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Patient Freedom to Choose or Refuse Treatment: Is Autonomy Upheld?

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ABSTRACT

Background: Medical professionals are put in ethical situations daily that require patients to sign informed consent or informed refusal of treatment. Looking back at the history of this controversial topic, ultimately, the decision rests in the patient's hands. Knowing one's patient's rights goes a long way in establishing personal autonomy to make those well-informed decisions. At times, the journey of a patient's health rights may still need to be clearly defined. **Purpose**: This literature review aimed to explore autonomy, discerning what is in the literature regarding the freedom to choose or refuse treatment. **Method:** This was a brief review of the literature. **Findings:** All human beings should be respected for their informed decision whether we agree or not. Healthcare professionals must give all individuals the right to be informed and allow them to make a competently informed decision on whether they should or should not consent to have a particular medical treatment performed. Ethical principles such as beneficence, non-maleficence, and justice are huge factors that allow the patient to decide for themselves is a human person's right. Every competent adult has the right to refuse or choose medical treatments. **Conclusion:** The American system of democratic law supports autonomy as such and upholds the right of patients to make decisions about their healthcare.

INTRODUCTION

Autonomy is one of the utmost basic ethical principles in healthcare. The principle behind autonomy is to allow everyone the right to make informed healthcare decisions. As noted in Figure 1, autonomy, beneficence, non-maleficence, and justice are the principles that guide healthcare ethics and allow the patient to make informed medical decisions about their own healthcare choices and outcomes. Beneficence is the path to take actions in the healthcare treatments that would only benefit the patient's outcomes. Non-maleficence is a measure that the healthcare professional takes all steps not to harm the patient. Justice requires the healthcare provider to explain all the benefits and risks and promote appropriate discussions without bias. Each principle has a role when navigating difficult situations where patients may be refusing medical assistance [1].

In the US, the Joint Commission on Accreditation of Healthcare Organizations oversees how informed consent is carried out in hospitals. The Joint Commission offers several safety actions to ensure the patient comprehends informed consent or informed refusal. Health literacy, communication, cultural diversity, if any of these are lacking, the patient may sign the consent and not understand what they are signing, or refuse to consent, again because they lack information [2]. The premise of informed consent is a relatively recent advancement in healthcare. In the past, patients relied on the physicians to care for them and their ailments because doctors swore to protect the patient and their well-being; consent was verbal or none [3].

