

## **Retaining Hope While Respecting Patients' Presumed Wishes: How Substituted Judgement Can Help**

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### **Article abstract**

It is not uncommon for families to wait in hopes of receiving test results that show a treatable mutation, such as in the case of lung cancer. Waiting for such test results can distract families from focusing on a patient's current pain and suffering, especially when families experience heightened emotions and anticipatory grief. The substituted judgement standard can be helpful in resolving ethical dilemmas by encouraging families to think about what decision a patient would have made if competent, thus preventing unnecessary pain and suffering. This case study sheds light on how the substituted judgement standard was used with a patient's family and how the family's hope for a treatable mutation affected their perception of the patient's clinical condition.



ÉTUDE DE CAS / CASE STUDY

## Retaining Hope While Respecting Patients' Presumed Wishes: How Substituted Judgement Can Help

Natalie Hardy<sup>a</sup>, Nico Nortje<sup>b</sup>

### Résumé

Il n'est pas rare que les familles attendent dans l'espoir de recevoir des résultats de tests qui révèlent une mutation traitable, comme dans le cas du cancer du poumon. L'attente de ces résultats peut empêcher les familles de se concentrer sur la douleur et la souffrance actuelles du patient, en particulier lorsque les familles éprouvent des émotions intenses et un deuil anticipé. La norme du jugement substitué peut être utile pour résoudre les dilemmes éthiques en encourageant les familles à réfléchir à la décision que le patient aurait prise s'il était compétent, évitant ainsi une douleur et une souffrance inutiles. Cette étude de cas met en lumière la manière dont la norme de jugement substitué a été utilisée avec la famille d'un patient et comment l'espoir de la famille d'une mutation traitable a affecté sa perception de l'état clinique du patient.

### Mots-clés

jugement substitué, prise de décision, éthique, cancer du poumon

### Abstract

It is not uncommon for families to wait in hopes of receiving test results that show a treatable mutation, such as in the case of lung cancer. Waiting for such test results can distract families from focusing on a patient's current pain and suffering, especially when families experience heightened emotions and anticipatory grief. The substituted judgement standard can be helpful in resolving ethical dilemmas by encouraging families to think about what decision a patient would have made if competent, thus preventing unnecessary pain and suffering. This case study sheds light on how the substituted judgement standard was used with a patient's family and how the family's hope for a treatable mutation affected their perception of the patient's clinical condition.

### Keywords

substituted judgement, decision making, ethics, lung cancer

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## INTRODUCTION

It is not uncommon for ethics consultations to be requested when families and providers disagree on how to proceed with a patient's care. Oftentimes, families request aggressive treatment in hopes of honoring and respecting their loved one, while the healthcare team strives to prevent suffering. Ethicists play a key role in facilitating conversation, mediating conflicting viewpoints, and helping surrogate decision makers. It is the role of the ethicist to mediate each party's goals and reach a resolution that respects each party's interests.

## CASE STUDY

B.C. was an elderly woman presenting with metastatic lung cancer, a cancer that forms when cells abnormally cluster together and spread to other parts of the body (1). B.C. was admitted as a new patient to the cancer hospital via the emergency centre (EC) and had shortness of breath and respiratory failure. Of note, she also had COVID-19 three months prior to being admitted to this institution. Given her poor lung capacity she had to be emergently intubated in the EC and was sent to the Intensive Care Unit (ICU) with metabolic acidosis (when the body produces excessive amounts of acid). In addition, she was also in septic shock (a dangerous and potentially life-threatening condition that can occur after an infection (2)) which resulted in extremely low blood pressure. As a result, B.C. needed to be on multiple vasopressors to help keep her blood pressure up. Her clinical picture was further complicated by progressive multisystem organ failure (a decline in the functioning of her respiratory, cardiac, and renal functions). Overall, the patient was extremely weak and was also of altered mental status, not able to recognize anyone or participate in any conversations. Since the patient was new to this institution, molecular testing was done to determine the kind of variant for her lung cancer and whether it could be treated.

