⁹ Responsibility paradox refers to the idea that the more I answer the more I am responsible. Reynolds uses this term to be more accurate to term infinite responsibility in Levinas’ Philosophy. See Reynolds (2016, p 787-789).

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“But there are never simply two because care is manifold. Whether with respect to family members, patients, or paid/unpaid dependency laborers, care always requires more than any responsive reification of an encounter with the face of a singular other. Care involves many faces and demands ample responses. There are always other others.”

In healthcare context, the notion of asymmetrical responsibility implies to assume the role than professionals have improving the communication and dialogue between patient, family and professionals. I maintain that, in order to make it possible, it is necessary to re-think about the role of the institutions on follow this purpose. In addition to Reynolds phenomenological analyses of dependency work, care ethics and responsive ethics, and considering that there are some kind of “relationships of inescapable, even desirable, inequality” (Fineman, 2017), as patient-healthcare professional relation, the responsibility involved on these relationships should be understood as asymmetrical. This “inescapable inequality” occurs in healthcare context because of “the care”, and this asymmetry is not a lack or an imbalance that we should try to solve. The basis of these relationships is not a commercial exchange: these relationships take place because someone (the patient) need to be taken care of for someone (healthcare professionals). It does not mean that the dialogue and communication between patients and professionals must be unequal, but it is the position that they occupy.

As Heidenreich et al. (2017) shows, professionals are concerned about the gap between patient decisions and what they believe is the best course of action to benefit the patient. They realize their commitment in regard to decision making process with the patient, understanding that the patient cannot make his or her own decisions if healthcare professionals do not promote and foster the decision making process. They are also concerned about exercise excessive pressure on the patient that can force him or her (Heidenreich et al., 2017). To what extent can healthcare professionals, trying to act in what they consider the best interest of their patients, influence or act against the values and wishes of their patients? In addition, healthcare professional’s concerns are also related to the institutional framework and in regard to how these institutions can support or

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provide adequate assistance for patients in difficult situations, and how this lack of resources or support for patients influence the professional's commitment (Heidenreich et al., 2017).

One important aspect in the performance of the professional work of care is the recognition of the asymmetrical responsibility that professionals have toward patients. But at the same time, it is crucial the recognition of the duties and obligations that the institutions and organizations have to assume towards the professionals who work there. In this regard, I claim that the responsibility to create an environment of care, in which the healthcare professionals, as well as the patients and families, are taken care of is an asymmetrical responsibility. This acknowledgement means that it is an ethical imperative that institutions managers, as well as professional societies, must address.

INSTITUTIONAL ASYMMETRICAL RESPONSIBILITY: THE DUTY OF CARE FOR THOSE WHO CARE FOR OTHERS

Vulnerability theory is a key element to explore the relationship between the asymmetrical responsibility of the institution towards the healthcare professionals. I have argued that in current medical ethics there is a gap between the reflection about patient's autonomy and the emphasis in physician responsibility. While autonomy has been highly theorized in bioethics, there is a lack of reflection about professionals responsibility on addressing relationships based on care, which also include to foster relational autonomy. The concept of asymmetrical responsibility is a key element to develop broadly and ethics of responsibility in agreement with the ethics of vulnerability I have explored. In the previous chapter I have shown that there is "a vulnerability that arises out of the experience of others' vulnerability" (Carel, 2009), and this vulnerability requires more recognition by the profession. Working in healthcare implies to face suffering, pain, death, etc., day by day. Since this is a fact intrinsic to the profession, it is necessary to recognized it and do not deny it. At the same time, I have claimed the institutions of healthcare can increase healthcare professionals experience of vulnerability in their work, since some institutions are not supportive spaces for care. It seems that there is a tension between the goal of improve relationships of care, emphasizing the professional's responsibility, and the claim for an asymmetrical responsibility that institutions need to assume, which means a more responsive way to care for professionals, implementing the resources and conditions at work. I have argued the necessity to emphasize professional responsibility because relationships of care are relationships of "inescapable inequality" (Fineman,

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2017). To manage this inequality inherent to healthcare professional patients relationships, it is require to accentuate the asymmetrical responsibility that professionals have. At the same time, how can we claim for the assumption of an asymmetrical responsibility of healthcare professionals without considering the institutional responsibility on addressing the necessity of “care for those who care for others” (Bodenheimer and Sinsky, 2014)? I maintain it is only possible to explain, understand and reflect about the face to face relationships in healthcare arena taking into account the institutional framework in which these relationships take place. Otherwise, it is not possible to improve relationships based on care. Vulnerability theory highlights is the need for care and connections that emerges from our vulnerability what make us reach out and form society (Fineman, 2013, p 22). These institutions form systems that play an important role in ameliorating and compensating for individual vulnerability, providing us with the resilience or resources to respond in specific times of crisis or opportunity (Fineman, 2013, p 22).

As it was maintained, care ethics and the response ethics from Levinas complement each other (Reynolds, 2016). Consequently, my argument is that the claim for the necessity of healthcare institutions to assume the asymmetrical responsibility they have towards healthcare professionals must be addressed by the inclusion of an ethics of care in the core of the institutions policies and practices. There are some important aspects that I consider necessary to include the ethics of care in the organizations. Held (2006, p 168) maintains:

“Caring relations, rather than what persons do as individuals, exemplify the values of caring. The small societies of family and friendship embedded in larger societies are formed by caring relations. More attenuated but still evident caring relations between more distant people enable them to trust each other enough to form social organizations and political entities and to accept each other as fellow citizens of states.”

Noddings (2003) ethic of care emphasize concrete people over abstract principles, giving greater weight to the affective than to the cognitive, to understand values as responses to human needs, and to educate morally through the creation of facilitating conditions for the learning of care.

