Congenital heart disease and social media

Kai Ma, Qiyu He, Zheng Dou, and Shoujun Li*



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Paediatric Cardiac Surgery Center, State Key Laboratory of Cardiovascular Disease, National Center for Cardiovascular Disease, Fuwai Hospital, Chinese Academy of Medical Sciences, Peking Union Medical College, Beijing, PR China

With advanced progress in information technology, people can easily access knowledge from various sources, especially from social media like self-media, we-media, independent media, or citizen journalism.¹ Capitalizing on the potential of social media, healthcare professionals can effectively disseminate healthrelated information to the public, who can access authoritative insights without the need for clinic visits. However, this ease of information sharing also carries the risk of misinformation being delivered, often stemming from inadequate accessment of individual health factors and needs, causing unsatisfactory outcomes.²

In developing regions of China, where healthcare resources are scarce and social media is easily accessible, individuals frequently turn to online sources for medical information. However, a formidable challenge arises from limited health literacy, making them susceptible to misinformation. As an illustration, several professionals tend to exaggerate the consequences of patent foramen ovale (PFO), suggesting potential links to migraines or strokes. Instead, many PFO can be managed under medication without any intervention.3 Another critical factor attracting the public to use social media for medical information is the availability to communicate with health professionals, which reduces the costs associated with in-person consultations. For example, basic-level echocardiography facilities may not offer precise diagnoses for congenital heart disease (CHD), especially for subtypes which are difficult to detect via fetal echocardiography, such as aortic diseases and pulmonary venous abnormalities. As a result, these patients may not undergo comprehensive investigations for accurate diagnosis and therapeutic recommendations. Thus, information from social media platforms should be interpreted with caution.⁴

Misinformation can also lead to serious health consequences. While the public may find it easier to access treatment information for CHD through social media, the complexity of these diseases often leaves them without the necessary knowledge to make informed treatment decisions. Most CHDs necessitate surgical correction or transcatheter intervention, and the strict selection of treatment strategy based on indications is essential to a favorable prognosis.⁵ Here, we introduce a few cases encountered in the daily practice of our centre. Many CHD patients prefer minimally invasive techniques for their cosmetic effects,⁶ but this is usually not clinically indicated to complex cases due to the limited surgical field. Unfortunately, the benefits of this technique on social media may perhaps be exaggerated in order to attract more patients, even for complex CHDs, which can lead to potentially unavoidable outcomes like unexpected reintervention or incomplete repair.

Thus, the fragmented nature of medical information obtained from various social media sources is detrimental to treating complex diseases like CHD that require high-level expertise, and we advocate that patients with CHD, particularly those with complex lesions, seek consultations at tertiary hospitals for comprehensive evaluation. This is essential for achieving optimal treatment outcomes.

To sum up, more patients fall victim to inappropriate treatments due to misinformation acquired through social media. These patients suffer unexpected re-intervention, which could have been avoided with appropriate initial treatment. We emphasize the need to improve health literacy of patients, survelliance and goverance on social media. In addition, there is a pressing need for original research to quantify the outcomes of CHD treatment between presentation via traditional pathways or social media to verify the pros and cons of what kinds of patients with CHD would benefit from this new pathway, and the potential risk factors which may predispose people to misinformation from social media. Consequently, we can harness this newly formed technology to improve and aid clinical practice of complex diseases.

Declaration of interests

All authors declare no conflict of interest.

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*Corresponding author.

E-mail address: drlishoujunfw@163.com (S. Li).

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Correspondence

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