

Ethical Concerns and Recommendations for Sharing Anatomic Pathology Images in Online Social Media Networks

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ABSTRACT

Anatomic pathology is a field that relies on visual examination to provide diagnosis. Photos of specimens and microscopic slides play an important role in pathology education. With the internet, sharing and seeing images from different patient cases has become efficient and accessible. However, ethical concerns may be raised since patient images are used for academic purposes in a public setting. Proper de-identification, informed consent and setting professional guidelines for sharing pathology images are suggested.

Key words: pathology, social media, digital pathology, ethics, policy

ISSN 2507-8364 (Online)

Printed in the Philippines.

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Received: 22 November 2023.

Accepted: 13 December 2023.

Published online first: 18 December 2023.

<https://doi.org/10.21141/PJP.2023.12>

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INTRODUCTION

Anatomic pathology is a branch of medicine that provides the diagnosis of different diseases by the examination of cells, tissues or body fluids. Anatomic pathology plays a very important role in cancer staging, guiding therapeutics and determining the cause of death. Anatomic pathology has two main subcategories -- autopsy pathology and surgical pathology. In autopsy pathology, the body and organs of a deceased patient are dissected and examined under the microscope to determine the cause of death. Surgical pathology is similar, but the examinations are performed on a surgically resected body part or organ from a living patient.

The field of anatomic pathology is highly visual. Images from different patient cases have great educational value to students, trainees and practicing pathologists. Exposure to different anatomic pathology cases improves the diagnostic skills of pathologists. Currently, many online communities allow sharing of medical images for discussion.¹ Educational medical communities may be seen in social media such as Facebook, Twitter, Instagram and YouTube¹ and social chat platforms such as Discord.² The online pathology community has not only provided medical education for everyone but has also provided the privilege of connecting with experts and experienced pathologists all over the world.³ Getting opinions from other pathologists can help in solving difficult cases and arriving at the proper diagnosis. This is very beneficial for resource-poor countries like the Philippines, where there are plenty of patient cases but pathology subspecialists are few.

Despite the good intention of sharing cases online to promote education, this learning activity does not happen in a private hospital conference room with a limited medical audience.⁴ Images from these cases can be publicly viewed. Hence, misinterpreting the academic intent of the images by non-medical users is not unlikely. Moreover, these images are acquired from patients who seek consultation mainly for medical treatment and *not* for promoting medical education.



Ethical issues on patient autonomy, privacy, confidentiality and non-maleficence are raised in the sharing of anatomic pathology images online.

ETHICAL ISSUES

Medical pictures cannot be generated without the patient. Medical pictures may only be captured if a person engages in a clinician-patient relationship or if a family member/legal entity consents to an autopsy. To receive medical treatment, the patients not only disclose their personal information but also allow a thorough examination of their bodies.⁵ Patients also allow examination of their specimens as part of the diagnostics for their treatment work-up. There is an implicit expectation in the clinician-patient relationship that clinicians will respect the patient's privacy and keep all the information in full confidentiality as part of the ethics of their profession.⁵

In the United States, electronic patient information is protected through the standards of the Health Insurance Portability and Accountability Act (HIPAA).⁶ Based on the HIPAA guidelines, patient confidentiality in medical pictures can be preserved by deidentifying the images.¹ However, sharing patient images is not only about patient confidentiality but also patient privacy. Privacy is for the person; confidentiality is for information.⁴ Privacy is the freedom of a person from unwanted scrutiny. Confidentiality is about keeping information protected from disclosure.⁵

In 2008, a video showing the surgical extraction of a metal spray bottle canister from the rectum of an unidentified patient went viral on YouTube.⁵ The video also showed giggling medical staff who were taking a video of the canister extraction using their cellphones.⁵ The patient was later informed by a barangay official about the viral internet video.⁵ The patient said he was unconscious during the procedure and was not informed that the medical staff would take videos.⁵ For this case, the patient was deidentified in the video and there was an attempt to preserve patient confidentiality. However, the patient was eventually identified.⁵

The video itself showed how the patient's privacy was violated and how the patient lost his autonomy to decide if the canister extraction could be documented. Moreover, sharing the video online may have violated the principle of non-maleficence by causing emotional harm to the patient through psychological distress and embarrassment. Getting and sharing photos from patient specimens outside the purpose of medical treatment raises issues on privacy, patient autonomy and non-maleficence.

