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Review

Bioethics: To What Extent Should Terminal Illnesses Be Concealed?

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Abstract: This paper will delve into the idea of concealment of terminal illness, a common practice in the past and in many countries today. I will explore Eastern and Western cultural roots and history for the concealment of terminal illness, followed by an analysis of the impacts of historical factors on this norm. I will then contextualize this issue in today's world, with relevant case studies that highlight the complexity and ethical dilemma of the problem. Then, I will compare the Western and Eastern perspectives on the concealment of terminal illness today, with a focus on the US and China as representatives of the West and the East. Finally, I will put together different perspectives and explore my perspective on this issue.

Keywords: terminal illness; concealment; bioethics; cross-cultural comparison; ethical dilemma

1. Introduction

Terminal illness refers to any medical condition that is expected to end in the death of the patient. It is a condition that is incurable and does not go away, which will accompany the patient until death. Common types of terminal illness include some types of cancer, heart disease, and failure of organs. Treatments for terminal illnesses are implemented to decrease pain, improve quality of life, and prolong life, but do not prevent a patient from dying from the specific illness. There isn't a specific period a patient with a terminal illness can survive - it depends on the severity and type of illness. The patient can last days, months, or even years. Physicians can approximate a survival period, but this prediction can be off [1].

The most dramatic impact of terminal illness is on the quality of life for patients, both physically and mentally. As treatment is implemented and the illness spreads, the patient is confined to medical support and experiences a deterioration of the body. Mentally, patients with knowledge of their illness will feel a sense of hopelessness and depression, while patients without knowledge of their illness might initially suffer less, save for the sense of anxiety from their hospitalization [2].

Due to the mental suffering that patients experience upon knowing that they are terminally ill, many cultures have historically practiced concealment, which includes generating or editing fake medical reports, intentionally hiding the patient's diagnosis and/or prognosis, and other forms of lying. Fundamentally, all these behaviors are aimed at clouding or blocking a patient's knowledge about their medical condition [3]. There are mainly two groups of people that the concealment of terminal illness is directed to - the patients themselves and young children who are related to the family. Family members justify concealing terminal illnesses as a form of protection - preventing patients and children from additional mental suffering that would only exacerbate the pain of the illness itself [3].

Concealment of terminal illness was a widespread trend across the world around fifty to sixty years ago. However, during the 1960s-1970s, Western countries (mainly

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North America and Western Europe) underwent a period of significant ideological transformation that changed this practice [4]. In Eastern cultures, by contrast, the practice remains relatively widespread. This paper aims to delve into the historical, current, and ethical aspects of the issue of concealment of terminal illnesses. Discussing some fundamental reasons for concealment establishes a strong foundation for the understanding of the differences between Eastern and Western perspectives. After establishing a basic understanding, the paper will explore the ethical complexities and dilemmas associated with this issue, as well as provide my insights into this issue.

2. History

2.1. Culture Roots of Concealment of Terminal Illness in the West

Historically, Western countries (including the US and other Anglo-Saxon countries) have had a widespread practice of non-disclosure of medical reports to patients. Around 3,000 years ago, in Ancient Greece, the Hippocratic writings suggested that physicians should be "economical with the truth, [...] reveal [...] nothing of the patient's future or present condition" [5]. As the Hippocratic Oath outlines, a physician's goal should be to improve the patient's well-being, following the principle of "do no harm" [6]. Revealing the truth to a patient would harm their psychological health, which would also impact their physical health. Therefore, the idea that lying to a patient is justified is the common belief toward the concealment of diseases, as expressed by Plato's idea of "avert the evil" in his text The Republic. Here, he draws an analogy between lies and medicine, suggesting that both are a means of avoiding evil consequences in life and medical practices. Therefore, Plato recognized that it is ethical to withhold the truth in medicine [5]. The Hippocratic idea further influenced Galenic Medicine during Ancient Rome around 1,800 years ago. Galen adopted the Hippocratic idea of concealment, believing that knowledgeable physicians should retain all the powers in medical treatments [7]. Then, in 1847, the American Medical Association (AMA) published a Code of Ethics. The code states: "The life of a sick person can be shortened not only by the acts but also by the words or manner of a physician. It is, therefore, a sacred duty to avoid all things which tend to discourage the patient and to depress his spirits" [5]. This text strongly supported non-disclosure, and it again echoed the idea that disclosure would mean risking a patient's mental state and directly shorten a patient's ability to survive an illness [5].

