Why do patients want information if not to take part in decision making?

Informed consent is a central pillar of clinical ethics. Patients ought to be given information about the nature of proposed treatments or interventions, about their risks, about alternatives (including inaction) and their costs and benefits. The standard justification of informed consent is that the disclosure of information is required so that patients can make their own medical decisions: information is the material that patients need in order to make their autonomous decisions about treatment.

There is, however, considerable evidence that some patients want information more than they want to take part in decision making; and some want information even when they want to defer medical decision making to clinicians.\(^1\)\(^2\)\(^3\)\(^4\)\(^5\)\(^6\)\(^7\) As Czaja, Manfredi and Price put it: ‘the desire for information and the desire for involvement in medical care are independent factors’.\(^8\) Auerbach concludes that ‘whereas most patients say they want detailed information, far fewer say they want to participate in decision making’,\(^9\) and that ‘across a wide variety of medical settings, patients report that they want detailed information about their condition and their treatment whereas stated desire for input into decision making is skewed more in the direction of physician-only or at least collaborative decision-making’.\(^10\) Such findings are puzzling. Why do patients want information about treatment options if they don’t want to make decisions on the basis of that information? What do patients want the information for?

These findings are a distinctive and puzzling addition to the evidence that many patients would be happy to defer decision-making to clinicians, and to adopt a passive—patient—role.\(^11\)\(^12\) Schneider goes so far as to refer to current informed consent procedures as involving a kind of “mandatory autonomy”\(^13\) a phenomenon described by Davies and Elwyn as the ‘paradox of imposing choice on patients’.\(^14\) The debate about mandatory autonomy underscores our puzzle in that it standardly assumes that patients who don’t want to take part in decision making won’t want information. Our puzzle arises with regard to those patients who don’t want to make decisions on their own: why do at least some of them still want information?

The evidence that leads to our puzzle is not just puzzling. It is problematic for methodological reasons. Different studies use different instruments to evaluate patient preferences, with different kinds of question (some specific, some general) and different scales.\(^15\) Some ask about what the patient has done, or will intend to do, to get information; others simply ask about “how important” information is to the patient. Stated information preferences may not translate into action.\(^16\) Auerbach suggests that “psychometrically sound instruments’ are needed if a proper evaluation of patients’ informational and decisional interests is to be obtained. Auerbach’s methodological critique seems well-founded and the need for methodologically more robust instruments is thus well-supported.

It might seem that in order to solve our puzzle we will have to resolve these methodological problems. It is argued here, however, that we can go some way towards answering our puzzling question without having to do so. Empirical studies are not the only way of finding things out. We can clarify, and learn something about, our informational and decisional interests from a philosophical perspective. More specifically, by reflecting on the nature of communication, and upon what we want and expect from communication, we can offer some reasons why patients may be interested in gaining information about treatment options even when they do not want to make
decisions themselves. The results of our discussion should be of relevance to those who seek to develop methodologically sound empirical studies of patients’ informational interests and how these relate to their decisional preferences.

It is a fact that communication is a complex, social activity that serves many different functions. Now, this point is one that has been made by others in the context of medical communication.17 For example, Ong et al identify three different functions that communication plays: (i) the creation and maintenance of a good inter-personal relationship; (b) the exchange of information; and (c) decision-making about treatments. But this kind of focus on the functions of medical communication will not directly solve our puzzle. This level of classification fails to engage with the various interests that shape and motivate communication, the variety of things that communicators want from communication, and the variety of things that we can infer from acts of communication.

By the time we are past early childhood most of us are expert communicators. We know how to use communication to satisfy our needs and desires, we know how to inform, assure, promise, deceive, console, ask, forgive, amuse and so on in a wide range of social contexts. We have a wealth of experience of communication as audience and speaker (and also other roles such as bystander, initiator, interrupter and so on). We know what we can do with communication, we know how it gets across our attitudes, desires and emotions, and we know how others’ communication is a good basis for inferring facts about their attitudes, desires, emotions and status. Acts of informing take place in this very rich communicative context. When one party informs another of something, there is typically much more going on than the mere transmission of an explicit “message” or “content”. Let us focus on speech. Speech takes place in social context where participants start off knowing—or at least believing—something about the status, role, attitudes, knowledge and interests of the other parties. The activity of speech allows participants to amend, revise, check and add to this background knowledge. Informative speech can tell audiences something about the world, whilst, at the same time, showing something about the speaker. Consider some of the adjectives used to describe speech: charming; pompous; impatient; kind; careful; edgy; domineering; bullying; sympathetic; careless; lazy; attentive, and so on. These adjectives are applicable because speech allows us to reliably infer facts about the speaker’s attitudes.

