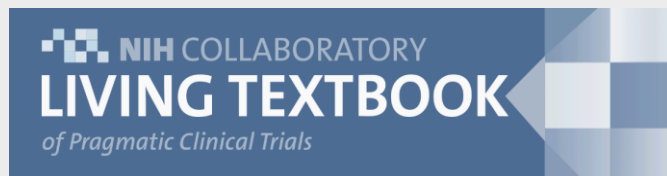


NIH Collaboratory
Grand Rounds



Misinformation as a Source of
Complication for Clinical Trials

Dr. Brian Southwell

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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.

Source: DasMahapatra et al. (2017). Clinical trials from the patient perspective: survey in an online patient community. *BMC Health Serv Res.* 2017; 17: 166. doi: 10.1186/s12913-017-2090-x

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”**



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healthessentials

What can we help you find?

October 7, 2016 / [Cancer Care](#)

10 Biggest Cancer Clinical Trial Myths Busted

Cancer researcher dispels common misunderstandings

Source: <https://health.clevelandclinic.org/10-biggest-cancer-clinical-trial-myths-busted/>

Misinformation and distrust of treatment?

- Example: Navar (2019) warns of inaccurate online claims that *statins cause memory loss, cataracts, pancreatic dysfunction, Lou Gehrig disease, and cancer.*

JAMA Cardiology



Source: Navar, A. M. (2019). Fear-based medical misinformation and disease prevention: From vaccines to statins. *JAMA Cardiology*. Available online: doi:[10.1001/jamacardio.2019.1972](https://doi.org/10.1001/jamacardio.2019.1972)

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- statins cause memory loss

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From whence does misinformation arise?

Questionable websites attempting to sell products...

The image shows the homepage of the Dr. Mercola website. At the top left is the logo "MERCOLA" with the tagline "Take Control of Your Health". To the right is a search bar with the text "Find Answers to Your Health Questions" and a magnifying glass icon. Further right are icons for a phone number "877-985-2695", a shopping cart, a language selector "EN", and buttons for "Sign in" and "Join".

Below the header is a dark blue navigation bar with white text for "HEALTH", "PETS", "FITNESS", "FOOD FACTS", "RECIPES", "BLOGS", "ABOUT DR. MERCOLA", and "SHOP".

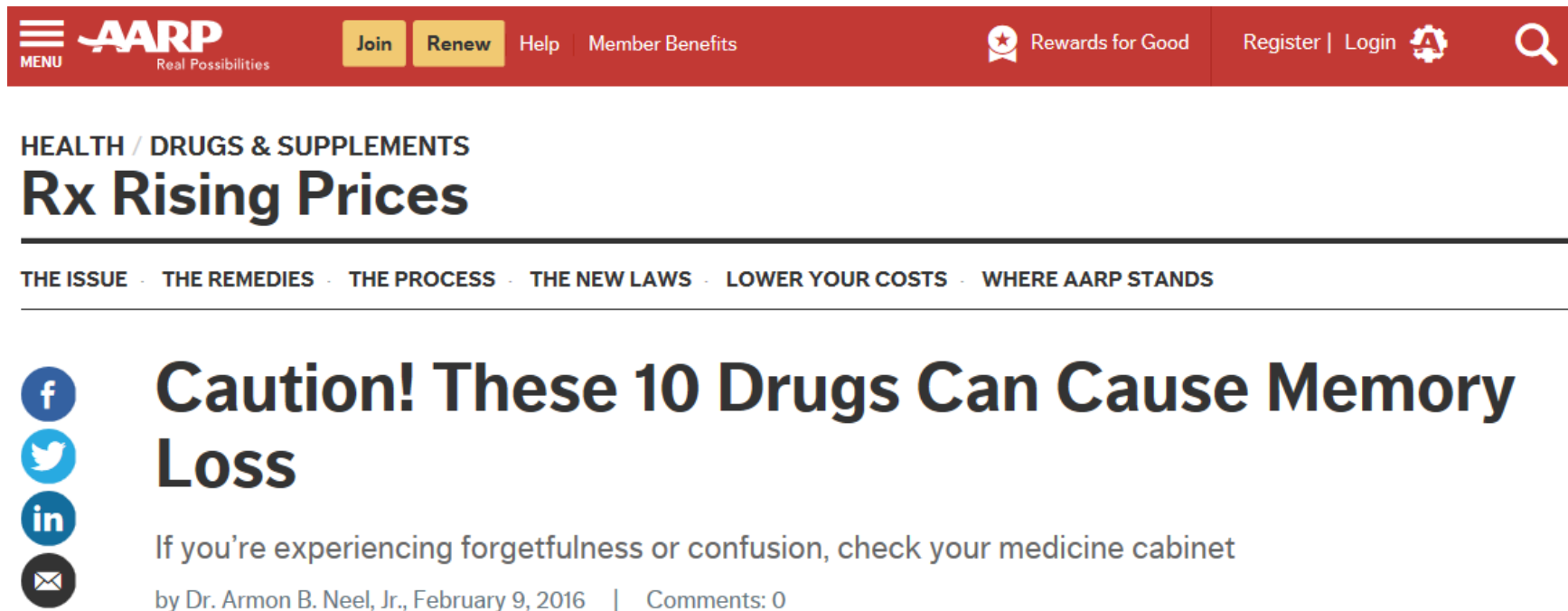
Underneath the navigation bar is a newsletter sign-up section with the text "Subscribe to the FREE #1 Natural Health Newsletter", an input field for "Enter your email address", and a "Subscribe Now!" button.

