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# Sharing clinical notes, and placebo and nocebo effects: Can documentation affect patient health?

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## Abstract

This paper connects findings from the field of placebo studies with research into patients' interactions with their clinician's visit notes, housed in their electronic health records. We propose specific hypotheses about how features of clinicians' written notes might trigger mechanisms of placebo and nocebo effects to elicit positive or adverse health effects among patients. Bridging placebo studies with (a) survey data assaying patient and clinician experiences with portals and (b) randomized controlled trials provides preliminary support for our hypotheses. We conclude with actionable proposals for testing our understanding of the health effects of access to visit notes.

## Keywords

placebo, placebo effects, electronic health records, clinical documentation, patient portals, nocebo effects

## Introduction

Clinicians in more than a dozen countries currently offer patients online access to part, or all of the notes they write and house on computerized devices (Essén et al., 2018). The practice—known as "open notes"—is growing. In the United States, currently, over 50 million patients are offered access to such personal medical information via secure online portals, and in March 2020 the federal government released a new ruling stipulating that digital accessibility to patients' records will become mandatory. From April 2020, general practitioners working for NHS England will be obliged, on a prospective basis, to share the clinical notes that they write with their patients.(Richards, 2020) In Sweden, where most patients can already read their clinical notes, all tax-funded health facilities were required to provide fully transparent patient access to electronic health records by 2020.

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In addition to legal, technical, and ethical challenges that pose ongoing obstacles to open notes (Blease et al., 2020a; 2020b; Hägglund et al., 2019; Mehta et al., 2019), many clinicians remain skeptical about the benefits to patients (Dobscha et al., 2016; Petersson and Erlingsdóttir, 2018b). Survey research reveals that many physicians fear access might cause confusion and anxiety among patients and could also disrupt workflow (Delbanco et al., 2012; Miller Jr et al., 2016; Petersson and Erlingsdóttir, 2018b). Mental health clinicians cite potential harms to psychiatric and psychotherapy patients if they were to read their clinical notes (Denneson et al., 2017; Dobscha et al., 2016; Petersson and Erlingsdóttir, 2018a). Yet, overall the majority of clinicians, including those who work primarily with mental illness, opine that sharing clinical notes with patients is a good idea (Delbanco et al., 2012; DesRoches et al., 2020; Petersson and Erlingsdóttir, 2018b).

In this paper we argue that both perspectives may be correct. Drawing on current findings in placebo studies and research into the practice of open notes, we hypothesize that, depending on their content, patient portal access to notes may generate both genuinely beneficial *and* genuinely adverse health effects by engaging perceptual and cognitive processes that give rise to placebo and nocebo effects, respectively. Specifically, we propose that the content and tone of clinical notes may influence expectancies via cues of clinician competence and empathy, and by documenting treatment rationale. Conditioning may also play a role.

We begin by providing a brief overview of research into these psychobiological pathways that are now recognized to elicit placebo and nocebo effects. Next, we propose four hypotheses describing how sharing clinical notes via patient portals might activate these mechanisms to modulate health effects. We then connect these hypotheses with current research into open notes and provide some evidence for the relationship between clinical note sharing, and placebo and nocebo effects. Finally, we suggest novel research designs and methodologies to expand this inquiry.

## Mechanisms and pathways of placebo and nocebo effects

Empirical and conceptual inquiry into the role of placebo and nocebo effects has burgeoned (Colagiuri et al., 2015; Evers et al., 2018; Wolters et al., 2019), and in recent years a mature scientific research program in "placebo studies" has emerged (Blease, 2018; Blease and Annoni, 2019). A wealth of research shows that placebo effects are genuine psychobiological events that trigger top-down cognitive processes to elicit measurable physiological effects that can be clinically beneficial. Although investigators have examined only a limited number of symptoms and conditions, several are apparently susceptible to placebo effects (Kaptchuk and Miller, 2015). These include some of the most prevalent complaints and conditions for patients seeking primary care: depression and anxiety (Kirsch, 2019; Sugarman et al., 2014), pain (Amanzio et al., 2001; Locher et al., 2017), alcohol dependence (Weiss et al., 2008), and irritable bowel syndrome (Kaptchuk et al., 2008; Vase et al., 2005). Studies demonstrate that placebo effects can substantially augment the potency of active pharmacological treatments (Amanzio et al., 2001), and a recent consensus paper composed by experts in placebo studies proposed that harnessing the power of placebo effects for prevalent conditions is a medically worthwhile pursuit (Evers et al., 2018).