Now, when a patient is asked, as part of a study, questions like: “Do you want to be informed about your treatment options?” “Have you appreciated being informed about treatment options?” such questions are posed to someone who has a grasp of some of the roles that such acts of informing can and do play. We value acts of informing for a number of reasons. For our purposes, the important point is that some of these reasons for wanting to be informed are independent of wanting to make decisions on the basis of the information received.

Before offering a short list some of these reasons, it is important to note two things about this list. The first is that items in the list are not meant to be ranked: the fact that different reasons are presented in a particular order is not meant to reflect an assumption that patients will in general find that kind of reason the most important in their deliberations. The second, related, point is that the reasons are not meant to be prised apart and viewed individually. The process of listing them introduces an artificial separation between them. The reasons should be taken as elements of a more complex, holistic, reason for wanting information, one that has elements that we can abstract and make explicit.
(i) Wanting to know reasons for action

In considering treatment options an informed consent “disclosure” plays the role of putting forward potential reasons for different kinds of action. That is, a specification of the relative risks of different courses of action can be, when coupled with other information and the patient’s own goals and interests, provide reasons for favouring one course of action over another. But our interest in knowing reasons for acting extends beyond our interest in making decisions. For example, human beings have a deep interest in historical explanation: interests in why agents acted as they did even though such reasons are not going to be used in current deliberation. This interest is even more pronounced with regard to actions that impinge upon, or have implications for, us as individuals. When a politician proposes a policy that will affect us, we want to know why: but not because we want to make the decision ourselves.

The giving of reasons is such a familiar part of our everyday communication that we take it for granted. A failure or unwillingness to give reasons can be distressing, insulting or demeaning. Primo Levi tells of his experience, having arrived in Auschwitz, starved and thirsty, trying to remove an icicle to drink from. A guard takes it from him. He asks why. The guard replies “There is no “why?” here”. Levi interprets this as the guard’s claiming that everything is forbidden. But we can also read it, perhaps more plausibly, as the guard’s insistence that the normal game of giving reasons will not be played, so any expectation of an explanation of action will not be met. The prisoner is so contemptible that no reasons need to be given.

Suppose a patient wants to completely defer decision making to her clinician. It does not mean that she does not have an interest in learning something about the reasons for acting. In some cases this may reflect a plain interest in knowing reasons (the kind of interest that could be satisfied by knowing the reasons after the fact).

(ii) Wanting respect

Human beings have a deeply entrenched interest in being respected. Respect means many different things. For our purposes the kind of respect that is of concern is “recognition” respect (rather than the “appraisal” or “evaluative” respect that is directed at people in terms of their achievements). Respect for persons is a species of recognition respect: recognising the person as an agent, with her own distinct interest and capacities to pursue her life as she sees fit.

We have already seen that a failure to give reasons can be indicative of a lack of respect. But it would be wrong to infer that it is only when communication involves the giving of reasons that respect can be shown. Acts of informing—which are our concern here, rather than other speech acts like requesting or directing—can readily show respect, or a lack of it.

It should be obvious that the manner of informing can show respect (or contempt). Although this is of relevance to a broader discussion of clinical communication, it is not of key concern to us here. Our concern is with the reasons that patients might have for wanting information, even though they don’t want to make decisions. Our puzzling evidence does not pertain to patients preferences for how they are spoken to, but acts of informing can show respect in another way. The fact that a clinician is willing to inform a patient about treatment options may be viewed as indicative of respect (provided it is done so in respectful manner). The clinician treats the patient as someone
who is capable of being informed, and who has an interest in being informed. A patient can have an interest in being respected without thereby wanting to make decisions herself. The findings by Joffe et al. support this line of thought. This US study sought to determine what it is that patients value in hospital care by correlating their evaluation of their care across a number of different variables with their willingness to recommend the hospital to others. The study found that the strongest correlation with a willingness to recommend was being treated with respect and dignity, and having confidence and trust in the clinicians: “These data suggest that, among the experiences measured in this survey, hospitalised patients on average value involvement in decision making less than other aspects of treatment”.

(iii) Establishing trust

When we trust another to do something we rely on them to act in certain (specified) ways that respect our interests. The fact that the clinician is willing to engage in communication may help to inspire confidence in the clinician as a trustworthy agent. The fact that she is willing to talk in detail about the intervention may be taken to be an indication that the clinician is honest, open, and has “nothing to hide”. In contrast, evasive speech, or trying to steer the patient’s questions away from details, may be taken as evidence that the clinician does not give a strong consideration to the patient’s interests.

