

How older adults and their caregivers view pain, depression and other patient symptoms

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Adults, especially older adults, may be in pain or depressed but not able to convey details of their symptoms and quality of life to their doctors for various reasons including cognitive impairment. A new study from

Regenstrief Institute and Indiana University School of Medicine researchers investigate whether adult patients and their proxies—typically spouses, children or other family caregivers—agree on what they tell physicians about a patient's symptoms and quality of life, information critical to clinical care.

The researchers found that patients and caregiver proxies agreed on severity of symptoms of pain, depression and anxiety as well as functional status between 50 to 60 percent of the time, with agreement on [physical symptoms](#) (pain and functionality) more likely than agreement on psychological symptoms (depression and anxiety).

Proxies tended to overestimate patient impairment at lower levels of symptom severity and underestimate at higher levels. Caregivers who were under a lot of stress were more likely to over-report their patient's symptoms.

"Unlike [blood pressure](#) and [blood sugar](#), symptoms like pain, depression or anxiety can't be objectively measured," said Regenstrief Institute and IU School of Medicine faculty member Kurt Kroenke, M.D., who led the study. "Our group is very interested in symptoms—signs you can't measure with an X-ray or a lab test. The only way to determine severity is with validated scales and if patients can't report for themselves, then the proxy's report is an important tool available to the clinician treating the patient."

Even when a patient is able to self-report, complementary observations from a proxy providing a confirming or disagreeing perspective may inform treatment decisions, according to Dr. Kroenke, a primary care physician.

The study of 576 older adult and proxy participants (188 patient-caregiver pairs as well as 200 patients without identified caregivers) also

found that when looking at group averages, patients' self-reports and caregivers' reports on patients were in line with each other because over and under reporting averaged out. Dr. Kroenke notes that this confirms the value of using proxy reports in research studies.

Paired patients and their caregivers who were White were 50 percent of study participants. An almost even percentage, 47 percent of the paired patients and 48 percent of their caregivers, respectively, were Black.

"Similar to what occurred during the pandemic, when we used rapid COVID tests rather than the more accurate PCR tests to make decisions about travel or attending events or other issues, because rapid tests were the best we had on hand, when patients can't complete a symptom scale, proxy reports, while not the best, are the best available and provide valuable information," said Dr. Kroenke.

Dr. Kroenke, a pioneer in the field of symptomology, has developed multiple patient-reported outcome measures that have been translated into 80 languages, including the PHQ-9 depression scale, GAD-7 anxiety scale, PEG pain scale and P4 suicidality screener. In this study patient-caregiver agreement was evaluated using four commonly-used scales, the PHQ-9, GAD-7, the PEG, and the SymTrak multi-dimensional symptom and functional impairment scale. SymTrak was also developed and tested by Regenstrief and IU School of Medicine researchers.

The research is published in the *Journal of Patient-Reported Outcomes*.

More information: Kurt Kroenke et al, Agreement between older adult patient and caregiver proxy symptom reports, *Journal of Patient-Reported Outcomes* (2022). [DOI: 10.1186/s41687-022-00457-8](https://doi.org/10.1186/s41687-022-00457-8)

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