This scenario depicts an extreme case of how clinicians can use a clinician-patient relationship to take images from patients and how sharing videos or images from patients can lead to emotional harm if done carelessly. But unlike this incident which did not benefit anyone, case sharing as an academic activity benefits the medical community and the general public.⁷ But still, using a clinician-patient relationship to get materials for online academic discussions, outside the patient's knowledge, threatens the public trust in the medical profession in

protecting their privacy and the patient's right to self-determination.⁴

In the Data Privacy Act of 2002 (Philippine Republic Act 10173), personal information is defined as any form of information whether recorded in a material or not, from which the identity of the person is apparent or may be ascertained by the person who holds the information.⁸ The Data Privacy Act states that personal information should only be collected for the specified and legitimate purpose that was declared.⁸ Additionally, the person who owns the information has the right to be informed whether personal information about him or her is collected, recorded, stored, retrieved or used.⁸ Following the Data Privacy Act, informed consent is necessary if any information from the patient will be used for purposes other than treatment. Informed consent protects the patient's privacy and autonomy.

Non-maleficence in online image sharing may be secured if there are clear professional standards geared toward sharing medical photographs. These standards will help guide medical professionals to avoid causing any accidental harm to patients and to display professionalism and liability even in an online environment.

To give some perspective, Twitter has 166 million daily active users.⁹ Facebook, on the other hand, has 2.7 billion daily active users.¹⁰ There is no data on how many Twitter or Facebook users are medical professionals. However, many young non-medical viewers may use medical images for entertainment. Informed consent may especially be important for images that contain culturally sensitive elements like genitalia, female breasts, dead bodies and children. These images are prone to sensationalism and may not be received neutrally by the non-medical audience.¹¹

In April 2018, the autopsy of a 16-year-old Dengvaxia™ (Sanofi) patient received online and public comments when the news talked about how the patient's organs were serially sliced and put into the body cavity outside their anatomic location.^{12,13} Facebook comments compared the organs to food (such as "morcon," "embotido" and "bopis").¹³ Many other Facebook users expressed hatred towards the doctors who performed the autopsy. There are Facebook users who said that the doctors who did the autopsy should be executed.¹³ However, few users knew that an autopsy procedure actually requires serial sections of the organs,¹⁴ and organs are not routinely returned to their original anatomic position after the procedure.

Even with the good intention of learning on an online public platform, the online audience is unpredictable. Let us consider this hypothetical situation: A new pathology trainee saw a vulvectomy specimen from a co-worker and took a photo of it. She uploads a picture of a resected vulva with giant warts (described in medical textbooks as "cauliflower-like"). The photograph is poorly taken with a blood-stained background and bad framing. Being a new trainee, she is not aware that vulvectomy is not commonly done and uploading a picture of a vulvectomy specimen immediately after a certain patient undergoes the procedure may potentially identify a patient. The trainee publicly uploaded the image using an anonymous

Twitter account and described the image as “A beautiful case of giant condyloma acuminata from a vulva of an 83-year-old showing the classic cauliflower appearance! Microscopic examination shows the classic koilocytic or raisin-like changes consistent with human papillomavirus infection. #GynePath.” A random teenage Twitter user saw the “cringe factor” on the image; so, he downloaded, edited and spread the image on the internet as a meme with the added phrase: “Yummy cauliflower!” The patient saw the meme and was able to identify the specimen as hers. She felt harassed. She also became very anxious to be identified after finding out that a vulva with the same clinical profile as hers is displayed and shared in public. She was also worried about the stigma associated with getting a tumor that originates from a sexually transmitted virus and the conflict it may bring to her private life.

