RECONCEPTUALIZING AUTONOMY FOR BIOETHICS

Genomics Highlights the Need for Normative Competence

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ABSTRACT

Autonomy plays a central role in bioethics, but there is no consensus as to how we should understand this concept. This paper critically considers three different conceptions of autonomy: the *default conception* prevalent in bioethics literature; a broader *procedural account* of autonomy drawing moral philosophical approaches; and a *substantive, perfectionist* account. Building on Rebecca Walker's critique of the *default conception* of autonomy, we will argue that a *substantive, perfectionist* approach both fulfils Walker's criteria for a conception of autonomy in bioethics and lends itself to application in practical scenarios. In so doing, we draw on scenarios from genomic medicine to show that a *substantive, perfectionist* approach not only offers a more conceptually adequate understanding of autonomy in more complex cases, but also lends itself to practical application by helping health professionals identify how they can maximize people's capacity to exercise their autonomy.

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INTRODUCTION

The concept of autonomy plays a central role in bioethics[1], but there is no consensus as to how we should understand it. The conception of autonomy deployed in applied ethics[2] can have crucial ramifications when it is applied in real world scenarios, so it is important to be clear. However this clarity is often lacking when autonomy is discussed in the bioethics literature. In this paper we outline three different conceptions of autonomy, and argue that a *substantive, perfectionist* approach meets the theoretical requirements for an account of autonomy and also provides practical guidance. As Rebecca Walker argues, bioethics requires a more conceptually adequate account of autonomy than the *default conception*. We will draw on her requirements for a theory of autonomy, but will also suggest how this approach can be relevant to practical scenarios. If patient autonomy is to be respected in real-world situations then we need to have an account of autonomy that allows us to know both how to respect it, and when we have successfully done so.

Although widely debated in the literature, one of the most influential accounts of autonomy is derived from Beauchamp and Childress' *Principles of Biomedical Ethics*. We will refer to this as the *default conception*, as it tends to be the assumed understanding of autonomy in bioethics when one is not otherwise specified. We will follow Walker's critique of this account and draw on scenarios from genomic medicine to highlight the importance of a *broader* view[3].

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[1] Since the literature refers to bioethics, biomedical ethics and medical ethics variably, it is not straightforward to use these terms clearly. We will use the term bioethics to refer to the ethical analysis of issues arising in the health and medical sciences which have a moral dimension. We recognize that the term "medical ethics" is often taken to refer to ethical issues arising specifically in medical practice, and "biomedical ethics" is restricted to ethical issues arising in health care more broadly, however for the purposes of this paper there are no significant difference between these terms and "bioethics". Hence we will favour the term bioethics but use all three interchangeably when the literature we cite does so.

[2] We recognize that the term "applied ethics" can be understood as straightforwardly applying moral theories to real-world scenarios, and consequently that the term "practical ethics" is sometimes used to indicate practical consideration of ethical issues. Despite this critique, we prefer the term "applied ethics" as it is more widely accepted.

[3] A note on terminology: by a broader account of autonomy we mean one that incorporates elements more fully developed in the moral philosophical literature, such as self-determination, critical reflection, authenticity, and that is sensitive to the person's social and relational context. Broad conceptions are distinct from a "narrow" understanding of autonomy, which focuses on informed consent as the process to achieve autonomy.

In pursuit of a more conceptually robust account of autonomy, we then consider *procedural accounts*, which determine the criteria for autonomy in terms of the process or procedure by which autonomy is exercised. These accounts are content-neutral in that the determination of whether a person has acted autonomously does not require any reference to the content of their action or decision, only the procedure by which they made it. Drawing primarily on Gerald Dworkin, we show that while such approaches address some concerns, their content neutrality is problematic for bioethics. Procedural conceptions of autonomy are distinguished from substantive accounts, which require some reflection on the content or substance of a person's actions or decisions.

Finally, we argue for a *substantive, perfectionist account*, based on Raz's conception of autonomy; one that incorporates the notion of normative competence. Normative competence refers to the ability of individuals to evaluate the different options or choices available to them by reflecting critically on their normative content. Such a substantive approach not only meets Walker's criteria for a theory of autonomy, it also provides practical guidance for how to respect autonomy in healthcare scenarios.

THE DEFAULT ACCOUNT OF AUTONOMY IN BIOETHICS

The principle of respect for autonomy is one of the central tenets of bioethics. While the importance of respecting patients and obtaining their consent was implicitly evident in the early bioethics literature (including foundational documents such as the *Declaration of Geneva* (World Medical Association 1948), the *International Code of Medical Ethics* (World Medical Association 1949), and the *Belmont Report* (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research1979), it was in Beauchamp and Childress's influential book *Principles of Biomedical Ethics*, first published in 1979 and now in its seventh edition (Beauchamp and Childress 2013) that the principle of respect for autonomy was more clearly specified. While this paper will not debate the validity of the four principles of biomedical ethics as articulated by these authors – respect for autonomy, beneficence, non-maleficence and justice – it is generally acknowledged that they have been influential in the bioethical discourse. Hence the concept of autonomy, while often not clarified, has a tendency in the bioethics literature to default to the one articulated by Beauchamp and Childress. For example, Hodgson & Spriggs in their articulation of a practical

account of autonomy for genetic counselling, do not define how they understand the term 'autonomous choices', the facilitation of which is one of the aims of genetic counselling. In another example, Bunnik et al examine the tension between new genomic and genetic tests and the principle of respecting patient autonomy. However their analysis focuses on the role of information in informed consent rather than autonomy per se (Bunnik et al. 2013). This tacit equating of autonomy and informed consent[4] is not unusual in bioethics, and Hildt recognizes the tendency in medicine to emphasize a narrow conception of autonomy, that focuses on provision of information (Hildt 2009).

Beauchamp and Childress's theory of autonomy emphasizes three conditions that must be met in order for a decision to be autonomous: intentionality, understanding and noncontrol (Beauchamp and Childress 2013). Intentionality means that the decision or action cannot be accidental; an agent has to intend to act in that way, it must be a deliberate action. The requirement for understanding says that the agent must have a sufficient grasp of the relevant facts and information in order to make the decision or take that action. While Beauchamp and Childress consider intentionality to be a binary property, understanding can vary in degrees. Due to this variability of understanding, a threshold must be specified as the acceptable level of understanding required in order for the action to be considered autonomous (and who should make this specification?). The third condition for autonomy is referred to as 'noncontrol', which means freedom from either external or internal controls. External controls include coercion or other undue influence by another person, while internal controls are mental states such as addiction or some forms of mental disorder that can interfere with decision making processes. Similar to the requirement for understanding, noncontrol is a scalar property, so a certain level (threshold) of noncontrol is needed in order for an action or decision to be considered autonomous.

The *default conception* of autonomy emphasizes the requirement that patients or research subjects *not* be coerced, unduly influenced, asked to decide with insufficient information, and so on. In other words, it is a primarily negative conception of autonomy since it focuses on what we must refrain from doing if we are to respect autonomy.

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[4] Notwithstanding this assumption, both these papers make valuable contributions to considerations of consent for genomic testing.