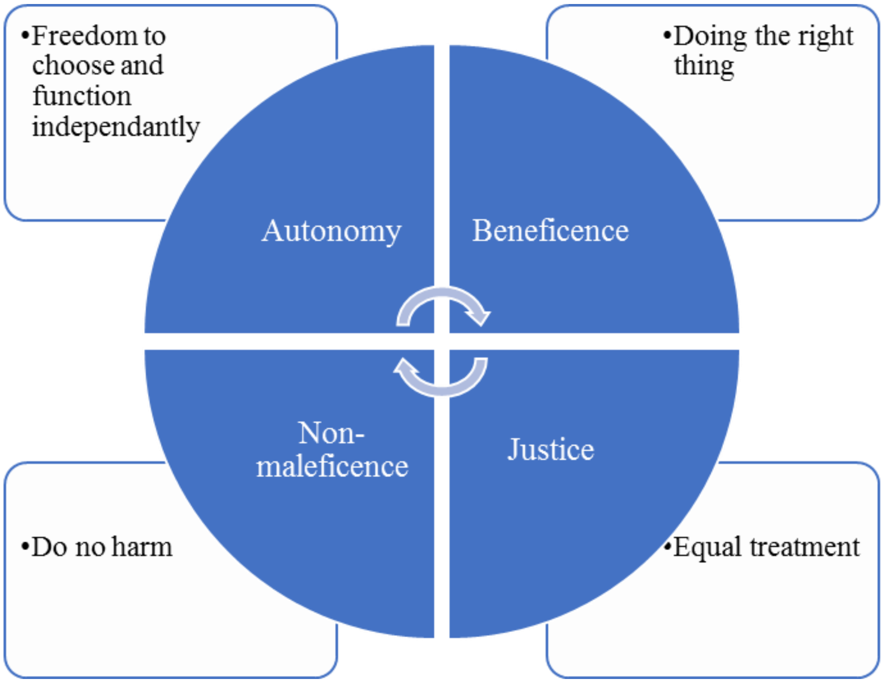

Figure No. 1: Guide to healthcare ethics

Autonomy

In 1973, a gentleman named Dax was the victim of severe burns from a freak accident [4]. Dax was a competent young man who refused treatment but received unwanted and excruciating painful treatment anyway. In 1986 he graduated from Law school and became an advisor and advocate for patient's autonomy and rights. During Dax's refusal of treatments, his mother took the refusal to court, where she was granted the right to have treatments continue even though a psychiatrist evaluated Dax and found him competent to make his own self-governing decisions. Dax, over 40 years later, had said that he would still, to this day, make the same choice of refusal of treatment, knowing the pain and agony that he was forced to live through for years [4]. Autonomy is the patient's right to choose or refuse treatment. Only a few decades ago, healthcare providers could treat patients against their will if the physicians saw fit to do so. Dax's case gave patient's right to refuse treatment and illustrated that competent patient could make informed decisions on their healthcare treatment.

The right to receive or refuse treatment is the fundamental right of autonomy (see Figure 2). Elizabeth Bouvia, a 28-year-old female, suffered severe degenerative arthritis, chronic debilitating pain, and cerebral palsy. As a form of treatment, she had a feeding tube placed against her will. The courts found her competent and allowed her the autonomy to have the tube removed and choose a natural death [5].

A 19-year-old refuses COVID-19 testing when arriving at the hospital to treat a gunshot wound to the abdomen. This patient is placing the community in danger and creating a possible crisis. If he does not have the virus, much-needed supplies and a COVID-19 designated bed are being occupied by a non-covid patient. Following patient autonomy can be interpreted as a positive right they may ask for but not demand as preferred treatment. Competing imperatives include professional autonomy and hospital policies [6].

In 1904 Mrs. Pratt sued her physician for performing a hysterectomy without obtaining her consent [7]. However, the Salgo case is what brought informed consent into light. Mr. Salgo sued his physician after becoming paralyzed after a trans-lumbar procedure. Mr. Salgo won the case because his doctor recommended it but did not inform him of the complications of the procedure. Informed consents are what patients sign before treatment. By informing the patient, we empower them to help them make the best decision [7].

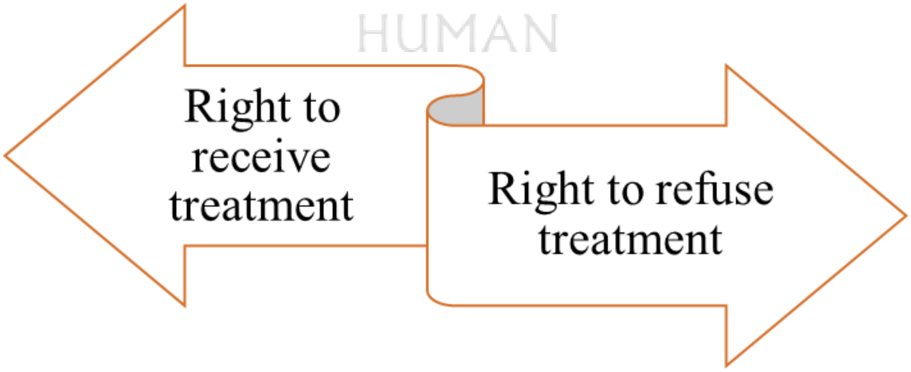

Figure No. 2: The right to receive or refuse treatment is the fundamental right of autonomy.

