'The Farewell' Offers Insights into HIPAA's Right to Access

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By Mary Butler

In the film <u>The Farewell</u>, Chinese-American actress and comedian Awkwafina plays a woman torn between two cultural approaches to death and dying when her character, Billi, learns that her grandmother has terminal lung cancer. Billi's grief is compounded when she learns that her family does not intend to tell her grandmother Nai Nai about the diagnosis—a common practice in China, where frank discussions about death <u>are still taboo</u>.

The film is based on a true story from director Lulu Wang's own experience, which she described on episode 585 of the NPR program *This American Life*. Like Billi, Wang moved with her parents to the United States from China as a young child and grew to embrace the American healthcare norm of giving patients complete information about their medical condition. In the film, Nai Nai's doctors perpetuate the cycle of misinformation, telling her that she's suffering the effects of pneumonia, while sharing the true information with her family members. In one scene, Nai Nai's extended family races to intercept the release of a damning CT scan report and convinces the radiologist to change mentions of "malignant tumors" to "benign shadows."

Billi and other more Westernized family members in the movie acknowledge that what they're asking doctors to do would be illegal in the US, which further advances Billi's perception that she's complicit in deception. Indeed, HIPAA's right to access clause would require that Nai Nai be the only one to read her test results unless otherwise designated—and no ethical physician would knowingly change his or her diagnosis at a family member's request. Access to one's own medical information and the empowerment that comes with that was one of the driving factors behind HIPAA's creation and is one of the cornerstones of the HIM profession. Yet, as recent analyses on this part of the law have revealed, providers still struggle with right of access compliance.

The Farewell smartly avoids judgment about which response to death is morally right or wrong. Instead, it emphasizes the different ways love is expressed and how that transcends borders and culture.

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