Bioethics

1. Patients’ rights
	1. Intended Learning Outcomes

By the end of the lessons, the students will be able to:

1. State the common rights and responsibilities of patients
2. Analyze the contradicting values in making moral judgment over some issues concerning patients’ rights, in particular concerning euthanasia and placebo;
3. Apply different ethical theories to make moral judgment.

*\*Prerequisite knowledge: Normative Ethics, the nature of morality, moral principles, moral reasoning, theory of conduct, theory of value & virtue (Refer to* [*‘NSS Ethics and Religious Studies Curriculum Support Materials - Compulsory Part: Ethics - Module 1: Normative Ethics’*](http://www.edb.gov.hk/en/curriculum-development/kla/pshe/references-and-resources/ethics-and-religious-studies/support-materials-compulsory-part-module-1-normative-ethics.html)*)*

* 1. Introduction

The Universal Declaration of Human Rights, formalized in 1948, recognizes “the inherent dignity” and the “equal and unalienable rights of all members of the human family”. In line with these basic human rights, the rights of patients are developed. Although Patients' rights vary in different countries and in different jurisdictions based on the cultural and social differences, some fundamental features are universal.

According to the World Health Organization (WHO), some of the fundamental features of patients’ rights are as follows:

*‘Patients receive treatment consistent with the dignity and respect they are owed as human beings. This means providing, at minimum, equitable access to quality medical care, ensuring patients’ privacy and the confidentiality of their medical information, informing patients and obtaining their consent before employing a medical intervention, and providing a safe clinical environment.’[[1]](#footnote-1)*

Deriving from the above, the following patients’ rights will be highlighted and further examined in this module:

* Right to know/information
* Right to decide/autonomy
* Right to confidentiality
* Right to complaint

In the lessons, students will learn the concepts of the above-mentioned patients’ rights, and go through the processes of handling the ethical dilemmas using different theory of ethics and approaches when some of the patients’ rights are infringed in some controversial medication situations, e.g. euthanasia and placebo.

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| **References:*** McWay, Dana C. (2010). *Legal and ethical aspects of health information management.* New York: Cengage Learning.
* Shannon, Thomas A. (2009, 4th ed.). *An introduction to bioethics*. New Jersey: Paulist Press.
* Tauber, Alfred I. (2005). *Patient autonomy and the ethics of responsibility*. Cambridge: The MIT Press.
* <http://en.wikipedia.org/wiki/Medical_ethics>
* <http://en.wikipedia.org/wiki/Placebo>
* <http://jme.bmj.com/content/30/6/551.full>
* <http://people.umass.edu/curtis/academics/researchtoolbox/pdfs/Placebos_Brody.pdf>
* <http://www.hkma.org/english/pubmededu/right.htm>
* <http://www.hpcsa.co.za/Uploads/editor/UserFiles/downloads/conduct_ethics/rules/generic_ethical_rules/booklet_3_patients_rights_charter.pdf>
* <http://www.ifc.org/wps/wcm/connect/afef2c004970bfb49909db336b93d75f/3EthcsPtntsrghts.pdf?MOD=AJPERES>
* <http://www.who.int/genomics/public/patientrights/en/>
* <http://www.wma.net/en/30publications/10policies/l4/>
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* 1. Teaching and learning processes

Suggested teaching period: 3 lessons

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| * 1. Patients’ rights and responsibilities
	2. Teacher asks the students to form groups (4-5 in a group) and brainstorm the following question in ‘Worksheet 1: What rights and responsibilities do patients have?’
	3. Each group presents their answers, and analyzes the most frequent patients’ rights and responsibilities they mentioned.
	4. Ask students to work in pair to complete ‘Worksheet 2: Comparison of the patients’ rights in US and Hong Kong’, and then discuss the answers with the whole class.
	5. Challenging level (optional): Ask students to think of some situations that exercising of some patients’ rights may cause moral dilemmas. To stimulate their thinking, ‘Worksheet 3 (Optional): Moral Dilemmas Caused by Patients’ Rights’ can be used.
	6. Moral Dilemma: Euthanasia – Right to die!
	7. Flipped learning: Ask students to watch the following online videos at home beforehand. Alternatively, teacher may divide the class into 2 groups and assign each group to watch one of them:
* Taking Mercy: Euthanasia debate *–(For: ‘Passive euthanasia’ and ‘mercy killing’ in Canada)*
	+ <https://www.youtube.com/watch?v=NxYmgrnGx_M>