Forced Compliance

This is often seen when a pregnant woman refuses medical treatment that the physician is recommending. When either the pregnant woman or the fetus has a medical condition that requires medical treatment that may or may not put either at risk, much consideration must go into ethical medical approaches and decisions. However, circumstances may arise during pregnancy in which the interests of the pregnant woman and those of the fetus diverge. Questions of how to care for the mother and the fetus come to an account of respect for the woman's autonomy over her own body and the fundamental ratio of maternal and fetal risk [8]. Hardacre [9] said that the process of informed consent is at the very heart of ethical research and practice. Curtin [10] stressed that adults can legally refuse medical treatment, even if that leads to their death. But the medical profession is also clear that doctors cannot be required to give treatment against their clinical judgement. Nurses as well as physicians must maintain integrity.

The American College of Obstetricians and Gynecologists (ACOG) recommends some form of directive counseling (see Figure 3). This counseling offers the OB-GYN a role in guidance, recommendations, and advice that aids in the patient's decision-making. This approach does not violate ethics, but it enhances the opportunity of informed consent or informed refusal. Discouragement of duress, manipulation, coercion, force, or threats of involving legal courts is the stance that the ACOG takes for these given situations. When informed refusal is noted, the physician should then acknowledge the possible limitations of the patient's knowledge of the clinical status, language barrier, cultural beliefs, social and value differences. Some other factors that should be looked at are whether the patient understands the risk and severity of the possible outcome? The patient should also be reassured that her wishes will be respected when recommendations by the physician have been refused [8].

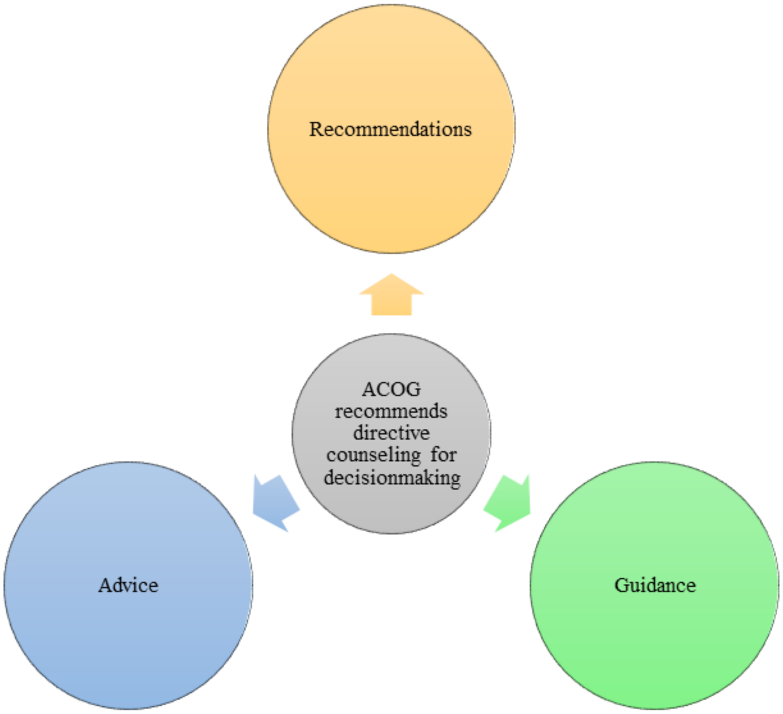

Figure No. 3: The American College of Obstetricians and Gynecologists (ACOG) recommends some form of directive counseling.

On the other hand, it is a human right for an alert and oriented person to have the freedom to choose or refuse treatment, even if medical personnel say otherwise. This also implies when the patient desires not to be resuscitated or go on hospice care even when family wishes are otherwise. The American Nurses Association propagated: Nurses must provide humane, comprehensive, and compassionate care that respects patients' rights but upholds the standards of the profession in the presence of chronic, debilitating illnesses and at end-of-life [11]. Butts and Rich [12] defined autonomy as the freedom and ability to act in a self-determined manner. Within the context of healthcare this basically means that everyone can decide for themselves what treatment they will or will not receive. The issue of choice implies that the patient fully understands the situation and makes the best decision based on their priorities and what they think will be in their best interest. This right to choose or refuse treatment nearly is synonymous with the issue of consent. Historically, the freedom to consent or not was not a guaranteed right.