A large promotional banner for "INDEPENDENCE DAY SALE EXTENDED!" features a "LAST DAY!" badge, an image of a product bottle, and the text "15% OFF SITEWIDE" with a "SHOP & SAVE" button. To the right of the banner, it says "FREE SHIPPING WORLDWIDE" with a note: "Free Shipping to US, Canada & Mexico Over \$49 & International Shipping Over \$150".


At the bottom, there is a featured article section with a background image of a hand pointing at a smartphone screen. The article is marked as a "TOP STORY" and has the headline "Is Wikipedia stealing the news? Part 1 of 2 — A special edition of Ghost in the Machine series, Part 7".

From whence does misinformation arise?

But also health education from advocacy organizations...







The screenshot shows the AARP website's navigation bar with the logo and tagline "Real Possibilities". Navigation links include "Join", "Renew", "Help", "Member Benefits", "Rewards for Good", "Register | Login", and a search icon. Below the navigation bar, the page is categorized under "HEALTH / DRUGS & SUPPLEMENTS" with the main heading "Rx Rising Prices". A horizontal menu lists topics: "THE ISSUE", "THE REMEDIES", "THE PROCESS", "THE NEW LAWS", "LOWER YOUR COSTS", and "WHERE AARP STANDS". The featured article is titled "Caution! These 10 Drugs Can Cause Memory Loss" and includes a sub-headline: "If you're experiencing forgetfulness or confusion, check your medicine cabinet". The author is identified as "by Dr. Armon B. Neel, Jr., February 9, 2016" with "Comments: 0". Social media sharing icons for Facebook, Twitter, LinkedIn, and Email are visible on the left side of the article.

MENU **AARP** Real Possibilities [Join](#) [Renew](#) [Help](#) [Member Benefits](#) [Rewards for Good](#) [Register | Login](#) 

HEALTH / DRUGS & SUPPLEMENTS
Rx Rising Prices

[THE ISSUE](#) · [THE REMEDIES](#) · [THE PROCESS](#) · [THE NEW LAWS](#) · [LOWER YOUR COSTS](#) · [WHERE AARP STANDS](#)

    **Caution! These 10 Drugs Can Cause Memory Loss**

If you're experiencing forgetfulness or confusion, check your medicine cabinet

by Dr. Armon B. Neel, Jr., February 9, 2016 | Comments: 0

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?

The New York Times

PERSONAL HEALTH

Weighing the Pros and Cons of Statins

By Jane E. Brody

April 16, 2018

Brody mentions FDA reference to risk of reversible memory loss but puts it in appropriate context.

Do we *misunderstand* misinformation?

