**Paper Title**: *Autonomy and choice in healthcare: Self-testing devices as a case in point*

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**Title**
Patient autonomy and choice in healthcare: Self-testing devices as a case in point

## Introduction

The growing number of self-testing diagnostic devices available for home use raises a number of ethical, psychological and social questions. Such devices allow individuals to test for a range of medical conditions in the absence of medical supervision. These devices are on sale in pharmacies, super-markets and a growing online industry where over a thousand tests are listed (Parliamentary Office of Science and Technology, 2003). It is now possible to test for HIV (albeit only one system approved) (Federal Drug Administration, (FDA) US, 2009), genetic markers (Levitt, 2001), response to coagulation therapy (Heneghan et al., 2006) and glaucoma (Ianchulev et al., 2005) without leaving one's home. The premise underpinning the nature and availability of these devices, which is noted in their marketing strategies, is that they assist individuals to be more autonomous in the assessment and management of their health by assuming a more independent role. Increased patient autonomy is assumed to be a good thing. In this paper we critique this assumption. We do not oppose patient involvement in care, but rather seek to critique a particular understanding of patient autonomy and its practical implications.

We propose that diagnostic self-testing is a specific instance of the application of a developing model of patient autonomy in healthcare policy and practice. Recent legislative change and health policy in Ireland and the UK support this direction (Department of Health and Children, Ireland (DoHC), 2008a; Department of Health UK, 2008). Patients are now granted increased independence in the management of their own health and associated decision-making. Various forms of paternalism are, for the most part, viewed as antiquated and sometimes unethical. Patient autonomy, choice and freedom in decision-making have been embraced as part of a progressive philosophy for healthcare delivery. Wilson (2007, p.354) refers to "the antipaternalistic assumptions" of modern bioethics which

are claimed to support these views. We suggest that policy-makers have adopted these 'assumptions' to underpin current healthcare policy with little substantive debate.

The aim of this paper is to reflect on these 'assumptions' and the extent to which autonomy, in so far as it is often construed as patient choice and freedom in decision-making, represents a progressive principle for healthcare delivery. The central thesis here is that current perceptions of autonomy do not represent a progressive philosophy for healthcare, as they fail to capture the multi-dimensional nature of the concept and undermine other significant issues such as relationality, care and responsibility. The paper draws on the philosophical literature and examples from the self-testing process to support this claim. The self-testing process represents a specific microcosm of greater patient involvement and autonomy in healthcare and therefore provides an ideal practical context for discussion. We conclude by offering an alternative account of autonomy which may better serve patients. We accept that autonomy is constituted, perceived and valued differently in various cultures. This paper draws primarily on the Irish, UK and US perspectives; therefore, we acknowledge that the discussion has relevance primarily in a Western context.[1]

*The argument*

The argument we propose may be outlined as follows. Current healthcare ethics and recent social policy documents uphold patient autonomy as a paramount ethical principle. This model of autonomy goes beyond merely encouraging participation as autonomy is increasingly portrayed as individual freedom to choose. Such a model is not a suitable benchmark for healthcare policy, or professionals, because (a) it represents a one-dimensional, sometimes misguided, perception of autonomy associated with the absence of constraints and (b) it denies important considerations of relationality, care and responsibility which may better serve patients. Therefore, healthcare practice and policy, which uphold the primacy of autonomy and equate it with increased patient choice and freedom in decision-making should be reviewed, or at least accepted with suitable qualification.

**Autonomy, freedom to choose and contemporary healthcare**

Prior to further discussion of autonomy, and its application in healthcare, some initial understanding of the term is required. A definition will not be outlined at this point as one of the central issues under discussion here is what the essential nature of autonomy is.[2] However; some sense of the term must be delineated to allow the argument to proceed. In general usage 'autonomy' refers to a multi-faceted concept encompassing such elements as "self-governance" and "self-rule" (Oxford University Press, 1997) The word is derived from the Greek 'autos' which refers to the self and 'nomos' which refers to laws. In this original sense autonomy referred to a political system shared by a group of citizens. A city in ancient Greece had 'autonomia' when its people were in a position to make their own laws (Dworkin, 1988).