Central to the practice of concealment was the perspective that the patient's role was passive [8]. This phenomenon is also known as medical paternalism, where physicians claim the absolute right to determine what treatment is best for the patient. This idea has roots in Roman texts such as Galenic Medicine, which asserts that the patient doesn't have enough education to fully understand their medical problems, and disclosure would only psychologically burden them. Despite this seemingly compassionate rationale, medical paternalism has also resulted in grave violations of human rights. In the Tuskegee Syphilis Experiment during the 20th century, around 400 African Americans were treated with syphilis despite the widespread use of penicillin after 1947. The patients were never told about their diagnosis of syphilis, resulting in the deaths or significant health effects of all experimental subjects [9]. While racism played a major part in the atrocity, the Tuskegee Syphilis experiment also shows the danger of seeing patients as passive instruments with no say in their medical treatment.

Thus, the cultural roots of Western practice of concealment of terminal illness can be attributed to two ideas: that it would protect the patient, and that the patient was a passive subject.

2.2. Culture Roots of Concealment of Terminal Illness in the East

Compared to the West, where medical concealment was seen through the lens of the individual-protecting the patient based on his needs-in the East, the cultural roots of concealment were often familial and communal. Across most East Asian countries, there is a

widespread tradition of filial piety [3]. This refers to the Eastern culture of respecting one's elders. This respect can come in many different forms, such as favoring the elder's opinions, honoring one's ancestors, and taking care of the elders. For individuals to take care of their elders, there are detailed traditions that guide their actions. For instance, texts and literature from the almost 2,500-year-old Confucian tradition frequently mention "Xiao", which refers to the concept of the children's duty to respect and be loyal to the elders [3]. In an Eastern society, someone who takes care of and frequently pays respect to the elders is also esteemed in their own family and community. Revealing a terminal illness to one's family members, especially elders, directly goes against the value of filial piety and fulfilling one's duty of caring for them. Furthermore, the Asian cultural emphasis on the collective-in this case, the family-raised the value of a group's opinion over the individual' s. Therefore, a family's opinion on what treatments to administer and what to do with a diagnosis and prognosis is more important. This gives the family more power than the patient, so it is often the case that a physician will talk to family members before speaking with the patient.

In addition to familial and communal values, superstition played a role in Eastern culture's approach to the concealment of terminal illness. In Asian cultures, there is a significant emphasis on avoiding talking about death, which is deemed to bring bad luck. For instance, the Chinese pronunciation of the digit "4" closely resembles the pronunciation of "death". Therefore, this number is seen as bringing bad luck. In many buildings in China, the 4th floor, 14th floor, and any floor with "4" in it is often skipped. Similarly, in Japanese culture, the pronunciation of "4" also bears the same resemblance to the pronunciation of death [10]. In cultures that take pains to avoid even homophones of death, directly discussing death is seen as a flagrant disruption of family balance and harmony. Hence, mentioning death is seen to be bringing death, or accelerating death, for patients with terminal illnesses. Therefore, talking about a terminal illness with patients is highly taboo in traditional Eastern culture [2].

In short, the Eastern cultural roots of the concept of terminal illness are mainly due to the tradition of filial piety, a collective culture, and superstition.

2.3. The Shift in Western Bioethics

From the 1960s to the 1970s, there was a significant shift in Western attitudes toward truth-telling in medicine. Originally, these countries had widespread medical practice of non-disclosure. Because of little regulation and oversight over this issue, physicians usually choose non-disclosure as it protects their interests, eliminating any possibility of conflict with the patients. However, progressive reforms during the mid to late 20th century increased the emphasis on individual autonomy and rights and demanded a deeper recognition of patient rights [11].

