Autonomy and the right not to know incidental findings arising during treatment response monitoring

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ABSTRACT

The moral right not to know (RNTK) is predominantly grounded in autonomy. This means that the scope, strength and nature of the moral RNTK is determined in light of the ethical principle of respect for autonomy. In this paper, I will further explore the relationship between patient autonomy and the scope of the RNTK in the context of treatment response monitoring. I focus on treatment response monitoring because novel challenges can be formulated against grounding the RNTK in autonomy in this context. I will consider three accounts of patient autonomy: Beauchamp and Childress' account of patient autonomy, Weimer's evidence-responsiveness condition for patient autonomy and Pugh's account of rational autonomy. Throughout the paper, I will illustrate the implications of these accounts of patient autonomy for the scope of the RNTK by asking which incidental findings (IFs) that arise during treatment response monitoring can be autonomously refused by metastatic breast cancer patients. I will conclude that although it becomes more difficult to autonomously refuse particular IFs on Weimer and Pugh's more demanding accounts of patient autonomy in the context of treatment response monitoring, they do not make it radically impossible to autonomously refuse any IF. Given the strength of the RNTK, this provides us with a strong reason to obtain, contrary to current clinical practice, patients' consent regarding the disclosure of IFs in the context of treatment response monitoring.

INTRODUCTION

Although the moral right not to know (RNTK) is widely endorsed, it is not entirely uncontested.[1] The main counterargument goes as follows. Individuals should be autonomous. Autonomy is a matter of being rationally self-governing. Rational self-governance requires the disclosure of all medically relevant information. Therefore, there exists a duty to know rather than a right *not* to know.[2–4] The conceptions of autonomy this counterargument relies on have broadly been characterised as duty views.[1] Such views state that people have a duty to be rationally self-governing. However, it is highly implausible that one should be *maximally* self-governing. Moreover, given the increasing amount of relevant medical information available, it is implausible that one should have *all* relevant knowledge in order to be rationally self-governing. Therefore, weighing rational self-governance with other concerns might lead individuals to forsake their future rational self-governance to some degree by presently foregoing some medically relevant information without thereby becoming radically non-autonomous. For these reasons, I set aside worries about whether the RNTK exists and go along with the common assumption that it can be grounded in autonomy.[5–7]

When grounding the RNTK in autonomy, the scope, strength and nature of the RNTK will be determined by the ethical principle of respect for autonomy.[8 9]

First, the *scope* of the RNTK will be determined by the demandingness of the underlying theory of autonomy. For even though it seems possible to autonomously refuse at least some medically relevant information, it will depend on the specific account of autonomy exactly *which* and *how much* information can autonomously be refused. For example, some theories of autonomy incorporate a rationality condition[10] that can affect patients' ability to autonomously refuse particular information (see Section "Rational autonomy").

Second, the *strength* of the RNTK will rely on how strongly one respects autonomous decisions. It has been argued that the RNTK is not absolute.[9 11] In McDougall's (p. 26–27)[11] words, it is not a 'non-outweighable right', but rather points towards a 'particularly important interest.' This sits well with the fact that the ethical principle of respect for autonomy is not taken to be non-outweighable either, but needs to be balanced with other ethical principles such as beneficence.[12]

Third, the *nature* of the RNTK will depend on the kind of respect autonomous decisions warrant. What it takes for healthcare professionals to respect autonomous choices can be spelled out in terms of the obligations they have towards people who make autonomous choices. For example, Beauchamp and Childress indicate that healthcare professionals have a *negative* obligation not to interfere with people who act on their autonomous choice. Pugh[10] agrees, but adds that healthcare professionals also have a *positive* obligation to *enable* people to act on their autonomous choices (see also discussions on autonomy in chronic illness[13]). Such differences regarding the kind of respect autonomous decisions warrant can impact discussions regarding the nature of the RNTK. For example, it has been pointed out that the RNTK can be conceived of as a liberty, a negative claim-right, or a positive claim-right.[8 14] Grounding the RNTK in Beauchamp and Childress' conception of respect for autonomy suggests that the RNTK is a negative claim-right, while Pugh's conception of respect for autonomy would add a more positive edge to the RNTK.