An understanding of autonomy as a feature of individuals is widely attributed to Kantian philosophy where individual agents, as opposed to societies, are viewed as the locus of autonomy (O'Neill, 1992). Within contemporary healthcare the term is often used ambiguously and inconsistently whereby different interpretations suggest different ways of respecting autonomy (Keenan, 1999; Aveyard; 2000; Slowther, 2007). Beauchamp and Childress acknowledge the multifaceted nature of the concept but define autonomy as; "self-rule that is free from both controlling interference by others and from personal limitations, such as inadequate understanding, that prevent meaningful choice" (2001, p.58).

The association of autonomy with lack of interference inherent within this definition is significant. It associates autonomy with freedom or liberty.[3] Foster (2009) denies any ambiguity in healthcare regarding the term autonomy and notes in a rather glib fashion, that everyone is quite clear what autonomy means. It refers to "straightforward libertarianism" (p.3). The libertarian view of autonomy is associated with freedom from constraints and reflects the notion of 'negative' liberty as articulated by Berlin (1969). In accordance with negative liberty one's freedom is in proportion to the degree of

non-interference. The libertarian context of autonomy, associated with individual freedom to choose, is growing in popularity in Western healthcare practice (Scully et al., 2006; Varelius, 2005) and creating a consumer like culture of free choice (Moreno, 2007). There is increasing criticism of this consumer culture within the literature. The basis of the criticism is that patient autonomy now takes precedence over professional judgement within the consultation process with potential negative consequences for patients (Downie, 1998; O'Neill, 2002; Mol, 2008). This position will be developed as the paper proceeds.

Contemporary professional codes of conduct, healthcare ethics texts and policy documents provide some empirical evidence of this shift towards greater patient autonomy. Gillon's (2003) proposal that autonomy should be upheld as the first principle has gained momentum in medical ethics. The Irish Medical Council's (2009) most recent direction to its members, while acknowledging some exceptions, asserts the patient's right to control what happens to her in accordance with her autonomy. One particular medical ethics textbook outlines autonomy as the "primary consideration in patient centered treatment" (Schwartz et al. 2002, p.8). The Irish Department of Health and Children has increasingly noted the need for greater patient involvement at all levels of health service delivery. This includes mental health service provision (DoHC, 2006), safety management (DoHC, 2008b) and chronic illness strategy (DoHC, 2008c). The latter policy states, as one of its core principles, that patients "should actively participate in the management of their condition" within a healthcare system that maximises opportunities for self-care (DoHC, 2008c p.22).

However, current policy goes beyond merely encouraging participation in one's own immediate health. A recent DoHC and Health Service Executive (HSE) document (DoHC and HSE, 2008c) outlines a global strategy for increased user involvement in the health services. The opening chapter suggests that service users should be central figures not only in matters affecting their own care, but also with regard to service design and provision. The language of the document is very consumer orientated. This language, and proposed initiatives such as a patient charter, supports the advent of the

patient as an autonomous discerning customer in the healthcare arena and significantly alters the patient/healthcare professional relationship (Mol, 2008). Ryan et al. (2010) associate the current increase in the use of self-testing devices with these policy shifts in a UK context. The authors suggest that patients may self-test as they perceive this to be a desirable aspect of self-care which is promoted by the government.

This rhetoric of patient autonomy now permeates healthcare practice and policy replacing previous paternalistic models of care and a culture of medical dominance (Rothman, 2001). This shift is attributed to a number of complex social developments. The literature provides a thorough account of these developments which include the advent of neo-liberalism, economic rationalism, consumerism and associated litigation, the commercialisation of medicine and an increasing lack of trust in doctors and healthcare institutions (Rothman, 2001; Willis, 2006; Eldh et al., 2006; Kapp, 2007).[4] Modern American bioethics[5] has also contributed significantly to this change where the principle of autonomy has gained increased prominence as the leading ethical principle underpinning healthcare delivery (Moreno, 2007). Moreno refers to "an autonomy-driven bioethics" (p.417) in the US fuelled by several social events including the blatant disregard for participants in the Tuskegee Syphilis Experiment (1932-1972), the emergence of the Belmont Report in 1973 detailing ethical principles for research and the influential Roe v Wade decision in 1972 which focused on personal rights and liberty.

