



Ives, J., Papanikitas, A., Myres, P., & Gregory, S. (2018). Shared decision making: a need for honesty? *British Journal of General Practice*, 68(671), 292-293. https://doi.org/10.3399/bjgp18X696557

Peer reviewed version

Link to published version (if available): 10.3399/bjgp18X696557

Link to publication record in Explore Bristol Research PDF-document

This is the author accepted manuscript (AAM). The final published version (version of record) is available online via RCGP at https://bjgp.org/content/68/671/292. Please refer to any applicable terms of use of the publisher.

University of Bristol - Explore Bristol Research General rights

This document is made available in accordance with publisher policies. Please cite only the published version using the reference above. Full terms of use are available: http://www.bristol.ac.uk/pure/about/ebr-terms

Shared decision-making – a need for honesty?

Jonathan Ives^{*1} Andrew Papinikitas² Paul Myres³ Simon Gregory⁴

1. Centre for Ethics in Medicine, School of Social and Community Medicine, University of Bristol, Canynge Hall, 39 Whatley Road, Bristol, BS8 2PS

2. Nuffield Department of Primary Care Health Sciences, Radcliffe Observatory Quarter, Woodstock Road, Oxford. OX2 6GG

3. Public Health Wales, Choosing Wisely Wales, 2 Capital Quarter, Tyndall Street, Cardiff, CF10 4BZ

4. Health Education East of England, 2-4 Victoria House, Capital Park, Fulbourn, Cambridge CB21 5XB

*corresponding author

In this analysis we challenge the conceptual honesty of 'shared decision-making', arguing that whilst it is held up as an ideal decision-making standard, it is used too often to describe (and justify) decision-making practices that are not shared at all. This is problematic because if the legitimacy of a decision relies on it being 'shared', but it is not in fact shared, the decision loses legitimacy, or is falsely legitimised by the appearance of being shared. We argue that the realities of clinical practice mean that genuinely shared decision-making is not completely impossible but difficult to achieve in a sincere and just manner. We articulate an intentionally controversial stance, with the aim of generating thought and debate.

Shared decision-making has been offered as a way of better respecting patient autonomy, leading to management plans or actions that are in tune with patient values and therefore improving concordance. It provides a platform for respecting autonomy whilst avoiding abandoning patients to their autonomy, by giving them information without assistance in interpretation; allowing them to arrive at informed decisions that are in accord with their beliefs, values and preferences. This ideal accords with the deliberative model of the clinician/patient relationship put forward by Emmanuel and Emmanuel (1) being morally preferable to a paternalistic or informative/commercial relationship.

In arguing that shared decision-making is the pinnacle of patient centred care, Barry & Edgman-Levitan (2) describe it in the following terms:

...the clinician offers options and describes their risks and benefits, and the patient expresses his or her preferences and values. Each participant is thus armed with a better understanding of the relevant factors and shares responsibility in the decision about how to proceed. (p781)

Commentators lament, however, that:

Unfortunately, this ideal is inconsistently realized today. The care patients receive doesn't always align with their preferences. (3, p6)

It is important to note that this misses the important point that the care actually received is not a good barometer for the extent to which the decision was shared. Numerous external factors can impact on the translation of that decision into treatment.

It is probably true, however, that fully shared decision-making is often not achieved; and in that case we ought to be motivated to change our practice to ensure that we meet the standard more often. In making this resolution we accept in principle that a failure to engage in ethically optimal shared decision-making is an ethical failure, because we are failing to do something that we ought to do.

We believe there are certain contingent and essential features of the clinical encounter that make attainment of fully shared decision-making frequently impossible. We offer the following 3 arguments in support of this.