OR / AND* [生命恩泉] - 解剖安樂死 Euthanasia: Facts and Myths (Part 1 & 2) *– (Against: Catholic views on euthanasia)*
* <https://www.youtube.com/watch?v=Smj-fKnFcm8>
* <https://www.youtube.com/watch?v=7l2xttRBUkg>
	1. During the lesson, ask the students to recap what they have learnt from the video(s). Based on that, teacher divides the class into 2 groups for the debate on ‘Patients have the right to euthanasia’. To facilitate their preparation and consolidation, ‘Worksheet 4: Debate on Euthanasia – Right to die!’ can be used.
	2. In the debate, students may evaluate the performance of both themselves and their peer using the evaluation tables in Worksheet 4.
	3. Moral Dilemma: Placebo – Do Patients have Right to Know?

3.1. Play the online video clip *‘Stuff They Don't Want You to Know - The Placebo Effect’* at <https://www.youtube.com/watch?v=v_feOG94IAs> (4 mins).3.2. Ask students to complete Task A of ‘Worksheet 5: Placebo – Do Patients have Right to Know?’. And then check the answers together.3.3. Ask student to complete Task B of ‘Worksheet 5’ in pairs.3.4. Teacher facilitates a class discussion.* 1. Conclusion and students’ self-evaluation
	2. Teacher reviews the key learning points of the topic on ‘Patients’ rights’ with the students.
	3. Ask students to consolidate their knowledge and evaluate their learning outcomes by completing ‘Worksheet 6: Summary & self-evaluation’.
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| Worksheet 1: What rights and responsibilities do patients have?

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| Patients’ rights |
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| Patients’ responsibilities |
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| Worksheet 2: Comparison of the patients’ rights in US and Hong Kong Part A: Patient Rights & Responsibilities in California, US*Watch the video by West Oakland Health Council (WOHC) at* [*https://www.youtube.com/watch?v=\_x7WCuZG8M4*](https://www.youtube.com/watch?v=_x7WCuZG8M4)*, and fill in the blanks.*

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| In California, patients have the rights to:1. Considerate, respectful and dignified \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. Present \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ and grievances
3. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ regarding their diagnosis, treatment and prognosis
4. Effective \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ and to receive language assistance
5. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_, \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ and \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ in regard to their care, information and records
6. Participate in \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ about the care, treatment and services
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| On the other hand, patients have the responsibilities to:1. Provide information that is \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ and \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ and express concerns about the care, treatment and services
3. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ related to and comply with agreed to treatment or care plan
4. Behave in a \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ manner
5. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ their own \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ through making proper choices
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**Part B: Patient Rights & Responsibilities in Hong Kong***Study the following extract, and answer the questions.*

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| Understanding the rights and responsibilities ensures high health care efficiency (by Department of Health, HKSAR)(extracted from <http://www.dh.gov.hk/english/useful/useful_dykt/useful_dykt_patient.html>)