Beauchamp and Childress do also consider health professionals' positive obligations to respect autonomy, which includes a requirement to undertake "actions that foster autonomous decision making" (Beauchamp and Childress 2013, 107) and the disclosure of relevant information. They focus primarily on what patients or research subjects need in order to decide autonomously, and doing so leads to an emphasis on decisions and how they are influenced. They turn their focus to mechanisms that can prevent undue influence, lack of information, and so on, thereby giving a detailed account of the requirements for informed consent. For Beauchamp and Childress, the requirement to respect autonomous choices provides the justification for informed consent procedures, and in fact they go so far as to say that "The basic paradigm of the exercise of autonomy in health care and in research is *express* or *explicit* consent (or refusal), usually informed consent (or refusal)" (p. 110).

Although this approach has its shortcomings (which are explored below), there are also benefits. There is no doubt that the negative requirements that obligate medical practitioners and researchers not to coerce, deceive, manipulate, or otherwise unduly influence patients and research participants are ethically important. Informed consent procedures, at a minimum, go towards reducing undue deception or coercion of patients, which has clear benefits. Such procedures also lend themselves well to practical application; they are concrete processes that institutions, medical practitioners and researchers can develop and implement, to fulfil certain ethical obligations to patients and research participants. In addition, Beauchamp and Childress' tripartite requirements for autonomy very closely match many jurisdictions' legal standards for informed consent, which allows health professionals (rightly or wrongly) to claim they are achieving ethical and legal practice concurrently.

However, this focus on processes and the negative obligations on health professionals has led to a narrowing of the concept of autonomy. Both the importance and ready implementation of Beauchamp and Childress' account of autonomy have contributed to its prevalence in medical ethics (Walker 2008), but this has come at the expense of a broader, more conceptually adequate understanding of the nature of autonomy. Informed consent, for Beauchamp and Childress, is the mechanism by which patient autonomy is

respected, but our contention is that there is more to autonomy than intentionality, understanding and noncontrol.

We will now outline Rebecca Walker's critique of this *default conception* of autonomy and her argument that a different concept of autonomy is required in bioethics. However, while accepting Walker's argument, we will reassess her conclusion that this is too hard to translate into practice. We draw on developments in genomic medicine to claim instead that autonomy, broadly understood, can be applicable to bioethics by considering the role that information plays in fostering autonomy. After this we will address concerns about *procedural accounts* of autonomy in an attempt to defend a *substantive, perfectionist* understanding of autonomy, one that both offers a conceptually adequate account of autonomy and can be of practical use in applied contexts.

Walker's Critique of the Default Conception: Failures of Self-Rule

Rebecca Walker (Walker 2008) has provided a set of criteria for assessing conceptions of autonomy.

She suggests that an adequate conception of autonomy should be able to do the following:

(1) Identify non-autonomous actions

(2) Explain what makes choices or actions autonomous

(3) Account for why we ought (morally) to respect autonomy.

Walker argues that medical ethics needs a new concept of autonomy, because what she calls "the common view of autonomy" (p. 595), which she identifies as the prevailing view as set forward by Beauchamp and Childress, fails in three important ways. To illustrate these failures, she makes use of three "problem cases" that demonstrate how the default conception of autonomy fails to meet the above criteria. In her scenarios, Beauchamp and Childress' requirements for autonomy are met, yet the patient fails to be autonomous:

(a) "Weak-willed William" who does not follow his physical therapy regime after knee surgery, despite his intentions to do so and his understanding of the consequences;

(b) "Desiree," a woman who strongly endorses feminist values and considers plastic surgery unacceptable, yet experiences an overwhelming desire to undergo plastic surgery herself to the point that she approaches a surgeon; and

(c) "Tim," a cancer patient with strong chances of survival only if he undergoes immediate treatment, who refuses treatment due to a temporary loss of the will to live, which he acknowledges as such. (Walker 2008 597-598)

In each of the cases, a person makes a decision[5] which is inconsistent with their values, long-term goals and preferences due to an impulsive or short-lived desire. However, each choice is made by a person who has a sufficient degree of understanding of the relevant facts, as well as their own values and goals, and who is not subject to the kinds of internal or external controls that contribute to a failure to be autonomous. In other words, they are intentional (each person acts deliberately), the patients all understand the relevant information, and none of them are being coerced; so they all meet Beauchamp and Childress' criteria for autonomous decisions. These decisions are the result of a different kind of problem with internal control, one not captured by Beauchamp and Childress' account of autonomy.

The inability of the default conception of autonomy to identify these actions as non-autonomous relates to the content-free nature of this understanding of autonomy. That is, this view of autonomy does not require any consideration of the content or substance of the actions, only the process or procedure by which they were decided. Walker argues that some decisions that are subject to internal controls would be considered autonomous. Her argument is that the *nature* of the internal control is what matters. Some internal factors which control people's choices and actions – such as oppression or weakness of will – would render the resulting actions non-autonomous. However other internal factors are central to a person's conception of self, and actions controlled by such factors – for example love for one's child, or a moral principle – would be considered autonomous. We will return to the shortcomings of content-free conceptions of autonomy in Section 0, as it is also a key problem with procedural accounts of autonomy.

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[5] For the purposes of this paper, there is not a substantive distinction between the terms "decision" and "choice". Although one might be more relevant or applicable in a given context than another, we will use them more or less interchangeably.

Walker also identifies another important reason why the default conception of autonomy has failed to identify the non-autonomous actions in her problem cases, namely that this view mostly tends to consider autonomy as a property of choices or decisions. In her problem cases, the person is taken to be otherwise autonomous, but their choice in this instance is not autonomous because it fails (in various ways) to reflect the agent's authentic goals and preferences. It is important to emphasize that Beauchamp and Childress outline conditions for autonomous *decisions*, not persons. The literature tends to apply the term *autonomy* in different ways; it has been used most often in the medical ethics literature as a property of decisions or choices (Wilson 2007, Beauchamp and Childress 2013), as opposed to a property of persons which is more prevalent in the moral philosophical literature (Dworkin 1988, Frankfurt 1971). In discussions of autonomous persons, their lives are sometimes referred to as having (or not) the property of autonomy, and on a robust Kantian interpretation, autonomy is considered as a property of 'willing' and principles for action (O'Neill 2002). Application of the term in such different ways has contributed to imprecision in how it is used.

The treatment of autonomy in medical ethics as – predominantly – a property of decisions secured by informed consent has made it more difficult for medical ethics to align with the broader (but largely separate) philosophical debate about the concept of autonomy as a property of persons or agents. The core business of medical ethics is to connect theory and practice in a meaningful way (Jennings 2016). One important task in this field is to synthesize the rich moral and political philosophy literature that informs a concept such as autonomy in a way that facilitates its application in the medical context. The disconnect between autonomy as a property of persons, as it is generally conceived in the philosophical literature, and as a property of decisions in the medical context poses a problem in making this translation. The lack of a single approach has made the requirements for autonomy in practical contexts more difficult to discern.

Walker claims that the failure of the currently dominant conception of autonomy in bioethics is symptomatic of a more general phenomenon, namely that conceptually adequate accounts of autonomy are not readily applicable to practical issues in biomedicine. We will argue against this conclusion, and show instead that a broader conception of autonomy requires an emphasis on more factors than just informed consent

processes, which is where the default conception naturally leads. Examining the role of information and the nature of the communicative interchanges between patients and clinicians in which consent is given or refused is a more fruitful way of respecting patient autonomy. Such an approach lends itself to a broader notion of autonomy that refers to the patient's social and relational context, and emphasizes the authenticity of their preferences and critical reflection upon their wider goals. We argue that this shift of focus is how a conception of autonomy that is adequate by Walker's criteria can also be useful in practice.