This period of drastic reforms began with the resurgence of the Civil Rights movement, with notable events such as the Montgomery Bus Boycott in the 1950s, the Freedom Rides in 1961, and Martin Luther King's peaceful demonstrations during the 1950s to 1960s. These efforts led to the passage of the Civil Rights Act of 1964 and the Voting Rights Act of 1965. During the same time, Women's Rights Movements were inspired by the successes of the Civil Rights Movement, with notable figures such as Betty Friedan and organizations such as the National Organization for Women advocating for all aspects of women's rights, such as workplace equality and reproductive rights. Again, this led to the passage of legislation such as the Equal Pay Act of 1963 and Roe v. Wade in 1973, which improved women's rights. While this period is typically seen as increasing regard for historically oppressed groups, such as minorities and women, its influence went deeper. It called attention to the sanctity of individual rights, an idea that filtered into medical practices, eventually challenging the traditional physician-patient dynamic [12]. Thus, the Civil Rights Movement and the Women's Rights Movement laid the groundwork for the rise of Bioethics and the increasing importance of patient rights [11].

The earliest case showcasing the concept of patient rights is the Salgo v. Leland Stanford Jr. University Board of Trustees case in 1957. This case established basic principles of informed consent, meaning that the physician has the duty of revealing all the information regarding the treatment of the patient. This includes risks, possible treatments, and other relevant information needed for patients to make choices. Therefore, the fundamental dynamics between the physician and the patient shifted from being physician-led to patient-oriented. Patients now have the right to make choices such as which treatment to administer, making medical decisions much more personalized and transparent [13].

The beginning of modern Bioethics was drastically influenced by several articles and books that raised public awareness of this topic. Henry Beecher published "Ethics and Clinical Research", a paper consisting of 22 case studies of medical non-disclosure, in the New England Journal of Medicine in 1966. He went on to publish several other papers that prompted readers to question the ethics of concealment in health care. The target audience of the journal was mainly physicians and researchers, and Beecher directly challenged their traditional views toward non-disclosure. Later, the founding of The Hastings Center in 1969 marked the beginning of Bioethics research [13].

2.4. Eastern History of Concealment

In the East, there were civil movements regarding Bioethics, but they differ from those in Western culture as they are much less prominent and have less influence on society.

Japan during the 1980s to 2000s is an example of a civil movement. During this period, there were massive scandals involving patients discovering hidden cancer diagnoses, leading to the Japan Medical Association urging physicians to be more transparent about their medical practices. However, in 1995, the Supreme Court in Japan ruled that doctors are not legally obligated to disclose patients' medical situations [14]. This example shows that in Eastern cultures, civil movements seldom take place, and even when they do, they don't have the drastic impact on society as those in Western countries.

Today, concealment of terminal illness still plays an important role in the East. A study done in China shows that 62.1% of the participants in this study don't know about their medical condition [15]. This discrepancy in ideology between East and West will be examined in the next section.

2.5. Perspective Impact of Cultural Difference Between East and West

The histories of both cultures evidence the differences between Eastern and Western approaches to the concealment of terminal illnesses. One main distinction is that the West values the idea of the individual, while the East sees an individual as part of a bigger collective. This difference hugely affects the difference in perspective of the East and West on the issue of concealment of terminal illness. The more individualist West advocates for a patient's rights to know and make decisions regarding their terminal illness, while this power vests in the family in the East. As a result, in the matter of concealment of terminal illness, the West believes it to be depriving individuals of their rights, while the East believes that a family's decision of non-disclosure should be valued more highly than the patient's opinions.

Moreover, a significant difference between Western and Eastern cultures is their view of traditions and history. The rise of Western Bioethics and the rising emphasis on patient rights is a result of not conforming to and sticking with the traditions. Instead, the progressive movements during the mid-20th century show that society constantly demands change. On the other hand, the East values traditions very highly. Many cultures in the East very much believe in the wisdom of ancient cultures and see their texts as moral instructions for how to live in modern society. This allows the East to maintain its long

traditions without changing them. This difference allows the West to challenge the traditional norms of non-disclosure, while the East sees it as part of their long culture not to be challenged.

3. Case Studies

Below are 6 different case studies that illustrate the ethical dilemma of the concealment of terminal illness. These case studies are split into two countries, the US as representative of the Western perspective and China as representative of the Eastern perspective. This allows a direct comparison between the differences in perspective and how that led to different practices of concealment, which will be explored in the last section of the case studies.