**Autonomy and Self-testing**

Moreno (2007) notes that patients' recognition of their right to autonomy in healthcare has greatly influenced the rise of consumerism and supported corporate interests with regard to direct-to-consumer advertising. The author mentions self-testing as a particular example of the interplay between increased patient autonomy and consumerism. Much of the debate regarding the value of self-testing diagnostic devices centers on their role in advancing an individualistic paradigm in

healthcare delivery, which replaces a previously more stringently controlled and professional-led healthcare system. This is particularly true in the context of ethical analysis where the ability to self-test and possibly diagnose without, or with reduced, professional support is seen as an example of extended patient autonomy and questioned on this basis (Modra, 2006; O'Lynn, 2007; Kearns et al., 2010*).* Self-testing diagnostic devices are marketed as a means to encourage patient participation in healthcare and improve overall health outcomes through the early diagnosis of disease (Simplicity-health, 2009). It is proposed that this early participation is a 'good' thing. Essentially these devices facilitate greater patient autonomy in the context of diagnosis and management of disease.

Studies which investigated the efficacy of diagnostic self-testing kits such as glaucoma computer based tests (Ianchulev, 2005); International Ratio testing (Henegan et al., 2006) and blood glucose monitoring (Towfigh et al., 2008; Alleman et al., 2009) display clinical results which support their value as diagnostic tools. However, despite the positive outcomes noted here, this is not the case for all home testing systems. There is considerable debate as to the value of home blood glucose monitoring, particularly in patients who are not treated with insulin, and research studies reveal different estimates with regard to clinical outcomes (Farmer et al., 2009). One study in the UK found that clinical outcomes in the context of blood glucose levels were improved when patient self-testing was replaced by a more proactive patient education programme (Harris and Cracknell, 2005). This study also revealed that patients were relieved not to have to self-test on a regular basis, as testing reinforced the illness role and resulted in feelings of failure and negative health related behaviours when results were poor. A considerable portion of self-testing diagnostic tools refer to home screening systems, e.g. prostatic antigen (PSA) tests as a method of screening for prostatic cancer. Despite one web-site declaring that 'early diagnosis significantly improves the outcome of any prostate disorder treatment' (Simplicity-health, 2009) the empirical evidence in the context of prostate screening suggests otherwise. There is no conclusive evidence that routine prostate screening improves health outcomes (Illic et al., 2006), and routine screening is not recommended in the general population but rather reserved for those who exhibit certain risk factors (Burger and Kass, 2009).

The literature with regard to the extended autonomy afforded to patients in the context of self-testing devices, though mainly discursive and non-empirical, raises similar concerns. There is a potential for self-testing devices, including screening initiatives, to promote a culture of the worried well (McMahon, 2009) and contribute to psychological distress due to the possibility of false positives (Modra, 2006) and the lack of pre-test counselling (Raffle, 2000; Kachroo, 2006; O'Lynn, 2007). Whellams (2007) makes a rather more sinister claim. The author contends that industry's eagerness to gain FDA approval for home HIV testing kits in the US was not proportionate to consumer demand for the product. Whellams's thesis is that corporate motivation for marketing these products is linked to the ease with which future diagnostic self-testing systems may then be commercially marketed. The UK Nuffield Council on Bioethics (2010) recently published an ethical assessment of the increased availability of medical profiling and online medicine. The report concludes that while certain developments may provide some benefits the claims are sometimes overstated and it urges caution, greater regulation and the banning of certain facilities including direct-to-consumer imaging.

**Examining current perceptions of autonomy in healthcare**

The argument under examination in this paper asserts that the current model of autonomy in healthcare does not provide a suitable benchmark for healthcare policy, or professionals, because (a) it represents a one-dimensional, sometimes misguided, perception of autonomy associated with the absence of constraints and (b) it denies important considerations of relationality, care and responsibility which may better serve the patient. We shall address the former point initially and present two principal arguments in support of our claim. Firstly, a broader philosophical account of autonomy goes beyond notions of 'negative' liberty to encompass an understanding of 'positive' liberty which is not necessarily related to the absence of constraints. Secondly, being autonomous is not solely concerned with acting on one's individual desires or wants in an isolated vacuum but demands an understanding of our societal connections. Our argument addresses a misrepresentation of

Kantian ethics which exists in some healthcare literature to the detriment of a richer understanding of autonomy.