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| The right to know1. Patients have the right to know the medical fee or charges in advance.2. Patients have the right to know the details of their illness, including diagnosis, progress, investigations, methods and effectiveness of treatment.3. Patients have the right to know the name, dosage, method of administration, uses and side effects of the prescribed medications.4. Patients have the right to know the purposes and common complications of any treatment procedures or investigations before they are performed, and whether there are any other alternatives.5. Patients have the right to obtain the information concerning their illness. They have the right to obtain a medical report or a copy of the medical record from relevant medical institutes or doctors. A fee may be required, so patients should ask in advance.The right to decide1. Patients have the right to consult more than one doctor before making decision to accept any treatment.2. Patients have the right to decide whether to accept or refuse any medical advice from doctors. If patients decide to refuse the suggestions from doctors, they should understand the consequences of their decision and be responsible for it.3. Patients have the right to decide whether or not to participate in medical research.The right to keep information confidential1. Without patients’ prior consent for disclosure, any information disclosed by patients during the process of management of their illness should be kept confidential by all medical personnel.2. However, in order to help the management of the illness, doctors may disclose the information to other relevant medical personnel. 3. Under special circumstances, if doctors suspect that the patients have committed crime or participated in illegal activities, the information may be disclosed to relevant authorities.The right to complaint1. Patients should understand and exercise their own “right to know” and try to communicate with medical personnel. This can ensure a better understanding of their own illness and the treatment process. If finally they are still dissatisfied with the medical personnel, they can make complaints.
 |
| Patients’ Responsibilities1. Patients should tell doctors frankly about their present illness, past medical history and other relevant information.
2. Patients should cooperate with medical personnel on any mutually agreed treatment plans or procedures.
3. Patients should not ask medical personnel to provide false medical information, to issue false receipts, sick leave certificates or medical reports.
4. Patients have the responsibility to pay the reasonable fee charged by relevant doctors or medical institutes.
5. Patients should follow the rules stipulated by clinics or hospitals and respect the rights of others patients and medical personnel.
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1. Comparing the patients’ rights stated by HKSAR and WOHC (cf. Part A), what are the common ones?
2. What do you think is the most important patients’ right? Why?
3. What other patients’ rights can you think of?
4. What are the common responsibilities of patients mentioned by HKSAR & WOHC?
5. Challenging level (optional): Why is it important to state the responsibilities when talking about patients’ rights?
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| Worksheet 2: Comparison of the patients’ rights in US and Hong Kong *(For teachers’ reference)* Part A: Patient Rights & Responsibilities in California, US*Watch the video by West Oakland Health Council (WOHC) at* [*https://www.youtube.com/watch?v=\_x7WCuZG8M4*](https://www.youtube.com/watch?v=_x7WCuZG8M4)*, and fill in the blanks.*

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| In California, patients have the rights to:1. Considerate, respectful & dignified care
2. Present complaints and grievances
3. Information regarding their diagnosis, treatment and prognosis
4. Effective communications and to receive language assistance
5. Privacy, confidentiality and security in regard to their care, information and records
6. Participate in decisions about the care, treatment and services
 |
| On the other hand, patients have the responsibilities to:1. Provide information that is accurate and complete
2. Ask questions and express concerns about the care, treatment and services
3. Follow instructions related to and comply with agreed to treatment or care plan
4. Behave in a respectful manner
5. Protect their own health through making proper choices
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**Part B: Patient Rights & Responsibilities in Hong Kong***Study the following extract, and answer the questions.*

|  |  |  |
| --- | --- | --- |
| Understanding the rights and responsibilities ensures high health care efficiency (by Department of Health, HKSAR)(extracted from http://www.dh.gov.hk/english/useful/useful\_dykt/useful\_dykt\_patient.html)

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| The right to know1. Patients have the right to know the medical fee or charges in advance.2. Patients have the right to know the details of their illness, including diagnosis, progress, investigations, methods and effectiveness of treatment.3. Patients have the right to know the name, dosage, method of administration, uses and side effects of the prescribed medications.4. Patients have the right to know the purposes and common complications of any treatment procedures or investigations before they are performed, and whether there are any other alternatives.5. Patients have the right to obtain the information concerning their illness. They have the right to obtain a medical report or a copy of the medical record from relevant medical institutes or doctors. A fee may be required, so patients should ask in advance.The right to decide1. Patients have the right to consult more than one doctor before making decision to accept any treatment.2. Patients have the right to decide whether to accept or refuse any medical advice from doctors. If patients decide to refuse the suggestions from doctors, they should understand the consequences of their decision and be responsible for it.3. Patients have the right to decide whether or not to participate in medical research.The right to keep information confidential1. Without patients’ prior consent for disclosure, any information disclosed by patients during the process of management of their illness should be kept confidential by all medical personnel.2. However, in order to help the management of the illness, doctors may disclose the information to other relevant medical personnel. 3. Under special circumstances, if doctors suspect that the patients have committed crime or participated in illegal activities, the information may be disclosed to relevant authorities.The right to complaint1. Patients should understand and exercise their own “right to know” and try to communicate with medical personnel. This can ensure a better understanding of their own illness and the treatment process. If finally they are still dissatisfied with the medical personnel, they can make complaints.
 |
| Patients’ Responsibilities1. Patients should tell doctors frankly about their present illness, past medical history and other relevant information.
2. Patients should cooperate with medical personnel on any mutually agreed treatment plans or procedures.
3. Patients should not ask medical personnel to provide false medical information, to issue false receipts, sick leave certificates or medical reports.
4. Patients have the responsibility to pay the reasonable fee charged by relevant doctors or medical institutes.
5. Patients should follow the rules stipulated by clinics or hospitals and respect the rights of others patients and medical personnel.
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1. Comparing the patients’ rights stated by HKSAR and WOHC (cf. Part A), what are the common ones?
* Right to know/information
* Right to decide/autonomy
* Right to confidentiality
* Right to complaint
1. What do you think is the most important patients’ right? Why?
2. What other patients’ rights can you think of?