3.1. The Western Perspective

3.1.1. Case 1: Salgo v. Leland Stanford

Salgo v. Leland Stanford is a landmark case in US medical history from 1957. This case established medical guidelines for informed consent for patients, requiring physicians to disclose medical details to their patients. In this case, Martin Salgo went to Stanford University's medical center after experiencing cramps in his legs. He underwent an aortogram, but the physicians failed to notify him of possible risks. After waking up, Salgo had permanent paralysis in his lower body, so he took this case to court. This case established a legal duty for physicians in the US to disclose any information on a patient's illness to the patient [16].

3.1.2. Case 2: An Automobile Accident

In Mark Sheldon's paper "Truth Telling in Medicine", he provides an interesting case involving an automobile accident that severely injured a woman. The woman has four children, two of whom are also involved in the accident, with one declared dead and the other in critical condition. After examining the woman, the physician thought that disclosing the information about the critical conditions of her two children would drastically weaken her condition [17].

3.2. The Eastern Perspective

3.2.1. Case Study 3: Mr. Chen's Heritage

Dr. Ning Xiaohong, the Chief Physician of the Palliative Care Center at Peking Union Medical College Hospital, shared the case of her 55-year-old male patient, Mr. Chen. He was diagnosed with advanced pancreatic cancer, with very little hope of survival over the next few years. Mr. Chen and his sister own a farm together, where they split the revenues. After Mr. Chen's diagnosis, his daughter was informed first by the physician. However, she chose to conceal this information from his dad, telling him that it was only a common inflammation and nothing to worry about. After Mr. Chen's death in half a year, his daughter wants to inherit his portion of the shares on the farm. However, Mr. Chen's sister had already transferred all of his shares under her name through a property rights exchange and lots of legal proceedings, which Mr. Chen's daughter was oblivious to. After hearing this news, Mr. Chen's daughter appealed to the court and sought mediation from lawyers and judges, but because Mr. Chen didn't leave any message of how he wanted his properties to be arranged, while Mr. Chen's sister had gone through a legal process of transferring the shares, there was nothing his daughter can do to retrieve Mr. Chen's part of the shares. After seeing them argue over this issue from the hospital to the court, and a family torn apart, Dr. Ning was very sentimental, saying, "This is definitely not the outcome that Mr. Chen wants to see. If he had been informed of his illness when he was alive,

he would at least have been able to make arrangements for the distribution of these important properties, and the current situation, where relatives have turned against each other, would not have occurred" [18].

3.2.2. Case Study 4: A Daughter's Filial Piety

Dr. Guo Yanru, the chief physician of the Department of Palliative Care in the Seventh Affiliated Hospital of Sun Yat-sen University of Shenzhen, shared a case of her 74-year-old patient with advanced lung cancer. She had just been admitted into the hospital when her daughter found Dr. Guo to ask for a very serious favor: "I have only one request. Don't tell my mother the true condition. I hope to treat it if possible. I don't want to save money on this matter, and I don't want other relatives to say I'm not filial because of this." Dr. Guo then asked her: "What do you think filial piety is? Isn't it also very important to tell the elderly about their true illness and ask them what they think?" The daughter didn't respond. Just three days later, the patient began to have problems breathing, and her daughter insisted on sending her to the ICU. She stayed in the hospital for 4 nights. However, her mother's condition only worsened. So by the end of the 4th day, the daughter asked Dr. Guo to let her mother out, wishing to spend the last moment of her life hugging and talking with her. However, half an hour after the patient was let out of the ICU, her heart stopped beating. The daughter expressed strong regret for letting her mother suffer in the last moment of her life and not giving her a chance to say a proper goodbye [19].

3.2.3. Case 5: A Patient's Final Will

Dr. Guo Yanru shared another case of her 37-year-old patient with advanced ovarian cancer. She had a high level of education, and she was also the mother of a 2-year-old girl. After the diagnosis, physician Guo truthfully told the patient about the details of her cancer. Three months later, her cancer worsened, and she could only survive with blood transfusions. One day, the patient asked Dr. Guo for a final favor: "Physician, I'd like you to give me a blood transfusion for another two weeks. My daughter will be two years old next week. I hope that on her birthday, she can still call me 'Mom', and when she calls me, I can still respond. Besides, I also need to handle some of my funeral affairs to provide some security for my parents and daughter." Dr. Guo followed her instructions, and the patient and her daughter celebrated her birthday in the hospital. After two weeks, the patient told the physician to stop the blood transfusions, and two days later, she died in her sleep [19].