Research has predominantly focused on "response expectancies" as the core mechanism of placebo effects (Colagiuri et al., 2015; Jensen et al., 2012; Kirsch, 1985, 1997, 2018). The majority of studies investigating placebo effects have concentrated on patients' consciously-held beliefs that a treatment will be effective (Berna et al., 2017; Vase et al., 2005). Patients' expectations in augmenting placebo effects are perhaps most clearly observed in so-called "open-hidden" experimental investigations (Amanzio et al., 2001; Tondorf et al., 2017). For example, in an experiment in a hospital setting, intravenous analgesics were administered to patients covertly (from another room) or openly (in full view of the patient). Evidence for the influence of patients' expectations was inferred from the finding that those

in the covert condition required a 50% higher dosage of analgesics to obtain the same relief as did those in the open condition (Amanzio et al., 2001).

However, it is also commonly theorized that expectancies can be shaped by other pathways, such as learning processes, particularly conditioning (Amanzio and Benedetti, 1999; Benedetti et al., 2003b); verbal instructions including the provision of a treatment rationale (Locher et al., 2017; Tondorf et al., 2017); and perceptions about others. Classical—or "Pavlovian"—conditioning refers to the learned associations between a neutral stimulus (e.g. a bell) and a biologically potent stimulus (e.g. food) to elicit a response (e.g. salivation) (Büchel et al., 2014; Kirsch et al., 2004; Rescorla, 1988). Its role in modulating placebo effects has been successfully demonstrated in a number of studies (Carlino et al., 2015; Colloca et al., 2006, 2008; Voudouris et al., 1985); research on conditioned placebo effects indicates further that the effects of conditioning may be mediated by response expectancies (Kirsch et al., 2014; Montgomery and Kirsch, 1997).

Verbal instructions can also influence expectancies about treatments. Recently, an innovative experiment in placebo analgesia found that placebos administered with a plausible rationale elicited significantly higher levels of pain-relieving placebo effects than placebos given without an explanation (Locher et al., 2017). In this study participants were prescribed "open label" placebos: that is, they were informed that the sugar pill might work by harnessing placebo effects. Crucially, in order for the open label placebos to work, it was not sufficient merely to prescribe placebos, clinicians had to offer a basic scientific rationale for their effectiveness (Locher et al., 2017).

Perceptions of clinicians' competence and empathy are also likely to affect treatment outcome expectancies (Howe et al., 2017, 2019). Drawing on well-established social psychology research that perceptions of warmth and competence constitute important dimensions of interpersonal interactions (Fiske et al., 2002, 2007), Howe, Crum and colleagues argue that patients' expectations about clinical interventions always arise in a social context (Howe et al., 2017, 2019; Zion and Crum, 2018): "*When forming impressions, humans readily and rapidly determine whether another person's intentions are benevolent (judgments of warmth), and whether this person has the ability to enact those intentions (judgments of competence)*" (Howe et al., 2017). Connecting these findings with research in placebo studies, it is hypothesized that patients' perceptions both about clinician competence and warmth are key factors in establishing treatment expectancies, and inducing placebo effects (Howe et al., 2017, 2019; Zion and Crum, 2018). Put another way, placebo effects may be enhanced by patients' perceptions that "the clinician gets it"—the practitioner displays knowledge, skill, proficiency, and personal effectiveness in relation to understanding the patients' symptoms and condition; and "the clinician gets me" through signals of support, compassion, and personalized engagement (Howe et al., 2019). Providing an understandable treatment rationale may enhance perceptions of clinician competence via displays of expertise; and/or clinician warmth, by demonstrating careful articulation of the treatment rationale, and/or by investing time in patient-centered care.