In this paper, I will further explore the relationship between patient autonomy and the scope of the RNTK in the context of treatment response monitoring. I focus on treatment response monitoring because the RNTK has not been investigated in this context and it seems possible to develop novel

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challenges against grounding the RNTK in autonomy that are specific to this context. I will use incidental findings (IFs) that arise during treatment response monitoring in metastatic breast cancer care as an illustration throughout the paper (Section 1). I will consider Beauchamp and Childress' seminal account of patient autonomy (Section 2), Weimer's work on an evidence-responsiveness condition for patient autonomy (Section 3), and Pugh's theory of rational autonomy (Section 4). I selected these three accounts of autonomy because they allow me to frame the discussion in a familiar way using Beauchamp and Childress' account and formulate two novel challenges against grounding the RNTK in autonomy that are specific to the context of treatment response monitoring using Weimer's and Pugh's accounts of autonomy. By showing that these challenges are ultimately unsuccessful, I will establish the right not to know more firmly in the context of treatment response monitoring. Besides investigating the RNTK in a novel context (i.e. treatment response monitoring) and indicating the relevance of rather neglected theoretical work on evidence-responsiveness and rational autonomy for the RNTK, this paper provides an important part of the theoretical foundation for future work regarding the management of IFs in the context of treatment response monitoring. For although patients' consent regarding the disclosure of IFs is currently not obtained in the context of treatment response monitoring, the fact that the RNTK can be grounded in patient autonomy gives us a strong, albeit pro tanto, reason to reconsider current clinical practice in that respect. I will not investigate how different accounts of patient autonomy impact the strength or nature of the RNTK, given that my case does not yield new insights in that regard.

TREATMENT RESPONSE MONITORING

Consider the following case. An elderly woman was diagnosed with breast cancer 2 years ago. Her subsequent treatment consisted of surgery and chemotherapy. Recently, she experienced a relapse. Her breast cancer has spread to her lymph nodes and bones. She knows that metastatic breast cancer is incurable, but wants to receive treatment in order to prolong her life. She agrees on an intensive treatment plan that might cause significant side effects. Furthermore, it is uncertain whether the metastatic lesions will respond to that treatment. Therefore, after a few months of treatment, a Positron Emission Tomography-Computed Tomography (PET-CT) scan will be performed in order to determine whether her breast cancer is progressive, stable or responds positively to her ongoing treatment. In light of the results, the elderly woman and her medical team might come to reconsider the intensive treatment plan they initially agreed on.

In this case, treatment response monitoring is performed by way of PET-CT scans in order to trace how the patient's metastatic breast cancer responds to her ongoing treatment. On these PET-CT scans, IFs can be identified. IFs can be defined as all findings that are beyond the initial indication of the test.[15] The indication of the PET-CT scan is treatment response monitoring of the patient's breast cancer. All findings that are unrelated to her breast cancer are thus incidental. Examples of IFs in this context range from emergencies such as aortic aneurysms to lesions suggestive of synchronous malignancy in the colon or thyroid, benign-looking lesions suggestive of cholecystitis or rheumatic myalgia and medically innocuous cysts.[16 17]

In what follows, I turn to a first account of patient autonomy in order to determine the scope of the RNTK in relation to IFs arising from treatment response monitoring.

THE STANDARD VIEW

Beauchamp and Childress'[12] account of patient autonomy still constitutes the standard view in medical ethics.[18] Their account identifies three necessary and together sufficient conditions for patient autonomy. First, the patient needs to have an *understanding* of the information that is material to the decision at hand. Second, the patient needs to form a plan on the basis of that understanding and act accordingly (ie *intentionality*). Third, her decision must be made in the *absence of controlling influences* such as coercion. This account of patient autonomy applies not only to treatment decisions but also to informational decisions. By consequence, the patient can refuse information autonomously as long as she does so with understanding, intentionality and in the absence of controlling influences.

On this account of patient autonomy, it is perfectly possible for patients with metastatic breast cancer to appeal to their RNTK in relation to IFs arising from treatment response monitoring. Consider an IF such as a lesion in the colon that is suspect for malignancy. A patient can understand that such an IF might arise during treatment response monitoring and that not being informed about it can result in substantial harm due to the lost possibility to diagnose and treat the underlying pathology in an early stage. On the basis of this understanding, she can conceive and accept the further implications of not being informed about such IF intentionally. Naturally, all of this can take place in the absence of controlling influences. Therefore, on Beauchamp and Childress' account, patients can appeal to a RNTK that is grounded in autonomy when facing IFs arising from treatment response monitoring as long as minimal conditions are satisfied.

