

Should We Inform The Patient?

Luis is 58 years old and has a history of hypertension, obesity, smokes 20 cigarettes a day and moderately consumes alcohol. A year ago he underwent treatment for pancreatic adenocarcinoma (at the head of the pancreas), receiving adjuvant chemotherapy. He was sent to the emergency room for fatigue, and lack of appetite as he had lost 10kg. He was assessed by a general surgeon who decided to request some outpatient tests (a tumor marker analysis and CT scan of the abdomen) and refer him for a consultation as a patient of priority. Luis did not show up on the day of the consultation, instead his daughter (Ana) came with the results from the outpatient tests that had been ordered when he was in the emergency room. She mentioned to Dr. Garcia that she read the results of the tests and that the cancer has recurred and that it seems to be liver metastases. Ana does not want her father to know the diagnosis, she explained that her father “has been very sad since the death of her mother 6 months ago”. Dr. Garcia read the results of the CT performed as an outpatient, which stated the existence of liver metastases and peritoneal carcinomatosis. Dr. Garcia asked, if and when this situation happens should he inform the patient or is it better to handle the case as requested by Ana?

Possible Courses of Action

- Stop treating Luis due to the conflict with his daughter.
- Respect Ana’s decision to not inform Luis, which is to say, continue to monitor him without informing him.
- Tell Ana that what she is asking for is wrong. The information is her fathers not hers.
- Remove Luis’s daughter from the consultation and call Luis immediately to inform him of his results.
- Explain to Ana that it is both legally and ethically necessary to inform Luis of his results.
- Negotiate with Ana given that the process he will need to go through will be difficult, that the best way to inform him if necessary is between both of them: how, when and where.
- Refer the case to Palliative Care who can help guide Luis and his daughter through the process.
- Make an appointment for Luis to have a consultation as soon as possible. Tell Ana that she may accompany him if Luis wishes.

Discussion

Conspiring and/or a pact of silence is a common situation in healthcare. It consists of not informing the patient about their clinical status at the request of their relative and / or relatives. The Conspiracy of Silence poses an ethical and legal conflict that puts the doctor between the

patient and their family and can end up, in some cases, complicating the clinical relationship. In the Conspiracy of Silence there is a conflict between the right to information (and, therefore, the right to make decisions) of the patient and the family decision to protect their relative, when they consider giving that information to the patient as harmful. However, in trying to protect the family member, they are actually hurting them. An uninformed (or poorly informed) patient doubly suffers during the health process: They not only suffer from the disease but they also suffer from the concealment of said disease and the inability to know and decide.

The right to receive information is essential for adequate healthcare. The information is necessary so that the patient may be well informed and thus may choose what is best for them during the care process. It is therefore a prerequisite for decision making and for trust in the clinical relationship. However, the patient has the possibility to choose:

- That the information be communicated to another person instead or ,
- That the information is not given to them nor any 3rd parties.

A patient who freely decides to decline receiving the information, must consent to the procedures and assume the risk of possible complications, if they wish to be treated, even though they are not informed.

Before a Conspiracy of Silence, the necessary information is as follows:

- Confirm with the patient what they know, what information they want to have, and whether they want to inform family or relatives of their pathology. It is the patient who should decide.
- Explain to the family carefully, that the right of healthcare information is an ethical and deontological and legal obligation of any healthcare professional.
- Suggest that other healthcare professionals participate (psychologists, social workers, lawyers) in order to help them through this difficult care process. If necessary, you can consult the BioEthics HealthCare Committee.
- Never abandon the patient, even if they do not wish to be informed.
- Record the decisions that are made in their medical file.

Recommended Courses of Action

- Explain to Ana that it is both legally and ethically obligatory to inform Luis. It is important that Dr. Garcia explains to Ana that giving the information is the responsibility of the Doctor to the patient and only if the patient requests can he give information to her regarding his clinical situation and care process.
- Negotiate with Ana, about the best way to inform Luis, if necessary between the two of them, given that the process will be hard. The ideal thing is that Dr. Garcia collaborates with Luis's daughter. You should start by explaining how important it is for Luis to know his clinical status and prognosis so that he can decide his life according to those expectations. In addition, the care process can be complex and require difficult decisions at the end of life, such as limitation of therapeutic efforts and shared care planning.

- Make an appointment with Luis as soon as possible, to give him the results of his tests and to explain his clinical status. Tell Ana that she may accompany him and be at the consultation if Luis wishes. Initially Luis will be asked what he already knows, if he wants to be informed and if he wants his daughter or other relatives to be informed. If so, Ana or the people Luis has chosen to accompany him in the information process may go to the consultation.
- During the first consultation Dr. Garcia should assess Luis's competence in order to determine what his decision-making capacity is.
- Additionally, Luis can be offered the possibility of a referral to a Psychologist to help him manage the news.

Sgd.: Bio Ethics and Health Law Committee Lavinia-ASISA

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