E.g. * Right to medical care of good quality
* Right to beneficence
* Right to non-maleficence
* Right to dignity
* Right to access to hospital records
* Right to voluntary participation in research
1. What are the common responsibilities of patients mentioned by HKSAR & WOHC?
* Provide accurate and complete information/medical history.
* Follow instructions / cooperate with medical personnel on any mutually agreed treatment/care plans or procedures.
* Behave in a respectful manner to both others patients and medical personnel.
1. Challenging level (optional): Why is it important to state the responsibilities when talking about patients’ rights?

Rights and responsibilities are the two facets of the same coin that make a balance by avoiding the maleficence of overemphasizing any of both edges. If patients’ rights are overstressed, other important considerations like medical personnel’s professional judgments and authority may easily be overlooked, which in return weakens the patients’ well-being. The responsibilities are therefore stated at the same time to secure the rights of both other patients and the medical personnel. |

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| Worksheet 3 (Optional): Moral Dilemmas Caused by Patients’ Rights What moral dilemmas may be caused by exercising the following patients’ rights?

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| Patients’ rights | Moral dilemmas |
| Right to decide/autonomy |  |
| Right to confidentiality |  |
| Right to beneficence *(i.e. ‘doing good / taking actions that serve the best interests of patients)* |  |
| Right to non-maleficence *(i.e. ‘doing no harm’ / avoiding taking any actions that harm the patients)* |  |
| Others (Please specify): |  |

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| Worksheet 3 (Optional): Moral Dilemmas Caused by Patients’ Rights *(For teachers’ reference)* What moral dilemmas may be caused by exercising the following patients’ rights?

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| Patients’ rights | Moral dilemmas |
| Right to decide/autonomy | E.g. A patient may request euthanasia according to his own wish to terminate his own life. |
| Right to confidentiality | E.g. The doctor may not be allowed to disclose the situation of a child patient who has been abused.  |
| Right to beneficence *(i.e. ‘doing good / taking actions that serve the best interests of patients)* | 1. E.g. The doctor may use artificial methods to prolong a terminal patient’s life regardless the pain and unwillingness of the patient and his family.
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| Right to non-maleficence *(i.e. ‘doing no harm’ / avoiding taking any actions that harm the patients)* | E.g. The doctor would not prescribe some effective drugs with side-effects which cause deteriorating of the patient’s health. For example, Tamiflu has been found an effective drug to treat ‘H5N1 avian flu’ but would cause many side-effects like wheezing, chest pain and irregular heartbeat etc. To apply the principle of ‘non-maleficence’, the doctor would not prescribe this, which may obstruct the patient’s recovery, or even cause death due to delay in curing. |
| Others (Please specify): |  |

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| Worksheet 4: Debate on Euthanasia – Right to die! Euthanasia refers the practice of ceasing one’s life prematurely in order to end pain and suffering. It is also known as ‘Mercy Killing’.Some people argue that ‘Patients have the right to euthanasia/die’. Do you agree?