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In addition, for Noddings, in the encounter with other human being, the vulnerability and needs of other people obligates us to take care of them. It is what happens when we cannot remain indifferent to the suffering of others and we decide to take charge, to care for the people who need us. The encounter with other human beings appeals to our responsibility with them. In this regard, her ethics is in accordance with the asymmetrical responsibility that arises from Levinas' philosophy, which I consider essential to incorporate in the institutional policies of organizations of care. The ethic of care manifests the encounter with the other from the reception, which allows the entrance of the other, not as a series of facts gathered in my consciousness, but through the feeling of a genuine other with unique needs. The practice of care arises from the recognition of the vulnerability of the other, not from obedience to moral principles. In short, for the ethics of care, the needs of other people become ethical appeals (Vazquez, 2009). Finally, among the aspects that I want to highlight, it should be noted that for Noddings the human being is a social being, who lives inserted in a web of relationships with others. Considering that we are born completely dependent and, even in adulthood, we remain interdependent. We not only depend on other human beings, but we are also affected by the conditions in which we find ourselves at each moment. Each of us is a relational entity and not a fully autonomous agent. Therefore, it affirms that our strengths and weaknesses are both, at least in part, induced, supported, increased or reduced by the intervention and the influence of those with whom we relate. That is why the ethics of care is a relational ethic, more based on the interpersonal relationship than on the moral agent. For this reason, the conception of care that it handles refers more to the interpersonal relationship in the moral encounter, than to the virtue itself of care as an abstract value. The relational use of care practice emphasizes the situation and concrete interpersonal relationship, through which morals are learned (Vazquez, 2009).

Cestari et al. (2017) emphasize the fact that care is revealed in the relations of the existence of the people who care and are cared for, involving consideration and respect in the modes of being, of proceeding as essence and human existence. On the other hand, the recognition of interdependence and asymmetry is in the core of ethics of care. As Pettersen (2011) maintains, "the ethics of care depicts the moral agent not primarily in terms of independence, equality of power

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and influence (...), rather, it conceives agents as mutually interconnected, vulnerable and dependent, often in asymmetric ways”.

I have maintained that it is necessary to develop an asymmetrical responsibility in the relationships of care that take place in the healthcare field, because relationships between healthcare professionals and patients are relations of “inescapable inequality” (Fineman, 2017). The way in which professional responsibility can be implemented in the context of healthcare is through the recognition of this intrinsic inequality between patients and professionals, to better address the moral responsibilities that arises from this encounter. However, as I also have maintained, the physician-patient interaction no longer occurs in the practitioner's office in which the practitioner, alone or in a small group of colleagues, has control over the structures that influence the interaction. Instead, these interactions occur within large organizations in which the practitioner or a small group of colleagues does not control the rules of the engagement (Mallia, 2013).

I claim that the most urgent aim that the institutions need to address is to develop an ethics of care in the core of the organizations. I believe that healthcare institutions have to develop policies and practices that must be articulated from an ethic of care. Placing care in the center can be a powerful tool in the attempt to improve care spaces, putting the emphasis on the improvement of the labor conditions of health professionals. If institutions does not pay attention and counteract professional’s problems at the workplace, the relationships with patients can not be improved. It is a fundamental strategy to increase well-being in healthcare professionals from an institutional response.

Thomas Lawrence and Sally Maitlis (2012) have developed a model of an ethics of care that can be incorporated in the core of organizations⁷⁰. Based on feminist literature on care ethics, they highlight care is a central dimension of relationships. The starting point of an ethic of care as the perspective of persons as relational and interdependent, morally and epistemologically, rather than independent, self-sufficient persons. Lawrence and Maitlis (2012) develop a theoretical framework relating an ethic of care to narrative practices in organizations and to the effects of those practices

⁷⁰ While their work is referred to organizations in general, I will refer in this work particularly toward organizations of healthcare.

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for work teams. After analyzing feminist literature on ethics of care⁷¹, due to an ethic of care emphasizes the importance of permanent and interdependent relationships as locations of care, their focus is on the narrative practices that take place in work teams. They maintain that one of the main effect of narrative practices based on an ethic of care is the progression of an “ontology of possibility”⁷² (Lawrence and Maitlis, 2012, p 642). One of the most relevant findings of this study is that they connect the study of care and compassion in organizations to the broad feminist writing. On doing it, they “reposition care in organizations not only as a powerful response to suffering, as it is commonly understood in the care and compassion literature, but as an ongoing source of strength for all organizational members” (Lawrence and Maitlis, 2012, p 642). Moreover, as the authors maintain, the impact of care in organizations include practical achievements and affective, moral, and relational effects on organizational members. To explore these effects, they reflect about the impact of an ethic of care on work team resilience⁷³.

I consider this study implies an important contribution in order to guide future actions to improve work environments at healthcare, focusing on how to increase the response on the care of professionals. One important aspect is that they place an ethic of care within the core of organizations as a strength for all the members of the organization, as well as for the organization in itself. The authors conclude that “an ethic of care has the potential to energize scholars to more deeply examine the social, psychological, and political dimensions of care and compassion in organizations” (Lawrence and Maitlis, 2012, p 659). In addition, as I have maintained, vulnerability is *the* human condition, and because of that, human being needs care. The ethics of care aims to consider caring for people as the underlying objective of all policies and practices developed in the organization. Based on the idea of recognizing the human condition of vulnerability, “relationship” should be the essential tool to promote strategies and policies considering the importance of care in each one of the activities of the organization. In addition, Lawrence and Maitlis (2012, p 655)

⁷¹ The authors refer the work of Held, 2005; Liedtka, 1996; Noddings, 2003; Sevenhuijsen, 2004; Wicks, 1996.

⁷² The authors refer to Ernst Bloch philosophy about the principle of hope. In *The Principle of Hope*, Bloch understands hope is not merely a subjective combination of desires and beliefs about probabilities or facts, but rather a thinking of metaphysical possibilities in the world and part of human capacities that make it possible to relate to that which is not yet, but which is already presaged in the objective potentials of reality. See Bloch, E. (1995). *The principle of hope*. Cambridge, MA: MIT Press.

