

Open notes in patient care: confining deceptive placebos to the past?

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ABSTRACT

Increasing numbers of health organisations are offering some or all of their patients access to the visit notes housed in their electronic health records (so-called 'open notes'). In some countries, including Sweden and the USA, this innovation is advanced with patients using online portals to access their clinical records including the visit summaries written by clinicians. In many countries, patients can legally request copies of their records; however, open notes are different because this innovation offers patients rapid, real-time access via electronic devices. In this brief report, we explore what open notes might mean for placebo use in clinical care. Survey research into patient access to their clinical notes shows that increased transparency enhances patients' understanding about their medications and augments engagement with their care. We reflect on the consequences of access for placebo prescribing, particularly for the common practice of deceptive placebo use, in which patients are not aware they are being offered a placebo. In addition, we explore how open notes might facilitate placebo and nocebo effects among patients. Bridging placebo studies with medical ethics, we identify a range of empirical research gaps that now warrant further study.

On 5 April 2021 in the USA, new federal rules mandate that—with few permitted exceptions—all providers offer patients online access to the information contained in their electronic health records.¹ Similar to online banking, patients using tablets, laptops or smart phones in the USA are now able to log onto secure health portals to read their clinical information. Access is not only to test results, lists of medications or appointment and referral dates but also to test the very words written by clinicians (so-called 'open notes'). Already, most patients in the Nordic countries are offered open notes and worldwide the practice innovation has spread to around 10 countries.² Despite multiple policy announcements in the UK,³ it is unclear whether or when the practice will be rolled out across the National Health Service (NHS). Notwithstanding, as transparency in medicine gradually takes hold, we suggest open notes may challenge some old and persistent vestiges of medical paternalism.

The use of placebos in clinical care has a long history.⁴ Placebo treatments are defined as interventions that are ineffective for a condition or set of symptoms but are nonetheless administered as if they were effective. Often categorised as 'pure' (eg, sugar pills, saline creams) or 'impure' or 'active' (eg, antibiotics for viral infections), studies also show that primary care physicians still reach for placebos today. In 2018, a systematic review and

meta-analysis of surveys from 13 countries found that impure placebo use was common among General Practitioners (GPs) with between 53% and 89% using placebos at least monthly and 16% and 75% prescribing them at least weekly.⁵ Findings also show that placebo prescribing is more common for patients with viral infections, sleep difficulties, pain-related conditions, fatigue and anxiety.^{6,7} In 2020, US primary care physicians described using impure placebos more often among patients with coughs, pain or functional disorders and medically unexplained symptoms.⁷ As one participant attested, 'it gets done all the time'.

Although primary care physicians may use placebos to offer hope, provide symptom relief or occasionally as a means to placate worried patients, deception in care risks ethical, medical and relational harms.⁸ Some ethicists have argued that deceptive placebos may sometimes be justified under narrow circumstances, for example, when no other therapy is available;^{9,10} however, others argue that deception risks derailing trust in physicians.¹¹ Moreover, honesty and transparency in care are necessary to support patient-centred care, to uphold the right of individuals to make their own treatment decisions and promote shared decision-making. In addition, patients with persistent medically unexplained symptoms are often vulnerable to feelings of marginalisation and placebos may further risk further doubts or disillusionment with mainstream care. Finally, misuse of medications can also contribute to antibiotic resistance and foster the misleading idea among patients that there is a 'pill for every ill'.⁶

Might open notes curb the use of placebos in clinical contexts? With full access to their medical documentation, it seems reasonable to postulate that open notes might reduce the opportunities for clinical deception. Indirect, although preliminary findings tentatively support this idea. In a web-based survey of 19 411 patients in the USA who accessed their outpatient notes for at least a year (response rate, 22%) and who reported being prescribed or taking medications, 64% described better understanding why medications were prescribed.¹² In the same survey, 57% of patients reported that reading their notes helped answer their questions and 32% reported that reading their note prompted them to seek more information about their medications.

On the other hand, a recent qualitative survey reported that a minority of patients who accessed their notes did perceive misrepresentations of visits or 'lies', though it is unclear whether or how this might have related to physicians' treatment recommendations or possible placebo use.¹³ Studies in the USA also suggest some reticence among clinicians to



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discuss open notes or to promote the possibility of portal access among patients. For example, in a recent survey of clinicians with experience of the practice (n=1628, response rate=27%), three quarters (75%, n=983) reported that in the last month they did not encourage their patients to read their notes.¹⁴ Whether physicians who prescribe placebos are more prone to use strategies aimed at hiding notes is not yet understood and more research in this area is warranted.