American Journal of
Preventive Medicine

CURRENT ISSUES

Misinformation as a Misunderstood Challenge to Public Health

Brian G. Southwell, PhD,^{1,2,3} Jeff Niederdeppe, PhD,⁴ Joseph N. Cappella, PhD,⁵
Anna Gaysynsky, MPH,⁶ Dannielle E. Kelley, PhD,⁶ April Oh, PhD,⁶ Emily B. Peterson, PhD,⁶
Wen-Ying Sylvia Chou, PhD⁶

Do we *misunderstand* misinformation?

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.

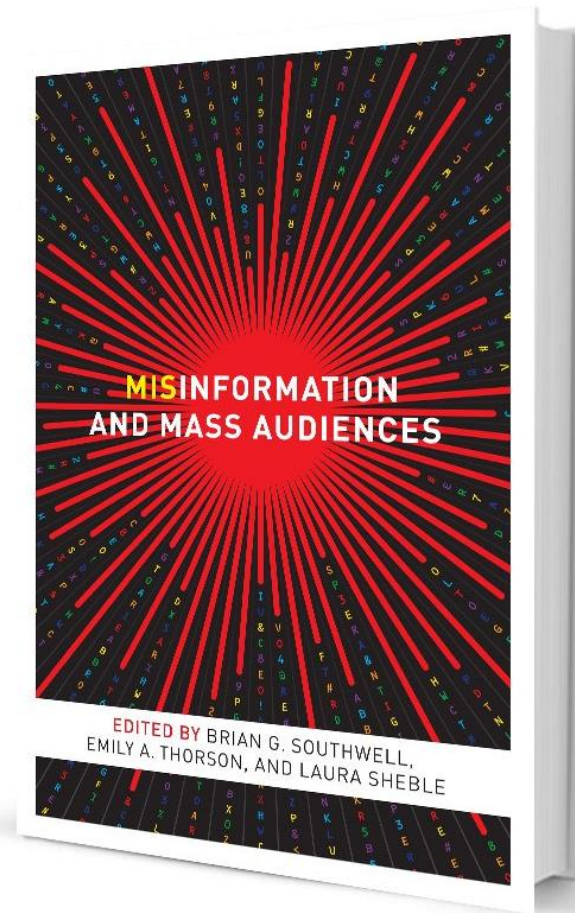
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Emerging literature on misinformation highlights our own humanity.



Do we
misunderstand
our own
vulnerabilities?

Do we
misunderstand
our own
vulnerabilities?



We need social connection.



We need hope for future.



The lack of either affords
opportunity for medical
misinformation effect.

