NIH Collaboratory
Grand Rounds

Misinformation as a Source of Complication for Clinical Trials

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Is misinformation a prime suspect for clinical trial refusal or treatment avoidance?
Does misinformation reduce clinical trial participation?

• **Information reach** – lack of information – is major concern:
  • Many patients willing to enroll yet few invited (DasMahapatra et al., 2017)
• **Misinformation** also likely discourages trial participation.

Misinformation about clinical trials?

Cleveland Clinic dispels key myths, including:

- “Informed consent exists primarily to protect researchers’ legal interests”
- “Clinical research patients are taking sugar pills”
- “You need to live near a major hospital to participate”

Source: https://health.clevelandclinic.org/10-biggest-cancer-clinical-trial-myths-busted/
Misinformation and distrust of treatment?

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From whence does misinformation arise?

Questionable websites attempting to sell products...
From whence does misinformation arise?

But also health education from advocacy organizations...
From whence does misinformation arise?

And even through diffusion of conventional journalism...

The New York Times

PERSONAL HEALTH

Weighing the Pros and Cons of Statins

By Jane E. Brody

April 16, 2018
From whence does misinformation arise?

Brody mentions FDA reference to risk of reversible memory loss but puts it in appropriate context.
Do we misunderstand misinformation?
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Southwell et al. (2019):

- Misinformation is not all equal in consequence.
- New media platforms differ from old in authorship, oversight, and algorithms.
- Misinformation can have indirect effects aside from acute, short-term ones.
- Misinformation correction may itself have unintended consequences.
- System-level challenges warrant system-level, future-oriented remedies.
Emerging literature on misinformation highlights our own humanity.
Do we misunderstand our own vulnerabilities?
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We need social connection.

We need hope for future.

The lack of either affords opportunity for medical misinformation effect.
Belle Gibson claimed to be healing her terminal cancer with wholefoods - but now it's proven to be a cruel web of lies.

Yet is Belle a hoax mastermind or simply inheritable? Only time will tell.

Fresh-faced. Earnest. Naive. When Belle Gibson speaks, she cries easily and muddles her words. She's passionate about avoiding gluten, dairy and coffee, but doesn't really understand how cancer works. All of which begs the question: is this young woman really capable of masterminding one of the biggest health and wellness frauds in history?
Anti-vaccination activists have enjoyed particular success in communities whose cultural isolation makes them easy prey for misinformation.
Our multifaceted vulnerabilities

- We are *biased toward acceptance*.

- There are *reasons why we share* misinformation.

- Our *regulatory approach (in democracies)* emphasizes post hoc detection.

- *Correction is hard.*
Was Spinoza right?

Images sources: Encyclopædia Britannica and biography.com
Why do people share misinformation?
Why do people share misinformation?

Some possibilities other than malice:

• Accidental or unintended spread
• Our needs for social bonding
• Information seeking and efforts for validation
Why rumors spread
Why rumors spread

• Discomfort of uncertainty
• Lack of corrective information

• Also: information as potential relationship currency
Might emotions make us vulnerable?

• Yes.
• Anger encourages inaccurate information acceptance.

Our *reactive* regulatory tendency doesn’t guarantee misinformation won’t appear
Studies support some *corrective* potential...

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... *direct rebuttal and large-scale exposure* needed.
Is misinformation culprit? Are we partly culpable?

Are we vulnerable to medical misinformation?
  • Yes

Is misinformation ever sown for others’ gain?
  • Yes

Is misinformation sharing between patients illogical or malicious?
  • Not necessarily

Is there a path forward?
  • Yes
What if...
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• we would turn to peer-reviewed research if it was accessible, available, and trusted?
• we could inoculate people against inaccurate sources while acknowledging common questions and concerns?
What do we need to do?
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- **Consider interaction** of human psychology, news norms, governance, and health systems.
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• **Monitor and seek to understand** – rather than prejudge – patient information environments.
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• **Consider interaction** of human psychology, news norms, governance, and health systems.

• **Monitor and seek to understand** – rather than prejudge – patient information environments.

• **Build and maintain trust** between health care systems and patients by acknowledging shared interests.
Let’s connect.

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