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(RESEARCH ARTICLE)



# Refusal of care in vulnerable people: Case of the elderly

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#### **Abstract**

Within the framework of the hospital, a medical act "can only be performed with the free and informed consent of the patient"... What are the levers for the healthcare professionals in order to have the care accepted? The problem that emerges from these first reflections is: "How can the healthcare professionals deal with a patient's refusal of care?"

The patient has the right to withdraw his consent, such as refusing an act, treatment or care. The refusal of care questions professionals even about the very meaning of their mission. It challenges them on the Health professionals-patient relationship, on its foundation and raises many ethical questions: when should we or not accept not to provide care to a patient who refuses it?

How to obtain the consent of a patient who refuses care? Am I mistreating when I give a patient treatment that is essential to him?

For this work, certain aspects and or dimensions of the refusal of care in the elderly from the healthcare professional's point of view and the role of Health professionals in dealing with this refusal but also on the legislation, ethics, deontology, law, the patient- healthcare professionals relationship, public health, as well as the contribution of multiprofessional care in this context . Health care professionals will have to take into account these dimensions based on the patient's autonomy, dignity and vulnerability. while respecting their consent or non-consent to care despite their illness, with the aim of adherence to the care of their patient, maintaining a relationship of trust, engaging in dialogue will make it possible to find a compromise, and ultimately respect the patient's autonomy.

Keywords: Care; Refusal of Care; Elderly; Healthcare Professionals; Consent; Legislation; Ethics; Public Health

### 1. Introduction

This research. Or work of reflection will allow us health professionals to create a professional identity.

To start, we had to choose a situation that challenged us. I then became interested in that of a patient admitted to general acute medicine for COVID+ pneumonia who refused to eat, drink and all forms of care. The ethical dilemma that this situation posed interested me, to carry out my analytical work. Indeed, I chose to deepen the particularity of the caregiver-patient relationship with an elderly person presenting with major anxiety.

Within the framework of the hospital, a medical act "can only be performed with the free and informed consent of the patient" [1]. This fundamental right can be found in the Charter for hospitalized persons. The corollary of this principle is that the patient has the right to withdraw his consent, such as refusing an act, treatment or care. However, we speak of refusal of care when, despite a shared decision-making process, no agreement can be reached with the patient around a care plan. This refusal of care then begins, when consensus is no longer possible. Remember that the law implies that

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all care is the subject of clear, fair, and appropriate information both in terms of the benefits and risks of an intervention or the treatment offered, and the risks of non-intervention. Thus, the refusal of care questions professionals even about the very meaning of their mission. It challenges them on the caregiver-patient relationship, on its foundation and raises many ethical questions: when should we or not accept not to provide care to a patient who refuses it?

In order to maintain quality support, it is essential that **Health professionals** question themselves and analyze the situation of refusal of care in a multidisciplinary team, with the aim of adherence to the care of their patient. To do this, maintaining a relationship of trust, engaging in dialogue will make it possible to find a compromise, and ultimately respect the patient's autonomy.

The elderly are also a population at risk and not the least because they are sensitive, either due to loneliness or depression. cognitive disorders, disruptive behavior stipulates the authors Thomas.T, Mélanie.H, Régis. A. in the title: Is the opposition to care expressed by an elderly person presenting with disorders neurocognitive disorders constitutes a refusal of care? [2].

Our work revolves around the problem of the refusal of care in an elderly patient, depressed and sad following the suicide of her husband by a gun, the reasons for which are not known. Thus, certain factors can increase the vulnerability of people aged over 75, such as sex (male), loss of spouse, physical illnesses (particularly disability or pain), changes in environment (such as entry into a retirement home or admission to hospital), loss of social, professional and family roles, isolation, abuse, depression. We have chosen to address this theme and more particularly the refusal of care in the elderly, because, in recent years, there has been an aging of the population, which represents  $\frac{3}{4}$  of the total population in France and which goes hand in hand with the increase in age-related illnesses.

In addition, according to research on the causes of refusal of care in the elderly, issued during the conference of September 19, 2017 at the Town Hall of the 17th arrondissement in Paris on the "Refusal of help and refusal of care - When home care becomes complicated" [3]; the authors and speakers talk about the causes and reasons that can lead to a refusal of care aid, which are:

- -of a psychiatric nature: Depression, bipolarity, psychotic pathologies which are disorders that can generate behavioral disorders, a feeling of persecution and therefore result in rejections.
  - psychological: In a context of loss of autonomy, the elderly can deny the disease or addiction. It is also possible that the person elderly woman wants to remain in control of her life, with this refusal which could reassure her and make her feel like a whole person.
  - of a socio-economic nature: Elderly people with a loss of autonomy do not necessarily know their rights and existing aid. This ignorance can be scary. Several support mechanisms exist, depending on the situation (Personalized allowance autonomy (APA), tax reductions, etc.).
- -of a cultural nature: Depending on religions, customs, care is not experienced in the same way. The relationship to the body, to illness, the language barrier are so many obstacles that can lead to a refusal of help and/or care. The depression in aging people is most often due either to personal circumstances, physical and/or psychological disabilities.

For this, we can act on their signs and symptoms of their disease as well as a follow-up with a psychologist could be effective. It is necessary to detect depressive syndromes in the elderly, which is not always easy as the symptoms can be masked. Depression is not inevitable in the elderly, it must be treated and the expression of suicidal ideation must be taken seriously. Limits are set by law, but any adult, able to consent, can at any time refuse care, even if his refusal could lead to his death. The person's decision does not have to be reasonable or justifiable in accordance with Article 46 of Ordinance No. 2020-232 of March 11, 2020, these provisions came into force by decree in the Council of State in October 2020.

However, in his professional practice, the healthcare professional can find himself faced with a refusal of care. Several questions then arise. This refusal can challenge him either on a relational level, but also on a legal and ethical level but also on his professional practice.

Thus the refusal of care, perhaps the potential signs of a difficulty for the patient, particularly in the establishment of a health care professional -patient relationship, must be understood above all as an incentive to communicate and above all not a reassurance. cause or rejection of the nursing function. This attitude is the essential condition to accompany the subject towards a decision of his own, whether it is the maintenance of the refusal or an acceptance of care. The objective of this research is therefore to propose rules for analyzing and understanding situations of refusal of care, which are based on multidisciplinary care.

