

A Patient-Centered Approach to Communicating Incidentally Discovered Silent Cerebrovascular Disease



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Introduction

Silent Cerebrovascular Disease (SCD): a highly prevalent condition involving vascular brain damage that lacks noticeable symptoms and often discovered incidentally¹.

- Associated with an increased risk of dementia, stroke & subtler functional impairments²⁻³
- Large discrepancies exist in approaches to SCD disclosure & medical management in absence of clinical trials & evidence-based treatment guidelines. Patients often perceive their clinician's explanation as vague/uncertain, leading to psychological distress and uncertainty about health management & risk reduction. 4-5

Additional considerations resulting from 21st Century Cures Act

- Cures Act: mandates rapid patient access to electronic health records (EHRs)
- Patients may learn of findings from an EHR alert vs conversation with clinician⁶

The Gap: There are currently no guidelines to support clinicians in providing patientcentered communication, counseling and education in response to SCD findings

Research Questions: What are the reported barriers to consistent, patient-centered SCD communication? What are potential strategies and solutions to overcome these barriers? What is the impact of the Cures Act on SCD communication?

Methods

- Study Design
- Qualitative methodology
- Literature review to inform research question and interview guide • Semi-structured interview guide development
- Purposive Sampling (profession; specialty) & Convenience Sampling used to recruit 12 participants
 - Review of hospital directories for clinician contact information
 - Clinician outreach emails
- Data

Collection

Recruitment

- Eligibility confirmed prior to interview
- Interviews conducted Feb.-April 2023
- Interviews were audio recorded, stored securely, transcribed
- Data Analysis
- Preliminary codebook developed (deductive & inductive) 50% interviews cross coded to ensure agreement & reconcile
- discrepancies
- Codebook refined & finalized by study team
- Transcripts coded/re-coded with revised codebook.
- Axial coding: organized codes into themes & subthemes

Preliminary Results: Participants

Tabla 1 Clinician Characteristics

| Table 1. Clinician Characteristics | | |
|------------------------------------|---|--------|
| Characteristics | Subcategory | N (12) |
| Sex | Male | 5 |
| | Female | 7 |
| Profession | Physician | 9 |
| | Physician Assistant | 3 |
| Specialty/ Subspecialty | General Neurology | 4 |
| | Vascular Neurology | 3 |
| | Cognitive & Behavioral Neurology | 1 |
| | Multiple Sclerosis (Neurology) | 1 |
| | Neuroradiology/Interventional Radiology | 1 |
| | Geriatrics | 2 |
| Practice Setting | Inpatient | 1 |
| | Outpatient | 9 |
| | Both | 2 |

Scan for Eligibility Criteria





Preliminary Results: Emerging Themes

Theme 1: Patient-Clinician Communication Barriers

Clinicians discussed challenges explaining nuances & medical complexities of findings to patients – particularly those with diverse communication needs (e.g., cognitive impairment, low health literacy, sensory processing challenges, language barriers); Exacerbated by time constraints

[patients] don't even fully understand what a stroke is...And then it's a whole different issue if [patients] have cognitive problems...how do we reliably communicate this to [patients] in ways that are effective?" (C3).

"Medical literacy is huge. This is a difficult topic to broach if some

Clinician Strategies

- Supporting Understanding: e.g., signs of low comprehension; repetition; teach-back method
- Tailoring: utilizing multiple means of representation, or adapting education delivery to suit the patient's unique communication needs

Potential Solutions

Communication Skills Training: participants noted need for training to equip clinicians with tools to effectively educate and communicate with patients

As part of medical education/mentoring

Theme 2: Practicing without Evidence-Based Guidelines

Participants noted ordering clinicians often lack comfort in ability to interpret & explain findings to patients in absence of specialized training & evidence-based guidelines. Clinicians have difficulty communicating uncertainty to patients, often resulting in explanation ambiguity/avoidance & patient confusion/distress

"I think that the biggest barrier is not enough knowledge... Despite the fact that we've known since the '80s that there are changes in the brain related to vascular disease that don't have symptoms, we still don't know in an individual what that means."

"The problem is if the staff doesn't understand how to ... explain this [SCD] ... they get bombarded with questions and when they can't answer those questions, it creates more angst" (C4)

Clinician Strategies

- Transparency: being honest & clear with patients about literature gaps & knowledge limitations as they relate to SCD findings
- Actionable Information: providing information on lifestyle modifications to slow disease progression

Potential Solutions

- Clinician Training: on SCD & imaging interpretation to support comfort among non-specialized clinicians
- Continued research on SCD prognostics/ risk reduction

Theme 3: Patient Access to Imaging Results without Supportive Protocols

Participants expressed apprehension re: timing of patient access to imaging. Reports have not been modified to be legible to a patient audience & often include trivial findings-contributing to patient distress, health system strain & clinician burnout

"... silent findings...don't mean that someone's had a stroke, and the way that they are reported...there's a lot of scientific jargon in there...it's not...meant for a lay patient population, so...those patients who read it... get freaked out or they start Googling" (C2).

"I don't have increased bandwidth...more hours...to be able to make calls all day...about results, and we don't have support staff to do that...So I feel like it's...a mandate without the resources to make it happen." (C11).

Clinician Strategies

Pre-Imaging Counseling: strategies to proactively alleviate patient distress prior to receiving imaging results:

- Preparing patients for possibility of unexpected findings
- Establishing plan for follow-up discussions
- Advising to avoid online research prior discussion

Potential Solutions

- Radiology Report Reform: modifying reports to be patient-friendly, in language & content
- Clinician Supports: increasing clinician support in order to respond to increased demand (e.g., hiring of support staff & patient educators)

Discussion & Implications for OT

Patient-Clinician Communication Barriers

- Disproportionately impact patients with diverse learning needs, thus, perpetuating existing health disparities
- OTs skilled at adapting health-related information and education to match each patient's literacy abilities, cultural sensitivities, & verbal, cognitive, social skills¹⁰
- OT involvement may help mitigate communication barriers:
- Consultation services for patient-centered communication
- Creation of SCD educational materials; principles of universal design

Practicing without Evidence-Based Guidelines

- Confirmed clinician uncertainty as source of SCD practice variation & subsequent patient distress described in previous studies⁴⁻⁵
- Further supports need for evidence-based treatment guidelines for
- Elucidated counseling strategies clinicians can use to help patients tolerate uncertainty associated with findings (i.e., transparency re: state of literature; providing actionable information on lifestyle modifications)

Patient Access to Imaging without Supportive Protocols

- While instant access to radiologic results was meant to increase patient autonomy, protocols have not been established to enable patients to utilize information in a meaningful way
- Veracity: "...refers to comprehensive, accurate, and objective transmission of information and includes fostering understanding of such information." 7; enables patients to utilize their autonomy8
- If reports are illegible to patients, do they support autonomy?
- Highlights need to re-think how imaging is presented to patients via
- Patient-centered interactive radiology reports found to \(\cap \) patient understanding & support positive experiences of online viewing while maintaining clinical integrity of reports⁹
- Systems-level adoption of similar infrastructure may be needed to enable comprehensive patient autonomy that Cures Act intends to facilitate and reduce strain on clinicians

Limitations & Next Steps

Limitations

- Modest sample size (N = 12)
- Convenience sampling
- Time constraints of research team (14-week DEC)

Further studies are needed to:

- Inform the development of SCD-specific educational intervention
- Better understand how to implement systems-level solutions suggested by key experts to support lasting change and improve patient care

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References