⁷³ The authors use this definition of resilience: the ability of a team to maintain a stable equilibrium in the face of adversity, in Bonanno, G. A. (2004). Loss, trauma, and human resilience. *American Psychologist*, 59: 20–28, p 20.

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focuses on how “caring narrative practices build team resilience through the development of an ontology of possibility and, specifically, through building potency, collective agency, and transcendent hope in teams”⁷⁴. By analyzing the organizational effects of caring practices, the authors show that care may have important effects on the beliefs of those who care and are cared for. The benefits from understanding narrative practices are important skills for the organizations. These tools can help organizations to situate an ethic of care in the center of the organization, highlighting the importance of storytelling in organizations as a leadership skill.

Institutions of healthcare need to assume their asymmetrical responsibility in providing the indispensable resources to make possible the improvement of face to face relationships of care, which has repercussions on a better care and safety of patients. The focus must be on both, how to improve patient care, through the implementation of well-being conditions of those whose care for them. Institutions need to develop a strong ethical commitment, emphasizing their asymmetrical responsibility towards these two aims. In addition, this purpose must follow the perspective of patient-centered care. Health care is a relationship between those who provide care and those who seek care, and organizations need to promote actions benefiting both parties Bodenheimer and Sinky (2014). The main aim of a relational centered-care professionalism should be focus in how to improve the best patient-centered care. For achieve this goal, it is necessary to understand and improve the institutional environments that affects clinician’s well-being⁷⁵. Focusing on how to increase the well-being of clinicians is the best way to provide a safety and quality care for society.

⁷⁴ They explain these three beliefs, linked to work team resilience. First, potency is the belief derived from the practice of constructing a history of sparkling moments. Potency has been shown to foster resilience under taxing conditions by reinforcing team goals and increasing a team’s persistence when task performance does not attain aspired levels and when the team faces adversity. Second, collective agency refers to the fact that contextualizing problems facilitates agency by positioning people as resourceful and intelligent rather than deficient human beings and through fostering resilience by highlighting the influence, but undermining the determining effects, of external discourses. A sense of agency also allows people to emotionally dissociate from the source of adversity, enabling a more respectful mode of interaction with each other that engenders in teams a belief in their collective agency. Finally, transcendent hope stems from constructing future-oriented stories. It may play a stronger role in fostering resilience because it is less likely to be dashed by unexpected setbacks or frustrations. Transcendent hope fosters resilience because it energizes teams without tying that energy to any particular outcome.

⁷⁵ Brenan et al. (2014) analyzed the positive results that investment on organizational professionalism has: 1) Increased in patient and community trust in the organization; 2) Improve patient safety, satisfaction and health outcomes; 3) Improve organizational performance and reputation; 4) Heightened sense of meaning and purposes that translates into greater staff morale,

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WHAT IS THE “DISEASE” THAT THE INSTITUTIONS NEED TO TREAT?

There are numerous examples about healthcare professional vulnerability experienced at the workplace, as I shown in chapter four. Some institutional factors that cause impotence, burnout or moral distress are lack of personnel, lack of administrative support, misbalance in power, inadequate organization of work, lack of communication, work overload, etc. (Ulrich and Grace, 2018; Oliver, 2018) All these problems can produce in the professional feelings of impotence, fear or frustration (Moreno 2016). In addition, the perception of unsafety environment for patients, and the fact that professionals cannot challenge these conditions can trigger moral distress (Berlinger 2016, 113). Specific organizational environments and cultures that are insufficiently resourced to support clinicians in their effort to provide the best care can be related to burnout or moral distress. Healthcare professionals become frustrated when organizational failures and barriers obstruct their ability to provide good care and impede their efforts (Brigham et al, 2018, p 2). The load healthcare professionals must carry day by day is due to the pressure to decrease the costs, raise clinical quality and improve patient satisfaction (Brigham et al, 2018, p 2). In addition, every year there is an increasing level of reports of medical and nurses suicide.

The relationship between burnout and clinical error is understood as bidirectional. Dyrbye et al (2017) shown several studies in which self-perceived medical errors were associated with worsening burn out, depressive symptoms, and decreased quality of life, suggesting a cyclical relationship between medical errors and distress. In addition, they shown other studies that have found that as the average levels of burn out of physicians and nurses working in intensive care units increased, so did the standardized rates of patient mortality, while the perceived quality of work in interpersonal equipment deteriorated (Dyrbye et al, 2017). They conclude that burn out among healthcare professionals is related to quality and safety, patient satisfaction and healthcare costs.

Squiers el al. (2017) analyzes of physician’s burnout maintain that part of the problem is that we are treating the symptoms and not the disease. They argue current efforts towards combating

well-being, engagement, retention and overall productivity; 5) Formative learning environments conducive to continuous improvement.

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burn out have become too myopic. Considering burn out is defined as an inappropriate response to stress, the prevention and treatment should be theorized in two ways: 1) a reduction in stressful stimuli, 2) an increase in the capacity to handle stress. In this sense, they maintain, organizational efforts appear to be only focus on the latter.

“If, for example, physicians were sailing on a leaking boat, health care institutions commonly appear to be suggesting that the physicians bail more quickly rather than helping them plug holes. Unfortunately, this strategy does not appear to be working, because the rates of physician burnout have continued to increase even as the problem of burnout has received greater attention in the literature” (Squiers et al., 2017).

This is the main problem: while ethical studies have been directed towards individual strategies to face stress and burn out, there not has been developed so much studies focusing on the organizational strategies to solve and manage these problems. It looks like the responsibility to respond to stress, burn out and moral distress is pushing professionals to perform an extra effort on addressing it. Moreover, the responsibility of institutions has not been enough emphasized. To counteract the increasing problems affecting well-being of healthcare professionals, institutions have the asymmetrical responsibility to implementing structural and organizational strategies to manage these problems.