(iv) Assurance of competence

One objection we might have to this line of thought is that trust always rests upon a willingness to refrain from knowing certain things: the parent who trusts the babysitter does not monitor the babysitter via a covert webcam. So, wouldn’t a desire for information be indicative of a lack of trust? Once again, it is important to bear in mind that placing trust is a complex activity that must take into account at least two elements: a trustee must keep the trusting party’s interests in mind (and not be swayed by self-interest when out of view of the trusting party) but she also must be competent and reliable. So, those placing trust must be able to assess, and gain assurances, that the trustee will meet both conditions. In giving information, the clinician shows herself to be knowledgeable.

There is a puzzle here though. How can a patient, who may lack medical knowledge and expertise, judge that the clinician is competent? After all, the patient may not understand what the clinician says. But the patient does not need to assess competence in the way that an examiner in a medical school does. The medical examiner has expert medical knowledge and wants to test the individual student to ascertain whether she possesses it too. The patient typically will not possess such knowledge but she will, by way of contrast, have good reason to believe that the clinician is someone who has already been accredited in terms of her competence and knowledge. We can view the disclosure of information as providing evidence that the clinician is willing to make explicit her knowledge with regard to this patient, and this condition. The fact that the clinician is willing to make these claims allows certain inferences to be made. Communicators know something about the risks that communication puts a speaker under: if the clinicians spouts a load of nonsense, she risks being found out (even if a patient is not expert herself, she may, for all the clinician knows, have close friends or family who are, or she may leave the consultation to consult the internet (which does raise its own problems)). So, the thought here is that receiving information from the clinician provides assurance of specific and relevant competence, and part of the rationale for this is that
patients know—perhaps tacitly—that the clinician would not risk making explicit incorrect information, in a context where such a disclosure is likely to pose risks to her.

(v) Assurance of deliberative resources

As stressed above, these reasons for wanting information are not meant to be taken in isolation. One reason why this is so is that one and the same act of informing can provide different kinds of assurance about the clinician. In addition to competence and trustworthiness, being given information about treatment options in advance of acting may give an assurance that the clinician has resources for decision making at her disposal, with a tacit implication that she will draw upon those resources in reaching a decision. That is, prior to acting the patient has assurances that whatever treatment option is decided upon—whether it be by the patient, the clinician, or both together—it will be based upon a consideration of reasons, alternatives, risks and so on. Suppose a patient—of the kind featured in Schneider’s studies—wants to entirely defer her decision making to a clinician. It is not irrational, or irrelevant to seek assurances that the decision will be made in a reasonable way, and the disclosure of information can provide this kind of assurance. That is, a patient can want to be assured that a good decision will be made (by someone else) without wanting to make that decision herself.

(vi) Opportunities provided by the context of communication

Our discussion so far has assumed a largely passive role for the patient: patient as audience. But when information is conveyed in a face to face exchange it is standard (though not essential) that speaker and audience can interact with one another. Of particular importance is the opportunity to ask questions, to seek clarification, to check claims, and so on. If the giving of information is bound up with an opportunity to ask questions then testing a patient’s interests in gaining information (either by asking her information preferences, or by asking her about her practices) may be testing for more than one, independent, element.

4. Conclusion

We began with a puzzle: there is evidence that patients seem to want information about treatment options, risks and the like, even when they do not want to take part in decision making. The methods by which such data is gathered may not be entirely adequate. We have sought here to sidestep the methodological worries by reflecting on the complex, multi-faceted, nature of communication. All that we need to make sense of the puzzling data is at least one reason why patients might want information about treatments, but not for making decisions about them. We have found more than one, but must leave it open for further discussion as to which reasons are operative, or important, in different contexts. In some contexts, some of these reasons may not be operative at all (for example, a patient may want information simply because she wants to know why things will be done, even though already has all the assurances she needs about the competence and trustworthiness of the clinician).

The discussion here also suggests a range of more fine-tuned questions that should be asked of patients. We have seen that a single communicative act can play many roles, and a patient may have a variety of overlapping, interconnected, but distinct interests in communication about treatment options. Because of this, it may be hard to prise apart different interests, but surely not
impossible. For example, patients could be asked which of the following they would prefer: meeting clinician to discuss treatment options; receiving the same information by email. Or, for those who express a willingness to defer decision making, questions could be asked of this cohort about whether they would prefer (a) no information; (b) information prior to treatment; (c) information post-treatment. If patients prefer information post-treatment to no information at all, this could even prompt further questions as to why such information was sought. These are merely suggestions, and it is hoped that the discussion here will be of use to those who seek to develop sound instruments for gaining information about patient information preferences.

REFERENCES

8 See reference 3: 556.
9 See reference 7: 196.
20 See reference 19: 106.

22 Lloyd, AJ. The extent of patients' understanding of the risk of treatments. Qual Health Care 2001; 10: 14-18.