*Autonomy, constraints and positive freedom*

We argue at this point that contemporary notions of autonomy in healthcare, as outlined above, can be questioned because autonomy is not necessarily synonymous with freedom to choose and is not dependant on the absence of constraints for its existence. The libertarian understanding of autonomy in healthcare subscribes to a negative perception of autonomy. This negative perception does not reflect "the positive element of self-determination essential to an adequate account of autonomy" (Young 1986 p.49). Delineating the differences between positive and negative notions of freedom and autonomy are central to this claim. If autonomy can exist in the presence of some constraining factors, then an anti-paternalistic healthcare philosophy which seeks to advance autonomy by promoting individual freedom to choose is fundamentally flawed.

In *Two Concepts of Liberty* Berlin (1969) delineates between positive liberty which is concerned with self-mastery and negative liberty associated with non-interference by others. Berlin's account of positive freedom echoes very much a Kantian perspective when he refers to the 'inner citadel' where people retreat as rational beings to free themselves from desires they know cannot be realised. Berlin tells us that we can free ourselves from obstacles in our path by abandoning the path in a self-determining manner through the use of critical reasoning. We will explain how this is possible in a clinical context later in this paper.

Carter et al. (2007, p.3) explain the distinction between positive and negative notions of liberty as follows:

> "In other words, when such a theorist [proponent of positive liberty] seeks to determine whether people are free, the focus is on what they have done or how they have done it. For a

> negative-liberty theorist the focus of any such enquiry is very different. In order to ascertain if people are free in some respect, a proponent of negative liberty asks not what they have done but whether they are unprevented from doing something".

This positive, self-determining sense of liberty is also supported by Dworkin's (1988) appraisal of autonomy. Dworkin refers to freedom as liberty and suggests that the terms liberty and autonomy should always be distinguished. He proposes that "autonomy is a richer notion than liberty" and relates to "the idea of being a subject, of being more than a passive spectator of one's desires and feelings" (p.107). Dworkin suggests that autonomy and freedom are not synonymous even though they may at times be linked. He suggests that in forcing a Jehovah's Witness patient to have a blood transfusion against her will one denies her liberty yet also her autonomy. However, in another example Dworkin explains that in deceiving a patient about his treatment, his freedom has not been denied but his autonomy is thwarted by the process of deception.

This reflects a re-occurring theme within philosophical literature that autonomy and freedom are distinctive and that freedom is not a necessary pre-requisite for autonomy. Scott (1998) articulates the difference by explaining that the animals in the field are free, but cannot be said to be autonomous, as they do not possess the attributes necessary for autonomous action, presumably, the ability to act as rational agents. It would seem therefore, as Scott explains that freedom is not a sufficient or even necessary condition for autonomy to exist. Seedhouse (1998, p.184) supports this proposal in stating that autonomy is not "necessarily related to the amount of options available" but is more context related. Seedhouse delineates between respecting and creating autonomy and suggests that one can create autonomy for another by not necessarily granting all their choices.

Dworkin cautions us against a concept of autonomy associated with significant independence. He contends that this understanding "makes autonomy inconsistent with loyalty, objectivity, commitment, benevolence and love" (p.21). This statement is particularly relevant in the healthcare context where

healthcare personnel are obliged to consider their professional commitments to care for patients. These commitments, and their inconsistency with the current autonomy rhetoric, will be explored as the paper proceeds.

At this point in the argument we suggest that a notion of autonomy that is equated with freedom to choose, in so far as this refers to negative freedom and the absence of constraints, is questionable. The discussion regarding positive freedom above raises the issue of one's desires which is also significant in debating the merits of contemporary understandings of autonomy.

*Autonomy, Kant, desires and relational responsibilities*

A philosophical analysis of autonomy to this point reveals that choosing to act on one's immediate desires may not be in accordance with one's autonomy. An autonomous approach to healthcare delivery which seeks to facilitate patient freedom of choice, with little interference, does not sufficiently appreciate that one's initially expressed desires may alter following a reflective process where other factors are considered. Being autonomous is not solely concerned with acting on one's individual desires or wants in an isolated vacuum but demands an understanding of our societal connections.

