Relational Autonomy, Maternalism, and the Nocebo Effect

Abstract (209 words)

In their target article, Fortunato et al. suggest that the nocebo effect, in which an individual experiences an adverse effect of medical treatment due to negative expectations, occasions a dilemma between autonomy and nonmaleficence. They work to resolve the dilemma by arguing that in some cases, nonmaleficence outweighs autonomy. In this commentary, we suggest that the concept of autonomy presumed to underlie informed consent practices is at the root of this predicament – not a *pro tanto* conflict between autonomy and nonmaleficence. We propose that if the concept of *relational* autonomy is utilized instead, this conflict dissolves. To concretize this conceptual point, we describe how the types of informed consent practices endorsed by the authors (in which disclosure is calibrated to the individual patient and follow-up is utilized) are actually widely practiced in Japan. Elucidation of these practices requires a wider lens on informed consent practices that includes support staff such as nurses and medical social workers as well as family members. These practices, best understood as *maternalistic* (rather than paternalistic), are ethically justifiable from a relational autonomy perspective. As we argue, there are good reasons to approach the nocebo effect from this perspective; doing so both dissolves the autonomy/best-interests dilemma and grounds concrete suggestions for reducing the nocebo effect.

Commentary Article (1,492 words)

Fortunato et al.'s target article extends both the ethical analysis and the clinical practice of nondisclosure by focusing on nocebo effects. Instances of this phenomenon occur when a patient experiences an adverse effect arising from his or her own negative expectations of a medical treatment, rather than from the treatment itself. The nocebo effect is inherently connected with the debate over the permissibility of nondisclosure, since it is the disclosure of possible side effects that is causally related to the increase in the probability of such effects occurring. According to Fortunato et al., practitioners thus face the "nocebo dilemma", since the possibility of disclosure-induced effects occasions an ethical dilemma between the principles of nonmaleficence and autonomy. The authors work to resolve this dilemma by arguing that nonmaleficence should be prioritized over autonomy in cases of nocebogenic risk, and by supplementing this argument with a clinical proposal intended to reduce the attendant loss to autonomy in a follow-up stage.

We question this way of setting up the discussion: framing the issue in terms of a *dilemma* is not, we contend, representative of what is at stake, and distracts from the nuanced dynamics at work in these kinds of cases. Our aim is to show that adopting a relational understanding of the concept of autonomy can, at least in cases where certain conditions are met, dissolve this putative dilemma between autonomy and nonmaleficence. This has implications for the structure of the ethical debate over nocebo effects, which we sketch using the framework of *maternalism* (Specker Sullivan 2016). We do not wish to undervalue the contribution made by Fortunato et al.'s article; their proposals for the practical dimensions of this issue are largely in line with the account we develop. Our objective is to ensure that practical proposals of this sort are grounded in a fuller appreciation of the relevant ethical considerations; the key to gaining access to this is, we suggest, to step beyond the constraints placed on this discussion by the standard understanding in bioethics of the autonomy/best-interests dilemma.

Our conceptual critique is directed, first and foremost, at the conception of autonomy assumed by Fortunato et al.'s argument. Beyond descriptors such as "laissez-faire autonomy"

and "autonomy qua informed consent", there is little explanation of what the authors intend by the term "autonomy". It is clear that a patient's or subject's autonomy and her best interests are thought to conflict (Fortunato et al. 8-9), and that the idea of *paternalism* best captures the features of this conflict (ibid. 16-17). Nonetheless, there are also indications that the authors are suspicious of standard descriptions of autonomy, as when they question whether patients' "purely self-determined choices" really do exist (ibid. 3). This suggests that they do not accept "laissez-faire autonomy" – by which we assume they mean the idea that giving patients information and then leaving them to make their own independent decisions is what is required for respecting their autonomy – as the *prima facie* or *pro tanto* duty it is often thought to be. This introduces a conceptual difficulty, as the authors understand the nocebo effect in terms of a dilemma between *pro tanto* moral duties, and yet they seem to challenge the moral significance of one of these obligations (when understood as laissez-faire autonomy). It is no surprise, then, that their argument develops in favour of prioritizing patients' best interests.