In public health, the refusal of care is based on: "The doctor must respect the wishes of the person after having informed them of the consequences of their choices. If the will of the person to refuse or interrupt a treatment puts his life in danger, the doctor must do everything possible to convince him to accept the essential care. No medical act or treatment may be performed without the free and informed consent of the person and this consent may be withdrawn at any time"[4]. Thus this information, consent or refusal must be traced in the patient's medical file so that each actor feels heard in their approach.

Starting from this postulate, I wonder: How to obtain the consent of a patient who refuses care? Am I mistreating when I give a patient treatment that is essential to him? What are the levers for the healthcare pofessionals in order to have the care accepted?

Thus the problem that emerges from these first reflections is: "How can the nurse deal with a patient's refusal of care?"

Throughout this work, we are going to describe in a clear and detailed way the situation which challenged us during the first part of my internship and which we also observed during my internships: The refusal of care in the elderly.

For this personal written work, I will therefore dwell on certain aspects and or dimensions of the refusal of care in the elderly from the caregiver's point of view and the role of the nurse (IDE) in dealing with this refusal but also on the legislation, ethics, deontology, law, the patient-caregiver relationship, public health, as well as the nursing contribution to multi-professional care in this context. To do this, I will follow a detailed plan starting from an introduction, the justification of this theme, the description of the chosen situation, the frame of reference centered on the four areas, namely legislation, ethics, ethics, the caregiver relationship, public health, then the nursing contribution to multi-professional care. After having described these 4 axes, I will, via an analysis, speak mainly of two axes, namely the legislation on the refusal of care in the elderly, and the multi-professional nursing contribution. I will end this written work with a conclusion, all accompanied and supported by literary and scientific references.

# 2. The appeal situation

The situation I have chosen takes place in the general acute medicine service located in a hospital . This service located on the 4th floor consists of 25 hospital beds divided into two sectors. Since the COVID+ pandemic, the service has been sectorized, with one side for contagious people, and the other non-contagious sector. The missions of the service are based on the management of pulmonary, infectious, endocrinologist, urological, neurological, gastroenterological, orthopedic and cardiac pathologies, but also the training of health professionals and research. Patients are recruited mainly through the emergency room or in scheduled hospitalization. For this, a multidisciplinary team made up of a nurse, a nursing assistant assisted occasionally by a nurse and a relay nursing assistant.

Mrs. X. is a 98-year-old patient who entered the service on January 19 via the emergency department for deterioration in general condition (AEG) for 15 days at her home. Mrs X lives alone in an apartment, has no children but is well surrounded by neighbors and her niece who lives in Germany, who come every week to visit her and support her psychologically and to stimulate her to food. In addition, his neighbors visit him every day.

Mrs. X benefits from daily home care, by private nurses who come to help her in the gestures of everyday life. Mrs. X has a history of hypothyroidism treated with Levothyrox, polymyalgia rheumatica since 2009, which worsened following the recent death by autolysis of her husband, the week preceding his hospitalization. When she arrived at the emergency room, she tested positive for Covid +, with a chest scan which showed lung damage at a height of 75%. In view of his age and his history and his illness, the doctors decided to limit the care.

Since the death of her husband, Mrs. X presents a major anxiety because they had decided to commit suicide together. The patient refuses to give the reasons that pushed her and her husband to make this decision.

My situation begins at 6 p.m., when the evening treatments are administered and the vital parameters are taken (saturation and temperature). I find a very agitated patient who grinds her teeth at the sight of me. I inform her that I am coming to administer her treatment, she pushes my hands away and spits out the medicine that I try to make her swallow. At no time does she speak. I try to obtain her consent but the patient still refuses and stubbornly closes her mouth so as not to swallow her treatment. Initially, I tried to convince the patient by informing her of the risk incurred if she did not take her treatment, then in a second step, I decided to implement a support interview to understand the reasons for her refusal. After several hours of discussion with the patient, she reluctantly agrees to take her medication. As I walked out of the room, and the emotions this situation caused in me, several questions arose:

- How to obtain the consent of a patient who refuses care?
- Am I mistreating when I give a patient treatment that is essential to him?
- What are the levers for the nurse in order to have the treatment accepted?
- So the problem that emerges is: "How can the nurse deal with a patient's refusal of care?"

### 3. Reference framework

To define my research work on the refusal of care, I would explore in the frame of reference, the refusal of care, an approach to public health through the refusal of care and the legislation which governs it but also the caregiver relationship neat, multi-disciplinary work.

### 3.1. Refusal of care

### 3.1.1. Definition

We speak of refusal of care when, despite a shared decision-making process, no agreement can be reached with the patient around a care plan. The refusal of care then begins, when consensus is not possible. It should be remembered that the law implies that all care is the subject of clear, fair and appropriate information both on the benefits and risks of the intervention or treatment offered and on the risks of non-intervention. Several texts evoke the principle of patient consent, here they are:

According to the code of medical ethics, "the doctor owes the person he is examining, that he treats or whom he advises, fair, clear and appropriate information on his condition, the investigations and the care he imposes on him. Throughout the illness, he takes into account the personality of the patient in his explanations and ensures that they are understood"[5]. The civil code tells us that "the integrity of the human body cannot be damaged, only in case of therapeutic necessity for the person. The consent of the interested party must be collected beforehand, or in the event that his condition makes an intervention necessary therapy to which he is not in a position to consent" (Articles 16-3 and 16-1).

(Onisep.2017). Also, the rights of patients are notified in the patient's charter hospitalized, title IV. This charter informs us that "no medical act can be performed without the consent of the patient, or if his condition makes this act necessary, to which he is not unable to consent" [6].

## 3.1.2. Refusal of care and legislation

The Civil Code states that the consent of the person concerned must be obtained before any act of care, even if the case where his condition necessitates a therapeutic intervention, to which he is not able to consent. For this, the legislator, through the law of March 4, 2002, relating to the rights of patients and the quality of the health system known as the "Kouchner law", has brought out a new right for the patient and in particular that of refusing.

Within health establishments, this freedom is found in the hospitalized person's charter of 2006 "a medical act cannot be performed without the free and informed consent of the patient" [7]. It must also be displayed in the passageways of hospitals, such as in the hospital lobby, waiting rooms and service corridors. These displays must allow all hospital users to know their different rights in the management of their health.

