

# Journal of Applied Research on Children: Informing Policy for Children at Risk

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Volume 13  
Issue 2 *Healthcare Misinformation and Child,  
Family, and Community Health*

Article 7

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2022

## Investing in Trust to Mitigate Misinformation

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### Recommended Citation

Wood, Jamie L. (2022) "Investing in Trust to Mitigate Misinformation," *Journal of Applied Research on Children: Informing Policy for Children at Risk*: Vol. 13: Iss. 2, Article 7.

DOI: <https://doi.org/10.58464/2155-5834.1527>

Available at: <https://digitalcommons.library.tmc.edu/childrenatrisk/vol13/iss2/7>

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## Investing in Trust to Mitigate Misinformation

### Acknowledgements

Thank you to Brian Southwell for helpful comments on this manuscript.

## Investing in Trust to Mitigate Misinformation

From the snake oil salesmen of the 1800s to the denial that HIV causes AIDS in South Africa, medical misinformation has propagated both within the United States and across the globe for decades. The COVID-19 pandemic, coupled with the global popularity of social media and ease of communication within and between developed countries, created the circumstances for an explosion of medical misinformation, creating what many experts called an “infodemic.” The prevalence of health misinformation became so concerning that the U.S. Surgeon General issued an advisory on the topic in 2021.<sup>1</sup>

Within the healthcare provider-patient relationship, evidence and anecdotes suggest that misinformation comes from both sides. Wood et al<sup>2</sup> documented that providers across multiple specialties experience hearing misinformation from patients when in the clinical environment. One example of physicians espousing misinformation is Christiane Northrup, MD. She practiced as an obstetrician-gynecologist for most of her career and published several best-selling books on women’s health. Now, she is no longer licensed to practice medicine and is listed by the Center for Countering Digital Hate as one of the “Disinformation Dozen”, a group of 12 people responsible for spreading ~65% of COVID vaccine misinformation.<sup>3</sup>

In this issue, Virginia Brown and Christine Thomas describe an underreported circumstance that contributes to the flow of misinformation between providers and patients. The authors examined the willingness of caregivers to share health information when patients suffering from mental illness are in a time of crisis. Their results show that a caregiver’s previous experience with the institution informs the decision to share health information, which could be critical to a provider’s plan of care. If a provider does not have all relevant information from the caregiver, then a plan of care may yield an unfavorable outcome. An unfavorable outcome could reinforce the caregiver’s decision not to share information when future crises arise, thus creating a vicious cycle of misinformation between the patient, provider, and caregivers. Caregivers feeling excluded from conversations regarding mentally ill patients is not new. A 2016 survey from the National Alliance for Caregiving found that 55% of respondents say they are not included by any providers or only included by some.<sup>4</sup>

Mental health care is a field often associated with stigma and shame, and these characteristics may inherently cause patients and family members to withhold information from providers. Verhaeghe and Bracke<sup>5</sup> showed in a study of Belgian patients that distrust in mental health providers

is associated with stigma, regardless of whether the stigma comes from the patient or external influences. This stigma can prevent the patient from getting satisfaction from the care experience; for example, if a patient expects to be treated badly because they are seeking mental health services, they are less inclined to trust the provider and therefore will be less satisfied with the experience. A 2015 study completed in the United Kingdom reported that Black patients experience higher rates of hospitalization for mental health treatment than do white patients, and Black patients report higher levels of mistrust in mental health services and providers.<sup>6</sup> The current report from Brown and Thomas highlights a unique aspect of mental healthcare: time-dependent treatment. Particularly during a crisis, when time is limited, caregivers may be reluctant to share information they believe is “not important” with a provider. The truth may be that the provider would use this information in the calculus of the plan of care. This appears to support the idea that time constraints have a suppressive effect on information sharing during the clinical encounter.<sup>7</sup>

While Brown and Thomas chose to focus only on patients suffering from an immediate mental health crisis, many other patients and providers will likely recognize this scenario. The likelihood that a provider has thought “if I had known about X, I would have done Y” is high, as is the thought from a patient “maybe if I had said X, the doctor would have done Y.” While these scenarios are only one drop in the ocean that is medical misinformation, there is good news. Concerted efforts to engender trust between patients, their caregivers, and healthcare providers will serve to mitigate this cycle of misinformation and strengthen the overall efforts of healthcare institutions to mitigate the broader spread of misinformation.