As it was argued, nowadays, we cannot reflect about “the face to face relationship” that takes place in the context of health care without considering the importance of the institutional framework where these relations occur. For healthcare organizations, a substantial ethical challenge is to define how to fulfill institutional responsibilities to patients, healthcare professionals and the community (Gallagher and Goodstein 2002). As Fineman (2017, pp 10-11) highlights: “Social problems need social or collective, not just individual, solutions(...) At the same time, social problems also require a confrontation with, and response to, situations of inherent or inevitable inequality”. Institution’s obligation should be direct to improve the professional environment: a structural turn to increase the culture of institutional care will be only possible taking together the necessity of care that patients and professionals have. In this sense, it is necessary a collective action between institutions and the state to promote and foster care of both, patients and professionals. A stronger ethical commitment, based on a culture of an ethics of care, is required to allow

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institutional managers to re-think and re-assess the way how care is understood and performed in the workplace. In addition, asymmetrical responsibility can guide an ethical response in which institutional responsibility is placed at the core of ethical reflection, as well as at the core of institutional health policies. This responsibility includes to promote and ensure all the necessary resources that allow healthcare professionals perform their work, reinforcing and supporting the role of care. These institutions must respond to patients and professionals, creating and ensuring the best environment for care.

The assumption of the institutional asymmetrical responsibility is essential in the effort to manage and cope as much as possible all the external factors that trigger stress, burnout and lack of well-being in healthcare professionals. These situations are highly dependent on institutional environment, as it has been shown. Due to that, it is essential to develop and increase the healthcare leaders and policies commitment to improve the workplace safety in a broader sense, which includes place in the core of organizational policies the care of health care staff as a main goal. Furthermore, as well as collective actions are required, each healthcare institution needs to attend the particular necessities and claims that arose in the context of the organization.

Burnout, depression, pressure and moral distress are some of the main problems that current professionalism have to address (Ulrich and Grace, 2018). Burnout is determined largely by external factors, rather than by personal characteristics: work-process inefficiencies, excessive work hours and workloads, work-home conflicts, problems with the organizational cultures, and perceived loss of control and meaning at work (Dzau et al 2018, p 313). As they highlight, through collective action and targeted investment, we can diminish burnout and foster well-being, as well as also help clinicians to provide the very best care to patients. Elements of the system as autonomy and control over practice, quality of work environment and shared governance are important organizational factors linked to the well-being of healthcare professionals. Moral distress also can be addressed by moral resilience (Lachman, 2016; Rushton 2016, 2017 and Heinze et al 2017). In this case, similarly than addressing burnout, the focus on the notion of cultivating moral resilience is on the individual ability. This ability implies self-efficacy, self-control, ability to engage support and help, learning from difficulties, and persistence despite blocks to progress (Rushton, 2016, p 116). Rushton (2016, p 116) maintains the necessity of implementing systems-focused interventions

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to create a culture of ethical practice that supports individual moral resilience. Some of the key factors that have been highlighted in the improvement of working conditions are shared values and mutual support in teams, managers concerned and open to talk honestly about the pressure, and find ways to mitigate it; and low tolerance to bad behavior (Oliver, 2018). In addition, it is necessary to create bridges between healthcare professionals and leader to increase communication, and allowing occasions to talk about the difficulties clinicians face in daily practice (Berlinger, 2016).

However, majority of interventions to alleviate burnout or moral distress make efforts on an individual perspective, trying to increase the abilities, skills of capacity of the individual to overcome these circumstances. Research suggests that organizational factors play a more important role in burnout, as Brigham et al (2018, p 3) show. In spite of the benefits of these proposals or models, it is important to highlight the main concern nowadays must be focus on develop collective actions to improve healthcare workplace. Professionalism in the context of healthcare is turning to organizational approach, considering the role that healthcare organizations play to promote appropriate environments that allow professionals to perform their work in the best possible way (Brennan and Monson, 2014). While institutional efforts have been focused on reinforcing professionals' resilience skills from an individual perspective, there is an increasing recognition that organizations additionally need to redesign the system in which clinical care is delivered (Wright and Katz, 2018, p 311). In this regard, one of the most important aims that is currently addressing in US as well as globally is the recognition of the fact that "care of the patient requires care of the provider" (Bodenheimer and Sinsky, 2014)⁷⁶. Brigham et al (2018, p 3) highlights that external factors carry more weight than internal factors in causing burnout. "Focusing on the individual suggests that burnout arises when individuals cannot adapt to the learning and practice environment; focusing on the organization suggests that it is the environment that must be adapted to promote the quality of care and well-being of physicians" Brigham et al (2018, p 3). Unfortunately, the majority of healthcare institutions function under the framework that burn out and professional satisfaction are the sole responsibility of the individual clinician. Organizations look for a restricted

⁷⁶ These authors recognize in their claim the idea of symmetry: "Health care is a relationship between those who provide care and those who seek care, a relationship that can only thrive if it is symbiotic, benefiting both parties." However, this assumption is not incompatible with the notion of asymmetrical responsibility.

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list of explanations or solutions that are not likely to lead to significant progress, for instance, individual training in mindfulness. “Such strategies neglect the organizational factors that are the primary drivers of physician burnout and are correctly viewed with skepticism by physicians as an insincere effort by the organization to address the problem” (Shanafelt and Noseworthy, 2017, p 131-132) The focus must be on strategies at the organizational level to reduce burnout and promote well-being.

SOME PROPOSALS TO ADDRESS THE INSTITUTIONAL ASYMMETRICAL RESPONSIBILITY: COLLECTIVE ACTIONS

The main goal must be collectively confronting the clinician-burnout crisis, the lack of well-being, the increasing reports of suicide and depression, etc. The problem, as Dzau et al (2018) maintain, is not the lack of concern about the severity or urgency of the crisis, or lack of will to act. Rather, there is a need to coordinate and synthesize the many in progress efforts in health care community and to generate force and collective action.