In addition, Article 36 of the Code of Medical Ethics also highlights the notion of consent to care and, conversely, refusal of care. Also, it is stipulated that "the consent of the person examined or treated must be sought in all cases" [8].

If the patient is unable to express his wishes, the doctor cannot intervene without his relatives having been warned and informed, except in an emergency or if it is impossible. However, the physician's obligations with regard to the patient when the latter is a minor or a protected adult are defined in article 42 which refers to the consent, mentioned in the fourth paragraph of the minor, "the minor, where applicable under guardianship must be systematically sought if he is able to express his will and participate in the decision" [9].

It is also said with reference to the consent, mentioned in the fourth paragraph: "the adult subject to a measure of legal protection with representation relating to the person must be obtained if he is able to express his will, if necessary with the assistance of the person in charge of his protection. When this condition is not met, it is up to the person in charge of the legal protection measure with representation relating to the person to give his authorization, taking into account the opinion expressed by the protected person. Except in an emergency, in the event of disagreement between the

protected adult and the person in charge of his protection, the judge authorizes one or the other to make the decision"[10]. Thus, when the patient, in a state to express his wishes, refuses the investigations or the proposed treatment, the doctor must respect this refusal after having informed the patient of its consequences. For this, Article L.1111-4 of the Public Health Code (CSP), makes it clear that everyone "has the right to refuse or not to receive treatment. The doctor has the obligation to respect the will of the person after having informed him of the consequences of his choices and their seriousness"[11]. This right to refuse appears to be fundamental in health law. Apart from emergency cases where it will be possible to override the consent of the person, the human body and the will of the patient cannot be harmed. Consent being required and acquired for the person, this implies that they can refuse care regardless of the situation, including at the end of life. Rightly, article L.1111-4 al 4 of the CSP specifies "that no medical procedure or treatment may be performed without the free and informed consent of the person and this consent may be withdrawn at any time" [12]. De facto, a patient who has previously accepted treatment can ask for it to be suspended at any time, even if it has already been undertaken.

But in order to be able to refuse, the patient must still be able to understand the risks inherent in this refusal and therefore have the necessary information.

Giving or, on the contrary, refusing to give their consent presupposes having been informed in a clear, fair and appropriate manner about their state of health. Thus, upstream of the right to refuse treatment, there is one of the most important patient rights: the right to information. This information must cover "the various investigations, treatments or preventive actions that are proposed, their usefulness, their possible urgency, their consequences, the frequent or serious risks normally foreseeable that they entail as well as the other possible solutions and the foreseeable consequences in the event of refusal" [13]

Thus, the question of the form of information arises. If no writing is required by law, it seems wise to trace the elements that may reflect a refusal of care, either through writing in order to protect the caregiver and that the entire care team can have access to all the information, the objective of which will be to find common ground with the person and thus promote their therapeutic alliance.

However, what are the limits of the right to consent?

There are situations where the patient is unable to give consent and will still receive care. On the one hand, it is the urgency or the impossibility of informing. An emergency is defined as "a serious and immediate danger to the life or health of an individual"[14], so in this situation, the patient's state of health does not allow an opinion to be expressed. Sometimes also, the patient's desire to be kept in the dark, for example of a diagnosis or a prognosis. In the latter case, the person must be informed in the event of a risk of transmission. However, this choice may challenge the caregiver. Indeed, what position should the health professional adopt in the face of a refusal of care that would endanger the patient's life?

First of all, respecting his decision is fundamental in order to be able to understand the reason for the refusal. The professional will then have the heavy task of doing everything possible to convince the person to accept the essential care. He may also call on another member of the medical or paramedical profession in this situation. All this information must be traced transparently.

In addition, when the person is at the end of life, refuse treatment, the new wording of article L1110-5-1 of the CSP provides that "when acts of prevention, investigation or treatment and care appear useless, disproportionate or when they have no effect other than the sole artificial maintenance of life, they may be suspended or not be undertaken, in accordance with the will of the patient and, if the latter is unable to to express their will, following a collegial procedure defined by regulation" .[15]

## 3.1.3. The Healthcare professionnal faced with the refusal of care: concerning nurse

Before talking about the nursing role in the face of refusal of care, it is necessary to look at the duties of nurses and the texts that govern them. According to this public health code, it is said that the nurse acts in all circumstances in the interest of the patient. Article R4311-1 of the Public Health Code states "the exercise of the nursing profession includes the analysis, organization, performance of nursing care and its evaluation, contribution to the collection of clinical and epidemiological data and participation in prevention, screening, training and health education actions" [16]. In the performance of nursing acts in accordance with the Public Health Code, the exercise of his skills is subject, except in certain special circumstances, to the consent of the patient. Even in the event that this consent proves difficult or impossible to obtain, the nursing staff, in this case the doctor, must seek it from the patient's relatives.

In MAP, as in all other care services, the nurse is confronted with a double requirement that is both legal and ethical: first, respect for the patient's autonomy, expressed by consent to care and the obligation of care. With regard to respect for the patient's autonomy, including when this is expressed by a refusal of care, the law of March 04, 2002, known as the "Kouchner Law", clearly specifies this notion of consent in article L 1111-4 ".[17]

Any person takes, with the health personnel and taking into account the information and recommendations that they provide, the decisions concerning their health [...] The doctor must respect the will of the person after having informed him of the consequences of his choices". As for the code of ethics, article 36 provides: "The consent of the person examined or cared for must be sought in all cases. When the patient, in a state to express his wishes, refuses the investigations or the proposed treatment, the doctor must respect this refusal after having informed the patient of its consequences". It also specifies "that no medical act or treatment may be performed without the free and informed consent of the person and this consent may be withdrawn at any time. When the person is unable to express his or her wishes, no intervention or investigation may be carried out, except in the event of an emergency or impossibility, without the person of trust provided for in Article L. 1111-6, or the family, or failing that, one of his relatives was consulted"[18]

But beyond the law, the ethical aspect, which includes the values that guide our actions, Tom Beauchamp and James Childress have described four concepts on which medical ethics is based:

- Beneficence, which reflects the desire to do well, to be useful to the patient.
- Non-maleficence, permanent desire for the caregiver to be useful and not to harm.
- Respect for the patient's right.
- Iustice, care must be fair.