- Ideal forms of shared decision making seem to rely on the assumption that the two parties engage in a deliberative and rational information exchange, through which they come to shared understanding and harmonious consensus on the most appropriate course of action. The majority of clinical encounters simply do not, and cannot, allow sufficient time to engage in the kind of dialogue required to arrive at genuinely shared decisions. Instead, what we tend to find is options are presented by the clinician, which are simply agreed to by the patient.
- 2) The Anglo-American medico-legal tradition has shaped consent into a negotiation where (with the exception of forced treatment and in the absence of external constraints of resource) the clinician and the patient each get one veto. Patients can refuse treatment that they do not consent to, and clinicians can refuse to provide treatment they believe to be non-beneficial or will cause clinically unacceptable harm. The fact that this right of veto exists and that GPs can choose, for example to: not mention homeopathic treatment as an option based on their

scientific beliefs; refuse patient requests for antibiotics on grounds of futility; not suggest certain options on resource grounds, limits the extent to which we can see very many decisions as genuinely shared. Any healthcare worker may have a distinct set of goals, beliefs, and values, and often these go unobserved unless they give rise to conflict – a phenomenon remarked upon by Fulford et al (4) in their work on values.

3) The assumption that information can be objectively conveyed without selection or interpretation (what is referred to as a 'conduit' model) is problematic, and affected by (inter alia): knowledge and power differentials, memory retention, fear, embarrassment, cognitive bias, cultural difference etc. As Manson and O'Neil (5) note, whilst critiquing contemporary notions of informed consent, the practice of giving information is complex and often opaque:

Neither full explicitness nor complete specificity is possible... For human agents, with varying beliefs, varying inferential commitments and varying vocabularies, the best we can hope for is a mutually agreed level of specificity in the disclosure of a particular transaction" (pp15-16)

If what we have said is plausible, then there are both contingent (limited time and right of veto) and essential (the imperfectness of communication) factors that will very often make fully shared decision-making untenable.

This leads us onto the horns of a dilemma. We must either accept that the majority of decisions made in clinical practice fall short of shared decision-making and consequently represent some form of ethical failure, or we must acknowledge fully shared decision-making, in most cases, is unachievable in current practice, and that this ought not be viewed as an ethical failure on the part of the clinician.

We suggest a move towards the second horn. There is something troubling about doctors being held up to an ethical standard that is, for the most part, untenable. This highlights a critique of ethics as a theoretical enterprise, often driven by political commitments, which makes proclamations about ideal forms of practice that fail to take account of context. Consider, instead, contemporary accounts of empirical ethics, that view practice as a starting point, and theory as a guide, in which the aim is to balance competing interests, practical features, and theoretical demands, to arrive at a workable, justifiable, solution. Ives (6) characterises this as a process of 'noble failure', in which we must accept that the ethical judgements we make are often necessarily constrained by the choices available to us, and the solution often requires justifiable compromise between what we might want in terms of ideal theory and what is possible. Essentially, this is a matter of recognising we are 'succeeding in doing the best we can' rather than lamenting that we are 'failing to do the best imaginable'.

We suggest that far from fully shared decision-making being required on every occasion, simple (informed) agreement, in the context of a fiduciary relationship, is often good enough; and the level of collaboration required for genuinely shared decision-making is only ethically required for substantively important decisions. Of course, what counts as a substantively important decision is itself an important question – with a general rule of thumb that this is determined by patients and their representatives. We suggest that greater honesty about when shared decision-making is genuine, and genuinely required, and when it is not, is needed. We call for an acknowledgment that a 'failure' to implement shared decision-making in every clinical encounter is not a failure at all – because one ought not feel morally obligated to do something that is not possible. This is not to say we shouldn't attempt to share information and responsibility, but the question of how far we ought to go to make fully shared decision-making possible remains moot.

References

(1) Emanuel E, Emanuel L. 1992. "Four Models of the Physician-Patient Relationship." JAMA 267:2221-6.

(2) Barry M, Edgman-Levitan S. 2012. Shared Decision Making — The Pinnacle of Patient-Centered Care. New England Journal of Medicine, 366(9):780–1.

(3) Lee E, Emanuel E. 2012. Shared Decision Making to Improve Care and Reduce Costs. New Engladn Journal of medicine. 368(1):6-8

(4) Petrova M, Dale J. Fulford B. 2006. Values-based practice in primary care: easing the tensions between individual values, ethical principles and best evidence. British Journal of General Practice, 56: 703-709.

(5) Manson N, O'Neil O. 2007. Rethinking Informed Consent in Bioethics. Cambridge University Press

(6) Ives, J. 2014. A method of reflexive balancing in a pragmatic, interdisciplinary and reflexive bioethics. Bioethics. 28(6):302-312