The Role of Information

A significant problem with the *default conception* of autonomy, with its focus on understanding, is that it emphasizes provision of information to patients. In the context of informed consent processes, this is often taken to be a requirement to provide maximum amounts of information. Information provision is a particularly relevant consideration in genomic testing, where the volume and dynamic nature of possible findings mean that a person can never be 'informed' in the manner that Beauchamp and Childress would advocate as necessary. The argument that the requirement to respect autonomy provides the justification for informed consent reinforces the obligation to provide information. Beauchamp and Childress specify that respecting autonomy "obligates professionals in health care… to disclose information, to probe for and ensure understanding" (Beauchamp and Childress 2013, 107). As outlined above, with informed consent taken to be the mechanism by which autonomy is respected there is a focus in applied contexts on providing information as a means of ensuring patients have enough information to make an informed decision. The emphasis on information provision was not necessarily Beauchamp and Childress' intent, however it has been a practical effect of their influential account of autonomy.

It has been disputed whether provision of comprehensive information is a necessary requirement for autonomy. Tom Walker (2013) queries the necessity of requiring a fully informed consent in order to respect patient autonomy. His argument is relevant because if

comprehensive information[6] is not the key to respecting patients' autonomy, then this lends weight to our contention that the emphasis on providing substantial (and increasing) amounts of information is not necessary for autonomy, and could actually be counterproductive to enhancing patient autonomy. Tom Walker claims that while only an autonomous patient can give informed consent, the requirement to respect autonomous choices does not imply a requirement to obtain fully informed consent.

On the *default conception of autonomy* in bioethics, the mechanism for respecting autonomy is informed consent. Therefore, an informed consent process must take place in order to produce an autonomous choice or decision, and this choice is what ought to be respected. Walker tests this approach by considering how to proceed if a patient has not made an autonomous choice. If the patient has not (or cannot) made an informed choice, then there is no guidance for the health professional because there is no autonomous choice that they are obliged to respect. For example, if a patient refuses a treatment that they do not understand, then a health professional (arguably, on the *default conception*) has no obligation to respect that choice. If a choice is not adequately informed, then it cannot be autonomous. Walker also acknowledges Beauchamp and Childress's additional (positive) requirement that doctors have an obligation to foster autonomous decision-making. This obligation translates into a requirement for doctors to provide the information required to make an adequately informed decision to consent to or refuse treatment. This requirement is distinct from the obligation to respect autonomous choices. Walker's contention is that the requirement to respect autonomous choices does not in itself confer on health professionals an obligation to secure an autonomous decision.

A key problem that Walker (like Rebecca Walker) has identified is the slippage between autonomy as a property of the person, and autonomy as a characteristic of a particular choice. Respecting the autonomy of a person is not the same as respecting their autonomous choices. Tom Walker's contention is that in order to respect a person's autonomy, it is only their *consent* that is required, not their *informed consent*. He argues that in order to consent to a treatment, a patient requires a general understanding of what will happen to them, but not the comprehensive risk benefit analysis that is often required

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[6] Walker's argument relates to the provision of information "over and above information about what in general terms is to be done to them", such as comprehensive information about the risks and benefits of a proposed procedure, alternatives, and so on.

under formalized informed consent procedures[7]. Walker's argument is consistent with O'Neill's contention not to provide extensive amounts of information (O'Neill 2003). She argues that in order to support the goals of informed consent, information needs to be provided in a way that is flexible and responsive to patients' desires for varying amounts of information. On this approach, patients are provided with a general overview of the proposed intervention, and have the opportunity to seek more information if they choose.

Tom Walker's argument that *consent* rather than *informed consent* is what matters when it comes to respecting patients' autonomy highlights a key problem that arises when autonomy is understood as a property of choices or decisions. If autonomy is taken to be a property of choices – which must be informed choices – this leads to a requirement to provide escalating (if not limitless) amounts of information to ensure that the choice is fully informed, and hence autonomous. Given that autonomy is a scalar property, there is an implication that the more information is provided, the more autonomous the decision becomes. While some amount of information is necessary in order to consent to a medical intervention, an autonomous person should be able to access the amount of information that they feel they require in order to make a decision. As demonstrated by increasingly complex informed consent requirements,[8] too much information can have a confounding effect and actually undermine the patient's understanding or ability to absorb the information.

Manson and O'Neill (2007) identify the drive to provide increasing amounts of information as the product of a series of misconceptions about communication. They argue that a focus on understanding the pertinent features of communicative transfers can shape a more effective method for informed consent. On their view, it is more fruitful to focus on the communicative and epistemic norms that underpin our communicative interactions with other agents, rather than the transfer of information. The focus on providing information has arisen in the context of certain metaphors about communication that

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[7] By contrast, the *Declaration of Helsinki* which safeguards the rights of human participants in medical research sets out in Article 26 a comprehensive list of the information which should be provided to research participants, some of which is detailed scientific and institutional information related to the study which might not increase research participants understanding of the likely impact on them of participation. http://www.wma.net/en/30publications/10policies/b3/index.html accessed 19/08/16.

[8] See, for example, the sample consent forms for genomic research provided by the US National Institutes of Health, available at: https://www.genome.gov/27559023/informed-consent-sample-consent-forms/ (accessed 23/03/2017).

Manson and O'Neill call the conduit/ container metaphors, which describe information as 'stuff' that can be held in a container (such as a document or a person) and transferred to another receptacle. In contrast to this metaphor, they argue that informing and communicating occur in communicative acts that depend on a detailed set of communicative and epistemic norms. These norms tend to be obscured by the prevailing metaphors about information and communication. Communicative acts are context-dependent, and take place against the background of the knowledge and attitudes of both the speaker and audience. They are fundamentally interactive and require the engagement of both parties. On such a view, the quantity of information provided is not the most relevant feature of the exchange. Rather, ensuring proper consent requires a focus on the appropriate kind of interaction between the patient and clinician. Similarly, the quantity of information cannot be taken to be an indicator of the patient's degree of autonomy. We will argue that factors such as whether the patient's choices appropriately reflect his or her authentically held goals and preferences are more relevant instead. Of course some information is required to make such a determination, but the process will vary for each patient and their preferred approach.

The problem with providing too much information is also related to the issue of choices. In explicating his perfectionist theory of the requirements for the capacity to live autonomously, Raz (1986) identifies the availability of an adequate range of options as one of the conditions. He argues that a greater number of options are not necessarily desirable, what is important is that there are enough options that differ in important ways. Too many options can actually undermine autonomy, because of what Dworkin refers to as the 'transaction costs' of making a decision (Dworkin 1988). If a substantial number of options are offered to a patient, then they must invest a significant amount of time and effort to acquire enough information to make a reasonable or rational choice, and then go through the process of evaluating all the options to make the choice. Subsequent to making such a decision, a person might be plagued by doubt as to whether they have made the correct choice. A patient faced with a medical decision is already likely to be stressed and vulnerable, so the process of working through the information required to assess a broad range of options could represent a burden to them rather than enhancing their autonomy.