Thus, in the exercise of her professional skills, the nurse will have to take into account these dimensions based on the patient's autonomy, dignity and vulnerability. In this context, the nurse must respect the patient's autonomy, i.e. act while respecting their consent or non-consent to care despite their illness.

However, it is accepted that the disease alters the patient's autonomy and ability to consent to care. It can reduce his ability to understand, appreciate, reason and guide the patient's choices. But this should not be an opportunity for the nurse to disregard respect for the dignity of the patient. As part of her professional activities, the nurse must develop a helping relationship with the patient during his hospitalization. The respect of his dignity passes by the recognition of the patient as a human person with recognized rights, that the only illness cannot deny him the existence, nor alter his range. As such, the patient has the right to respect for his intimacy, his private life, the consideration, which the alteration of his autonomy and/or the chronic nature of the disease cannot deprive him of. In this context, the nurse must scrupulously respect the rights of the patient. On this subject, Didier Sicard emphasizes that: "the patient's vulnerability implies special attention from the nurse in terms of care"[19]. For this, caregivers will be able to "develop multiple tacts, benevolent practices to ensure patients quality care regardless of their vulnerability caused by the disease"[20].

Thus the decision to respect a patient's refusal of care or to intervene despite it, results from an arbitration in a conflict of values between the principle of beneficence and respect for the patient's autonomy. This principle of autonomy is subordinated to respect for the dignity of the human person. The care of a patient is part of a caregiver-patient relationship and underlines the importance of the multidisciplinary team, with diversified and complementary professional skills. It presupposes an ongoing relationship, an established project involving the caregiver, the patient and the entire intervening team. It is based on respect and trust. It allows the patient to remain an actor in his illness, to be able to express his choices and that these are respected.

For this, the caregiver and the patient must create a link. This link, we know it under the name of the caregiver-patient relationship.

## 3.2. The caregiver-patient relationship

The individualization of the care of a patient results in its uniqueness. The singularity of care represents what is specific to each of us, that is to say, what identifies us or differentiates us from others. Each person has his own emotions, his story, his character.

According to Walter HESBEEN [21], Care is the special attention that a caregiver has for a person or his relatives or a group of people in order to help them in their situation by using, to materialize this help, the skills and qualities that

make it professionals. The caregiver-patient relationship must take place in a climate of trust, made active listening, observation, support, checking the patient's understanding or even welcoming their emotions: the caregiver-patient relationship must require our full attention. Walter H. In his definition also sees that It is not enough to be in relation for there to be care: it is a necessary but not sufficient condition. The relationship cannot be treated alone, it is the relationship and the ability of the caregiver to reflect on this relationship and on this relationship that will bring about the conditions of relief for the person.

It is also a relationship of trust in which the sick person remains free, and the caregivers are not the only ones to decide on the therapeutic choices that correspond to them. He must participate, whether in the choice of care offered to him, to accept them but also to refuse them if necessary.

In this relational framework, the nurse will have to take into account not only the legislative and regulatory texts which govern the practice of her nursing profession but also the context of the care and the hospitalization methods of the patient. The nurse will have to analyze the priorities and discover that behind the disease there is a human being. This approach will lead to good treatment when it analyzes the patient's habits and past. This relationship is not intended to make the patient dependent but to help the patient get through this ordeal and find a satisfactory functioning in life. This caregiver-patient relationship reflects the interaction between two people in a care situation. Thus, in her own role, the nurse must listen, examine, advise, educate or treat. According to Carl Rogers, the helping relationship is based on the following postulate: "every individual has sufficient potential to manage all aspects of his or her life" [22]. Thus, the patient becomes that person who can no longer on his own manage to manage the activities of life on his own and whose professional, among others the nurse, is there to help him regain his capacity for personal direction. To release the potential of the person, Carl Rogers suggests respecting three fundamental elements: "empathy, congruence, unconditional positive consideration or unconditional positive reception" [23].

In this carer-patient relationship, communication occupies a central place, because it is through communication that the various actors understand each other better and that the relationship of trust is established in which the carer will have to be accepted by the patient, in him transmitting in simple terms, the models and rules to follow for an acceptable, peaceful and profitable therapeutic process for the patient. As such, Alexandre Manoukian affirms that "the development of the relationship of trust between caregiver and patient is based on the helping relationship" [24]. Far from confining empathy simply to putting oneself in the other's shoes, it involves self-confidence, trust in the other and marked trust in the relationship. In this relationship, the nurse engages in the world of the patient, invests the intimacy of the other and in this case, the caregiver will have to show that he is interested in the patient and that the latter is important to him. This commitment is one of the means by which caregivers show the patient that he is at the center of his care and the resulting care. Through this helping relationship, caregivers understand what the patient is going through. In other words, caregivers come to better understand the patient, his attitudes, his beliefs, his feelings, his way of life. The caregiver's behavior will allow the patient to be accepted and to recognize himself in the care. This helping relationship involves changes in the behavior of the patient in the management of the disease, his health, his life.[25]

With empathy, congruence is linked, which is by definition the authenticity of human attitudes and behaviors. It reflects the concordance between what is expressed, what is felt and the awareness of our emotions. Otherwise, the balance between awareness and experience. Congruence creates a healthy mindset conducive to self-actualization. The relationship of congruence allows the professional to protect himself against the possible dangers of burnout and the patient to feel in a climate of trust and to be himself congruent.

## 3.3. Refusal of care in the elderly and public health

In France, lung diseases are classified as long-term illnesses (ALD). They constitute a real public health problem insofar as the management of these conditions takes place over a long period ranging from years to decades. The care related to these conditions is fully covered by health insurance. Beyond their duration, chronic diseases have serious repercussions on the daily life not only of the patient but also of the caregivers and everyone around the patient. Indeed, these chronic diseases have social, psychological and economic repercussions on the life of the patient and those around him. According to the WHO, chronic conditions are "conditions of long duration which generally evolve slowly" [26] and can have organic, psychological or cognitive causes. They result in a seniority of several years with an impact of the disease on daily life and a functional limitation of activities, participation in social life, and dependence on medication. The uncertain nature of this evolution represents one of the main factors in the refusal of care, which implies the uninterrupted search for the patient's consent. Sometimes we hear from patients, "I am no longer taking this treatment, I have lost the sensitivity of ...", or "I have gained weight or I become like a vegetable". With these words, some patients evoke experiments in their bodies to refuse to continue taking the treatment.

