Health Literacy Challenges of Returning Neuroimaging Incidental Finding (IF) Radiology Reports in Research

Jody Shoemaker, MS, CCRP, CIP; Caitlin Rancher, BA, Mind Research Network
Linda Petree, BA, CIP, The University of New Mexico
Mark Holdsworth, PharmD; John Phillips, MD; Deborah Helitzer, ScD, University of New Mexico Health Sciences Center

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Background
Returning MRI IFs to research participants can potentially create health literacy challenges, as recipients must be able to interpret and make appropriate healthcare decisions based on complex medical terminology. Therefore, disclosing IFs can be perceived as presenting difficulties for participants, research institutions, and the healthcare system.

The purpose of this study was to identify differences in stakeholder perceptions related to the health literacy challenges encountered by participants who received an MRI radiology report.

Methods
Researchers retrospectively surveyed participants who had received a radiology report from an MRI research study and conducted focus groups with participants, parents of child participants, investigators, physicians, and IRB members. Qualitative thematic analyses were conducted using standard group-coding procedures and descriptive summaries of health literacy scores, and radiology report outcomes were examined.

Discussion
Although survey participants self-reported high health literacy skills during focus group discussions, others expressed difficulty understanding how to interpret and take appropriate action based on that information. Investigators expressed concerns that while they feel ethically inclined to return findings and acknowledge that participants desire to have the information, some participants struggle with interpretation and time is spent addressing these concerns. Physicians, on the other hand, were more inclined to want to only share actionable findings and a few viewed full disclosure (including non-actionable findings) as time “wasted to deal with this kind of thing” and “inconvenient.” Furthermore, IRB members viewed IF disclosure similar to informed consent in that it should be presented in language understandable to the individual.

Prior work from our group and others suggests there is a strong ethical mandate to return all IF reports to research participants, with many downstream benefits for individuals and research in general. The challenge is that language in IF reports can be difficult for participants to understand and, although full disclosure has the potential to negatively impact participant welfare and the healthcare system, there is no empirical data to support this. This study suggests that radiology reports, or IF reports in general, may benefit from accompanying resources that explain findings in lay language, which can help reduce the challenge of communicating findings.

Our ability to assess participant’s health literacy skills was limited by the skewed sensitivity of the brief health literacy assessment utilized. This measure more accurately captures low to inadequate health literacy and may not identify individuals with adequate or high health literacy.

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