3.2.4. Case 6: A Son's Regret

Kang Lin, the Director of the Department of Geriatrics at Peking Union Medical College Hospital, shared a case about his patient, Mr. Wang. He was diagnosed with advanced esophageal cancer, and his son told the physicians to conceal the truth from his father, saying that it was only a minor esophageal inflammation. His son also rejected chemotherapy to treat his father. As the cancer developed, the esophagus was blocked by a tumor, so the physician inserted a stent to stretch the esophagus. This allowed Mr. Wang to eat only food that are soft, and he was very happy and thought his illness had gone away. One day, the stent was broken when Mr. Wang was eating steak. At this point, the cancer had advanced to the stomach, and it was very risky for the physician to replace the stent because it could cause gastric acid reflux and even aspiration into the lungs. The physicians suggested that his son tell his dad the truth and let him make a decision, but he didn't do so. The son explained to the physicians that although he would want to know the truth if he were in his father's position, he believed that his father was very weak and that knowing the truth would worsen his condition. So the son decided to ask the physicians to place another stent in Mr. Wang's esophagus. However, as the physician pre-

dicted, Mr. Wang had gastric acid reflux, leading to his death shortly after. His son regretted the decision not to tell his father the truth after Mr. Wang's death, and he blamed himself for making his father die in pain [20].

4. Discussion

After understanding the history and current situation of concealment of terminal illness, both in the East and the West, this section provides a discussion about the current situation. I will present my argument, as well as address common counterarguments to my claims.

4.1. My Argument

After learning about the Eastern and Western perspectives, it is clear that the two differ drastically. They lie at the two ends of the spectrum, with the Eastern belief of non-disclosure and the Western belief of disclosure. I believe that both approaches are too polarizing, leading to some extreme decisions. The middle ground is what I believe in, and what I will establish in my argument.

The middle ground, though, might seem hard to establish as a patient only has the definite choice of disclosure or non-disclosure. However, to say definitively that one choice is better than the other in all situations is too extreme. A decision should be made according to the specific situation of the patient, and this decision should be made through healthy and constant communication between the physician and the patient's family, the two groups that are caring for the patient. To identify what decision to make in which situation is especially hard, but in fact, it is quite simple: a physician's decision should be the one that inflicts the least amount of harm on the patient. Still, it is difficult to judge the extent of harm disclosure might bring. I believe that it is up to the physician to use their experiences to guide the decision-making process. This idea will be discussed further in one of the counterarguments. Additionally, for a specific case, disclosure might impact the patient differently at different times, so the timing of the disclosure is also crucial, and again, it is up to the physician to guide this decision [17].

With all that said, why would the middle ground and assessing the harm to the patient be the best choice? This question brings us back to the fundamental role of a physician. As outlined by the Hippocratic oath, the fundamental principle for a physician is to "do no harm" [6]. However, in regard to this issue, both disclosure and nondisclosure would bring harm to the patient. As mentioned in the introduction, disclosure would add further mental burden and even physically weaken the patient, while non-disclosure would bring anxiety and harm the interest of the patient to prepare for their death. Therefore, in a matter where both decisions bring harm, a physician should look to make the decision that brings the least amount of harm.

Now, I will discuss all the case studies in section 3, providing some examples to support my argument. Case study 1 advocates disclosure in any context. This can be problematic, though, when disclosure does more harm. For example, in case study 2, the woman herself is already in critical condition, so disclosure would directly put her life at risk. Additionally, disclosure wouldn't help her children recover, so non-disclosure would be justified, but disclosure should be the practice after the woman recovers. This case also highlights the importance of timing in disclosure.

Case study 3 displays the view of concealment. It is clear that the family's decision to conceal terminal illness led to future family conflicts. In this case, disclosure would have been a better choice as soon as Mr. Chen was diagnosed, as Mr. Chen still had half a year to process and prepare for his death and further arrangements for the family. Additionally, Mr. Chen's right of testamentary is violated, as his sister made all the decisions of his inheritance for him without his knowledge. This wouldn't have happened if the family had been transparent about his medical condition. This would have brought less harm to

the family, and Mr. Chen possibly would have been happier if his family hadn't gotten into this conflict after his death.