Correlatively, nocebo effects are often described as "negative placebo effects" and are believed to be mediated by patients' negative expectations about an intervention or a prognosis, resulting in adverse health responses, including pain, and with larger numbers of side effects associated with prescribed treatments (Benedetti et al., 2007; Colloca and Benedetti, 2007). Research into nocebo effects is more limited and there is no evidence that perceptions of low competence or low empathy, or lack of treatment rationale elicit these negative effects (Howe et al., 2017). Studies do suggest that adverse health effects are triggered by patients' *negative* expectations about interventions (Barsky et al., 2002; Benedetti et al., 2003a). In a study of beta blockers prescribed for cardiac disease and hypertension, informing patients that side effects might include erectile dysfunction led to twice as many men reporting this problem, compared to those not informed (Silvestri et al., 2003). Experimental studies focusing on pain indicate that nocebo

effects engage specific regions of the brain involved in pain processing (Koyama et al., 2005). Open-hidden paradigms have also been applied to nocebo studies with illuminating results (Benedetti et al., 2003a; Colloca et al., 2004). For example, in a study of postoperative pain among patients who received morphine for 48 hours, participants were allocated to either an open or hidden interruption in analgesic administration (Colloca et al., 2004). Those in the open condition were advised that morphine had been stopped; among patients in the hidden condition, morphine administration was stopped surreptitiously. After 10 hours, more patients in the open group requested additional pain-killers, suggesting that the verbal disclosure influenced expectations and, as a consequence, experiences of pain.

## Hypotheses: How open notes might generate placebo and nocebo effects

Connecting evidence from placebo studies with the relatively novel platform of open notes, we propose that fully transparent patient portals may generate both placebo and nocebo effects.

Specifically, we hypothesize that patients may experience placebo effects under the following circumstances:

> *Hypothesis 1*: Clinical notes convey positive expectations about the success of the treatment, and/or the patient's progress/prognosis; *and/or*
>
> *Hypothesis 2*: Patients perceive the clinical notes to convey a persuasive rationale for treatment(s); *and/or*
>
> *Hypothesis 3*: Patients perceive clinicians to be competent (e.g. the notes demonstrate complete and accurate information about the patients' conditions, and proposed treatments), and warm (e.g. the notes provide a high level of personal support, encouragement, and empathy for the patient's circumstances).

In addition, we propose that patients may experience nocebo effects if:

> *Hypothesis 4*: Clinical notes convey negative expectations about the success of the treatment, including potential negative side effects.

We also suggest that there may be interactive effects between some of these hypothesized pathways. For example, communicating positive treatment outcome expectations may also enhance perceptions of clinician competence, thereby further boosting placebo effects.

## Preliminary evidence that sharing notes might generate placebo and nocebo effects

### *Preliminary evidence for response expectancies*

As conveyed in *Hypothesis 1*, we propose that the tone and content of clinical notes may play a direct role in influencing response expectancies among patients. By communicating encouraging and optimistic messaging anticipating the effectiveness of a treatment plan, and/or the patient's progress, there is potential to modulate the size of placebo effects among some patients. Currently, qualitative studies suggest that at least some individuals may experience positive emotions after reading their notes, and that the content of the note prompted these responses. For example: for example: *"I enjoyed seeing my progress documented;" "Writes excellent very nice and specific notes that make me feel good, that I'm making progress with myself and that she sees the changes in me"* (O'Neill et al., 2019). However, it is not understood whether these positive responses can be attributed to placebo effects, facilitated by reading clinical notes. Nonetheless, as a result of open notes some participants do appear to experience positive expectancies: for example: *"I feel less helpless and perhaps more hopeful"* (Gerard et al., 2017).

### *Preliminary evidence for provision of a treatment rationale*

Studies show that many patients misunderstand or misremember what is communicated to them

about their medications and treatment plans (McCarthy et al., 2012). Survey evidence suggests that many patients report better understanding of treatment rationales a result of open notes, and this may provide a novel pathway toward eliciting placebo effects (Locher et al., 2017; Tondorf et al., 2017). For example, evidence from primary care indicates that patient understanding is enhanced by reading clinical notes (Esch et al., 2016). In a large survey across three disparate US health centers in 2017, access to notes enhanced patients' grasp of the rationale behind treatments and recommendations: 73% (16,354/22,520) rated reading their notes as very important for taking care of their health, 70% (15,726/22,515) as important for feeling more in control of their care, and 66% (14,821/22,516) for remembering their care plan. Only 3% of patients (737/22,304) reported being very confused after reading their notes (Walker et al., 2019). In the same survey, of 19,411 patients who read their notes and reported being prescribed medications, 14% responded that reading their notes made them more likely to take medications as prescribed (DesRoches et al., 2019).