It is in this context that the caregiver will have to establish a relationship of trust to strengthen the therapeutic alliance by using negotiation. This commitment of the caregiver will depend on the commitment of the patient in the care. It should be noted that chronic diseases in which respiratory diseases, degenerative diseases such as Alzheimer's disease, chronic psychoses, pose serious public health problems in their management. Some chronic illnesses quickly make patients bedridden, involving new choices of hospitalization either at home with outpatient care staff, or long-term hospitalization in specialized establishments for some or medical establishments for others. This evolution implies the adaptation of caregivers to the new developments imposed by chronic diseases, including pulmonary diseases. The expenses devoted to them are enormous and will be even more so because they not only require long hospitalizations but because the reception structures sometimes remain unsuitable and limited to the needs posed by the patients and their pathologies.

The aging of the population and the increase in life expectancy will raise new challenges in terms of the financial and human resources to be mobilized to respond to this care of this category of polypathological and polymedicated patients. Staff training and modern adapted reception structures will constitute additional specific needs that society will have to prepare to respond to effectively and appropriately. This evolution of chronic diseases also questions the distribution of tasks at different levels of institutional stakeholders, regional, general and state councils. The experience developed by the Assistance Publique de Paris consisting in the creation of reception and orientation units for the elderly (UAOPA) constitutes an institutional response likely to alleviate emergencies for the elderly deserves to be reinforced for harmonious functioning.

### 3.4. Nursing contribution to multi-professional care

The nurse participates and acts within a multidisciplinary team which converges towards a single goal: the interest of the patient and his well-being. In this care team, trust and respect for the word of the other fundamentally guide the entire organization in which everyone within this multidisciplinary recognizes the skills of the other. These skills are found in Article R4311-1 of the Public Health Code which indicates that: "The practice of the nursing profession includes the analysis, organization, performance of nursing care and their evaluation, contribution to the collection of clinical and epidemiological data and participation in prevention, screening, training and health education actions" [27]. Thus in all of these activities, nurses are subject to compliance with professional rules and in particular professional secrecy. They carry out their activity in conjunction with other professionals in the health sector, the social and medico-social sector and the educational sector.

In other words, the nurse acts within a multi-professional team in which she is subject to the respect of professional secrecy. In the context of refusal of care by the MAP patient, the relationship between the caregivers is crucial. The diagnosis of the disease and its evolution depend on the collaboration between doctors and nurses, i.e. the entire healthcare team. With regard to the aforementioned article, the nurse in her contribution to the diagnosis "communicates to the doctor any information in his possession that may contribute to the establishment of the diagnosis and the implementation of an appropriate treatment" [28]. In this multidisciplinary team, the nursing auxiliaries acting under the responsibility of the nurse, help the nurses in the administration of oral treatments previously prepared by the nurse, can record the vital parameters and transmit them to the nurse without appreciating the value. They take care of the hygiene of the patient, his environment and contribute to his comfort.

As part of this multidisciplinary care, nurses must maintain a friendly relationship and avoid false accusations that could vitiate harmony and compromise the quality of patient care. The nurse, far from coordinating all the care activity, will have to ensure the proper maintenance of the care file by ensuring the traceability of medical and paramedical interventions. In collaboration with the dietician, she aims to promote a diet adapted to the diabetic patient for example, with the occupational therapist proposing activities to compensate for the reduced mobilization of Mrs. C, the physiotherapist who will adapt the physical activity with regard to her loss of mobility.

In this set of activities contributing to the well-being of the patient, the social worker and the psychologist also participate in supporting the patient with a view to his well-being.

But for the continuity of care, the refusal of care by the patient should not constitute an opportunity to definitively interrupt the care. The nurse must warn the doctor to assess other tools likely to convince the patient to resume care or to engage in multi-caregiver interviews to try to convince the patient to accept care. This activity of the nurse is part of her professional obligation under article R4312-41 of the public health code which establishes that "If the nurse decides, subject to not harming a patient, not to provide care, or is obliged to interrupt it, he must explain the reasons to this patient and, at the request of the latter or his relatives, give him the departmental list of nurses mentioned in l L. 4312-1"[29].

Moreover, within the framework of her own role, the nurse takes note of the patient's refusal and notifies it in the medical file (report of the interview) with a view to good traceability of the patient's care. Even if the patient spontaneously chooses to contact another nurse, the nurse must provide the prescribing physician with the information necessary for continuity of care. If necessary, he transmits to the doctor designated by the patient or by his relatives and with their explicit agreement the summary sheet of the nursing care file for a good follow-up.

This multidisciplinarity makes it possible to respond to the patient's refusal of care by mobilizing resources by organizing multidisciplinary consultation to build a therapeutic alliance with the patient's relatives, in particular the trusted person to understand the reasons for refusal. Indeed, some refusals are debatable and only constitute a call for help, listening or the need for more permanent support. Some patients experience hospitalization as an abandonment of the family, a lack of consideration of which the refusal of care is the expression. The authorization of family visits, the delivery of certain means of communication such as the mobile phone to help him communicate with his family, makes it possible to convince the patient to resume care. In certain circumstances, the refusal of care results from the refusal of hospitalization. Some patients view hospitalization as imprisonment. Others think that the refusal of care makes it possible to break the isolation generated by hospitalization, especially if it is under duress, because several stakeholders will be able to listen to you and allow you to express yourself. However, some refusals are final. The patient manifests an inability to consent to care and in this context, the responsibility of the medical team based on the principle of good treatment, while respecting the dignity of the human person, will have to assess what is sometimes indecision, irrational consent rather than a clear refusal of care. It is in this order that we must analyze the notion of consent as it was expressed by Emmanuel Hirsch in 2011 according to which "The notion of consent implies that of the contract, while the collection of assent refers to the idea of ensuring that the sick person does not express any manifest opposition over time"[30 ].

