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Volume 3, numéro 3, 2020

URI : <https://id.erudit.org/iderudit/1073790ar>

DOI : <https://doi.org/10.7202/1073790ar>

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Éditeur(s)

Programmes de bioéthique, École de santé publique de l'Université de Montréal

ISSN

2561-4665 (numérique)

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Citer ce document

Anderson, G. S. & Sadighpour, L. (2020). Patient Confidentiality and Ethical Behaviour as a Professional Commitment in Dentistry: A Case Study in a Genetic Disorder. *Canadian Journal of Bioethics / Revue canadienne de bioéthique*, 3(3), 134–136. <https://doi.org/10.7202/1073790ar>

Résumé de l'article

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ÉTUDE DE CAS / CASE STUDY

Patient Confidentiality and Ethical Behaviour as a Professional Commitment in Dentistry: A Case Study in a Genetic Disorder

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Résumé

Un engagement professionnel en faveur de la confidentialité des patients peut parfois être en contradiction avec d'autres principes de bioéthique. La prise de décision pour les médecins et leur équipe peut être difficile au milieu de ces principes contradictoires, et malgré les meilleures intentions du praticien, la rétention d'informations peut avoir des conséquences potentielles telles que le préjudice causé à autrui.

Mots-clés

bioéthique, professionnalisme, confidentialité, trouble génétique, amélogénèse imparfaite

Abstract

A professional commitment to patient confidentiality may sometimes contradict other principles of bioethics. Decision-making for doctors and their team can be challenging amidst such conflicting principles, and despite the practitioner's best intentions, withholding information can result in potential consequences such as harm to others.

Keywords

bioethics, professionalism, confidentiality, genetic disorder, amelogenesis imperfecta

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INTRODUCTION

Ethical conduct is the cornerstone of professional practice in healthcare. Failure to maintain an ethical behavior creates a loss of trust between clinician and patient, which may compromise treatment processes and outcomes (1). In addition to ethical considerations, there are legal requirements specific to each jurisdiction in which medical and/or dental practice takes place. Among the prescripts outlined in many Codes of Ethics (2,3), patient confidentiality is deduced from bioethical principles such as patient autonomy, beneficence, and non-maleficence. There may be situations, however, where confidentiality contradicts certain principles of bioethics such as non-maleficence, leading the clinician into an ethical dilemma. In these situations, making sound decisions may be difficult, especially for clinical students and/or young practitioners. Studies have revealed that practitioners occasionally fail in handling ethical challenges due to a lack of experience, skills, and confidence (4). In medicine, scenarios involving confidentiality have been discussed in the literature, but such case studies may not be as readily available for dental practitioners. The following case was managed by one of the authors (LS) involving issues of privacy and confidentiality in the dental office. It is presented and analyzed to illustrate competing ethical principles and legal elements that arise in clinical practice.

CASE STUDY: A YOUNG WOMAN WITH AMELOGENESIS IMPERFECTA

A 25-year old woman has been your patient for 5 years. She is the only member of her family that suffers from amelogenesis imperfecta, an inherited disorder, in this case with an autosomal recessive pattern, causing her dentition to be malformed, extremely discoloured and presenting with unusual pits and grooves (Figure 1). Her dentition has now been fully restored, and since she was very satisfied with the results, she requested an appointment for her fiancé. She specifically asks you not to tell him about her condition. The fiancé subsequently attends the office for a dental check-up.

Figure 1. An adult dentition affected by hypoplastic amelogenesis imperfecta



Source: L Sadighpour, with patient's consent

ETHICAL ANALYSIS

Health care professionals have an ethical duty to maintain patient confidentiality. In addition, health professionals operate within a legal framework which outlines the circumstances in which disclosure of personal health information is prohibited, permitted or mandated. In this particular case, the dentist's initial inclination is that the history of amelogenesis imperfecta should not be revealed to the patient's fiancé. Given the fact that amelogenesis imperfecta is an inherited condition that may affect the couple's children, the dentist may be concerned that the fiancé will remain unaware of the patient's disorder despite posing future genetic risks to their offspring. While understanding the need to preserve the patient's confidentiality, the dentist may also be concerned about possible repercussions arising from the fiancé's realization that information regarding the patient's disease was withheld. Such a reaction may presage a regulatory complaint or civil claim.