Metastatic lung cancer is typically treated through aggressive chemotherapy (drugs that kill abnormally growing lung cancer cells). Unfortunately, this treatment also kills healthy cells. In recent decades, molecular testing, a method allowing for more precise identification of abnormal mutations, insertions, and deletions in the patient's DNA, has been developed (3). Although molecular testing can increase the precision of care and thus reduce side-effects, it can take 1-4 weeks to receive test results after tissue is sent for analysis (1). Such prolonged wait time can cause patients and families to hope for a treatable mutation, while patients like B.C. suffer, and when palliative care options are likely more appropriate. The patient's family was informed that an untreatable mutation might be found, yet they decided not to "believe it." It can be difficult for families and surrogates to choose palliative care when the results of the test are unknown – some might feel as though they are giving up on the patient, while others continue to operate through an ethos of "fighting" and doing everything clinically possible.

## SURROGATE DECISION-MAKING AND ETHICS

B.C.'s family was holding on to hope of an answer that their mother might have a treatable cancer. Her family was denying all the other issues at hand, which included B.C.'s declining mental status, poor physical condition, and increasing pain and suffering with continued care. The primary care team felt there was a disconnect by the family between what was happening to their mother (organ failure and her cancer prognosis). Consequently, the care team wanted to have a goals of care meeting with B.C.'s family to address realistic goals and to avoid further suffering for the patient.

A goals of care conference was held with the family, which included the patient's three daughters. The healthcare team gave a detailed clinical update and described B.C.'s sudden decline. The team recommended transitioning the patient to comfort care due to her decline and likelihood of demise. The daughters did not want to be disrespectful of their mother and had great difficulty in changing any code status or focus of care (away from aggressive to end-of-life care). They asked the team for more time until the molecular results were available before deciding. On the morning of the patient's eventual death, she further desaturated, was on a 100% ventilation setting, and her blood pressure medication had to be increased.

The ethical issue in the case of B.C. stems from respecting the decisions of surrogates who are unrealistically hopeful despite a patient's poor prognosis, especially when the surrogates' refusal to implement comfort care causes the patient additional suffering. In this case, the care team could not engage B.C. to elicit what her wishes would be, and there were no available advanced directives to guide decision-making. Thus, the ethicist mediated the care conversations in accordance with the substituted judgement standard. According to Dubler and Liebman (4), the substituted judgement standard asks surrogate decision makers to make decisions based on the patient's inferred wishes and what the surrogate knows about the patient's values, behavior, and past pattern of decision making. In other words, surrogates must "stand in the shoes" of the patient and make decisions in the manner they would have if decisional. Importantly, the standard acknowledges family members as having the most intimate knowledge of the patient, their worldview, and identity as a person (5). It is the role of the ethicist to help families to make decisions solely in terms of what the patient would have wanted if they had decisional capacity.

During the goals of care conference, the ethicist asked each sister to explain what their mother was like as a person, how she lived her life, and what her values were in difficult times. If the patient was capable of making a decision at this moment, would she want to wait for the molecular results, or would she prefer to be receiving comfort and palliative care? The daughters described their mother as a stoic kind of woman who always got on with the job. They believed that waiting for the laboratory results and hoping for a potential chance of treatment would be what their mother would have done if she were able to make the decision.

The family was going to discuss change in care focus from aggressive to comfort. However, recent changes in legislation of the local jurisdiction (Texas, USA) had precluded any physician from unilaterally (with the support of a second physician who has not been involved in the care of the patient) changing a patient's code status and change the focus of care (6). As several discussions were ongoing about what the patient would have wanted, the care team had to wait for the family to guide the way forward pertaining to interventions. Sadly, B.C. declined even more and had a cardiac event – she passed away 3 hours before the molecular results were known. The results indicated that B.C. had a non-treatable mutation.

## CONCLUSION

Using the substituted judgement standard is beneficial when a patient's wishes are unknown, there are no advanced care documents, and surrogates wish to respect what the patient would have wanted in a given situation. The ethicist in this case had an essential role in facilitating conversation around a patient's values and history of decision-making. As B.C.'s case shows, it can be difficult to put familial concerns aside when thinking about what decision a patient would make, but ethicists are an important part of helping families keep a patient's values at the locus of decision-making.

## QUESTIONS

1. When operating through the substituted judgement standard, what mediation techniques can ethicists employ to prevent families from clouding their judgement about what the patient would have done?
2. If the sisters had disagreed on what their mother would have wanted, how should the ethicist have proceeded?

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