BELLE GIBSON

FOUNDER OF THE BEST-SELLING APP AND
COOKBOOK *THE WHOLE PANTRY*

My life-long struggle with the truth

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

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



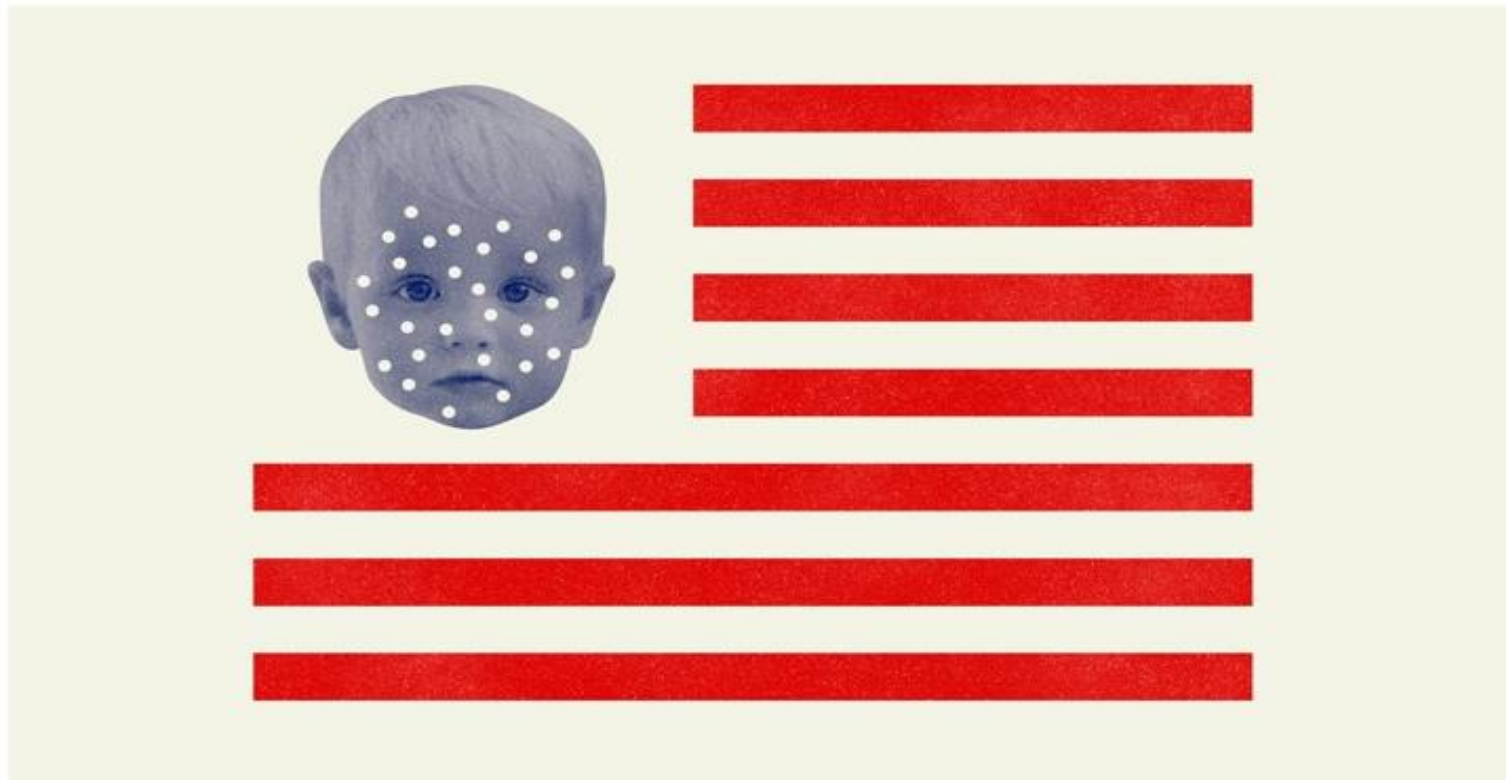
Image: *The Australian Women's Weekly*

HEALTH

What the Measles Epidemic Really Says About America

The return of a vanquished disease reflects historical amnesia, declining faith in institutions, and a troubling lack of concern for the public good.

PETER BEINART AUGUST 2019 ISSUE



“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*.

Applause from Miranda Cheatham, Nancy Watzman, and 32 others



Brian Southwell

Director, Science in the Public Sphere @ RTI International, Faculty Member @ Duke University and UNC-Chapel Hill, & Public Radio Professional @ WNCU (90.7 FM)

Mar 28 · 5 min read

Why we lie to ourselves and others about misinformation

Or, why we underreport our spread of misinformation—just as we do about other behaviors like smoking, drinking, and unprotected sex



Was Spinoza right?



Images sources: Encyclopædia Britannica and biography.com

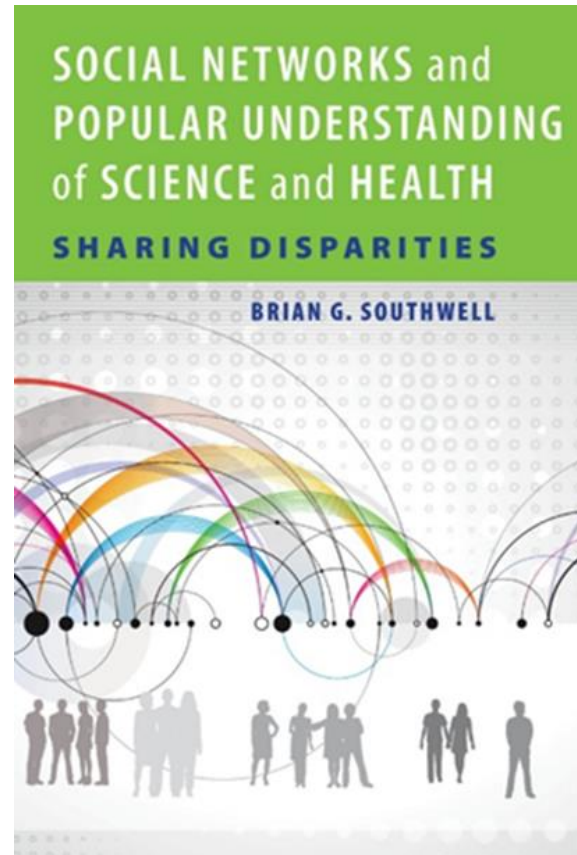
Why do people share misinformation?

