Study: Older patients with chronic conditions benefit from reading medical appointment notes
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Results from a new study in the Journal of the American Geriatrics Society suggest that older adults with chronic conditions gain significant benefits from having these notes. Credit: Beth Israel Deaconess Medical Center

As of April 2021, federal law requires U.S. healthcare organizations to provide patients with access to their electronic health records, including outpatient visit notes. Previous studies have shown that patients who read their visit notes report feeling more in control of their care, remembering their care plan better and trusting their clinicians more. Patients with a single chronic condition, such as diabetes, report that they better understand their medications and potential side effects.

In a paper published in the Journal of the American Geriatrics Society, clinician-researchers at Beth Israel Deaconess Medical Center (BIDMC) examined survey data to assess how patients with multiple chronic conditions perceived the benefits and risks of the increased transparency offered by open visit notes. The cross-sectional study examined patients' self-reported experiences from three healthcare organizations with up to seven years of experience offering patients access to their notes through online patient portals.

"Managing multiple chronic conditions and juggling various medications can be a time-consuming and frustrating experience for older patients and their care partners," said corresponding author Catherine M. DesRoches, DrPH, executive director of OpenNotes at BIDMC. "Findings from this study suggest that these patients and their care partners could receive important benefits from accessing their notes. Healthcare organizations should work to maximize patient engagement with this newly available health information both through patient portals and through other methods to ensure that patients and the healthcare systems reap the full benefit of this increased transparency."

DesRoches and colleagues invited more than 136,000 patients to participate in a survey via patient portals at three healthcare organizations in the United States: BIDMC in Massachusetts, University of Washington Medical Center in Washington State, and Geisinger Health System in Pennsylvania. More than 21 percent of patients responded. After the researchers excluded patients younger than 65, the analytic sample included 7,688 patients who had read at least one clinical note on the patient portal in the previous 12 months.

Eighty percent of survey respondents reported reading notes for more than a year. Nearly three quarters of respondents said their notes were "very important" for taking care of themselves, and six in ten said reading notes helped them feel more in control of their care. When DesRoches and colleagues specifically looked at patients with two or more chronic conditions, they found that patients in this group were more likely to have read four or more visit notes. Those with multiple chronic conditions were also more likely to say that reading their notes helped them understand and feel more comfortable with their medications and to take them
as prescribed.

Fewer than five percent of older adults reported being more confused or worried after reading their notes. However, DesRoches acknowledges that figure may be misleading. Because of the self-selective nature of surveys, respondents were likely more technologically savvy and/or enthusiastic about outpatient notes than the average patient. Additionally, respondents were majority white and female, had at least a high school education, were retired, and English speakers, and the majority had no more than two chronic conditions.

"The overall lack of diversity among respondents limits our ability to draw inferences for minority, low income, or less educated patient populations who are already marginalized by the 'digital divide' in health care," said DesRoches. "Previous studies show that older patients are less likely to be offered information about patient portals, and when offered, they are less likely to register for and use them. Although access to online information offers promise to patients, health systems should strive to ensure that all older patients have access to appropriate information in a format that is most usable and useful for them."

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