EVIDENCE-RESPONSIVENESS CONDITION

Although Beauchamp and Childress clearly indicate what is required to make a treatment decision autonomously, they have surprisingly little to say about what is required for a patient to *remain* autonomous *throughout* her long-term treatment. This theoretical lacuna has been noted in the literature on autonomy in chronic illness.[15 19] In order to compensate for this theoretical lacuna, I turn to a niche literature on an evidence-responsiveness condition for autonomy.[20–24] The basic idea is that in order for a patient to remain autonomous throughout the execution of her long-term treatment, she must be responsive to evidence about her changing medical and personal situation. In response to this evidence, she might reasonably come to reconsider her initial treatment plans. Or metaphorically, "an autonomous agent does not merely set herself on a particular course and then lock the steering wheel in place […], but must maintain some form of ongoing control over her direction in life—must keep her eyes on the road and her hands on the wheel" (p. 212).[24] The most comprehensive evidence-responsiveness condition is offered by Weimer, whose account is compatible with Beauchamp and Childress' account of autonomy. Weimer (p. 230)[24] states that the evidence patients need to be responsive to is "that which it is reasonable to expect the agent to recognise as offering a reason to reconsider her pro-attitude(s)". This sits well with Beauchamp and Childress' reasonable patient standard for information disclosure. Weimer indicates that such information arises "when a treatment proves significantly less effective than was anticipated or its side-effects more severe, when new symptoms arise or new diagnoses are made, when new treatment alternatives

are available, and so on" (p. 231).[24] IFs can result in a new diagnosis. Moreover, serious.[25][i]

IFs arising in the context of treatment response monitoring are likely to offer patients a significant reason to reconsider their ongoing treatment plan on further investigation. They might do so by impacting the overall prognosis of the patient or her ability to cope with her ongoing treatment.[26 27] Therefore, remaining autonomous throughout a long-term treatment requires the disclosure of serious IFs.

Let us consider the following claim. Making an autonomous treatment decision *implies* a commitment to remaining autonomous throughout that treatment. If so, then patients with metastatic breast cancer who make an autonomous treatment decision cannot appeal to their RNTK in order to refuse being informed about serious IFs given that remaining autonomous necessitates their disclosure. The underlying idea is that if the burdens of making the treatment decision autonomously (eg digesting information, sorting through the options, etc.) do not outweigh the value of autonomous decision-making, it is difficult to see how the arguably more limited burden associated with remaining autonomous could outweigh the value of remaining autonomous.

However, the burdens associated with remaining autonomous might increase as the patient's health deteriorates, as much as the patient might come to reassess the value of autonomous decision-making. Therefore, making an autonomous treatment decision can at most be taken to imply a *defeasible* commitment to remain autonomous throughout that very treatment (ie the claim under consideration needs to be mitigated). By consequence, the patient can appeal to her RNTK once her health state deteriorates or she comes to reevaluate her decision-making strategy.

Furthermore, the burdens associated with remaining autonomous can *reliably be expected* to increase as the treatment progresses. With these prospects in mind, patients might reasonably take a risk at becoming non-autonomous during their future treatment by refusing information regarding serious IFs from the very start. They would, thereby, in some respect, reject a commitment to remaining autonomous throughout their future treatment. In short, making an autonomous treatment decision does not preclude patients from simultaneously and autonomously rejecting information about any IFs.

Two remarks are in order. First, even if an evidence-responsiveness condition does not render it impossible for patients to appeal to their RNTK in the face of even serious IFs, an evidence-responsiveness condition offers an interesting way to challenge patients who do appeal to their RNTK in this context. After all, this information refusal would, at first sight, be in tension with the way the patient previously made her treatment decision. Second, contrary to Beauchamp and Childress, and underlying the previous remark, the patient's treatment decision and her decision regarding the management of IFs are not considered independently here. This link is provided by the evidence-responsiveness condition which acknowledges that choosing a treatment autonomously and autonomously reconsidering that very treatment in light of novel evidence are closely related endeavours.

[i]I use the term "seriousness" in a rather encompassing way to indicate the medical and personal relevance of an IF. Given that the validity of my argument does not depend on the IFs being serious in a particular way, I do not differentiate between "dimensions" or "aspects" of seriousness.

RATIONAL AUTONOMY

Beauchamp and Childress' account of patient autonomy does not include a rationality condition. Pugh[10] has recently argued that Beauchamp and Childress' conditions of understanding, intentionality and non-control should be complemented with a rationality condition. The conception of rationality Pugh incorporates into his theory of autonomy is procedural rather than substantive. This means that whether or not a patient's decision is autonomous does not depend on *which* values and desires the patient endorses, but exclusively on *how* the patient's values and desires *relate* to each other and the decision. That is, as long as the patient's decision sufficiently coheres with the patient's values and desires, the choice is said to be rational. It is important to emphasise that the patient need not choose what is *most* coherent with her values and desires in order to be rational. All that is required for choosing rationally is that the choice coheres with the person's values and desires to a *sufficient* degree. In other words, you can be rational without being fully rational.