In case study 4, the patient's daughter herself regretted the choice not to disclose her mother's condition. She had only a few days left, and excessive treatment, while not disclosing the condition to the patient, only led her to die without much preparation. Her mother would have appreciated the information about her situation early and spent the last few days with her family.

In case study 5, the patient is prepared for her death after the physician's notice. The information didn't harm the patient; rather, it allowed her to be prepared. However, it is interesting how the physician chooses to disclose directly to the patient, not their family, first. Is it because she has a high level of education? Does that make the patient more prepared to receive information about their medical condition? I believe that the only factor guiding a physician's decision should be the patient's medical situation. This case study, therefore, again emphasizes education for physicians on making better decisions, which I will cover in the next section.

In case study 6, the concealment of the patient's illness led to his negligence regarding his eating habits. His false positive belief about his medical condition prompted him to eat hard things, eventually breaking the stent. Moreover, his son's decision to conceal is because of his belief that it would worsen his dad's medical condition. Although the intention is good, the assessment of whether the truth would do more harm than good should be the collective decision of the family and the physician, with the physician leading the discussion due to their expertise in the patient's condition. We also notice the recurring theme of regret. In all of these cases involving a family's regret, the decision of concealment is made solely by the family.

Concealment of terminal illness is a complex issue that should be decided according to the situation. Physicians should abide by the principle of doing the least amount of harm, but this differentiation is nuanced in many situations that require a physician's expertise.

4.2. Addressing Counterarguments

Many argue for absolute concealment or disclosure. These are covered in the second section of the paper, where Eastern and Western perspectives are outlined and compared. Belief in concealment stems from cultural traditions and physicians' unwillingness to disclose. The perspective on disclosure is due to an emphasis on individual rights.

Cultural traditions, especially in Eastern countries, dictate an individual's decision regarding the concealment of a terminal illness. These traditions, although being an essential part of one's identity, shouldn't be prioritized above the patient's health when they would do more harm to a patient. Many traditions, however, directly put a patient's health at risk, as we have seen in the case studies. For instance, the Eastern tradition of filial piety might seem to be in the best interest of the patient, but in fact, it is the opposite after some thought. Filial piety forces an individual to care for their elders and family, not because they truly care about their family, but because they see it as an obligation to conform to societal norms. In case study 4, the daughter would have disclosed her mother's terminal illness to her if she were considering the interest of her mother. However, she doesn't do so because she is pressured to act as if she is caring for her mother. Filial piety, therefore, is in fact self-centered, maintaining the family member's reputation while directly putting a patient's health at risk.

Another reason for concealment was the physician's unwillingness to disclose due to their belief in medical paternalism, and often, physicians speak to family members first, who would make a decision, as seen in the case studies. This is a fundamental issue regarding education for physicians that should be changed. A physician's role shouldn't only be medical care, but also communication with family and leading the decision-making regarding ethically complex issues such as concealment of terminal illnesses. After

receiving education about this type of decision-making and gaining experience from practice, a physician should guide the family into making a better decision.

The emphasis on individual rights is one of the crucial factors for the Western bioethical view of disclosure. Again, I believe that a person's right to their medical conditions should be prioritized after the patient's health. In case study 2, for example, the emphasis should be on saving the woman's life first, and then considering whether to disclose her children's condition.

Concealment and disclosure both present drawbacks that would negatively affect the patient's health.

5. Conclusion

Historically, both Eastern and Western cultures practiced concealment for different reasons. Later, the rise of Western Bioethics altered the Western practice of concealment while the East maintained its cultural roots of concealment. However, a definite say in whether to conceal or disclose a patient's terminal illness often presents cases where a patient's health would be more negatively damaged. It is, therefore, a matter of finding the balance between the two that is crucial. This balance is decided by a number of factors, the most important being the physician and the family members of the patient. As shown in the case studies, these two parties are most heavily involved in the decisions of concealment or disclosure for patients. Therefore, healthy and constant communication between them is significant for deciding whether to conceal, and the timing of concealment. Another huge aspect of this decision is hugely influenced by the cultures of specific societies - the likes of filial piety and collectivism in the East and individualism in the West. These factors, though, should be prioritized behind the health of the patients, ensuring a decision that would do the least harm to the patients first.

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