Autonomy in the Genomics Context

We can see the shortcomings of focusing on the provision of information as a way to respect patient autonomy in medical decision making in some areas of medicine such as genomics. The default model of respecting autonomy via informed consent requires health practitioners to disclose all relevant information to the patient, including details about their condition, options for testing and treatment, likely outcomes of proposed interventions, the limitations and risks of interventions, and so on. Bunnik et al (2013) argue that even for genetic tests in relation to a single condition, this represents a significant amount of information to process, and requires several counselling sessions. However for genomic testing, which involves looking at many genes at once and which can include looking at every expressed gene or the whole genome (and which can also give rise to dynamic or uncertain information), adequately informed consent in its traditional form quickly becomes a practically impossible goal. Genomic testing that may identify additional variants (of either known or unknown significance) complicates provision of pre-test information. Appelbaum et al propose four different models for informed consent in genomics (Appelbaum et al. 2014) which take varying approaches to informing patients of the breadth of possible incidental findings, including when, how and by whom the information is provided.

The difficulty of providing adequate information in genomics has been recognized. For instance, in its 2013 recommendations on reporting incidental findings, the American College of Medical Genetics and Genomics, whose 2013 policy statement states:

> To respect preferences in the same manner as with targeted testing, the patient whose exome or genome is sequenced would have to undergo an extensive, and possibly overwhelming, amount of genetic counselling for numerous conditions unrelated to the primary indication for sequencing. (Green et al. 2013, 568)

While these recommendations are controversial for other reasons and have since been softened, this comment demonstrates recognition by practitioners in genomics that providing comprehensive information – or even sufficient information to grasp the potential outcome of sequencing – is an impractical notion in this context. Similarly, Koenig explains that when the human genome was first mapped the Clinton administration's Advisory Committee on Genetic Testing stated that when genomic testing became widespread "the ideal of full disclosure… would collapse" (Koenig 2014 33).

To illustrate this, consider Amendola et al's example of a sixteen month-old boy diagnosed with a brain tumor (Amendola et al. 2015). His family were recruited to a study involving somatic tumor and germline whole exome sequencing in childhood cancer patients. The results returned to participants included: tumor-specific variants with clinical utility (i.e. capacity to influence clinical care); variants in cancer susceptibility genes that are either pathogenic or have uncertain significance; and other 'incidental' findings that are medically actionable. In this child's case there were no tumor-specific variants that could impact his clinical cancer care, nor were there any (known) pathogenic variants in genes associated with cancer predispositions. However, the child did have a maternally inherited pathogenic variant in the *SCN5A* gene that has a known association with Long QT syndrome, a rare heart condition. These results had several implications for the family: both the child and his mother were referred to cardiology for assessment and ongoing follow up. Cardiology evaluation determined that the child was "genotype positive, phenotype negative" – namely that he had no indication of cardiac symptoms. In addition, the lack of a clinically significant tumor-specific variant meant that the child's cancer care should proceed as originally planned.

This example highlights the layers of informational complexity that can arise in the context of genomics, and the implications that can arise for other members of a patient's family. It would not have been plausible for the clinical team to conduct an informed consent process that covered all the possible findings that could have arisen as a result of the blood and tumor exome sequencing[9]. However, in the process of pre-test and post-test clinical interactions, the healthcare team had opportunities to find out what was important to the family. The father expressed that his chief concern was whether the tumor-specific exome sequencing would find a variant associated with chemotherapy resistance, and since this was not found his primary response to the test results was relief. Regarding the incidental finding, this case shows the importance of communicating to patients (and, where appropriate, their families) the potential variation and uncertainty of genetic results.

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[9] It is recognized that this case is problematic for several reasons, including uncertainty about the penetrance of the genetic variant associated with LongQT syndrome. It is therefore subject to debate whether this finding should have been returned in the absence of a family history. However, this complexity is out of scope for the purposes of the current discussion.

When considering what would constitute adequate information to make a fully informed choice before undergoing genomic testing, there are several characteristics of the information that need to be discussed. Genomic information can be voluminous and highly complex, but it can also be ambiguous. It almost always requires interpretation to be meaningful. Newson et al (2016) propose a definition of 'genomic uncertainty' that arises both from the characteristics of the information itself – particularly its probabilistic nature, ambiguous implications, and complexity – and also from how the clinician or patient interprets or understands that information. Interpretation of results from genomic testing is mostly based on analyses of large population databases that are neither representative nor complete. A further dimension of complexity is that results are typically probabilistic in nature. While people can generally grasp probabilistic reasoning, it can be difficult to make sense of the implications of a probabilistic result when it is layered with other dimensions of complexity and ambiguity. An identified variation might be thought to be correlated with a certain phenotype or predisposition, but the penetrance can be variable and the strength of the correlation imprecisely known. To maximize the patient's capacity to be autonomous, the inherent uncertainty of genomic findings must be acknowledged and appraised in the medical decision making process, and in particular in the communication between clinicians, patients, and their families.

The breadth of possible results is also difficult to communicate to patients. As in the example of testing the sixteen month-old given above, if testing is undertaken in an attempt to explain a known condition, without significant filtering of data[10] there is always the possibility of identifying a variant unrelated to the condition or of unknown significance. Since in this case the child did not display a phenotype for the supposedly medically actionable finding of the genetic variant associated with Long QT syndrome, the typical notion of medical test results being 'good' or 'bad' news does not seem to fit. Rather, clinicians have an opportunity and responsibility to help patients understand how to respond to results.

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[10] It is recognized that some filtering of data is inevitable in all genomic sequencing. While one approach can be to target testing to ensure the findings are relevant to the core clinical question, there remains a possibility that unrelated variants will be found. It is beyond the scope of this paper to discuss different approaches to filtering in genomic testing.

We have argued that the idea of providing enough information to allow patients to make an adequately informed decision is neither practical nor desirable, and is nearly impossible in the context of genomics. There is also empirical evidence that patients do not wish to be overwhelmed by excessive information (Brothers et al. 2016). In considering how we ought to respond to genomic uncertainty, Newson et al (2016) point out that while genomic testing is often sought with the goal of reducing uncertainty, it can fail to do so and might introduce new kinds of uncertainty. They argue that uncertainty should not be treated as something negative that we should seek to eliminate, and that it should be acknowledged both prior to and after genomic testing. They highlight the importance of engaging with the various forms of uncertainty at all stages of testing, and of health professionals working with patients to identify responses to different kinds of uncertainty. They emphasize the importance of building resilience and promoting patients' welfare, while acknowledging the complexity of communication in the context of genomic testing. They point out that enabling patients to choose autonomously requires health professionals to engage in a more interactive discussion with patients to facilitate their decision making process, rather than providing them with the relevant information and leaving them to decide. Approaching genomic testing via the concept of uncertainty serves to highlight the shortcomings of the default conception of autonomy, which relies heavily on a traditional informed consent model. This approach does not allow for a value-neutral engagement between patient and practitioner around the uncertainties that exist prior to genomic testing, and which might arise following it, because choices about how to present information and options make a difference.

We have seen that the default conception of autonomy in biomedical ethics, and its associated focus on information provision, is highly problematic in the context of genomic medicine due to the complexity of the information being sought and disclosed and the different dimensions of uncertainty of genomic information. Rebecca Walker's critique of this conception of autonomy also highlights the shortcomings of taking autonomy to be a property of decisions. Using a procedural account of autonomy, which emphasizes (among other aspects) the importance to autonomy of a critical process of self-reflection, may provide a viable alternative.