A growing body of research shows that placebo effects offer genuinely beneficial relief for some symptoms and conditions including depression, anxiety, pain, migraines and irritable bowel syndrome.¹⁵ Acting as a digital extension of the clinic visit, it has also been proposed that open notes might be a forum that engages cognitive and perceptual processes that elicit placebo effects.¹⁶ On this hypothesis, reading notes may enhance trust, empathy and confidence in physicians, thereby harnessing therapeutic placebo effects without the need for deceptive placebos. Qualitative studies confirm that greater transparency can offer reassurance; for example, 'I feel less helpless and perhaps more hopeful'¹⁷ or as one patient remarked, 'It was very comforting to have my recollections and understandings confirmed'.¹⁸ Another patient attested, 'It made the relationship stronger, the trust was there, because they were willing to talk to me about (the diagnosis)... instead of stuffing it under the carpet'.¹⁹ Conversely, among those who perceive discrepancies or incongruities between their notes and what was discussed in visits, patients report strained trust in clinicians.^{13 19}

In recent years in placebo studies, there is burgeoning research into so-called 'open-label placebos' ('OLPs') and studies suggest honestly prescribed placebos might still elicit therapeutic placebo effects.²⁰ To move beyond clinical trials into clinical practice, however, there must be both robust evidence for OLPs and evidence of their acceptability to patients. So far, it remains unknown whether patients who might otherwise benefit may be confused or offended by this novel treatment, perhaps believing that in prescribing OLPs physicians thereby diminish the medical importance of the patient's symptoms or consider the patient's condition to be 'all in their head'.⁸ However, since patients who access their clinical notes report better understanding about the rationale for treatments and greater trust in their clinicians,²¹ open notes might prove to be a particularly useful tool for facilitating patient understanding about how OLPs work and in helping boost shared decision-making about their use for certain symptoms and conditions.

Finally, a possible unintended effect of open notes is nocebo effects, whereby negative expectations about treatments give rise to unwanted symptoms. After reading their notes, patients do report greater understanding of possible adverse effects of medications.¹² In a recent analysis of patients with serious mental illness diagnoses who read their notes, 50% (n=662) patients reported better understanding about the possible side effects of their medications, 60% (n=798) patients reported the notes helped answer questions about their medications and 39% (n=514) patients said access prompted them to seek more information about their medications.²² We suggest that findings such as these underline the urgency to find ways to resolve the ethical tension between transparency in disclosing treatment side effects with the potential to 'do harm' as a result.²³

In summary, much remains to be understood about the influence of open notes on the prescribing of placebos and on the implications for placebo and nocebo effects in clinical practice. As medicine embraces greater moves towards transparency, it remains an open question whether deceptive placebo use will decrease and/or whether patients are more able to better discern

when they have been offered placebos. We close by noting that there is a persistent 'digital divide' in use of patient portals with older, lower income and minorities more likely to be underserved by access.²⁴ Therefore, if placebo and nocebo effects are indeed facilitated by open notes, some patients may be more likely to benefit (or be harmed) as a result of accessing their notes. If encouraged to read their notes, it is also possible that patients who may be more vulnerable to disparities in the distribution of placebo effects in face-to-face encounters²⁵ might reap benefits not available in clinic visits. These and other questions remain to be investigated.

To take this research agenda further, we suggest researchers prioritise three key areas. First is the influence of open notes on deceptive placebo prescribing. We recommend the use of closed-ended surveys to examine possible changes in the frequency of placebo use pre and post implementation of open notes. In addition, qualitative studies could usefully investigate clinicians' attitudes, practices and experiences with respect to deceptive placebo prescribing when patients are offered rapid access to their online clinical notes. Second and equally important is the perception about deceptive placebo use among patients. Using mixed methods surveys, it would be valuable to explore whether patients who have accessed their notes are better placed to detect placebo use and furthermore, how this influences trust in their provider. Third, experimental studies, including randomised controlled trials, could be used to explore the influence of patient access to medication information in their clinical notes, including disclosures about possible adverse effects, on nocebo effects. Such studies could provide important information on how to ethically balance risk of nocebo effects with transparency and shared decision-making among patients.

With portal access to their clinical notes, physicians will need to be more mindful that patients may be reading what they write. In the new era access, it will be for patients to choose whether to read their notes. And, regardless of placebo or nocebo effects, in the future, it will be for each individual to decide whether truth is a tonic or if too much information is—for them—a bitter pill to swallow.

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