Recently, the National Academy of Medicine (NAM) has proposed a conceptual model to capture the complexity of clinician’s well-being and resilience. They have developed a tool to explain the different factors affecting clinician well-being and resilience (figure 1). The goals of this tool are to increase the visibility of clinician burnout, to improve organizations’ understanding of challenges to clinician well-being, to identify evidence-based solutions, and monitor their effectiveness (Dzau et al., 2018). While this figure shows the external and the individual factors, more accent is now on the external factors, which are fundamentally institutional dependent. At the center of the figure, is the main objective, which is patient well-being. Around it, there is the relationship between clinician and patient, and around, the clinician well-being, showing the importance of maintain a balance between these three goals. The individual factors identified are organized in three areas: health care role, personal factors and skills and abilities.

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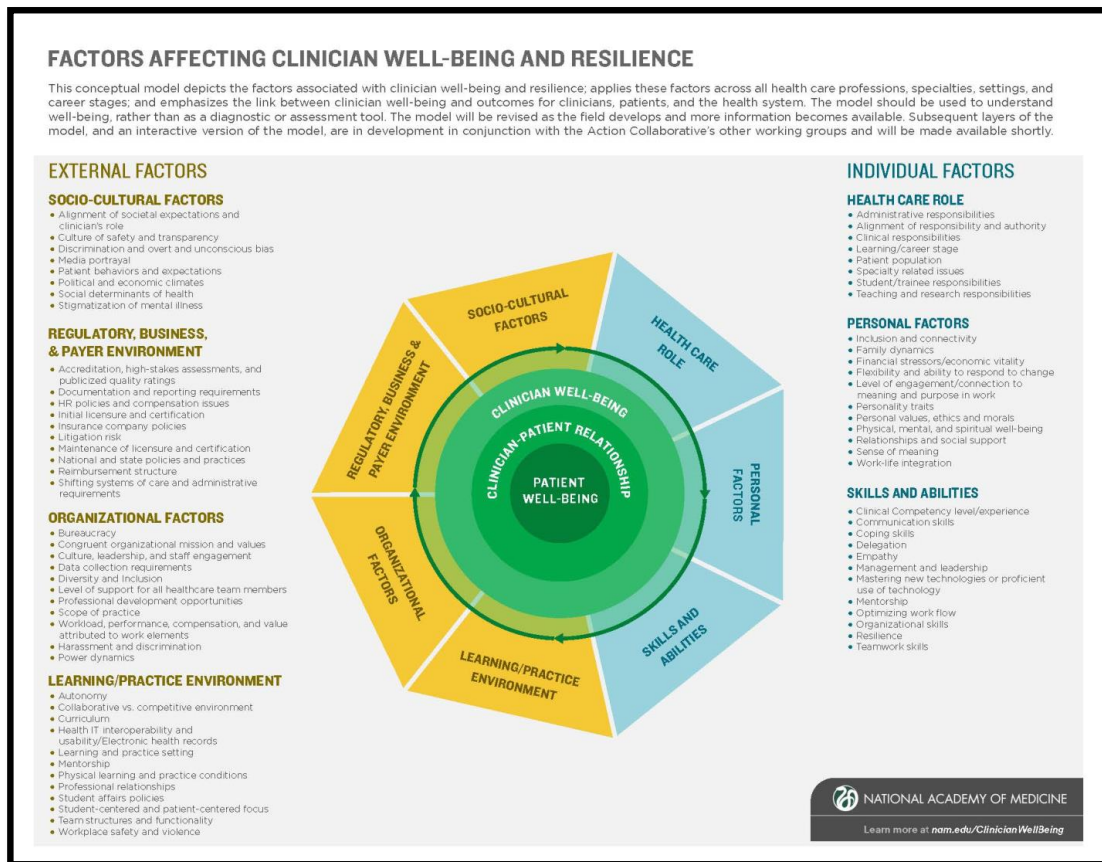


Figure 1. Source: NAM Action Collaborative on Clinician Well-Being and Resilience, 2017. <https://nam.edu/initiatives/clinician-resilience-and-well-being/#publications>.

Describing the external factors, NAM working group identify four main areas. First is socio-cultural factors, as culture of safety and transparency, alignment of societal expectations and clinician's role, among others. Second area is regulatory, business, and payer environment. In this area, some of the issues I want to highlight are documentation and reporting requirements. The third aspect is the organizational factors, as bureaucracy, congruent organizational mission and values, professional development opportunities and power dynamics, among others. Finally, the fourth space is for learning and practice environment, which includes autonomy, mentorship,

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professional relationships, team's structures and functionality and student-centered and patient-centered focus. This figure is an excellent tool to lead clinical leaders to develop different collective actions to improve daily practice, focusing on how to care of professionals as the key element to improve the patient-centered care.

Additionally, Brennan and Monson (2014, p 645) identified some benefits related to investment in organizational professionalism, as improved patient safety, satisfaction and overall health outcomes, improve organizational performance and heightened sense of meaning and purpose, among others. Some of the strategies they consider should be promoted are: a) leadership development, b) foster an organizational professional identity, c) cultivate the core values of teamwork, d) support for autonomy, and e) foster employee well-being and engagement.

Shanafelt and Noseworthy (2017) drive one the deeper analyzes of strategies that it is necessary to implement into the organizations for success on navigating the problems around healthcare professionals well-being⁷⁷. They analyze nine strategies that can be implemented in organizations to address these problems from a structural and organizational commitment. I consider important five of them⁷⁸ relevant for our purpose:

1.- Recognizing the problem of burn out and demonstrating that the organization cares about the well-being of healthcare professionals. They claim the necessity of quantify and assess different factors related to well-being, such burnout, engagement, professional fulfillment/satisfaction, fatigue, emotional health/stress, and various dimensions of well-being/quality of life. They maintain that, while all medical organizations routinely measure what they consider critical to achieve their mission (volume, patient quality / safety, patient satisfaction, cost, net operating income, etc.), well-being of healthcare professionals is not measure in the same degree for all the institutions. However, nowadays there are enough evidence to know that clinicians well-being is equally central for the organization and, therefore, should be measured.

⁷⁷ Some of the strategies they describe have been operationalized at Mayo Clinic, as they show.