We propose that, based on Fortunato et al.'s own comments, the concept most appropriate to their understanding of autonomy is *relational*, not *informational*. Relational autonomy is the idea that our autonomy competencies – to recognize, enact, and reflect on our values, desires, beliefs, and commitments – are formed, developed, and revised through interactions with others (Meyers 1989; Mackenzie and Stoljar 2000). As so conceived, an individual's autonomy is not at odds with her best interests, but is of a piece with it. We believe that the authors default to autonomy qua informed consent instead of relational autonomy, and as such reject this view of the relationship between autonomy and best interests (Fortunato et al. 8-9), due to their use of the framework of paternalism to capture the ethically salient features of the nocebo effect. Paternalism is intimately intertwined with laissez-faire autonomy: it describes situations in which an individual's autonomy is violated in favour of her best interests. Consequently, the principle of antipaternalism, which has long held an orthodox position in bioethical debate, is thought to ensure that individuals have the opportunity to make their own decisions independent of external influences and with full knowledge of the relevant facts.

Yet this is not exactly the problem of the nocebo effect. The worry is not about the benefits and risks of a physical act (e.g., surgery), but rather that the *information* required for this full informed consent practice can itself be the cause of harm. The nocebo effect suggests that some information may harm patients through their expectations of certain side effects. For these patients, negative expectations have physical ramifications. These physical ramifications are not without consequence, and they also are not independent of autonomy: for many people, to suffer such (potentially unnecessary) side effects is to experience the diminishment of one's autonomy competencies. In their final analysis, Fortunato et al. imply that the cause of the side effects is either a unique feature of the *patient*, or a specific quality of the *information* (ibid. 15-17). In other words, they treat information as a metaphysically independent entity that is conveyed from one party (the physician) to the other (the patient), with harm resulting either from the patient's psychology or from the quality of the information. Yet what is more likely (and as their nod towards Wells and Kaptchuk's (2012) "contextualized informed consent" proposal reinforces) is that adverse side effects result from the situation as a whole – this includes *how, when*, and *to whom* the possibility of side effects is disclosed. Relational autonomy acknowledges that harm can result from *this* physician disclosing information in *this* way to *this* patient.

The problem, then, is not that there is a *pro tanto* dilemma between the principles of autonomy and nonmaleficence, or even that they are in conflict, but that clinicians do not have a reliable method for determining how and when to disclose information to patients such that harm will not result. As it happens, this is exactly the practical problem faced by

clinicians in Japan, where diagnoses such as cancer can be withheld from patients if it is thought that such diagnoses will harm them and adversely affect future treatment decisions (i.e., restrict their autonomy). Japanese clinicians do not conceptualize this as a principled dilemma and their practice does not face an impasse; instead, they rely on family and trained support staff, such as nurses, medical social workers, and clinical psychologists to apprise them of the patient's traits and attitudes, and to help them determine the likelihood that full disclosure will be harmful (Specker Sullivan 2017). This practice approaches informed consent as *multi-staged*, recognizing that the preservation and development of autonomy competencies for any given situation is an ongoing process, and as involving multiple parties. The temporary withholding of a diagnosis is conceptualized not as a choice in favour of best interests over autonomy (a paternalistic decision), but as a decision that preserves the patient's capacity for exercising autonomy competencies in the future by not causing harm in the present. As Fortunato et al. themselves note, the practical constraint with this kind of contextualized approach is that physicians may have neither the training nor the time to individualize their approach to each patient in this way; this is the reason for involving family and support staff.

The concept of *maternalism* captures the ethically salient features of these Japanese informed consent practices, as well as of the nocebo effect. Maternalism can be defined as acting for the benefit of another person *and* taking that person's autonomous will into account, yet without an explicit expression of consent or assent by the person on whose behalf the decision is made (Specker Sullivan 2016). While classic antipaternalist arguments view this type of action as paternalistic (arguing that without an explicit expression there cannot be certain knowledge of the acted-upon person's autonomous will), maternalism proposes that certain relationships, characterized by trust and understanding, provide the epistemic grounding for such interpersonal knowledge, and that actions based in this knowledge need not violate autonomy.

We propose that, for situations such as the nocebo effect, maternalism is a better analytical tool than the autonomy/best-interests dilemma relied on in this target article. Nondisclosure of harmful information is not paternalistic if it supports the patient's goals and values (and thus her autonomy competencies). While this maternalistic decision does rely on close knowledge of the patient, this is the type of information gleaned through trusting relationships formed with family and support staff. Recognizing and encouraging the role of support staff in disclosure and informed consent may be one way to respond to practical concerns about the implementation of contextualized, or *maternalistic*, communication practices.

Bibliography
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