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| For | Against |
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Self-evaluation

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|  | Self-evaluation5=outstanding , 1=very poor |
| Am I able to make substantial arguments? | 5 4 3 2 1 |
| Am I able to give concrete examples to support my arguments? | 5 4 3 2 1 |
| Am I able to present my view/arguments in a logical and systematical way? | 5 4 3 2 1 |
| Am I able to respond to the arguments made by the counterpart? | 5 4 3 2 1 |

Peer evaluation

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|  | Peer-evaluation5=outstanding , 1=very poor |
| Is the counterpart able to make substantial arguments? | 5 4 3 2 1 |
| Is the counterpart able to give concrete examples to support their arguments? | 5 4 3 2 1 |
| Is the counterpart able to present their view/arguments in a logical and systematical way? | 5 4 3 2 1 |
| Is the counterpart able to respond to the arguments made by our side? | 5 4 3 2 1 |

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| Worksheet 4: Debate on Euthanasia – Right to die! *(For teachers’ reference)* Euthanasia refers the practice of ceasing one’s life prematurely in order to end pain and suffering. It is also known as ‘Mercy Killing’.Some people argue that ‘Patients have the right to euthanasia/die’. Do you agree?

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| For | Against |
| This is a humane way to cease pain and suffering for terminal patients. | * Some ‘terminal’ illnesses may be healed in the soon future given the rapid medical advancement.
* Legalizing euthanasia and assisted suicide leads to suicide contagion. People may think that killing themselves is a legitimate solution to their problems.
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| Patients have the right to determine their own life. | * People cannot play God. Our life is in the hand of God.
* Sometimes patients may make a wrong decision of ending their life in an undeliberated way.
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| It can reduce the public expenses on health care. | Life is invaluable. |
| It helps preserve the dignity of the patients who have been tortured by illness and have lost autonomy.  | The improvement of hospice care can help maintain patients’ dignity and reduce pain.  |
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| Worksheet 5: Placebo – Do Patients have Right to Know?Placebo, sometimes known as ‘sugar pill’ or ‘flake medicine’, is a non-medicine prescription intended to deceive the patients. It can be in forms of pills, creams, inhalants, injections and etc. Sometimes patients with a placebo treatment will have a perceived or actual improvement in a medical condition. This is called the ‘placebo effect’.

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| Task A: Placebo & Placebo Effect*Watch the online video clip ‘Stuff They Don't Want You to Know - The Placebo Effect’ at* [*https://www.youtube.com/watch?v=v\_feOG94IAs*](https://www.youtube.com/watch?v=v_feOG94IAs)*, and then answer the following questions:** + 1. Placebo is a real medicine.
* True
* False
	+ 1. What is the main purpose of using placebo?
* To deceive patients.
* To prove the efficacy of the real drug in clinical trial.

3. Which of the followings are true about the ‘double-blinded placebo control test’?* The purpose of the test is to measure if the medicine actually has an effect on patients.
* 2 groups of patients are involved - 1 group receives placebo, and the other receives real drug.
* Both the doctors and the patients involved do NOT know who are taking placebo.
	1. Research shows that the effectiveness of placebo to patients is the same across the world.
* True
* False
	1. Some patients taking placebo also have a clinical improvement; and sometimes placebo may even outperform the real medicine.
* True
* False
	1. What are the factors that may influence the effectiveness of placebo?
* Patients’ believe about the placebo
* Pills’ colour
* Location of the test
* Surrounding facilities
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| Task B: What makes placebo effective?*Study the cartoon below and answer the questions.***Option 1:**“The drug can certainly make you better!Make sure to take it every day!"**Option 3:**“Truly speaking, this is only placebo without any property of a medicine."**Option 2:**“I am not sure that the drug will have an effect. But you can try." http://www.bioethikos.org/tag/clinical-ethics/* + 1. Which way of saying (Option 1/2/3) do you think would let the patient have more confidence in the ‘drug’? Why?
		2. What are the pros and cons of ‘placebo test’?