This view conflicts with the 'negative' understanding of autonomy in healthcare which is often attributed to Kantian ethics. We propose here that Kant's philosophy is often misinterpreted in healthcare literature to the detriment of a richer understanding of autonomy which may better serve patients' best interests. As a case in point, the medical ethics textbook, noted earlier which portrayed autonomy as the paramount ethical principle, contended that respect for autonomy is linked with respect for persons and an associated Kantian philosophy which suggests non-interference with one's "plans, ambitions and choices" (Schwartz et al. 2002, p.8). This is not necessarily how Kantian philosophers perceive his work.

In *Groundwork of the Metaphysic of Morals* Kant (1998) sets out an a priori metaphysic of morality. Essentially the categorical imperative, its supreme principle, outlines what one ought to do unconditionally; "act only in accordance with the maxim through which you can at the same time will that it become a universal law" (G 421). In accordance with this imperative people's duty is to act only in a manner that they *will* their actions to become a universal law of nature. Kantian ethics is often portrayed as a judicious approach to morality where a rational being acts solely on the basis of principles which are self-embodied and not causally determined or influenced by outside forces. This understanding of Kantian ethics is often misconstrued as referring to the autonomous agent and his autonomous choices. However, contrary to misinterpretation, Kant's *autonomy of the will* does not refer to autonomous action; rather it refers to the practical reasoning employed in "determining choice to action" (Heubel and Biller-Andorno, 2005, p.7).

Onora O'Neill echoes similar concerns with respect to misrepresentation of Kantian morality. In *Autonomy and Trust in Bioethics* O'Neill (2002, p.74), takes issue with a number of distinguished philosophers who isolate Kant as a major proponent of individual autonomy. "They accuse Kant of identifying autonomy with self-control and independence, with extremes of individualism and with blindness to the ethical importance of the emotions and institutions" (O'Neill 2002, p.74). O'Neill argues that Kant's unique understanding of autonomy is "quite different from the ethically inadequate conceptions of individual autonomy so commonly ascribed to him."

O'Neill proposes that a careful reading of Kant's work provides no evidence for a Kantian autonomy rooted in individualism. The term 'autonomous individuals' does not appear within Kant's writings. Rather, as O'Neill explains, he refers to the 'autonomy of principles' associated with a duty towards others and respect for their rights. O'Neill's thesis is that Kant's reference to 'self-legislation' refers primarily to a 'legislation' that is formulated by oneself in accordance with a number of universal principles (which includes one's duty towards others) as opposed to referring to the 'self' legislating for oneself in isolation from others. The 'self' is reflexive. O'Neill's argument is that those who

associate individual autonomy with Kantian ethics focus on the notion of 'self' as opposed to the 'legislation' element of the term. Based on her analysis O'Neill presents the notion of 'principled autonomy' which is most strongly associated with the principle of obligation. The issue of obligation is highly significant in the context of the current argument as it represents one of the alternative perceptions of autonomy which may better benefit patients. We will return to the alternatives later in the paper but for now we shall continue to outline the misinterpretation of Kantian philosophy as highlighted by others.

Paley (2002) also rejects an isolated interpretation of Kantian autonomy. He refers to the 'myth' that Kant supports a view where individuals make ethical decisions in a detached manner and in isolation from the associated context. He takes issue with an ethics of care which is framed in opposition to Kant and outlines a convincing argument for an ethics of care underpinned by Kantian philosophy. Paley refers to Kant's *Formula of Humanity* whereby one is obliged to treat individuals as ends in themselves and suggests that adherence to the categorical imperative requires one to seek out the 'ends' of another individual so that one can seek to make them one's own. Similarly, Heubel and Biller-Andorno (2005) note that in applying the *Law of Universality*, the first formula of Kant's categorical imperative, one is obliged to consider the accordance of one's maxims with those of others. Therefore an accurate understanding of Kantian morality appreciates that Kant "cannot reasonably be accused of ignoring the fact that autonomy is about our commitments to other people" (Paley 2002, p.135).

Consider an asymptomatic woman who wishes to test herself for the breast cancer gene BRCA1 using a home-testing kit.[6] Prior to sending off the required saliva sample she discusses this with her partner who points out the lack of family history and the fact that a pre-disposition to the disease does not necessarily mean one will develop it. He is concerned that knowledge of the gene will affect his partner's outlook on life, and their life together, and tells her so. The woman, previously so certain of her wish to undertake the test, now alters her choice and decides not to proceed as she deems her

inquisitiveness of lesser importance than the value she places on her relationship and current well-being. She makes this decision following a process of critical reflection. She does not feel coerced by her partner but values his input and sees merit in his contribution.