⁷⁸ The other 3 strategies are: a) cultivate community at work, b)to use rewards and incentives wisely, and c) provide resources to promote resilience and self-care. Although the authors recognize that the main emphasis for organizations must be to optimize the practice environment and create a healthy organization culture, they maintain that organizations also need to provide resources in order to facilitate the implementation of individual strategies to prevent burn out, deal with anguish and promote well-being.

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2.- Leadership has a direct effect on the professional satisfaction, the evidence suggests that leadership behaviors of the supervisor play a critical role in the well-being of clinicians who lead. Shanafelt and Noseworthy (2017) also maintain that, to be effective, leaders must know what motivates the team and professionals.

3.- The third strategy consists in developing and implementing targeted interventions. They describe a stepwise process for targeted work unit interventions, which include, among others: team meets with work unit leaders, focus groups, which goal is to acknowledge the challenges/issues that are beyond the control of the work unit and for the consulting the higher-level leaders in the organization responsible for these aspects, and work unit leader facilitates the change, leading remaining aspects of the process and empowering task force.

4.- Align values and strengthen culture. It is important for organizations to be sensible of factors that influence culture, assess ways to keep values fresh, and periodically analyze whether actions and values are aligned.

5.- Promote flexibility and work-life integration. The long hours of work as well as shift work makes it difficult to integrate the professional and staff life. Due to that, two aspects in particular important to the well-being are the policies related to flexibility and working life integration.

6.- Developing the evidence-based strategies that this organization, as well as other centers, will implement. The authors highlight that vanguard institutions have this additional responsibility.

To sum up, there are some strategies and practices that can be collectively addressed and must be implemented within healthcare institutions:

- a) To implement a model of an ethics of care in the core of organizations is the main claim. If we develop all the policies, strategies, etc. of the organization on the basic base of care, there is an important turn. Not only in healthcare institutions, but specially, the ethical framework of care aims to consider caring for people as the underlying objective of all policies in the institution. A framework based on the idea of recognizing the human condition of vulnerability, welcoming differences and diversity and trying to be applied to the particular and concrete of that organization. Its central tool: the relationship. Focusing on ethics of care can lead organizations to comprehend

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and know more about how to design the framework in which all the policies and practices that arise from the institution take the concept of care in the center.

- b) Institutions need to address lack on well-being, moral distress, burn out not from an individual focus perspective, but for a collective perspective. It is an institutional problem, and solutions need to be developed in the core of the organization. At the same time, it is important to develop synergies in order to facilitate solutions collectively.
- c) Developing organizational responsiveness implies to incorporate and cultivate values of cooperative teams, such as self-respect, mutual-respect and equality in the team.
- d) It is necessary to create bridges between healthcare professionals and leaders to increase communication, and allowing occasions for conversations about the difficulties clinicians face in daily practice. For instance, it is necessary for leaders to dedicate some time to meet with the team, to increase the feedback between the leaders and healthcare staff. In addition, new technologies can be useful tools to facilitate conversations about problems that professionals face day by day. Nevertheless, for this purpose, leaders need to be really engaged in the wish to contain and manage the problems staff is facing day by day.
- e) Using the conceptual model proposed by the NAM to identify specially what are the external factors affecting clinician well-being and resilience. It is necessary to work on the diagnosis of the problem, as a first step, identifying the main sources of problems. On the other hand, also each institution should search what are the main problems in their own workspace, to manage them better. While some external factors are common, the way how these factors are performed are different depending on each institution.
- f) At the same time, the conceptual model proposed by the NAM is an excellent tool to be included in the studies and training of clinicians and leaders. One of the major benefits on using this tool is that it provides a common language and a common reference to address these problems using the same strategies. Potentially, this is a synergic way of improving the efforts in a more efficient way.
- g) Using the same tool allow researchers to find more coherence among different studies. One of the difficulties addressing the same research problem (for instance, moral distress) is the difficulties we face when we want to collect the results of different studies. To have common tools is also excellent for researchers.

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CONCLUSIONS

In this chapter, I have developed some aspects of the concept of asymmetrical responsibility that are relevant in the context of healthcare professionalism. The starting point of this reflection was the recognition of the constitutive and inherent inequality of relationships of care. Understanding this feature, our focus is not on the attempt to try to compensate and turn equal relationships, but it is to better assume professional responsibility required to manage the moral duties that arise from these kind of unavoidable unequal relationships. I have claimed the notion of asymmetrical responsibility in the core of healthcare relationships, at the bedside level, requires the institutional support to lead professionals and patients to increase their care. For this purpose, it is essential to design more collective actions between different institutions, a stronger ethical commitment and a relational thought, that allows institutional managers to re-think and re-assess the issues about care in the workplace. In addition, a focus on vulnerability approach can lead organizations towards the recognition of the need to develop resources and educational strategies to solve problems arising for the daily practice of healthcare professions. The notion of asymmetrical responsibility, together with Fineman's theory of vulnerability, can illuminate professionalism's studies to find strategies to take care of those who care for other in the workplace.

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CONCLUSIONS

I. ALL OF US ARE VULNERABLE

This thesis began with the question on how to understand vulnerability in Bioethics today. From the analysis of the current opposition between two main philosophical approaches to this question, I found in the literature a lack of deep understanding of the universal or anthropological approach to the concept of vulnerability. I realized the need to develop a normative theory in Bioethics that would allow us to develop an ethic of vulnerability based on the recognition of our shared human condition: we are all vulnerable. In Bioethics, most academics, although they recognized the universality of the concept of vulnerability, criticize this theoretical approach, arguing that this basis is not practical to address current problems in the field. On the contrary, along these pages I have demonstrated how a universal concept of vulnerability can be applied into Bioethics field to face some of the most urgent and acute problems in healthcare nowadays.