We know from multiple surveys and studies that the general public is primed to trust those working in the healthcare field. A survey from the Pew Research Center in 2022 asked U.S. residents if they were confident that medical scientists act in the interest of the public good; overall, 78% of respondents said they have a fair amount of confidence that this is true.<sup>8</sup> The American Board of Internal Medicine Foundation commissioned a study in 2021 surveying ~2100 U.S. residents asking how high is your level of trust in your healthcare provider; most responded that they have a high degree of trust.<sup>9</sup> Both of these surveys do show some discrimination among income brackets and ethnic populations, but this is a good starting point from the perspective of mitigating misinformation. People, in general, want to believe what their provider tells them regarding their personal health.

The practice of shared decision making has become the accepted model for healthcare decisions. Within this model, a provider discusses all options to treat a given condition with the patient, using the best available

evidence to support those options. In this way, the patient is an active participant, rather than a passive subject.<sup>10</sup> In their report published here, Brown and Thomas argue that the principles behind shared decision making should extend to caregivers as well, particularly in times of crisis when caregivers are those entrusted to know and carry out the wishes of the patient.

Sisk and Baker developed a working model of how trust is developed and maintained within the provider-patient relationship.<sup>11</sup> Their model includes competence-based trust and relation-based trust and notes that trust should be established and maintained before clinical care reaches a crisis point. They offer multiple suggestions of techniques for how to build trust, acknowledge this work is time-consuming and challenging, but argue it is a worthwhile investment. Their model was built with pediatric relationships in mind, but we can easily extend it to the relationships explored here by Brown and Thomas. Both pediatric patients and patients suffering from severe mental illness typically rely on the presence of a third party, either parents, legal guardians, and/or trusted caregivers. When considering the information sharing perspective, bi-directional, open communication should be viewed as an integral part of the maintenance of trust. After all, patients and caregivers have a vested interest in the plan of care, and because “Dr. Google” is easily accessible, they may want to discuss potential treatments that are not grounded in strong clinical evidence. Although providers are trained to practice evidence-based medicine (EBM), they should incorporate the principles of shared decision making to value and respect the sources of information a patient and/or caregiver brings to the clinical encounter. If the provider follows best practices to build and maintain trust with patients and their caregivers, then perhaps patients/caregivers will be more receptive to listening when providers explain/debunk misinformation in favor of treatments supported by stronger evidence. Incorporating information exchange is an excellent way for providers not only to correct inaccurate information, but also to listen and understand why the patient is interested in a certain topic. In return, the patient should feel validated, which builds and supports the trust in the relationship. Finally, Pokhilenko et al<sup>12</sup> found that women experience a higher degree of trust in physicians and are more involved in the shared decision making process. Since the burden of caregiving falls largely on women, at least in the U.S.,<sup>13</sup> providers have a vested interest to build and maintain trust in these relationships, which includes the reciprocal exchange of accurate information to provide the best care for the patient.

Incorporation of misinformation mitigation into shared decision making is only one strategy to contain how misinformation spreads.

Innovation and education have great potential to make substantial impacts in this effort. National Public Radio recently reported on an at-home hospital care program sponsored by Mayo Clinic, which offers patients the option to recover at home after major medical procedures.<sup>14</sup> Patients are connected to medical providers via internet-enabled devices and virtual visits 2 to 3 times a day. This type of program may provide a path for caregivers to be more comfortable disclosing information because they are in a more comfortable environment. This model could also work well for those who care for patients with mental illnesses; not only are the caregivers in a relaxed and calm environment, but the patients are as well. For patients prone to mental health crises, regular and sustainable access to providers may increase the flow of accurate information between the caregivers and providers as well.

In addition to innovations for patient care, those of us working to educate health professions students need to teach them about misinformation, its implications, and strategies for their encounters with it. We are now in an era in which students have grown up with the world of the internet and social media, which includes all the benefits and detriments. If we make a point to teach them about this issue during their education, some students will take an interest and devise creative solutions. As educators, we should not neglect this potential.

In speaking with healthcare providers, we know that misinformation is a problematic challenge. But, as Brown and Thomas have shown, we must keep in mind that patients and their caregivers can be frustrated by misinformation as well. The problematic challenge of misinformation cannot be solved overnight, but the systemic and collective efforts of many people working across institutions to maintain trust in relationships will be a first step toward mitigation.

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