In other words, the patient and caregivers are actors in the care. Trust must be at the center of this care activity, in which everyone contributes. The refusal of care by the patient paralyzes this balance and threatens his well-being which stems from the commitment of the caregiver and the patient. This commitment is the basis of the factors of change, that is to say the establishment of a relationship of trust, the strengthening of the therapeutic alliance and the use of the method of persuasion which involves transmissions targeted as a means of ensuring continuity of care for comprehensive and effective management.

# 4. Analysis

In the analysis of my work, the understanding of certain concepts and the definition of certain verbs prove to be important in order to assess the scope they reserve in the development of our subject. Consenting to care means having the capacity to understand, appreciate, reason or express one's choices. Conversely, refusing care means opposing the care offered, refusing to accept it as such for various reasons (intrusion into private life, denying any dependence on the subject).

The analysis of this theme on the refusal of care in the elderly will focus on 2 dimensions which are as follows:

- · Legislation, ethics and deontology
- The nursing contribution to multidisciplinary care

In this analysis, the nursing role of which I was able to be an actress will be highlighted in the care of the patient within the multidisciplinary team under the guidance of my professional supervision during my internship.

## 4.1. Refusal of care in the elderly: legislation, ethics and deontology

The law of March 4, 2002 recalls a general principle relating to the foundation of medical ethics according to which the patient's consent is a fundamental element of the care relationship. This implies respect for patient choices, within the framework of dialogue, listening, communication and an exchange of information that take into account the requirements of medicine and the missions entrusted by society. The physician must respect the person's wishes after having informed him of the consequences of this choice. Faced with a vital risk, the doctor can dispense with the patient's consent. According to article L.1111-4, if the person's desire to refuse or discontinue treatment puts their life in danger, the doctor must do everything possible to convince them to accept essential treatment. It is important to note that a person who suffers is a vulnerable person. [31] In this context, hospitalization creates a specific situation that favors the accentuation of the vulnerability of the person. In the case of the patient who motivated this work, age is already another factor of vulnerability in itself. These aspects are elements to be analyzed by the IDE, which must listen in order to put in place appropriate strategies and solutions to deal with them.

In this context, the execution of nursing care involves considering the person, working in an approach centered on the patient, his living environment, his context, his experience, his story, his illness, his emotions, his feelings, his becoming. The hospitalized person should not be considered only as a patient but also as a subject with rights to be respected.

We have already seen that the refusal of care by a patient creates a delicate situation for the caregiver. But instead of trying at all costs to provide care against the patient's will, the nurse should seek to understand the origin of this refusal, the reason for the refusal, while shedding light on the consequences of this refusal. On this subject, Aline Corvol, underlines that "the frontal confrontation of the caregiver who seeks to convince the patient to accept the care without understanding the reasons will only aggravate the situation". Similarly, the anthropologist F. Balard has shown that "many refusals reflect the claim of a right to choose, therefore a desire to exist, to assert oneself. To preserve this identity weakened by age and/or illness, some people prefer to refuse all elements that could reveal an addiction. Faced with this type of refusal, securing the person in his identity, by recognizing what he is as a person and not as a "sick person, can then facilitate his acceptance".

Conversely, the confrontation of a caregiver trying to convince the patient to accept care without analyzing the factors and causes underlying the refusal does not contribute to relieving the patient's suffering, but aggravates the situation which could recur [32], for lack of having identified and brought solutions to the patient. Thus, the application of patient care involves placing the patient at the center of care. In other words, respecting the patient's own choices without any constraint. To do this, the nurse must listen to the patient and develop a relationship of trust. In this context, the nurse must create a climate of benevolence and attentiveness likely to help the patient understand his refusal of care and its consequences. It is in a climate of serenity and trust that the patient may be led to freely express his or her consent or otherwise to treatment. In this context, the nurse's role is not limited only to respecting the medical prescription but also to respecting the patient's wishes even in situations where the patient's consent is not a priori a prerequisite.

The question of the obligation of care and the autonomy of the patient to freely refuse care found a solution through the law of March 4, 2002 relating to the rights of patients and the quality of the health system. [33] The refusal of an informed person, who understands the consequences of his refusal, must be imposed on the caregiver. Despite the family's often legitimate desire to protect them, the sick person has the "right to risk" and may in some cases prefer, for example, "to die at home" rather than benefit from care without their consent. The caregiver's role is then to clarify his choice by explaining the consequences of refusing care, and, as far as possible, calling on the multidisciplinary care team for solutions adapted to the patient's situation in the event that the patient does not realize the consequences of his refusal. This difficulty in understanding may be due to cognitive disorders (judgment disorders, for example), psychiatric (paranoid delirium, depression, etc.) or psychological (denial i of the situation...) which may or may not be reversible.

Since the patient's illness and hospitalization make the patient's balance vulnerable, this situation requires caregivers to have the ability to listen, support and communicate to improve the caregiver-patient relationship. The objective of this care relationship is to establish the necessary trust allowing the person being cared for to explain their fears. The refusal of the patient's care can include several aspects, including his autonomy. Mrs C is hospitalized in the MAP service, her autonomy is affected by other pathologies.

In the case that led to this work, the nursing role was active listening, attention, with empathy, benevolence creating a relationship of trust that allowed him to act as an intermediary with d other stakeholders. Thus the nurse, as part of her role, will have to dialogue with the patient to offer her a choice.

This patient who initially refused care only to finally accept it, after several attempts alternating between different care staff, these ended up being administered, because of the nurse's helping attitudes, through empathy, benevolence, listening, communication, with the aim of establishing a therapeutic alliance, but also a relationship of trust, so that she can accept food and care in our situation. This refusal in the investigations came from a state of depression, loss of desire and taste for life, patience wanting to let oneself die for personal reasons secondary to the suicide of one's spouse, and abandonment, isolation she lived, which was insurmountable to her. Dying as it seems to her, at this moment simpler than getting treatment and living without her husband, does this mean that the refusal will not happen again later.

In this hypothesis, the nurse is confronted with realities: respect for the autonomy of the patient and benevolence. For this patient, the nurse must respect her decision to refuse care and also respect her nursing role, which remains taking care of the patient with the aim of relieving her physically and psychologically through her own role, her role on prescription, but also its role in collaboration.

Refusal of care is the fact of the patient refusing any form of care contributing to his well-being, including comfort care, for hygiene it is often more worrying in the sense that it creates discomfort for those around the patient as well as for the caregiver.