Self Determination

An essential right that patients possess is the right of self-determination, the right to make the ultimate decision concerning what will or will not be done to their bodies [13]. Exploring the reasons why patients refuse treatment brings us to many possible scenarios. Many times, the reason is because of fear and or possible misunderstanding of the medical treatment. Many times, it is because of finances, and often it is because of personal beliefs, morals, and values that the patient and possibly their culture holds. The Patient Self-Determination Act (PSDA) is a federal law. The act's purpose is to ensure compliance on the patient's behalf if the patient is no longer able to communicate their healthcare wishes. With Advanced Care Directives, living wills, and Durable Power of Attorney in place, the patient's rights to self-determination will be followed, carried out, and protected (see Figure 4). With any of these directives in place, it makes it easy for the healthcare team and family to continue to follow the patient's healthcare wishes [14].

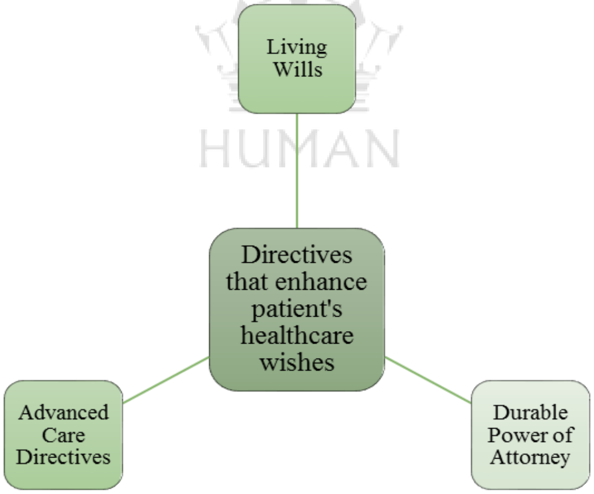

Figure No. 4: Directives that enhance patient's healthcare wishes.

Decisional Capacity

Competent determination is a crucial issue about proper discernment of a patient's objective judgment. When a patient has been determined to be incompetent, all their autonomy for making their own healthcare decision is taken away. Lack of competence or even questioning an individual's competence deprives the individual of the power to make informed healthcare decisions for themselves [13].

Competence, also known as decisional capacity, is essential to the patient's ability to make autonomous medical decisions. Assessments must be made to determine the patient's capability to make treatment decisions for themselves. Healthcare professionals must decide if a patient can make these decisions for themselves. Sometimes some conditions need to be resolved, such as hypoglycemia or intoxication. Once these conditions resolve, the patient can make informed, competent decisions for themselves. One must remember that age alone is not a reason to determine a patient is incompetent. In determining a patient's decisional capacity, four elements must be taken, understanding, appreciation, reasoning, and expression. The patient must understand what it is they are refusing, apply and appreciate their situation, the reason they are choosing to refuse treatment and communicate that reason [15]. Determining whether a patient can make informed decisions is a crucial task that all healthcare professionals must take. When a change in their cognitive ability is noted, the healthcare individual must look at possible reasons for why. Exhaustion from being in the hospital setting, hypoglycemia, and adverse effects from medications may cause cognitive issues. Once this has been resolved, the patient should be allowed to make an informed, autonomous decision.

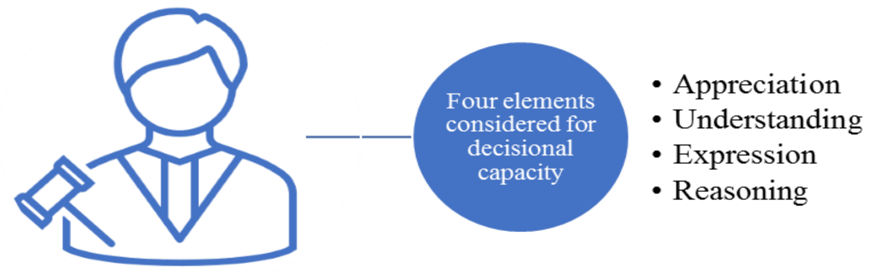

Figure No. 5: In determining a patient's decisional capacity, four elements are to be taken into consideration.