PROCEDURAL ACCOUNTS OF AUTONOMY

As outlined above, the focus in biomedical ethics on negative obligations of healthcare professionals has led to the dominance of informed consent processes as the mechanism by which patient autonomy is respected.[11] Having argued that this default conception of autonomy falls short in several ways, we will now consider a broader philosophical account of autonomy and how it can be applied in bioethics. We focus on (Gerald) Dworkin's account (Dworkin 1988) as a notable and influential example of this type of theory. Dworkin is not the sole proponent of such a view, but his and Frankfurt's (Frankfurt 1971) are among the more prominent accounts of autonomy as a capacity of persons based on a procedural approach.

Dworkin's Autonomy

Dworkin provides a selected sample of uses of the word 'autonomy' to illustrate the imprecision of the concept's use. It has been variously described as freedom (both 'freedom to' and 'freedom from'), sovereignty over oneself, a combination of freedom and responsibility, a characteristic requiring rational reflection about rules, an ability to choose how to think and act, freedom from obligation, and being ultimately responsible for one's own decisions (Dworkin 1988). Dworkin goes on to outline the desirable qualities of a theory of autonomy, which include logical consistency, empirical possibility and ideological neutrality. An adequate account should also explain why autonomy is considered valuable, and must be relevant to both the moral principles and the judgements (whether empirical, normative or conceptual) that we make about autonomy. These features identified by Dworkin are reflected in Rebecca Walker's third requirement, namely that an account of autonomy should explain why we ought (morally) to respect it.[12] Building on these requirements, Dworkin develops the following definition:

> [A]utonomy is conceived of as a second-order capacity of persons to reflect
> critically upon their first-order preferences, desires, wishes, and so forth and the

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[11] That is, the emphasis has been on what healthcare practitioners should *avoid* doing – namely coercing patients or allowing them to make uninformed decisions.

[12] The question of why, morally, we ought to respect autonomy is important but is beyond the scope of this paper.

capacity to accept or attempt to change these in light of higher-order preferences
and values. By exercising such a capacity, persons define their nature, give meaning
and coherence to their lives, and take responsibility for the kind of person they are.
(Dworkin 1988, 20)

This is a robust definition of autonomy as a property of persons, and despite some debate[13] it remains relevant today as a basis for our understanding of the concept of autonomy. We will argue for an account of autonomy that differs from Dworkin's in that it takes the content of decisions and actions into account.

Dworkin is clear that autonomy is a property of persons or agents (rather than of decisions). and this clarity in itself goes some way to enabling a more specific understanding of the concept. On his view, failures of self-rule such as those in Walker's problem cases above could be corrected through the process of critical reflection and adjustment. Her "weak-willed William", upon realizing that he was not following through with his therapy regime, could examine his beliefs and desires – which all support him doing the exercises – and consider the reasons why he is not doing the therapy. It could be that he has too great a need for rest, other competing priorities, or other desires that are stronger than his desire to achieve the benefits of the prescribed therapy. He could then either seek to adjust his first-order desires in light of his higher-order preference for a full recovery, or if he is unable to do this he might need to seek some support to ensure he does the exercises. Similarly, Desiree who seeks plastic surgery despite her strongly held feminist values, might discover through a process of critical reflection that in addition to her negative beliefs about plastic surgery she also has certain desires (for example, to look a certain way) that have prompted her to approach a plastic surgeon. By considering the tension between her values, goals and desires she could work through her priorities to determine the most preferable course of action for her. This would be the one that most closely reflects her total set of values and is most likely, on balance, to help her achieve her authentic goals.

A broader understanding of autonomy is also helpful in the context of genomics, given the inherent uncertainty in genomic information. Consider a woman who is seeking genomic testing, as she has a strong family history of various cancers with no familial

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[13] Key criticisms of Dworkin's account include the problem of infinite regress, the emphasis on the individual, and its content neutrality – all of which are addressed later in this paper.

mutation yet identified. On the *default conception* of autonomy, it would be beneficial to outline a comprehensive range of possible results of this test, to enable her to make informed decisions about relevant screening and preventive interventions. However, conversations with the woman might also reveal that her underlying motivation for seeking genomic testing is to reduce her anxiety, a motivation that might not be satisfied by untargeted sequencing. In this case, her request for genomic testing is motivated by a first-order desire to reduce uncertainty, based on a higher-order desire to take action to reduce her chances of being diagnosed with cancer herself. Further exploration of her underlying desires and the impact (if any) that the testing could have on the uncertainty she feels, could enable her and her geneticist to formulate an alternative plan that more effectively meets her preferences, than unfettered information provision might do.[14]

Considering how these types of cases play out in order to safeguard the patients' autonomy illustrates why we should focus on the autonomy of persons rather than decisions. Each of the decisions made by Walker's subjects meets Beauchamp and Childress' requirements of being intentional, informed and not controlled in the sense required for the default conception of autonomy. But, Walker's examples are problematic on Dworkin's view, because the choices do not align with the subjects' long-held values and preferences. They also match our intuition that the individuals are not acting autonomously. This demonstrates the strength of Dworkin's conception of autonomy. On his criteria, these autonomous people have failed to exercise their autonomy in this instance, as they have not engaged in sufficiently critical reflection and adjustment of their goals, beliefs and preferences into a coherent set. If they had done so, then that process would constitute an explanation for why the choice could be considered autonomous.

This process of critical reflection is the mechanism by which Dworkin's view fulfils Walker's second criterion, namely the requirement that a theory of autonomy is able to explain what makes a decision or choice autonomous. This is particularly valuable in bioethics, as it provides insight into how healthcare professionals can enhance patients' capacity for autonomy. This is clearly evident in Walker's problem cases, as each of her characters would likely benefit from some support in working through their process of

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[14] Alternative approaches might include preventive screening and lifestyle changes, although they could also include more targeted genetic testing

critical reflection. William, for example, might have some physical or logistical barriers to undertaking his treatment that are significant enough that they override his desire to secure the benefits of adhering to his therapy regime. Helping him to overcome these is an important way that his healthcare team could support him to exercise his capacity for autonomy. Similarly, in Tim's situation his healthcare provider should be able to recognize that his refusal of treatment is not consistent with his long term or higher-order desires and preferences, and accordingly might seek ways to support him to come to a decision that is more authentically aligned with his goals. These examples show that a broader understanding of autonomy such as Dworkin's procedural approach can be useful in applied scenarios and can provide practical guidance as to how health professionals can support patients to exercise their autonomy.

Relational Autonomy

Incorporating a relational element into a conception of autonomy is a way of strengthening procedural accounts, and is consistent with a Dworkian approach. Some procedural theories of autonomy have been the subject of feminist critiques that argue that the focus solely on the particular patient's situation and their process of critical reflection is fundamentally individualistic (see for example Mackenzie and Stoljar 2000, Donchin 2000, Dodds 2000). A focus on the individual provides insufficient recognition of an agent's social and relational context, and how these factors bear on their capacity for autonomy. Furthermore, procedural accounts can also fail to identify social oppression that could undermine autonomy. Donchin (2000) emphasizes two relational dimensions to autonomy. One is in the context of the patient-physician relationship, which is inherently interpersonal; with all the attendant complexities of power and communication. Manson and O'Neill's explanation of the communicative interchanges in which medical decision making takes place captures this relationality. However, Donchin also points out that in order to safeguard patients' autonomy it is also important to pay attention to their macro societal influences and how these can affect their choices. She explains that people exist fundamentally in relation to others, so all that we do takes place in this social context. Further, the activities involved in exercising autonomy – such as reflecting, planning, choosing, deciding – are themselves social activities that often involve others or are done in

ways that are subject to influence by our relationships and social context. Family relationships can be particularly pertinent to medical decision making, as family members' lives can often be impacted significantly by healthcare choices.