The presence of clear standards on sharing health information outside the purpose of treatment can make medical case discussions safe for both the patient and the healthcare provider. This paper recommends guidelines to promote the online academic activity of case sharing among medical professionals while protecting the patient’s privacy, confidentiality, autonomy and non-maleficence.

RECOMMENDATIONS

Deidentification

Confidentiality is the top priority when sharing any form of patient information publicly. To protect patient confidentiality on image sharing, a patient should not be identified in any way through their images. Based on HIPAA standards, patient data may only be shared publicly once they are de-identified.¹

The HIPAA Privacy Rule has described **eighteen (18) personal health identifiers** that should be removed for deidentification.¹⁵ These identifiers are:

1. Names
2. Geographical subdivisions smaller than a state
3. All elements of dates directly related to the individual (date of birth, date of admission, date of discharge and date of death. Also, all ages over 89 years or elements of dates indicative of such age)
4. Telephone numbers
5. Fax numbers
6. E-mail addresses
7. Social security numbers
8. Medical record numbers
9. Health plan beneficiary numbers
10. Account numbers
11. Certificate/license numbers
12. Vehicle identification or serial numbers including license plate numbers
13. Device identification or serial numbers
14. Web universal resource locators (URLs)
15. Internet protocol addresses
16. Biometric identifiers including finger and voice prints
17. Full face photographs and any comparable images
18. Any other unique identifying number or code

Aside from the identifiers specified by the HIPAA Privacy Rule, any other potential identifiers should be removed or modified to completely protect the patient’s information.

Potential identifiers on photos should be removed. These include identifiers intrinsic to the patient (anatomic anomalies, birthmarks, scars), on the patient (unique clothing, jewelry, piercing, tattoos) and around the patient (unique setting, surroundings or location).¹⁶

Sufficient alteration of clinical details is recommended to obscure any potential detail that may lead to patient identification.¹⁶ Potential identifying clinical details include date, unusual or newsworthy circumstances and small geographic subdivisions.¹⁶ Approximating the age instead of using the actual exact age is also recommended.¹⁶

Exchangeable image file format (EXIF) data in the images should also be removed.¹⁷ These are embedded technical meta-data that are created by the digital camera when a photo is created. These may include the camera model, photography settings and the specific date and location when the image was taken.¹⁷

Informed consent

Informed consent is important to protect patient autonomy and privacy. Informed consent should be voluntary. However, patients may feel coerced or obliged to give their consent to their physicians. Patients may be concerned that denying their consent may affect the quality of treatment they will receive. Hence, it may be necessary that informed consent is requested before the patient engages in the clinician-patient relationship through outright declaration of hospital/clinic guidelines.

If the consent was not requested before establishing the clinician-patient relationship, separate informed consent for specimen photography may routinely be requested for all patients who will undergo surgery/autopsy.

This paper suggests that the acquisition of consent be a part of a routine workflow procedure and be facilitated by a staff or committee who is not directly involved in the patient’s medical consultation or treatment. This is to avoid coercion of the patient, relative, or guardian, to have medical images uploaded for online academic purposes.

The informed consent should emphasize the following points:

- The patient has the right to decline specimen photography unless the photography is needed as part of the treatment protocol. Declining will not affect the clinician-patient relationship, or the quality of medical care given to the patient.
- Anatomic pathology images are highly valuable in medical education, training and advancement. Sharing images of actual patient cases will indirectly but greatly benefit the general masses.
- Capturing anatomic pathology images does not pose any medical risk or will not affect the patient’s treatment/procedure.
- The images will be photographed by qualified professionals capable of doing proper medical photography. The images will be handled professionally and treated with respect.
- Patient confidentiality will be protected by removing all identifiers and any potential identifiers from the images. Clinical details which may potentially identify

the patient will be altered. Images will not be shared immediately if the time of upload itself may potentially identify a patient.

- The images will be available not only to the medical audience but to the public audience.
- The images may permanently be available on the internet. Once posted, the image may be downloaded by any internet user or be transferred to another website.