Qualitative findings also suggest that reading clinical notes may improve grasp of treatment rationale. For example: "*I like knowing what the results of my tests mean. The records [laboratory results] show the numbers but the notes provide the interpretation in regards to my personal health status," "I appreciate the open exchange and the opportunity to correct any possible misunderstandings,"* "*It is an opportunity to be more knowledgeable about my condition and how I can manage it better"* (Gerard et al., 2017).

Around a quarter of health organizations that share open notes in the US currently invite patients to view mental health notes. Many patients accessing mental health notes also report enhanced understanding about their condition. At the end of a 20-month long pilot study, 98% ($n = 44$) participants at an outpatient psychiatric clinic expressed a desire to continue reading their mental health notes online (Peck et al., 2017). Patients reported better understanding of their mental health (69%, $n = 31$), and remembering their care plan (69%, $n = 31$) (Peck et al., 2017). In a study involving patient access to their psychotherapy notes ($n = 85$), more than half of patients rated notes as "very important" or "extremely important" for feeling more in control of their care (O'Neill et al., 2019). Although empowerment is a multi-dimensional concept in which patient knowledge is only one aspect, qualitative findings suggest that reading notes can improve understanding of what goes on in appointments and therapy sessions (Cromer et al., 2017; O'Neill et al., 2019; Peck et al., 2017). For example: "*It was confirming. It helped me understand my situation*"; "*helps affirm what I am working on*" (O'Neill et al., 2019).

By allowing patients greater time to read and reflect on what their clinician communicated away from the pressures of the face to face visit (Blease et al., 2020b), open notes may offer important opportunities to enhance response expectancies, and thereby facilitate placebo effects, via the provision of treatment rationales within online documentation.

## *Preliminary evidence for perceptions of clinician competence and warmth*

To enhance positive expectations via the competence/warmth pathway (Howe et al., 2019), we predict that depending on the tone and content of the documentation, reading clinical notes might enhance patients' perceptions of clinician competence ('the clinician gets "it"') and/or perceptions of clinician warmth ("the clinician gets me") (Howe et al., 2019). Many patients describe feeling empowered by reading their notes and report enhanced satisfaction levels with clinicians. After a year-long US pilot study ($n = 4592$), 37% of patients reported feeling better about their physician after reading their notes, with 62% expressing no difference (Bell et al., 2017). Around half (54%) of the primary care physicians ($n = 99$) believed that patient satisfaction with them had increased as a result of open notes, with similar numbers (51%, $n = 61$) believing that patients trusted them more (Bell et al., 2017). It is not yet

known whether increased levels of patient satisfaction are mediated by perceptions of clinician competence.

Comparable findings have emerged from studies of patients with mental illness. Interviews among Veterans Health Administration mental health clinicians and nurses believe that access to notes can empower patients, shift power dynamics in clinical sessions, and facilitate patient-centered care. If used carefully, open notes may enhance the therapeutic relationship (Denneson et al., 2017). To date, small sample surveys of access to mental health notes suggest that some patients express greater confidence and trust in their clinician as a result of reading their clinical notes (Cromer et al., 2017; O'Neill et al., 2019; Peck et al., 2017). For example, in a study of access to therapists' notes, one third of participants (32%, $n = 21$) described trusting their provider more, with 60% ($n = 39$) reporting no change (O'Neill et al., 2019). Again, while we might infer a connection between patient trust in clinicians and perceptions of clinician competence, there is no direct evidence that the former is affected by the latter. However, free text commentary accompanying surveys suggests that perceptions of clinicians' skills and abilities might be augmented after reading notes. For example: "*[Reading the note] gave me insight into the evaluation process my doctor used and gave me confidence in his abilities* (Bell et al., 2017); *"I see how much my doctor really makes an effort to list and address my concerns"* (Gerard et al., 2017).

