

This is an Accepted Manuscript of an article published by Taylor & Francis Group in *The American Journal of Bioethics* on 24 May 2017: available online: <http://www.tandfonline.com/10.1080/15265161.2017.1314048>.

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”

1
2
3 and “autonomy qua informed consent”, there is little explanation of what the authors intend
4 by the term “autonomy”. It is clear that a patient’s or subject’s autonomy and her best
5 interests are thought to conflict (Fortunato et al. 8-9), and that the idea of *paternalism* best
6 captures the features of this conflict (ibid. 16-17). Nonetheless, there are also indications that
7 the authors are suspicious of standard descriptions of autonomy, as when they question
8 whether patients’ “purely self-determined choices” really do exist (ibid. 3). This suggests that
9 they do not accept “laissez-faire autonomy” – by which we assume they mean the idea that
10 giving patients information and then leaving them to make their own independent decisions is
11 what is required for respecting their autonomy – as the *prima facie* or *pro tanto* duty it is
12 often thought to be. This introduces a conceptual difficulty, as the authors understand the
13 nocebo effect in terms of a dilemma between *pro tanto* moral duties, and yet they seem to
14 challenge the moral significance of one of these obligations (when understood as laissez-faire
15 autonomy). It is no surprise, then, that their argument develops in favour of prioritizing
16 patients’ best interests.
17

18
19 We propose that, based on Fortunato et al.’s own comments, the concept most
20 appropriate to their understanding of autonomy is *relational*, not *informational*. Relational
21 autonomy is the idea that our autonomy competencies – to recognize, enact, and reflect on
22 our values, desires, beliefs, and commitments – are formed, developed, and revised through
23 interactions with others (Meyers 1989; Mackenzie and Stoljar 2000). As so conceived, an
24 individual’s autonomy is not at odds with her best interests, but is of a piece with it. We
25 believe that the authors default to autonomy qua informed consent instead of relational
26 autonomy, and as such reject this view of the relationship between autonomy and best
27 interests (Fortunato et al. 8-9), due to their use of the framework of paternalism to capture the
28 ethically salient features of the nocebo effect. Paternalism is intimately intertwined with
29 laissez-faire autonomy: it describes situations in which an individual’s autonomy is violated
30 in favour of her best interests. Consequently, the principle of antipaternalism, which has long
31 held an orthodox position in bioethical debate, is thought to ensure that individuals have the
32 opportunity to make their own decisions independent of external influences and with full
33 knowledge of the relevant facts.
34

35
36 Yet this is not exactly the problem of the nocebo effect. The worry is not about the
37 benefits and risks of a physical act (e.g., surgery), but rather that the *information* required for
38 this full informed consent practice can itself be the cause of harm. The nocebo effect suggests
39 that some information may harm patients through their expectations of certain side effects.
40 For these patients, negative expectations have physical ramifications. These physical
41 ramifications are not without consequence, and they also are not independent of autonomy:
42 for many people, to suffer such (potentially unnecessary) side effects is to experience the
43 diminishment of one’s autonomy competencies. In their final analysis, Fortunato et al. imply
44 that the cause of the side effects is either a unique feature of the *patient*, or a specific quality
45 of the *information* (ibid. 15-17). In other words, they treat information as a metaphysically
46 independent entity that is conveyed from one party (the physician) to the other (the patient),
47 with harm resulting either from the patient’s psychology or from the quality of the
48 information. Yet what is more likely (and as their nod towards Wells and Kaptchuk’s (2012)
49 “contextualized informed consent” proposal reinforces) is that adverse side effects result
50 from the situation as a whole – this includes *how*, *when*, and *to whom* the possibility of side
51 effects is disclosed. Relational autonomy acknowledges that harm can result from *this*
52 physician disclosing information in *this* way to *this* patient.
53

54
55 The problem, then, is not that there is a *pro tanto* dilemma between the principles of
56 autonomy and nonmaleficence, or even that they are in conflict, but that clinicians do not
57 have a reliable method for determining how and when to disclose information to patients such
58 that harm will not result. As it happens, this is exactly the practical problem faced by
59
60

1
2
3 clinicians in Japan, where diagnoses such as cancer can be withheld from patients if it is
4 thought that such diagnoses will harm them and adversely affect future treatment decisions
5 (i.e., restrict their autonomy). Japanese clinicians do not conceptualize this as a principled
6 dilemma and their practice does not face an impasse; instead, they rely on family and trained
7 support staff, such as nurses, medical social workers, and clinical psychologists to apprise
8 them of the patient's traits and attitudes, and to help them determine the likelihood that full
9 disclosure will be harmful (Specker Sullivan 2017). This practice approaches informed
10 consent as *multi-staged*, recognizing that the preservation and development of autonomy
11 competencies for any given situation is an ongoing process, and as involving multiple parties.
12 The temporary withholding of a diagnosis is conceptualized not as a choice in favour of best
13 interests over autonomy (a paternalistic decision), but as a decision that preserves the
14 patient's capacity for exercising autonomy competencies in the future by not causing harm in
15 the present. As Fortunato et al. themselves note, the practical constraint with this kind of
16 contextualized approach is that physicians may have neither the training nor the time to
17 individualize their approach to each patient in this way; this is the reason for involving family
18 and support staff.

19
20
21 The concept of *maternalism* captures the ethically salient features of these Japanese
22 informed consent practices, as well as of the nocebo effect. Maternalism can be defined as
23 acting for the benefit of another person *and* taking that person's autonomous will into
24 account, yet without an explicit expression of consent or assent by the person on whose
25 behalf the decision is made (Specker Sullivan 2016). While classic antipaternalist arguments
26 view this type of action as paternalistic (arguing that without an explicit expression there
27 cannot be certain knowledge of the acted-upon person's autonomous will), maternalism
28 proposes that certain relationships, characterized by trust and understanding, provide the
29 epistemic grounding for such interpersonal knowledge, and that actions based in this
30 knowledge need not violate autonomy.

31
32 We propose that, for situations such as the nocebo effect, maternalism is a better
33 analytical tool than the autonomy/best-interests dilemma relied on in this target article.
34 Nondisclosure of harmful information is not paternalistic if it supports the patient's goals and
35 values (and thus her autonomy competencies). While this maternalistic decision does rely on
36 close knowledge of the patient, this is the type of information gleaned through trusting
37 relationships formed with family and support staff. Recognizing and encouraging the role of
38 support staff in disclosure and informed consent may be one way to respond to practical
39 concerns about the implementation of contextualized, or *maternalistic*, communication
40 practices.
41
42
43

44 *Bibliography*

- 45 (1) Fortunato et al., 2017. 'When respecting autonomy is harmful: A clinically useful
46 approach to the nocebo effect', *The American Journal of Bioethics* x: x-x.
47 (2) Mackenzie, C., and Stoljar, N., 2000. *Relational Autonomy: Feminist Perspectives on*
48 *Autonomy, Agency, and the Social Self*. Oxford University Press.
49 (3) Meyers D.T., 1989. *Self, Society, and Personal Choice*. Columbia University Press.
50 (4) Specker Sullivan, L., 2016. 'Medical maternalism: Beyond paternalism and
51 antipaternalism', *Journal of Medical Ethics* 42: 439-444.
52 (5) Specker Sullivan, L., 2017. 'Dynamic axes of informed consent in Japan', *Social Science*
53 *& Medicine* 174: 159-168.
54 (6) Wells, R.E, and Kaptchuk, T.J., 2012. 'To tell the truth, the whole truth, may do patients
55 harm: The problem of the nocebo effect for informed consent', *The American Journal of*
56 *Bioethics*, 12: 22-29.
57
58
59
60