The relationality that comes from being part of a family has an added dimension of relevance in genomics, given that genetic information is shared within families. Results of a genetic test can reveal significant implications for other family members. The negative obligations by which patient autonomy is respected on the default account involve refraining from coercing or otherwise unduly influencing patients, and ensuring they are properly informed to consent to medical interventions. However the default conception makes no reference to the patient's family members.[15] The default conception of autonomy does not factor in how the patient's family and social context can work either to enhance or undermine their autonomy.

In contrast, the process of critical reflection that Dworkin outlines can incorporate consideration of the patient's social and relational context, specifically as it affects their preference-formation and decision making processes. The process of critical reflection is socially situated, as are a person's values, goals and preferences. When undertaking the kind of critical reflection necessary to adjust or accept one's first-order preferences in light of higher-order values and goals, people will engage in discussions with family members or trusted friends, health and medical professionals, as well as reflecting upon the broader social dimensions of their life such as their housing or employment situation, which could impact treatment decisions. In this way, a procedural account of autonomy provides a mechanism by which the relational dimensions of autonomy can be incorporated. This is important in all medical decision making, but especially so in the context of genomics. In the example of the woman seeking genomic testing due to a family history of various cancers, if a mutation had been found in a relative this would have implications for her. Iterative decision making processes are fundamentally embedded in the person's social situation, and their relationships help to determine and refine their higher-order preferences and

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[15] This is not to argue that providers of genetic or genomic testing do not themselves account for family members. Indeed, this is a standard aspect of the pre-test consent process. But it is not reflected in the accounts of autonomy that are predominantly used in genetics and genomics literature.

values. Understood in this way, procedural accounts of autonomy such as Dworkin's can incorporate the relational aspects of autonomy.

Procedural Autonomy Beyond Dworkin

There are several advantages to a Dworkian account of autonomy in bioethics. However, the hierarchical nature of the endorsement process has been considered problematic. In other words, the process of critically reflecting on one's first-order preferences and goals in relation to second-order preferences and goals does not stop, potentially, at the second-order level. Further reflection on these preferences is required in relation to higher-order goals, and so on. Beauchamp and Childress (among others) object to the 'split-level' nature of Dworkin's account and similar accounts of autonomy which require endorsement of first-order desires by second-order ones. The objection centers on the requirement for higher-order preferences and values that inform a person's capacity to reflect critically upon their first-order preferences and desires, and they argue that such a requirement leads to an infinite regress. Paradoxically, this would then limit autonomy.

However we contend that a reflective process of authentication – understood differently to the validation by higher-order preferences – can be a way of ending the regress. For a person to feel that their (first-order) preferences or desires are authentically theirs, they require the capacity for some sort of reflection on how these immediate desires cohere and align with their well established and tested beliefs, values and preferences. If a former smoker experiences a sudden desire for a cigarette, she can reflect on her desire for good health, her associated preference not to be a smoker and recall how she came to this via the experience of quitting smoking. Weighing up the current desire against her more established preferences, she can make the decision not to smoke at this moment. The higher-order goals or preferences do not require validation by other goals, but rather can be deemed by a person to be authentically theirs by a process of rational reflection that does not necessarily appeal to higher-order values, but can examine the substance or content of the desires or preferences. Juth (2005) explains that authenticity requires a person to have a positive attitude towards the desire (such as acceptance or approval), and this needs to incorporate an understanding of how they came to have the desire. In the case of the former smoker, she does not have a positive attitude towards her desire to smoke now, in

part because she understands that it is provoked by an addictive response. She adjusts this first-order desire in light of this understanding as well as her higher-order goals for good health, and therefore authentically identifies with the desire not to smoke. The higher-order goal for good health do not require further authentication, because by examining the substance of this goal she can confirm its authenticity without appealing to other values[16]. When this confirmation is considered alongside the understanding of what prompted the desire to smoke, the first-order desire to smoke can be exposed as inauthentic. The requirement for authenticity is one way to break the potential infinite regress of goals and preferences.

While procedural accounts have many advantages over the default conception of autonomy, they are content neutral. That is, these accounts do not refer to the content or substance of what the goal or preference is about, and as such it is not possible to determine their authenticity. To be able to determine whether they have a positive attitude towards a goal or desire, the person needs to understand the process by which they came to have it and whether it is truly theirs. In order to make this assessment, reflection on the process is insufficient. To use Rebecca Walker's term, no "black box" (Walker 2008 595) account of autonomy – namely one that focuses only on the characteristics of the patient (as competent) and the process by which the preference came about – can adequately meet her criteria. In order to identify actions which are not made autonomously, reference also needs to be made to the content of the goals, preferences and desires that lead to those actions. A content neutral conception of autonomy (which also includes the default conception, as it ensures autonomy by implementing informed consent procedures) does not enable the right kind of reflection upon a person's immediate and long-held desires, goals and preferences that is needed to ensure their autonomy. Another significant problem that Walker identifies with black box theories of autonomy is that they fail to provide a moral imperative to respect patient autonomy. If autonomy comes down to certain characteristics of the patient and the process by which they come to a decision, this does not offer any compelling reason why that decision ought to be respected. Hence we will

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[16] It could be argued that the goal of good health is underpinned by a desire for a conception of a "good life" or a desire to maximize flourishing. However, in many cases an agent can cease the regress at the goal of good health because by reflecting on the content of this preference it can be determined to be authentic without need for further consideration.

now turn to a substantive conception of autonomy that incorporates a Razian perfectionist approach and assess how such an account can address the content issue.

SUBSTANTIVE PERFECTIONIST AUTONOMY

So far we have followed Rebecca Walker's critique of the *default conception of autonomy* in bioethics, and have argued that a Dworkian *procedural account of autonomy* goes some way to addressing her three criteria that an account of autonomy must fulfil. However, the outstanding problem for both these accounts is their inability to account for some scenarios in which autonomy fails, as they do not require agents to reflect upon the content or substance of their goals and preferences, as long as the correct procedure has been followed. We will now outline a *substantive, perfectionist account of autonomy* that incorporates the notion of normative competence, and show how such an approach addresses Walker's criteria and also can be of practical use in applied bioethics.

Razian Perfectionism

Some recent papers in the bioethical literature have referred to a perfectionist understanding of autonomy as a broader conception which is beneficial for considerations in bioethics (see for example (Vayena 2015, Blasimme and Vayena 2016)). Perfectionism as a moral theory directs us to pursue the best possible human life. There are variations of the theory that have different definitions of 'a good human life' (or perfection) but it is typically considered to be an objective standard and one that we should care about promoting for all people, not just ourselves. In order to live an excellent human life, it might be argued, one must have the capacity to reflect upon and determine one's own goals and preferences and to have those preferences respected wherever feasible. Since perfectionism depends upon an objective understanding of excellence as a measure of human lives, the determination of whether a person's goals and values are perfection-promoting necessarily requires consideration of the content of their beliefs and attitudes, not merely the procedure by which they came about.