My analysis of the vulnerability theory developed by Martha Fineman has focused on the main aspects of this theory, in order to better understand how this framework can contribute to Bioethics studies and research. The recognition of vulnerability as *the* shared condition of human beings, leads us to assume that vulnerability is constant, there is no more or less vulnerability, but more or less resources to deal with it. Thus, it is not a matter of paying more attention on the characteristics of the people to include them and list them as belonging to vulnerable groups, because they have a series of features that make them vulnerable. We are all vulnerable, what makes some people require more protection are not their characteristics, but precisely the lack of sufficient support from the institutions and the state. In this way, the focus is not on individuals, but on how the state and institutions must promote the necessary conditions for individuals to have more strategies to manage the inevitable vulnerability of the human condition. That is why resilience constitutes an essential resource. In this regard, resilience can be only understood in connection with institutions and the state providing it or not. Resilience is not a personal choice, a

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personal responsibility of individual to develop it. Needs collective support, from society and their institutions to be developed.

This theory can contribute a lot to Bioethics field. Particularly, in this research I have focused on the implications of the theory in Clinical Ethics. However, it is a matter of fact that Vulnerability Theory can contribute to other areas within Bioethics, like environmental ethics or research ethics.

I have found some implications of this approach in Bioethics:

- a) The necessity of criticize the current Autonomy Principle in Bioethics, since the way how the principle is understood and applied generate problems and it reflect a myth.
- b) The possibility of rethink autonomy as a relational term in the context of healthcare.
- c) The concept of vulnerability contains a normative challenge, and it is possible to elaborate an ethics of vulnerability because of the normative force of the term, which interpellates us to action of care.
- d) Vulnerability theory can improve relationships and communication in healthcare, specially between professionals and patients, but also between professionals and the institution.
- e) Vulnerability theory provides a framework from which it is possible to analyse problems of justice in healthcare, especially those who arise from neoliberal policies that benefit the private healthcare sector, while public health services have become weak. These policies have had repercussion on the well-being of clinicians, increasing moral distress and burn out.

Based on these implications, I have developed three main areas of analyses. First one is the necessity to rethink the concept of relational autonomy. The second one is how to better understand the relationships between institutions of healthcare, clinicians and patients and their families, focusing on Professionalism commitment. And the third one, is the importance of reflect about social justice in healthcare, focusing on responsibility in terms of asymmetry. These three main areas constitute the chapters of this thesis.

II. RELATIONAL AUTONOMY AND VULNERABILITY AS NECESSARY LINKED TERMS

I have argued the need to implement a relational thinking and analysis in bioethics, to deal with the different practical problems that arise from everyday practice. In this relational turn, I include the link between vulnerability as a human condition and relational autonomy. Vulnerability theory

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has also emerged against the “myth of autonomy” (Fineman, 2004), which paradigm is the liberal idea of autonomy that understands the subject as self-sufficient, individualistic, etc. I agree with the criticism of the liberal conception of autonomy, because of the problems that arise as a consequence of this conception, as I have claimed.

On the one hand, it is true that vulnerability theory rejects the liberal notion of autonomy, without applying other way of understanding or transforming this notion of autonomy. On the other hand, given that in the particular field of clinical ethics, the recognition of the right of patients to make informed decisions is irrevocable, I maintain the need to develop another way of understanding autonomy in bioethics. From my research, and focusing specially in clinical ethics, I advocate relational autonomy as a key concept in the attempt to challenge the triumph of the principle of autonomy in bioethics. In addition, I have argued the importance of considering the inextricable relationship between the concept of vulnerability and relational autonomy: we can realize that autonomy and vulnerability are not incompatible. I have maintained these are two aspects of the human condition are strongly related. While we are all vulnerable, through the network of relationships where we are embedded it is possible to develop a capacity to autonomy, understanding it relationally, and only through the recognition of the relationality involved in these two terms.

III. CLARIFYING AND DEVELOPING RELATIONAL AUTONOMY TERM

While there is a huge literature in Bioethics about the term of relational autonomy, at the same time there is a lack of clarification, or systematization on the definition of the main characteristics of this term. Through the connection with vulnerability concept, I have developed what are the main characteristics that relational autonomy term content. Including the notion of vulnerability in the development of relational autonomy term, I understand relational autonomy as a capacity to make decisions, not as individual, self-sufficient person, but as a being embedded in social relationships. I have found five features of relational autonomy: relationships, capacity for decision making as a procedure, process along the life course, professional commitment and collectivity.

First, one of the main aspects highlighted by the concept of relational autonomy is the importance of the relationship. It is required to develop relational approaches in clinical context

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that focus on the interaction between the patient (or the patient and his or her family) and the healthcare professional and the institution. Second, I have maintained that it is required to respect the right of patients to make their own decision, not deciding under pressure, not being oppressed. But at the same time, in the core of healthcare, relational autonomy emphasizes the capacity for make decisions, and not only the legal right (represented on the informed consent model) for respect the patient’s decisions, regardless how these decisions occur. Relational autonomy term insists on the process how these decisions take place. In addition, as a capacity that needs to be developed, I have argued relational autonomy is not only refers to a specific moment; far from that, it represents a life course process to be able to make the best decisions. While autonomy principle is understood as a punctual moment that occur when patient needs to consent or accept a health care treatment or practice, relational autonomy is the result of a process in which the patient and their family is involved when he or she need to be care. The fourth aspect focus on the professional’s responsibility on fostering relational autonomy. As a capacity, it needs to be fostered by professionals in each one of the encounters with the patient, in different moments of their course life, and it will require not only information, but also education for health and tools for deliberation. Focusing on relational autonomy, the responsibility for decision making process is shared between the patient and the health care professionals, but more accent is now in the professional commitment. It is required a supportive relationship, based on care, that allow to flourish all the conditions for make decisions. Finally, relational autonomy also highlights the network of relationships where all of us are involved. Relational autonomy is not an individual attribute or capacity; it is only possible in the core of a community. In the context of healthcare, this community is conformed for patient, the family, health care professionals, and the institution. Relational autonomy should be understood and promoted considering the impact of decision making process on all of these participants, and the repercussion and also possible support that can be achieved.