The treatment decisions patients with metastatic breast cancer make tell us something about their value pattern. At the bare minimum, it indicates that they value the benefits and harms associated with that treatment in such a way that the former outweigh the latter. Furthermore, it seems fair to assume that the values and desires of patients with metastatic breast cancer will not change drastically in the limited time between the choice to embark on a treatment for their breast cancer and their choice regarding the management of IFs. Therefore, the values that drive the treatment decision can be taken to drive the decision regarding the management of IFs as well. The question then becomes whether metastatic breast cancer patients can rationally choose to refuse IFs in light of the values and desires they committed themselves to by accepting their treatment for breast cancer.

In the best case scenario, patients with metastatic breast cancer can expect to obtain about five extra life years by undergoing intensive long-term treatments that come with more than significant side effects.[28 29] Compare this rough balance of benefits over harms with an IF such as a benign-looking lesion in the thyroid. In such cases, there is a relevant false positive rate (ie a significant number of those IFs will not lead to the diagnosis of thyroid pathology on further examination). Moreover, invasive and potentially harmful investigations will need to be performed in order to obtain a diagnosis of a disease which would, if undiscovered, not have been very likely to significantly affect the patient's health anyway.[16 17] Together with the psychological impact of such diagnostic work-up, it seems perfectly well possible that a patient with metastatic breast cancer does not take the benefits associated with such an IF to outweigh its harms. In other words, patients with metastatic breast cancer can rationally decide to forego information about non-serious IFs, such as benign-looking lesions in the thyroid suspected of thyroiditis.

More serious IFs, such as a lesion in the colon that is suspect for synchronous malignancy, have a more favourable benefit-harm profile. After all, the medical benefits associated with the early detection of a synchronous colon cancer that might affect the overall prognosis of the patient vastly outweigh the potential harms associated with the investigations required to secure a diagnosis (eg biopsy). At first sight, then, it seems difficult to maintain that patients with metastatic breast cancer who take the benefit-harm profile associated with their treatment for metastatic breast cancer to be acceptable can rationally refuse information about serious IFs that come with a better benefit-harm profile.

For two reasons, however, it does not seem to be radically impossible for a metastatic breast cancer patient who chose to receive an intensive long-term treatment to rationally forego information about even serious IFs. First, particular patients might be so devastated by the prospect of being diagnosed with a synchronous cancer that this psychological harm does offer a very weighty reason against disclosure. Second, rationality requires that the patient's decision *sufficiently* coheres with her values and desires. Therefore, even if refusing serious IFs might not be fully rational in light of the associated medical and psychological benefits and harms, it might perfectly well be rational.

Two remarks are in order. First, even if accounts of rational autonomy do not make it impossible for patients to appeal to their RNTK in the face of even serious IFs in the context of treatment response monitoring for metastatic breast cancer, a rationality condition does offer grounds for challenging patients who wish to appeal to their RNTK in such cases. After all, if the patient takes the benefit-harm profile of her treatment to be acceptable, it is, at first sight, unclear why the arguably even better benefit-harm profile of serious IFs is unacceptable to her. Second, and underlying the previous remark, the link a rationality condition draws between patients' treatment decisions and their decisions regarding the management of IFs is different from the link the evidence-responsiveness condition provided. For while the latter points towards the fact that the particular way in which patients make treatment decisions (ie autonomously) might have implications for which evidence they should be responsive to during their treatment, the former points towards the fact that the particular treatment decisions patients make might rationally restrict which decisions they can make regarding the management of their IFs.

CONCLUSION

I have explored how different accounts of patient autonomy can affect the scope of the RNTK in relation to IFs in the context of treatment response monitoring. I formulated two challenges towards grounding the RNTK in autonomy on the basis of Weimer's work on evidence-responsiveness and Pugh's account of rational autonomy. Neither of these challenges proved successful in the sense that they did not make it radically impossible for patients to autonomously refuse IFs in the context of treatment response monitoring. Nevertheless, they do make it relatively more difficult to autonomously refuse IFs in this context than Beauchamp and Childress' account of patient autonomy did. By addressing these challenges, I have more firmly established the RNTK in the hitherto overlooked context of treatment response monitoring.

This paper suggests an important line of further research. At present, patients' consent is not obtained before disclosing IFs in the context of treatment response monitoring. However, the theoretical territory charted in this paper indicates a very strong, albeit pro tanto, reason to challenge current disclosure policies. Therefore, future work should explore whether obtaining patients' consent regarding the disclosure of IFs in the context of treatment response monitoring is overall ethically desirable.

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