The extent to which she has chosen 'without interference' is arguable yet it is a step further to suggest that her autonomy has been violated 'because' of the interference, as notions of negative liberty would suggest. We propose that in this example her autonomy has been facilitated, as opposed to violated, through a dialogue which encouraged her to critically reflect on her initial desires. This reflects the positive sense of liberty as noted by Berlin (1969, p.46) earlier in this paper. We suggest that in this case the woman has retreated to the "inner citadel" which Berlin refers to using her rational capabilities to reconsider her initial desire to undergo the test. This rational self-dialogue, as Berlin outlines, reflects a Kantian understanding of autonomy whereby one's freedom is not constrained if she willingly imposes restraints on herself. In this case the woman has willingly refrained from taking the test following a reflexive process which considered her partner's position. We suggest therefore at this point, that one's decision making processes need not necessarily occur in isolation as some interpretations of Kant's work suggest.

Marcia Baron (1995), in a somewhat similar fashion, addresses some of the criticisms of Kantian morality, particularly feminists' accounts (Noddings and Gilligan) which condemn the emphasis on duty in his philosophy as being devoid of emotion and connection with others. Baron contends that this misinterpretation is partly due to a mistranslation of the *Groundwork*, particularly a translation by Paton (Kant 1991) which alters the meaning of Kant's philosophy. Paton's translation attributes moral worth to those actions which are done 'for the sake of duty' as opposed to using the correct translation 'from duty'. This is significant because as Baron explains one may act 'from duty' in accordance with Kant's universal law but at the same time seek to recognise and fulfil one's commitments to others. However, if one acts for the 'sake of duty' it suggests that duty embodies both one's motive and the

desired result. Baron contends that “one’s goal in acting from duty need not be to do one’s duty. Duty should be our motivating conception and need not be our end” (1995, p.12).

In accordance with this perspective one may act not solely because one sees it as one’s *duty* to do so, but may seek to assist others at the same time. This reflects Korsgaard’s commentary on the *Groundwork* (Kant, 2008) suggesting that the needs of others are significant for moral agents who fulfil these needs because they see helping as their duty. In this context a sense of duty and natural inclination towards others, and their concerns, can coexist.

At this point in the argument we propose that it is reasonable to reject a model of patient autonomy which is based on an individual’s freedom to choose in the absence of constraints. This model is not desirable as it is based primarily on ‘negative’ perceptions of liberty which fail to appreciate the more ‘positive’, reflexive and self-determining notions of the concept. Furthermore, this version of autonomy is often rooted in a misinterpreted account of Kantian philosophy. Kant does not advocate an individualistic autonomy. His categorical imperative represents an abstract formulation of moral philosophy which does not demand that one exist in isolation from others. In fact, the categorical imperative requires that one consider one’s maxims in the wider social context (Heubel and Biller-Andorno, 2005). The analysis to this point suggests that in accepting a model of patient autonomy based on freedom from constraints we are excluding possible alternatives which may be worthwhile. The model of autonomy, based on negative liberty, is rejected here because it denies considerations of relationality, responsibility and care which may better serve the patient population. In what follows we shall address these concepts individually but they are interconnected in ways that cannot, and we suggest ‘should not’, be obliterated.

*Relational autonomy and individual autonomy*

The notion of relational autonomy is significant here. One may reject initial desires and wants, not solely for one's own ends, but to meet the responsibilities one has to others by virtue of one's relationships. Relational autonomy represents a broader notion than individual autonomy. One's decisions may be one's own while simultaneously influenced by one's relationships to others. Responsibility to others is an integral component of the decision-making process. Relational autonomy suggests that individual autonomy fails to capture the interdependent nature of our lives where decisions affect not only us but those around us. Relational autonomy is particularly attributed to feminist philosophy but is also ascribed to by communitarians and proponents of identity politics (Christman, 2004).

Christman (2004, p.143) refers to relational autonomy as:

> "the label that has been given to an alternative conception of what it means to be a free, self-governing agent who is also socially constituted and who possibly defines her basic value commitments in terms of inter-personal relations and mutual dependencies".