IV. IMPROVING RELATIONSHIPS IN HEALTHCARE

The theory of vulnerability provides an indispensable framework from which to think about how to improve relationships, improving empathy and resilience. I have applied vulnerability approach

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into the context of relationships in healthcare, to show and analyze how vulnerability is a central condition of care relationships. I have shown how, in addition to patients and their families, it is necessary to take into account vulnerability from the perspective of healthcare professionals: these professionals also face day by day suffering. I have maintained professionalism needs to improve its commitment in response to the vulnerability from three perspectives: patients and their families, health care professionals, and the institutions. Considering our shared vulnerability between patients and the professionals who care for them, which also include the vulnerability in institutions, is a way to improve relationships and resilience in healthcare. I have argued the importance of apply a relational approach to the understanding of everyday practice of nurses, doctors and other healthcare professionals. I argue our acknowledgment of shared vulnerability is essential in professionalism studies, and to think about how to introduce this knowledge in healthcare formation and studies is a big challenge that we need to confront.

By emphasizing vulnerability as one guide for professionalism in healthcare, it is necessary to consider that professionals experience their own vulnerabilities in their encounters with patients. This can lead to the promotion of empathy and solidarity in caring relationships and it should to be prized rather than avoided or denied. However, the ability to introduce shared vulnerability into therapeutic relationships requires continuing self-awareness and self-care, and this involves the self-understanding that physicians, nurses, healthcare professionals share the same vulnerabilities than patients experiments. Our acknowledgment of this shared vulnerability is essential in professionalism in healthcare.

V. RELATIONAL PATIENT-CENTERD PROFESSIONALISM

I have analyzed the fracture that it is produced in the core of professionalism: while professionalism have focus mainly on the normative reflection about moral values, skills and abilities that professionals need to develop, it is required to address attention to the complexity of practice nowadays in the stressful environment of healthcare systems. I have developed the notion of relational patient-centered professionalism to confront this gap. Healthcare systems need courage and leadership to counteract and prevent the difficult situation that healthcare professionals are worldwide facing. From the perspective of a relational patient-centered

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professionalism, I argue it is necessary to understand the importance of vulnerability in healthcare context, as well as in enhancing professional values.

Taking into account the perspective of the patient helps us to make visible the impact that relations of care have in patients and their families, and that sometimes may go unnoticed by the professionals themselves. In addition, in the health field, the vulnerability of professionals must be recognized and studied, especially in regard to the institutional circumstances that trigger adverse situations. Moreover, from the recognition of professional's own vulnerability, as has been exposed, positive situations can be generated that give rise to closer relationships of trust and help between professionals and patients. Finally, it is essential to generate an institutional culture with a strong ethical commitment that is attentive to the demands and needs of both patients and professionals. Without this institutional support, it is not possible to address the enormous problem of healthcare staff lack of well-being. I have found necessary to develop a relational approach on professionalism to look for the best institutional strategies to stop moral distress and burn out in professionals, while promoting healthcare responsibility towards patients and families' relationships. This is and must be the greatest challenge of healthcare professionalism in our days.

VI. ASYMMETRICAL RESPONSIBILITY AS A KEY CONCEPT IN PROFESSIONALISM IN HEALTHCARE

I have shown the lack of balance between the huge impact that autonomy principle has taken within bioethics and the absence of a similar reflection about professional responsibility in regard to create or establish the basic conditions that allows relational autonomy to emerge. For manage this gap, I have developed the concept of asymmetrical responsibility as an essential theoretical tool to address professional responsibility in the context of healthcare. Within the current practice of medicine and nursing, the emphasis on autonomy has led to a lack of development of ethical theorization on professional responsibility in healthcare relationships. I have argued vulnerability theory and relational autonomy concept has an important impact in the way how relationships of care between healthcare professionals and patients are performed. Relational autonomy emphasizes the importance of the relationship between the patient and the healthcare professional in the process of decision making in regard to health. While the

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responsibility for decision making process is shared between the patient and the health care professionals, we must emphasize the professional commitment. That is the reason why I claimed the idea of “asymmetrical responsibility” need to be implemented in bioethics and professionalism.

I have claimed that this asymmetrical responsibility that takes place in the core of healthcare relationships, at the bedside level, requires the institutional support to lead professionals and patients to increase resilience, especially to the institutional commitment to manage and address problems arising from everyday practice, that lead professionals to face difficult situations. For this purpose, I consider it is required more collective actions between different institutions, a stronger ethical commitment and a relational thought, that allows institutional managers to re-think and re-assess the way how care is understood and performed in the workplace. To address attention toward healthcare well-being is the most emergent duty in healthcare field nowadays.

VII. INSTITUTIONAL ASYMMETRICAL RESPONSIBILITY IN HEALTHCARE

I have maintained to support healthcare systems as relational spaces for care needs to foster resilience in healthcare professionals, patients and in the system itself. To improve clinicians well-being to achieve personal satisfaction and commitment in the workplace, requires a strong and ethical institutional compromise, assumed as a duty of care for those who take care of others. This is what I have called the assumption of the institutional asymmetrical responsibility. This ethical duty is essential in the effort to solve majority of the external factors that trigger stress, burnout and lack of well-being in health care professionals. While some aspects of healthcare professions are intrinsically sources of suffering (like be witness of suffering of others), it is essential to develop and increase resilience in healthcare staff to manage these situations, and especially, to cope with the external factors that have been identified for National Academy of Medicine last year.

Only through a focus on collective actions focused on diminish burnout and foster well-being is the only possible way to provide the very best care to patients. Turning the traditional focus of interventions to alleviate burnout from the individual level to the collective institutional and organizational level, can be possible to achieve well-being, quality and safety for all in the teamwork in healthcare. Professionalism in this sense needs to turn to an organizational approach, to promote appropriate environments that allow professionals to perform their work in the best possible way.

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Institutions of healthcare must create and ensure the best environment to care. For this purpose, it is required a stronger ethical commitment, based on institutional asymmetrical responsibility.

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