Many patients express feelings of validation ("*being heard"*) and of practitioner empathy. For example: "*I felt like someone cared. May seem quite simple but it was a nice human touch"* (Gerard et al., 2017); *"I always appreciate how well my therapist captures what I've said and how I'm feeling"* (O'Neill et al., 2019). Some describe an enhanced therapeutic alliance with their clinician. For example: "*[The note] helps me feel that my [doctor] and I are partners in promoting my health"* (Gerard et al., 2017), "*I felt that my therapist was really listening to me"* (O'Neill et al., 2019). Although tentative, these findings provide promising indications that cues of both empathy and warmth may already be communicated by some clinicians via clinical notes.

### *Preliminary evidence for nocebo effects*

Open notes may also be a platform that produces negative expectancies and nocebo effects. In the large 2017 patient survey, of the 19,411 respondents who read their notes and were prescribed medications, 45% reported that they were more aware of the possible side effects of their prescriptions as a result (DesRoches et al., 2019a). A proportion of these respondents may also have derived nocebo effects from reading this information. In qualitative studies, some psychotherapy patients report feeling more negative about their progress as a result of accessing their clinician's notes. For example: "*The notes seemed separate from having a social worker as an ally in personal growth. I felt disempowered"*, "*The therapist only said supportive things to me but the note seemed judgmental in a negative way. After reading it, I felt badly, like she didn't like me as much as I thought"* (O'Neill et al., 2019).

Negative expectancies may also arise if patients experience incongruencies between what is expressed by clinicians in face-to-face clinical encounters, and what is communicated in their notes (Cromer et al., 2017; O'Neill et al., 2019). For example: "*I felt uncomfortable that she told me one thing yet I read something else in the note. I don't know that I would see her again due to this"* (O'Neill et al., 2019).

Furthermore, in light of findings that access to notes may enhance understanding about treatments, patients may also become more vulnerable to nocebo effects. In a pilot study of access to psychiatric notes, Peck and colleagues found that most patients surveyed reported better understanding the potential side effects of their medications (82%, $n = 37$) (Peck et al., 2017). Whether enhanced understanding of possible side effects translates to increased nocebo effects has not yet been explored.

## Future directions

Survey research provides a useful starting point for mounting hypotheses about placebo and

nocebo effects related to open notes. However, most surveys of patients' experiences of open notes in primary care contexts have been restricted to a few medical centers in the US, limiting the generalizability. In addition, only a small number of surveys have investigated access to psychiatric and psychotherapy notes, and in at least one of these studies, clinicians decided which patients should have access (Peck et al., 2017). As with all survey research, results are based on self-report, and responses may have been biased by individuals who were more engaged with patient portals and/or those who had more negative or positive experiences as a result of reading their clinical notes. Several RCTs examining the effects of sharing access to electronic health records have yielded positive results, but these studies are hampered by small sample sizes, and methodological limitations including the supplementation of patient portal access with clinician interventions (Goldzweig et al., 2013; Simon et al., 2011). Only few studies have investigated symptoms or conditions that are particularly responsive to placebo effects (Jones et al., 1999; Tuil et al., 2007).

To connect open notes research to research in placebo studies researchers will need to systematically collect well-validated measures of placebo/nocebo related processes such as treatment-related expectations. We suggest that future research into the connections between placebo and nocebo effects, and access to clinical notes should therefore encompass a range of novel approaches. First, independent thematic coding, the use of linguistic analysis software (Kahn et al., 2007; Pennebaker et al., 2007), or natural language processing (Rahimian et al., 2019), may be used to assess the length of notes, and their syntactic and semantic structure. Results of these findings might then be compared to patients' evaluations of their notes. This could help to probe whether objective linguistic markers are predictive of patients' responses—including expectations about treatments, perceptions of clinician competence and empathy, and understanding of treatment rationale. Where possible, we suggest that validated measures should be used to assess patients' expectations about treatments, their subjective understanding of treatment rationales, and perceptions of clinician competence, and empathy. Importantly, although there are a number of instruments for assessing patient satisfaction with clinician communication, specific measures should be employed whenever possible, such as measuring of perceptions of clinician empathy following access to clinical notes.