This holds great resonance for the healthcare environment. Patients do not make decisions in isolation from their families, dependents and social commitments. However, despite some objections to the concept of relational autonomy, which are concerned with both its inherent logic and normative implications[7,] we suggest that it provides a framework in which autonomy can be understood as a concept which is compatible with the interdependent nature of our lives.

Meyers (1989) account of autonomy as both relational and practical is particularly relevant here. Meyers, similarly to Paley and Baron above, takes issue with an isolated autonomy framed in opposition to socialisation whereby one acts independently of relationships with others. Meyers (p.178) contends that the process of socialisation is critical to an understanding of our true or authentic

selves, and that in turn knowledge of one's true self is essential for an autonomous agent as "without reasonably accurate self-portraits, people cannot be self-governing". This 'alternative' model of autonomy, as Meyers describes it, involves the enactment of a number of autonomy competencies: self-discovery, self-definition and self-direction which are, at least in part, socially constructed and render an isolated free-will account of autonomy "dispiritingly fatalistic as well as incomplete" (p.43).

The self-testing phenomenon again provides a platform for this discussion. Kearns et al. (2010) debate the autonomous and relational dimensions of the individual and propose that while diagnostic self-testing tools can advance individual autonomy through independent testing and decision-making, the results obtained have implications for one's "relational responsibilities" (p.201). Somewhat similar to the example of breast cancer gene testing above, the paper explains this position in the context of a man who finds that he is infertile through use of a home testing kit. Does he have a moral obligation to share these results with his partner and thus fulfil his relational responsibilities? The authors raise further contextual issues with regard to home testing and utilise the work of Charles Taylor to highlight that diagnostic self-testing is not something that occurs in a vacuum but rather holds great significance for those who experience the diagnosis. The paper offers an important dimension to the debate here as it suggests that decisions about diagnostic self-testing cannot be viewed in isolation from the associated contextual issues. We contend at this point that autonomy is a relational concept and not dependant on freedom from constraints in so far as constraints are perceived as input from those who exist in association with us. A model of autonomy which ignores the relational dimensions of a patient's existence does not encompass the reality of the patient's experience.

*Professional responsibility and autonomy*

The above focus on autonomy as relational is primarily in the context of patients' relational responsibilities towards their significant others. However, there is another dimension to this relationality; the relationship that exists between healthcare professionals and patients, and the responsibilities that exist by virtue of those relationships. In both contexts autonomy is not merely

relational but based on obligation or responsibility. The responsibilities and obligations of the healthcare professional are for the most part acknowledged.

As noted above O'Neill (2002) outlines a 'true Kantian' notion of principled autonomy which involves acting on universal principles of obligation as opposed to an isolated, individualistic autonomy. O'Neill's thesis is that the triumph of autonomy has 'contributed' to a mistrust of healthcare professionals as opposed to the other way around. Principled autonomy, in accordance with O'Neill's analysis, rejects coercion and deception and provides a basis for a trusting relationship. We propose here that in practicing principled autonomy, and considering their obligations towards their patients, healthcare professionals can contribute towards an environment of trust. Principled autonomy offers an alternative to the libertarian account of autonomy, associated with freedom to choose, delineated earlier in this paper.

Consider a patient who contacts his doctor requesting an MRI (an expensive radiological diagnostic test) in response to reoccurring knee pain. His doctor is reluctant to order the test as his clinical judgement suggests it is not required. The patient is currently receiving medication for a recent diagnosis of gout. The doctor is eager that the medication would be trialled for a period of time before entering into further diagnostic and treatment regimes. Furthermore, the physician is aware of the cost of the test and the carcinogenic risks of frequent and unnecessary radiology. The doctor provides this information to the patient. If the doctor refuses to prescribe the investigation it could be argued that the patient's autonomy has been denied. However, it could also be argued that the doctor has acted in accordance with principled autonomy which recognises his autonomy and associated obligations and relational responsibilities towards the patient. The doctor may also be acting in accordance with his responsibilities towards other patients who may require the test in a climate of limited resources.[8]

Through a process of dialogue the patient agrees, albeit with some reservations, to continue the current treatment regime. Perhaps this more interdependent, principled understanding of autonomy,

which takes account of the professional's responsibilities, by virtue of their role, and skilfully encourages the patient to engage in critical reflection, might better serve the patient. In this case the doctor has put the principle of non-maleficence before the principle of autonomy. Hofmann and Lydashall's (2008) paper addressing the use of extensive radiological services supports this course of action. The authors contend that an overreliance on autonomy in radiology can result in exposure to unnecessary radiation. Furthermore, patient autonomy can be misused to reduce the physicians' responsibilities (they may avoid law suits as error is less probable), increase the popularity of the profession (as patients get what they want) and generate further income for the medical facility (if this is a legitimate consideration). This example supports the central thesis here that a libertarian model of autonomy which fails to take account of professional responsibilities is not one which best serves the patient's interests.