Several causes can be at the origin of a refusal of care, (or a refusal of help), in the elderly person, the literature refers to psychiatric causes, such as loss of memory, behavioral disorders, secondary to neurodegenerative diseases, Dementia syndromes are also the cause of refusal of care. Just as the fear of following a heavy, painful treatment, the possible failure of other therapies, or discomfort, malaise generated by a specific treatment (Regional Federation for Research in psychiatry and mental health Hauts-de-France, in partnership with the Hospital Ethics Area and University of Lille).

The refusal of care (RS) thus leads to discomfort, a lack of understanding, of logic of the share of caregivers, relatives, given the age of the patient; in this sense:

For what reason a refusal of care when you are sick even though you could be better? Is it the fear of painful exams? a lack of understanding of care? or a lack of confidence in caregivers? Or can the refusal of all care not sometimes be a suicidal equivalent, the expression of a pathology such as, for example, depression?

From there how to consider the SR, are all aware, thoughtful and understanding? or realistic? But can we only seek to clarify and characterize admissibility?

A carer in his concern to take into account a wish, must respect a right, that of the patient to refuse care, on the other hand, the caregiver has the wish and the desire to treat, and he engages his legal responsibility (with an obligation to provide assistance to anyone in hazard). In the elderly, the refusal of care becomes more complicated given that doesn't age change the relationship to illness and death? But are there really moments, situations in life, where it is legitimate to refuse care? And that choice if the elderly person is no longer able to decide? Is it the entourage, the caregivers, the institution? [34]

Respect for the refusal of care by the patient is part of the caregiver-patient relationship governed by the code of ethics stipulating that the nurse "will act in all circumstances in the interest of the patient" [35]. Sometimes, in certain situations, caregivers may be led to impose care on the patient in one way or another. This situation can be synonymous with a form of violence for the patient, and the benefit of the proposed care must be evaluated as best as possible in a collegial manner with the multidisciplinary team, but especially with his family. This so-called care under constraint in a hospital environment generally intervenes with people whose mental disorders require immediate care. This legal device sometimes involves physical or chemical restraint because the person will be "locked up" without their consent. Indeed, it is established that no act or care can be administered é without the free and informed consent of the patient and this consent can be withdrawn at any time. However, faced with a life-threatening risk, the doctor can dispense with this consent in order to perform essential care for the patient.

But this right to consent and refusal is essential from an ethical point of view in a society that has a philosophical tradition of respect for the person and his autonomy, but the fact remains that in certain situations, nurses, doctors and other paramedics find themselves confronted with situations of refusal which appear contrary not only to medical logic, but also to what they consider to be in the interest of the people. In our situation, the health professionals had respected Mrs. X's autonomy and her psychic privacy by accepting the refusal while explaining to her the consequences of refusing care after several attempts at negotiation. This allowed us to shed light on the origin of this refusal of care by involving other professionals, including the nurse's aide and the other nurse on the team.

This is why we have found that certain reactions of patients to care do not stem from the logic of care but from the way of doing things and the way in which we perceive things as caregivers. In many clinical situations, the refusal of care is in fact only a point of call or a clinical sign testifying to the suffering or despair of the patients, two points that the caregiver has the mission of precisely combating so that the person get better and live better, whatever his condition. This is the case of this patient in whom the refusal of care contained psychological suffering, depression and a feeling of abandonment. In the internal medicine department specializing in geriatrics or in an establishment, the caregivers are often faced with patients, and or residents who refuse care. most often, it is a refusal of treatment, medically, surgically, however, this refusal can also and above all be on hygiene, grooming, or care also called nursing. This sometimes generates guilt in the caregiver, a feeling of failure, especially if in the end the treatment in question is ultimately imposed. Should we leave this absence, this refusal care in the name of individual freedom?

In general, this behavior results at home in what is called Diogenes syndrome, defined by American geriatrician Allison N. Clark in 1975 as a disorder of the behavior leading to neglected and even unsanitary living conditions. This syndrome

includes but is not limited to an extreme form; compulsive hoarding which is a behavioral disorder that leads to neglected living conditions, social isolation, lack of shame, apathy and a compulsive propensity to hoard waste. It is usually seen in older people and may be a sign of the development of dementia. ". (A. Clark, G.D. Mankikar and I. Gray. The Lancet. February 15, 1975). [36]

In institutions, such a consequence is not accepted by those who deal with the patient, the various health professionals, and his entourage in the 21st century. It is rather seen possibly as a failure for caregivers and a kind of indignation by others who would take it as a lack of dignity for those cared for.

This sometimes puts the patient's wishes in contradiction with those of caregivers who are not of the same period, the latter having received an education and professional training strongly hygienists. In addition, there are few staff compared to the needs commonly accepted. They are imposed a pace of work that forces them to go too quickly, which predisposes to the reluctance of the people assisted.

Understanding a refusal of care and responding to it require training in this task and being able to devote time to it. Otherwise, it would result in stress for the stakeholders, professionals and more or less adequate attitudes that can lead to a certain blockage of the patient and the risk of violation of the ethics of care.

In practice, hygiene is often an imperative, and it is not uncommon for an elderly person either forced to wash or be washed, leading to a possible confrontation between residents and caregivers. The means of constraint are not lacking in the face of a vulnerable person. The limb maintenance can be part of this arsenal. Once the hostile relationship has been established between caregivers and cared for, it becomes more difficult to return to the essential appearament. The adapted attitudes must therefore be known and applied from the first difficulties, even if in this area there is no miracle recipe.

This reality raises questions about the limits of respect for the will of people who must resort to residential accommodation.