Another thought may be how one could be truly informed during the consent process if the medical personnel explaining the procedure does not quite understand the procedure or medication, whether because of lack of education, experience, or bills such as the Right to Try. It is also important that the readability of consents should coincide with the reading level of most of the patients [16].

Refusal Depends on Severity of Illness and Past Trauma

On average, 4% of the patients who refuse treatments in the emergency department will return to the acute care setting within 30 days, increasing the patient's mortality rate [15]. There are very few studies on the consequence of refusing medical treatment or why patients refuse medical recommendations. The Rothman [17] study found 226 patients who would participate in the research. These patients who participated in the study had advanced chronic disease from chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), and advanced cancer. The patients were interviewed for over two years. Every month the participants received phone calls, and questions asked about their healthcare and if any medical treatments were refused. Approximately every four months, the trained research staff would do an in-home interview. This interview asked if the patient had refused any recommended medical treatment by their physicians and why. Of the 226 participants, 16% stated that they had refused some recommended treatments. They found the most common recommended yet refused medical recommendation was the cardiac catheterization procedure.

The report documented the most common reason for refusal was fear from 41% of the participants [17]. The study also found that these advanced chronic disease participants who refused recommended medical treatments had a greater mortality risk. At the end of the study, 8 (4%) participants had dropped out, 26 (12%) had died before the research was finished, and 3 (1%) patients were too sick to participate at the end of the study. This study found that most refusing patients for medical treatment are those persons with advanced chronic diseases. The study found, 17% of CHF patients refused treatment while only 3% of the patients with cancer or COPD refused treatment. Patients who lived alone refused treatment at 13% vs. 3% of those who had a spouse at home. For those who participated in the study, they found that patients who had cared for a chronically ill loved one in the past refused treatment at 9% vs 4% who had never cared for an ill loved one [17]. As illustrated in Figure 6, for consent to treatment or refusal of treatment, the decision must be voluntary, and the patient must be appropriately informed.

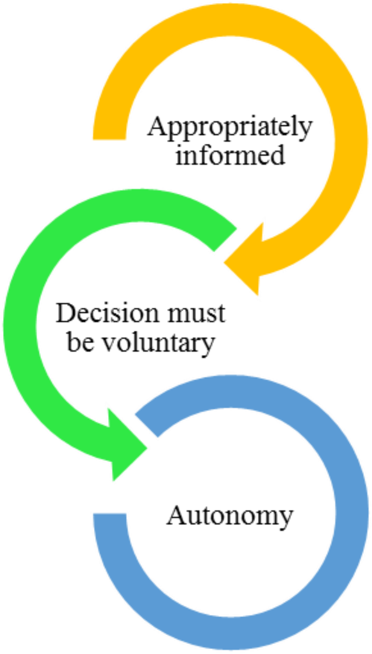

Figure No. 6. For consent to treatment or refusal of treatment, the decision must be voluntary, and the patient must be appropriately informed.

CONCLUSION

One of healthcare's most challenging aspects is when a patient refuses medical healthcare recommendations. Studies show that most of the refusing patients are those who do not understand healthcare literacy. Healthcare providers must explain the benefits and risks of consenting or refusing the recommended treatment. This would include not putting your beliefs or thoughts and feelings onto the patient and their family members when choosing a treatment path that you disagree with due to personal opinions. The other category that plays into refusal is the patients with advanced chronic illnesses. Many times, patients in this category are afraid of the possible outcomes or have taken care of a loved one with chronic illness and know the struggle of the disease process. Healthcare professionals must remember the ethical obligation that the competent patient must be given the autonomy to make self-governing health care decisions for the respect and rights of those refusing medical treatments.

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