Other clinical trials could compare different types of standardized or enhanced forms of open notes, and test how these are perceived by patients. For example, in one condition, clinicians could undergo training in clinical note-writing aimed at optimizing factors relevant to placebo effects. Clinicians might undertake a web-based course on patient-centered communication practices in open notes, aimed at improving understandable, supportive, and empathic writing skills (Dobscha et al., 2019). Similar to a placebo effect study conducted by Kaptchuk et al, clinicians could be tasked with incorporating several, specific cues into their clinical note-writing—such as an encouraging comment, a personal detail about the patient, an indication that the clinician understands the patient's health concerns, and a clear rationale for treatment recommendations (Kaptchuk et al., 2008). A second condition could involve a neutral, or no training clinician group. At set time periods, appraisals of patients' outcomes for placebo-effect responsive conditions could then be performed. For example, assessment of patients' primary symptoms, as well as adherence to treatments, could be measured, along with subjective patient health reports. We acknowledge, however, that setting up such a trial could be challenging since clinician blinding may not be possible. In addition, training in clinical note-writing might augment the quality of interpersonal care patient visits thereby interfering with accurate measures of the influence of documentation on placebo effects.

Beyond research into documentation, the very offer, or refusal, by clinicians to provide patients with ready access to their clinical notes may influence placebo and nocebo effects. While this issue is moot in some countries such as Sweden and the US where access to open

notes is mandated by law, conceivably in other regions even the act of inviting patients to read notes may increase response expectancies, and thereby placebo effects by enhancing trust in clinicians, and perceptions of clinician competence and empathy. On the other hand, explicit refusal to provide access to clinical notes may diminish clinician trust (O'Neill et al., 2019), driving negative expectations about prognoses and treatments, leading to nocebo effects. Both theories—that positive *and* negative decisions about providing access to clinical notes also may directly incur health effects—deserve exploration (DesRoches et al., 2019; Wright et al., 2015).

Finally, research might also venture beyond open notes to include not just the documentation but the medium through which it is shared (Gruszka et al., 2019; Torous and Firth, 2016). Evidence shows that users of digital devices often experience affiliative feelings, with many experiencing anxiety if separated from their smartphone (Clayton et al., 2015; Sapacz et al., 2016), and scales have been developed that intend to measure the therapeutic alliance that is formed with an application or program, rather than a person (Berry et al., 2018). We are aware of only one experiment that found placebo analgesia can be induced via the use of online communication (Pontén et al., 2019). Perceived sophistication of mobile Health ("mHealth"), encompassing the novelty and/or the design of apps, may increase expectations about the effectiveness of these interventions. Associative learning between neutral features of apps, or patient portals, and positive user experiences may engender conditioned placebo effects. Correlatively, some patients may learn to associate negative responses—for example, anxiety associated with distrust of technology—leading to negative conditioned responses upon accessing clinical notes via portals (Lopez et al., 2019).

## Conclusion

Inviting patients to read their notes can be interpreted as a potential treatment tool—one that must be utilized with care. The hypotheses proposed in this paper now require experimental research to investigate whether clinical notes can augment placebo and nocebo effects. We conclude with a final word of caution. Although desirable to maximize therapeutic benefits of placebo effects by communicating positive expectations to patients via clinical notes, this aspiration raises ethical considerations about upholding honesty in the disclosure of clinical information (Blease, 2012, 2019). If the hypotheses in this paper are empirically supported, it will be important to train clinicians to write notes that balance transparency (Blease et al., 2020b) with communication techniques that maximize the benefits of placebo effects, and minimize the harms of nocebo effects (Alfano, 2015; Blease, 2015; Evers et al., 2018; Fava et al., 2017; Klein et al., 2016).

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### Author contributions

Conceived the paper: CB, CD, JW. Wrote first draft: CB. Contributed to revisions and rewriting: IK, TD, JW, JT, MP, CD, MH.

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No ethical approval was required for this study.

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