A key proponent of perfectionism is Joseph Raz, a political philosopher who conceptualizes autonomy in the context of his moral account of freedom (Raz 1986). Raz

identifies three elements that comprise the conditions for autonomy: appropriate mental abilities; an adequate range of options; and independence (p. 372). The latter refers to freedom from coercion and undue manipulation, which is a prevalent feature of many accounts of autonomy. In the first condition – appropriate mental abilities – Raz includes not just competence but also the ability to understand what is required to achieve one's goals, and undertake actions that will lead to their attainment.

In order to make meaningful choices that will lead to the attainment of goals and the best possible life, (as with the procedural account of autonomy) there must be a suitable range of options between which to choose. However the perfectionist account goes further too. In describing the range of options, Raz explains a number of factors that contribute to their adequacy. One important consideration is that the options should range over both choices with long range, significant consequences, as well as those that seem trivial. In other words, we should be able to exercise our autonomy both in terms of developing and pursuing longer term significant goals – such as our occupation, personal relationships, and so on – but we also need to have some control over the smaller day-to-day decisions, such as when to wash, what to wear, the route we take to work, and so on. He also points out that the quality of the options matters more than the quantity, which concurs with Dworkin's contention that more choices are not necessarily better. There is little value – nor contribution to our self-determination – if we can choose between hundreds of nearly identical houses in practically identical locations. A far preferable range of options is between either a small flat in the inner city, or a larger house in a suburb further from the city center. This smaller range of options represents a more genuine choice, because the option chosen will make a significant difference to the subject's life.

A Razian perfectionist account of autonomy also needs to assess the content or substance of the available choices. It is not possible to determine whether they represent an adequate or meaningful range based on their number or the processes by which they were generated, because their content (what they are *about*) matters in this determination. In order to know whether a given range of options have the capacity to improve the quality (increase the perfection) of a person's life, it is necessary to examine the substance of the options themselves. We now return to Rebecca Walker's argument for the requirement of substantiveness, namely that we must know what the actions and decisions are about in

order to make a determination as to whether they constitute an exercise of autonomy (or not), and also to explain why they ought to be respected.

Black boxes and normative competence

The requirement for an adequate range of options – where their quality is more important than how many options there are – is a factor that cannot be assessed without knowing the content of the options. In other words, we cannot know if a range of options is adequate without looking inside the black box. No amount of scrutiny of the process by which the options or choices were arrived at can determine their value or adequacy, because we need to know what they are about in order to make that assessment. Rebecca Walker's criteria pick up on this requirement, because so-called 'black box' accounts of autonomy cannot account for a moral requirement to respect it. Her counterexamples also show that the substance of people's preferences is relevant to determining whether they represent an exercise of autonomy.

Some failures to exercise autonomy – such as those introduced by Rebecca Walker as counterexamples to the *default conception* of autonomy – involve a lack of 'normative competence'. This is a neo-Kantian notion that refers to a failure to identify norms and decide whether or not to apply them in the context of one's decision making. Wolf (Wolf 1993) explains that normative competence is the capacity for individuals to evaluate different available options based on their normative content, and make better or worse choices. The notion that 'some choices are better than others' implies a universal standard of morality. However it is our contention that this is compatible with value pluralism. While the topics of universal morality and value pluralism are beyond the scope of this paper, as Wolf points out it is not necessary to commit to the existence of "a unique, universally applicable, complete, and optimal system of values" (p. 124) in order to allow for some universal comparisons of the relative value of different choices.

Take for example Walker's problem case Desiree, who approaches a plastic surgeon despite her strong feminist ideals and belief that plastic surgery is "an unacceptable acquiescence to male dominated social norms" (p. 598). While Desiree is otherwise autonomous and is capable of undertaking a process of critical reflection, she lacks

sufficient normative competence to evaluate the social norms causing her to choose to approach the surgeon. If she did, she would understand that her action is caused by an internalized social norm (a desire to conform to a certain standard of attractiveness), and because of this etiology of the desire she would know that another choice would be better for her by virtue of being more consistent with her overall beliefs and values.

Similarly, when healthy individuals purchase whole genome sequencing through direct-to-consumer providers, they are arguably responding to the rhetoric of individual empowerment currently used to market such tests, and misunderstandings about their potential impact. In order to exercise their autonomy effectively they need to reflect critically on the limits and drawbacks of the test, and how obtaining it might align (or not) with their broader goals.

What this means for the concept of autonomy is that the normative competence of the subject is significant in order to meet Walker's criteria. It is useful and important for identifying actions that are not autonomous and explaining what makes choices or actions autonomous, even though a refined *procedural account* of autonomy that takes the person's social and relational context into account would (arguably) go a long way towards meeting those criteria. However, in order to explain why we have an obligation to respect autonomous choices it is necessary to consider the content of the action or decision.

Walker considers different varieties of internal controls that can have an impact on our decision making. She points out that all choices or actions are controlled, but some kinds of control are autonomy-undermining and others are not. Even when an autonomous person chooses freely and authentically their action or decision is controlled by their own values, desires, and so on. For example, a person might choose to access a genomic test because she identifies as a person who seeks information and embraces technology. In this case, the controls on her decision making are internal, but they are features of herself that she identifies with and embraces, and therefore she acts autonomously when she makes that decision. What is important in order to distinguish autonomous from non-autonomous choices, Walker claims, is that the right kind of relationship has to exist between the self (or will) and the person's choices. The nature of this connection, or "the core features of self-rule" (Walker 2008 604) is what an adequate theory of autonomy must explain. This is not a black box procedural understanding of autonomy because the relationship between the self

and the choices cannot be formed without reference to the content of the choices and the person's sense of self.

The internal controls which impact on the choices made by the people in each of Walker's three examples are not identified with by each of the people who make the decisions. They represent failures of the self (as authentically identified with by the person) to express itself in the individual's actions. In order to determine whether the controls that affect an autonomous person's decision making process support or undermine their autonomy, it is necessary to have access to the content of both the decision and the person's goals and values as relevant to the decision. To make this determination requires a degree of normative competence. Walker gives the example of actions from love – such as snatching one's child to save them from a hazardous situation – as actions that are controlled by something that necessitates action and is fully controlled (in the sense that the person has no other option but to act in that way), but does not undermine the person's autonomy. This is because loving their child is a feature of the person that they accept and embrace as part of their identity. However on a black box procedural account of autonomy it is not possible to distinguish internal controls that undermine autonomy from those that do not. What matters, for Walker, is whether the person accepts or rejects a particular influence, the determination of which requires them to exercise their normative competence. Doing so can involve making quite subtle distinctions, and contributes to the difficulty of applying such an account of autonomy to scenarios in practice.

Requirements of Autonomy in Bioethics

Up to this point we have argued that a *substantive, perfectionist account* of autonomy which requires an assessment of the person's normative competence can effectively meet Walker's criteria for a theory of autonomy. This approach can identify actions that are not autonomous, and explains why actions or decisions are considered autonomous, even in situations where there are fairly subtle controls influencing the decision process. It also fulfils Walker's third requirement, which is that an account of autonomy must explain the normative requirement to respect autonomy. Identifying autonomy as self-rule – or requiring a capacity for normative competence in autonomous persons – accounts for the moral dimension to autonomy, as it is via this connection

between the self and their actions that a person can exercise their capacity for morality. It is by exercising this appropriate form of self-rule that people can act as moral agents, and this provides a normative justification for respecting that self-rule, or the autonomy of the person.