This paper would also like to suggest a forum regarding the ethical standards for collecting and using microscopic images for academic reasons. Microscopic images are not identifiable and may only be captured using specialized tools. The possibility of waiving the informed consent for this type of anatomic pathology images may be debatable, however, this paper suggests opening this topic for discussion by legal authorities, medical communities and public representatives.

Online professionalism

To maintain nonmaleficence in sharing photos of specimens, standards should be set on how sharing should be done properly and professionally. All medical professionals should be educated on how they should act online, especially when handling patient information. Trainees and students should be informed about the proper dissemination of information materials and the standards on image sharing in classroom settings, conferences, publications, symposia and the internet.⁵

The following guidelines and standards are recommended to uphold medical professionalism among pathologists and other medical professionals in sharing medical images online:

- Uploaders of anatomic pathology images should not be anonymous. The medical professional should show good intention, transparency and liability by displaying their name, nature of work and/or institution on their online account.
- A professional account, separate from a personal account, is suggested to set the medical context of a medical or academic post.
- Images should follow institutional or societal guidelines for medical photography.
- The storage device containing the photographs should be secured.
- The pathologist should be always respectful when presenting or discussing a case online. A good reputation should be set so as not to undermine public trust in the medical profession.¹⁸
- Language or images that may provoke sensationalism should be avoided since the internet has an audience coming from all ages and backgrounds.¹¹
- Patient confidentiality should be protected by deidentification. All identifiers and potential identifiers from the images and the clinical information should be properly removed. Once an image is uploaded, it should be assumed that the image will be on the internet permanently.¹¹
- The images should be watermarked with the pathologist's name or username to ensure that the pathologist will be recognized or liable if the image is detached from the original post. Watermarking

prevents plagiarism and using images without referencing has legal implications.⁴

- Since there are no enforcers of online professionalism in image sharing, pathologists should privately and politely inform a medical professional or trainee who commits online misconduct.
- Assigning credible pathologists as moderators (if applicable) in these social network platforms will help in enforcing online professionalism. For severe misconduct, a moderator can report a user to the social media administrator or ban a user from using a social network platform/server.
- Professional agencies and medical societies should enforce online professionalism and apply penalties for online misconduct that involves patient information.

Other recommendations

Medical societies should collaborate with social networking companies to enforce ethical standards in sharing and discussing medical images. Online social platforms should develop clear policies and guidelines on patient-related images. If this type of image is allowed, the platform should specify rules to maintain good ethical standards (such as deidentification, watermarks, and proper language) for this type of content. The consequences for violation of these rules should also be implemented. Features may be developed to confirm the identity of a user to prevent malicious fake accounts from taking advantage of the images shared in the online discussions. Confirming the identity of the user will also increase the reliability of the academic information shared by the user. Furthermore, a specific platform for medical professionals to share patient cases may also be specifically designed to optimize medical discussions while maximizing privacy and security.

CONCLUSION

Uploading pathology images for academic use may seem harmless with patient de-identification. However, the ethical concerns of uploading patient images on the internet go beyond confidentiality. Patient images are not meant to be shown publicly on the World Wide Web by their healthcare provider (Figure 1). Furthermore, patient images are not created to be immortalized digitally in the global system of interconnected computers. Using patient material for educational purposes is a sensitive matter. While no standards have been established for posting anatomic pathology images online, it is our responsibility as medical professionals to protect patients. Any post, tweet, pin or share can stay on the internet permanently or can be downloaded privately by anyone. Nothing should be posted that may be inappropriate in any public forum or can undermine patient privacy, confidentiality and autonomy.

On the other hand, sharing anatomic pathology images with the international medical community provides immense learning opportunities and growth for medical professionals and trainees. It also provides a medical network that provides connections in seeking expert opinions from all over the world and for starting research collaborations.¹⁹ With the continuous development of online social networking, more possibilities unfold for medical professionals that may help in improving health services and for medical advancement.

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