The facet of "self-negligence" as it is conceived and envisaged by the entourage family and carer often means that certain pressures from relatives, caregivers become important. We cannot perform treatment under duress, therefore with the patient's refusal, which is why some schools make it a rule never to perform treatment without the patient's consent, such as Humanitude, founded by Yves Gineste and Rosette Marescotti, who are for a relational approach made of benevolence and empathy allowing to accomplish gestures still often imposed. In which the patient is given confidence in a relationship that is both respectful and based on a multitude of attitudes adapted to the smallest words and gestures. The opinions of relatives, of the family if possible are collected. A multidisciplinary consultation should always be undertaken in these difficult cases. (Yves G; Rosette .M. 2008 p.49).[37]

# 4.2. Nursing contribution to multi-professional care

Due to their training, the nurse has the theoretical and practical knowledge likely to assess the problems posed by the patient and to implement appropriate actions. During my internship, I understood that the nurse works in a multidisciplinary team within which the exchange of information, transmissions and personal experiences contribute to the care of patients. In this multi-professional team made up of doctors, paramedical staff, but also medico-social staff, the dietician, the psychiatrist, the health executives, the social worker, the occupational therapist, the psychologist, the nurse constitute an important element and is one of the privileged interlocutors, in the global and personalized care of the patients. The nurse ensures the coordination of care through targeted transmissions in the care file, contacts other professionals intervenant when the patient raises the problem that falls within the competence of each stakeholder.

More specifically, in the context of the refusal of care, the nurse will do what is possible to bring back, without any form of constraint, the patient to accept the care by involving other care partners. The contribution of each stakeholder makes it possible to alleviate the anxiety and anguish often experienced by patients who sometimes feel misunderstood by the care team. This taking into account of the patient in all his dimensions, will make it possible to limit the failures of the treatments and above all, the refusal to care. In caring for the patient, the nurse also plays a role in coordinating the activities of the various stakeholders, in supporting his care pathway, by keeping the care file during his hospitalization. In this context, the good keeping of the patient's file with targeted, regular transmissions makes it possible to follow the evolution of the patient and sometimes to report any changes in his care.

In my situation, the transmission in the patient's file of the refusal of anticoagulant and hypertensive treatment allowed the doctor to plan a medical interview in which I was able to participate, to try to understand how Mrs X who was

regularly taking her treatment came to refuse his treatment. The psychologist's intervention made it possible to understand Mrs X's suffering and anxiety and to organize support interviews which allowed her to express herself freely and justify her refusal by the fact that he has the impression of being a burden for the others and that recently, no one has come to visit him. In this psychological suffering, the nurse is an essential interlocutor within the multi-professional team. He works in collaboration with the doctor, the psychiatrist concerning the psychiatric pathology, and the caregivers concerning the hygiene of the patient and his environment, the dietician for the meal and the diet adapted to the patient. This bedridden patient encountering difficulties in mobility because of her condition motivated the intervention of the physiotherapist, via nursing transmissions. This accompaniment, this follow-up, this support, this help improves the autonomy of the patient who is hampered by his condition.

This collaboration is carried out in compliance with the rules of professional ethics and deontology, legislation and the dignity of the human person. It is within this framework that the nurse will have to demonstrate his professional skills of listening, communication, coordination, know-how, interpersonal skills to improve the psychological suffering of the patient by involving all the professionals of the care, each according to his skills in the interest of the patient.

### 5. Conclusion

During this internship in specialized internal medicine at the APHP, in nursing care, I was able to develop and acquire enriching skills and practical knowledge, both personal and professional. I knew how to invest myself in learning, as well as the nursing approach in the care of patients. I acquired not only technical gestures but also relational ones while respecting the dignity of the patient. Beyond the necessary technical gestures, I acquired the values of interpersonal skills, know-how necessary for nursing practice. So I learned to work in an approach centered on the well-being, well-being, of patients. My role is to contribute to the care of the patient, with an approach that requires listening, communication and education skills to facilitate the harmonious integration of the patient into the care program decided by the multidisciplinary team in which the patient and the nurse play a decisive role. The practice of the nursing profession is regulated by the nurses' code of ethics, which contains the rights and duties that nurses must observe scrupulously and regularly in the exercise of their professional practice.

During this work, we were able to see through interviews, hospitalized patients suffering from chronic pathologies in anxiety-depressive episodes manifesting themselves in several ways, in this case in the elderly, the loss of self-esteem, of the desire to live, these being in a deep malaise, leading to the refusal of care.

Elderly people with the onset of senescence, with geriatric diseases, or not, often experience a refusal of care. This refusal poses serious difficulties in the treatment. It involves strengthening the caregiver-patient relationship, the helping relationship, listening through, better communication allowing the patient to clearly express their thoughts to obtain their consent to care. This approach requires the nurse to respect ethical and deontological principles, in particular respect for the rights of the patient, beneficence, non-maleficence, justice, respect for the autonomy of the patient, and his dignity. It is therefore necessary to establish a care project centered on the patient, which places the latter as an actor in his care, with his informed consent as a commitment to care.

Within the framework of my written work, the reflection on this problem which is the refusal of care in the elderly person, was centered on two dimensions in the center of my analysis, which is the role of the nurse in front of a situation of refusal in an elderly person. The ethical legislative dimension, deontology multi-professional care. It has been established that in the exercise of his professional practice, the nurse exercises his own role, a role on prescription and a role in collaboration, in his daily life, and implements adapted, appropriate care, to relieve the patient. In these physical but also psychological components. It turns out that these roles are confronted with the patient's consent, which must be free and informed.

During our work we understand that the refusal of care includes several aspects involving the patient's autonomy in care and the obligation of care. The patient's refusal to care poses a double problem: that of the patient's right to care, which must be expressed freely and in an informed manner, and that of the caregiver's duty to help the patient accept care without constraint. Faced with the refusal of care, the nurse must assess the benefit/risk ratio. It is at this level that the ethical dimension intervenes to seek the balance between autonomy and beneficence. The nurse will seek to first understand the reason for the patient's refusal to care and seek, without judging, the patient to establish communication and a relationship of trust with the patient. The IDE in his relationship of trust with the patient also serves as an intermediary with other professionals, and stakeholders in a concern for organization, adaptation of the personalized care project, involving the multi-professional team in order to help the patient to express his thoughts, his perception of care, his feelings with the ultimate goal of obtaining his consent to care. This relationship, once established, will make

it possible to guide the helping relationship with respect for the patient's dignity and autonomy, a condition for the patient's decisive commitment to care.

In view of the experience acquired during my internship, and as a future nurse, I will be able to mobilize my knowledge based on legislation, the code of ethics, good professional but also relational practices, while placing particular emphasis on listening, communication, know-how, interpersonal skills in order to improve patient care within a multidisciplinary team.

## Compliance with ethical standards

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