The dentist therefore seeks a solution to this dilemma. In this case, the dentist wishes to honour the ethical principles of autonomy and beneficence and respect patient's confidentiality. At the same time, the dentist does not want to withhold information that could prevent potential harm to come to future children and would want to respect the principle of non-maleficence.

In addition to the ethical considerations and, depending on the jurisdiction in which the clinician is practicing, there will be legal requirements that mandate confidentiality of personal health information. This will include physical, medical, dental and emotional information. However, such legislation may be complex, and the associated legal intricacies are beyond the scope of this paper. In Ontario for example, disclosure of personal health information is absolutely prohibited under many circumstances, while in other situations it may be permitted and/or is obligatory (5,6).

In various Ontario laws, health care providers are permitted or mandated to disclose personal health information to certain government organizations, law enforcement authorities and even family members when:

1. A patient has given consent
2. Required by law
3. Non-disclosure may result in a significant risk of serious harm to the patient or others, in which case a decision is made based on a balance between non-maleficence and beneficence (5-7)

From a legal perspective, the doctor's duty in the first two circumstances (#1 & 2) is conclusive. For example, certain infections such as HIV, tuberculosis, and viral hepatitis must be reported to public health authorities. In the last situation (#3), where the potential for serious harm may be present, the clinicians' professional judgment is necessary. For example, if a patient threatened to commit a criminal act which would likely result in serious injury to another individual, the health care professional would be obligated to breach patient confidentiality and report to the appropriate authorities.

With respect to genetic information, due to its unique nature and possible implications for the health of relatives, the duty of confidentiality will be subject to the regulations and guidelines established in different jurisdictions. For example, according to French medical, law genetic information should be communicated exclusively to the patient and not to relatives. However, a physician's duty to warn of genetic risk is legally unclear in Canada (7,8).

In reviewing many available guidelines regarding disclosing patients' genetic risk information (8,9), three approaches have been advocated:

1. Patients should communicate genetic information to their family members.
2. Genetic health professionals should encourage patients to do so, and
3. Health care professionals should support their patients throughout the communication process.

The College of Physicians and Surgeons of Ontario, in one of their advice documents related to the protection of personal health information (10), suggests that “it is not uncommon for physicians to be asked by a family member or friend about the condition of a patient or for information about the patient’s health. These situations can be challenging to manage, as the circumstances under which Personal Health Information Protection Act (PHIPA) allows you to do so are limited” and that “unless otherwise permitted or required by law, Personal Health Information (PHI) can only be shared with third parties with the express consent of the patient”.

Non-consensual disclosure is much more likely to be defensible when such disclosure might limit or prevent serious, imminent danger to others. For instance, some genetic disorders, such as breast cancer for which highly predictive tests as well as effective prevention and treatment measures are available, may meet the criteria for disclosure. Amelogenesis imperfecta is not a life-threatening genetic disease and the severity of disease expression may vary depending on other factors, such as gene location and new mutations (11). The occurrence of this disease cannot be prevented, although the affected dentition can be effectively treated. Therefore, this condition would not meet the threshold for disclosure of personal health information and patient confidentiality must be maintained. Albeit, the patient should be encouraged to discuss the condition directly with her fiancé.

In summary, in the current case both the legal position and the ethical duty are clear and congruent, which would hopefully offer reassurance to the clinician that the non-disclosure decision is appropriate. The concept of confidentiality at first glance may seem rather elementary, such that personal health information remains a private matter between the patient and practitioner. It can be very tempting, however, for a doctor to engage with individuals who are assumed to be part of the patient’s inner circle. This may include a spouse, child, or fiancé and would therefore have implied consent from the patient to receive confidential information. It may be expected that similar ethical challenges to the one presented await the dental practitioner and are therefore somewhat easier to manage despite the temptation for disclosure. More serious genetic disorders, however, are likely to generate a formidable challenge to both an ethical and legal resolution.

Reçu/Received: 17/05/2020

Conflits d'intérêts

Aucun à déclarer

Publié/Published: 16/11/2020

Conflicts of Interest

None to declare

Édition/Editors: Marleen Eijkholt & Julien Brisson

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