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| Pros | Cons |
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3. Challenging level (optional): Do you think that using placebo is moral? Please explain your answer by applying theories of ethics. |

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| Worksheet 5: Placebo – Do Patients have Right to Know?*(For teachers’ reference)*Placebo, sometimes known as ‘sugar pill’ or ‘flake medicine’, is a non-medicine prescription intended to deceive the patients. It can be in forms of pills, creams, inhalants, injections and etc. Sometimes patients with a placebo treatment will have a perceived or actual improvement in a medical condition. This is called the ‘placebo effect’.

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| Task A: Placebo & Placebo Effect*Watch the online video clip ‘Stuff They Don't Want You to Know - The Placebo Effect’ at* [*https://www.youtube.com/watch?v=v\_feOG94IAs*](https://www.youtube.com/watch?v=v_feOG94IAs)*, and then answer the following questions:** + 1. Placebo is a real medicine.
* True
* False
	+ 1. What is the main purpose of using placebo?
* To deceive patients.
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3. Which of the followings are true about the ‘double-blinded placebo control test’?* The purpose of the test is to measure if the medicine actually has an effect on patients.
* 2 groups of patients are involved - 1 group receives placebo, and the other receives real drug.
* Both the doctors and the patients involved do NOT know who are taking placebo.
	1. Research shows that the effectiveness of placebo to patients is the same across the world.
* True
* False
	1. Some patients taking placebo also have a clinical improvement; and sometimes placebo may even outperform the real medicine.
* True
* False
	1. What are the factors that may influence the effectiveness of placebo?
* Patients’ believe about the placebo
* Pills’ colour
* Location of the test
* Surrounding facilities
 |
| Task B: What makes placebo effective?*Study the cartoon below and answer the questions.***Option 1:**“The drug can certainly make you better!Make sure to take it every day!"**Option 3:**“Truly speaking, this is only placebo without any property of a medicine."**Option 2:**“I am not sure that the drug will have an effect. But you can try." http://www.bioethikos.org/tag/clinical-ethics/* + 1. Which way of saying (Option 1/2/3) do you think would let the patient having more confidence in the ‘drug’? Why?
		2. What are the pros and cons of ‘placebo test’?

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| Pros | Cons |
| * Patients may get healed without any side-effect of a real drug (Consequentialism)
* It can provide clinical proofs on the efficacy of the real drug, which helps advancement of the pharmacy industry, that in turn benefits more patients in the long run (Utilitarianism)
* It saves cost of the public medical expenses, as ‘sugar pills’ are much cheaper than real medicine. (Utilitarianism)
 | * It infringes patients’ right to know, right to dignity, and right to autonomy, which are of high value (Value ethics)
* It is a dishonest act in itself (Kantian/Deontological ethics)
* It may delay real medical treatment for the patient (Consequentialism)
* Patients may have to pay an unreasonably high price for the ‘sugar pills’ in order to believe they are real medicine, which infringe the virtues of truth and fair (Virtue ethics)
* Since placebo effects are psychogenic, after quitting placebo, the patient may feel even worse (Consequentialism)
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3. Challenging level (optional): Do you think that using placebo is moral? Please explain your answer by applying theories of ethics.*(Refer to the Q2’s answers)*  |

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| Worksheet 6: Summary & Self-evaluation – Patients’ rightsWrite down the key learning points of this module.

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| 1. Patients’ Rights
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| 1. **Patients’ Responsibilities**
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| 1. **Moral Dilemma: Euthanasia – Right to die!**
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| (D) Moral Dilemma: Placebo – Do Patients have Right to Know? |
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| 2. |
| 3. |
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**Evaluate how well you have learnt** (please put a ‘🗸’)

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|  | Very good | Good | Fair | Poor |
| 1. Patients’ rights
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| 1. Patients’ responsibilities
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| 1. Moral Dilemma: Euthanasia – Right to die!
 |  |  |  |  |
| 1. Moral Dilemma: Placebo – Do Patients have Right to Know?
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What question(s)/area(s) you want to learn more in this module of ‘Patients’ Rights’? |

1. <http://www.who.int/genomics/public/patientrights/en/> [↑](#footnote-ref-1)