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

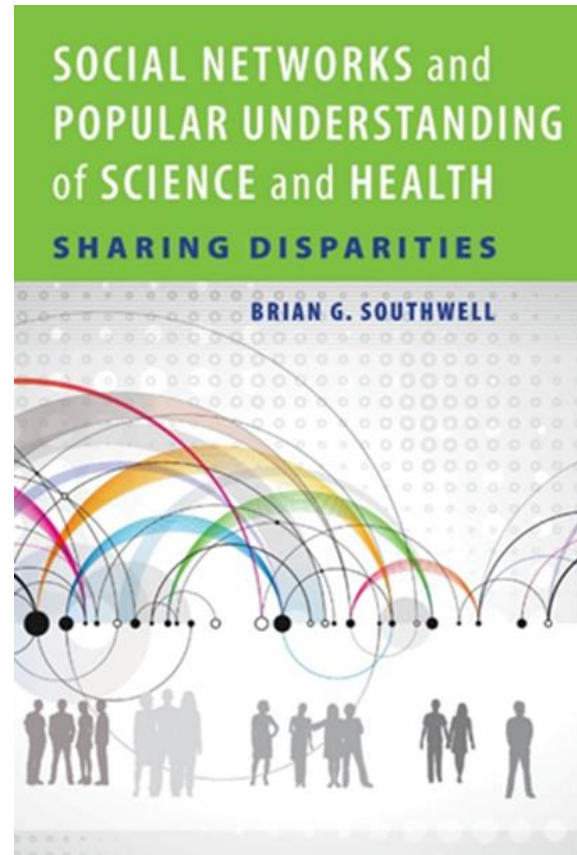
Why rumors spread



Why rumors spread

- Discomfort of uncertainty
- Lack of corrective information

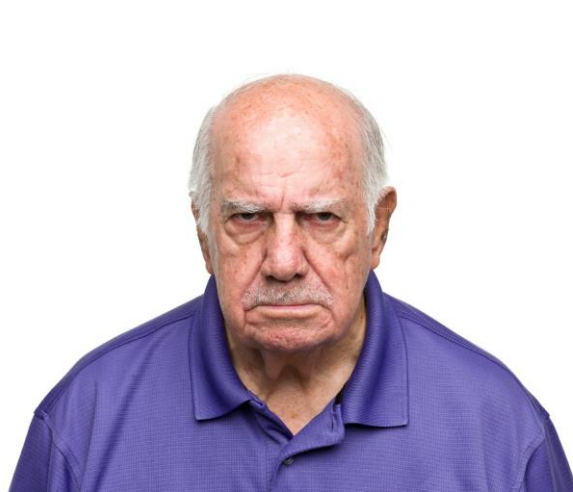
- Also: information as potential relationship currency



Might emotions make us vulnerable?

- Yes.
- Anger encourages inaccurate information acceptance.

Example: Weeks, B. E. (2015). Emotions, partisanship, and misperceptions: how anger and anxiety moderate the effect of partisan bias on susceptibility to political misinformation. *Journal of Communication*, 65, 699-719.



Our *reactive* regulatory tendency doesn't guarantee misinformation won't appear



Studies support some *corrective* potential...

- Aikin et al. (2015). *Journal of Communication*.
- Aikin et al. (2017). *Research in Social and Administrative Pharmacy*.
- Bode & Vraga. (2015). *Journal of Communication*.

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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...



What if...

- we find (and share) misinformation when earnestly searching for answers?



What if...

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- we would turn to peer-reviewed research if it was accessible, available, and trusted?



What if...

- we find (and share) misinformation when earnestly searching for answers?
- 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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What do we need to do?

- **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.

Dr. Brian Southwell

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[@BrianSouthwell](#)