However, for a theory of autonomy to be relevant and useful in bioethics it must also have the capacity to be applied in practice. Walker contends that what she terms a conceptually adequate account of autonomy becomes more difficult to implement in practice. While the analysis of the appropriate connection between a person's authentic self and the rational determination of their will might offer insight into whether or not they are exercising their autonomy in making a particular choice, this does not necessarily offer a reason to respect that choice in instances where they have not acted autonomously. Walker clarifies two levels at which this kind of a theory poses challenges in terms of implementation. In the first instance, identifying when there is a failure of self-rule – such as weakness of will, irrationality, and so on – is not a procedural matter, but requires an exploration of the patient's underlying values, goals and preferences and the process of arriving at the decision in question. Furthermore, even if the success or failure of self-rule with respect to a particular decision could be reliably determined – which is highly unlikely – this does not offer a reason to interfere with or overrule an otherwise autonomous person's decision.

While it is true that a broader conception of autonomy does not lend itself to procedural implementation in the form of informed consent or similar formal processes, we argue that such a view can nonetheless be extremely useful in practical application. To show how a broader conception of autonomy can be practically applied, we will draw on Manson and O'Neill's agency account of information and communication (Manson and O'Neill 2007), which represents a shift away from the misconceptions that arise from the metaphors we use about information. Such metaphors have the effect of obscuring the communicative and epistemic norms that underpin the interactions between patients and clinicians in which informed consent is sought. Going back to Walker's requirements for an adequate conception of autonomy (the ability to identify non-autonomous actions; explain what makes actions or choices autonomous; and account for why we have a moral obligation to respect autonomy), an account that is based on a level of normative competence requires

just such an awareness of communicative and epistemic norms in order to determine whether a decision has been made autonomously. To clarify this claim, we will highlight some key features of Manson and O'Neill's 'agency model' of communication and argue that understanding clinical interactions on this model will help health professionals to implement a broader notion of patients' autonomy. The model of communication they describe shows how professionals in a busy healthcare system can proactively work to enhance patients' autonomy.

Manson and O'Neill (Manson and O'Neill 2007) reconceptualize informed consent in terms of what they call an agency model of communication, which draws attention to the characteristics of communication in a medical decision making context and how such interactions can be approached in order to maximize the patient's capacity for autonomy. They draw attention to various metaphors at work in the prevailing model of informed consent, and propose an alternative understanding. According to Manson and O'Neill, the prevailing approach to informed consent is based on a distorted understanding of the nature of information and how we communicate. They emphasize that informing and communicating are actions and interactions that can only take place against the backdrop of a normative framework that underpins those interactions. They describe what they call the conduit and container metaphors which imply that information is a substance or 'stuff' that can be created, held, and transferred between people and places. These metaphors emphasize the content of communications at the expense of focusing on the acts involved. The emphasis on *content* obscures several key features of the *acts* in which communication take place.

Of particular relevance to how we understand autonomy in healthcare, communicating and informing are actions that depend fundamentally on the audience and the context in which they take place. A doctor explaining her patient's genetic condition will communicate in a very specific manner when talking to him. If she were explaining the same patient case at a conference to an audience of medical peers, she would communicate very differently. The conduit and container metaphors also tend to obscure the fact that informing occurs against a backdrop of certain epistemic and ethical norms. If either the speaker or the audience fails to adhere to these norms then communication cannot happen. The conduit metaphor about informing causes us to overlook these aspects of

communicative interactions and "downplays the complex social and normative framework that must be in place and must be respected for effective communication" (p. 49).

By contrast, Manson and O'Neill's agency model of communicative transfers acknowledges that both the speaker and the audience have various commitments of their own (what they know, understand, need, desire, and so on) but also share a normative structure that allows communication to take place. The normative structure includes language but also things like a belief that the other person is not seeking to mislead them, that they will follow through on their promises, and so on. In the healthcare setting, the patient needs not only to understand that the doctor has sufficient medical knowledge to explain their condition accurately, but also that they will tell the truth, apply their understanding of the condition to determine the most appropriate treatment, seeks the best outcome for their patient, etc. Similarly, the doctor needs to think that the patient is telling the truth about their symptoms, will volunteer any relevant information, and so on. Manson and O'Neill point out that when we acknowledge all the relevant implicit knowledge and context that underpins any communication, the notion of providing 'full disclosure' becomes nonsense.

Such an understanding of communicative interactions between patients (and their families) and healthcare professionals aligns well with a substantive, perfectionist account of autonomy and shows how such a conception of autonomy can be implemented, even in busy healthcare settings. By drawing attention to the assumptions and implicit knowledge that underpins any communicative interaction, healthcare professionals can be more attuned to when it might be helpful to make certain assumptions explicit, or when a patient might require further exploration or explanation of an aspect of their care. Consider Juth's (2005) suggestion that one of the ways a person can fail to be autonomous is if their desires are not authentically theirs – which also reflects Rebecca Walker's counterexamples. Take her example of William who does not follow through with his physiotherapy after knee surgery. If a health professional can identify his underlying beliefs (that physiotherapy will be effective in facilitating his recovery) and desires (for a full and speedy recovery), they can intervene – in the form of asking some contextual questions – to determine if there are other barriers such as logistical ones that might be undermining his autonomy. Health professionals are in a position to help patients such as William to resolve their failures of

self-rule. The patient's autonomy can be enhanced by communicative interactions which have a purpose – such as increasing someone's understanding of something, or wanting to bring about (or clarify) a person's attitude to something – and are responsive to offering rational evidence that is sensitive to the audience receiving it. A flexible and adaptive approach like this can be adapted to enhance patients' autonomy in many applied medical scenarios, and is particularly relevant when considering contexts such as genomic medicine where there is a great deal of complexity and uncertainty. An interesting consideration which is beyond the scope of this paper would be to apply this understanding of autonomy to different medical decision making scenarios, both clinical and in a research context. We see the potential to apply this kind of approach as new models of consent are proposed in genomics, to foster a more flexible and adaptive form of communication (Kost, Poppel, and Coller 2017). If the healthcare practitioner seeks to increase the patient's understanding of the proposed intervention in a way that responds in reference to the patient's values and goals, they can enhance the patient's capacity to exercise their autonomy. In this way, Manson and O'Neill's agency model of communication can support the practical application of a substantive, perfectionist conception of autonomy.

CONCLUSION

We have argued that how we conceptualize autonomy matters in bioethics, and that it can be of practical relevance in applied scenarios. Following Rebecca Walker's critique of the default conception of autonomy, we have showed that conflating autonomy with informed consent is problematic and that bioethics benefits from a broader understanding of autonomy which draws on the moral philosophical literature. Genomic medicine in particular is an area that highlights why it is unhelpful to emphasize provision of information. It is our contention that a substantive, perfectionist account of autonomy is the most relevant and useful for bioethics, and that the notion of normative competence – the capacity for individuals to reflect upon their available choices in relation to their values, goals and preferences – is important to show why health professionals have a moral obligation to foster patients' autonomy. An agency model of communication provides practical guidance for how this conception of autonomy can be fostered proactively in healthcare settings.

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