An understanding of relational autonomy places an additional responsibility on healthcare professionals; an obligation to be diligent and skilful in ascertaining the extent to which choices are autonomous. Atkins (2006) applies Meyers' relational autonomy to the healthcare context. In acknowledging the need for critical reflection by the autonomous agent Atkins suggests that such reflective processes involve consideration of one's relationships with others and societal forces. Atkins proposes that healthcare professionals can play a skilled role in assisting these reflective processes to allow the realisation of a richer notion of autonomy which is not limited to free isolated choices. In this context the healthcare professional is obliged to go beyond a patient's initial expression of preferences to illuminate the reasons for these preferences and the societal influences which have underpinned them. This is particularly relevant in circumstances where patients choose to reject therapeutic interventions

*Professional care and patient autonomy*

Consideration of the concepts of relationality and responsibility suggests that they are important elements of a richer notion of autonomy that seeks to achieve good patient outcomes. These concepts are closely linked with the concept of professional care. Holm (1997) uses the term "protective responsibility" to articulate the sense of obligation experienced by healthcare professionals towards patients in their care. Holm coined the term following an extensive grounded theory investigation of the moral problems experienced by doctors and nurses in practice. It relates to the healthcare professional's awareness of the vulnerability patients by virtue of their ill-health, and their need for assistance with decision-making regarding care interventions.

'Protective responsibility' does not accept autonomy as absolute but recognises that something else may be required to maximise patient well-being in times of ill health. Holm (1997, p. 127) explains the term as follows:

"When you meet the patient you meet another human being who is vulnerable, who often trusts you, and whose life you can influence in a significant way. This creates a special responsibility towards the other human being, which can be difficult to understand for outsiders, but which nevertheless plays a significant role in the deliberation of health care professionals."

Protective responsibility may provide a suitable model to bridge the abyss that exists between the more stringent positions of autonomy and paternalism. It recognises the interdependent nature of the patient/doctor relationship. This links with Mol's account of the 'logic of care' which she frames in opposition to the 'logic of choice'. Mol (2008, p.43) articulates clearly the tensions that exist when a libertarian model of patient choice permeates healthcare. In *The Logic of Care,* Mol outlines a compelling account of the realities of a consumer-based culture in healthcare. Mol's central thesis is that a 'logic of choice' is not consistent with a 'logic of care' and may lead to 'poor' care. Mol is not concerned with the abilities of individual patients to exercise choice but rather how circumstances of

choice emerge and evolve. From her observations and interactions with diabetic patients Mol concludes that more choice does not necessary lead to better care. While the logic of choice is concerned with patients as customers and autonomous, independent individuals, the 'logic of care' suggests a far more messy landscape. In accordance with Mol's analysis (p.62) "the logic of care is attuned to people who are first and foremost related". Mol encourages doctors to cease 'managing' patients and return to 'doctoring'.

Downie (1998) shares a similar perspective in language very closely related to Mol's account. He compares a 'market relationship' to a 'professional relationship' and contends that while serving the bests interests of patients is a feature of the latter, it is not a priority in the former. Downie associates this market relationship and consumer understanding of autonomy with Mill's account of autonomy whereby one is free to act as she wishes, regardless of how irrational those wishes may be, provided her choices do not cause harm to others. In accordance with Downie's analysis, a healthcare system which refers to patients as customers fuels a culture of 'consumer autonomy'. This may condone a patient persisting with treatment which medical evidence suggests unnecessary or futile. Downie outlines an opposing 'rational autonomy' which he associates with Kantian accounts of autonomy. This links with O'Neill's (2002) perspective above in so far as Kantian autonomy is more considered, than often portrayed in the healthcare context. One makes decisions not solely on one's initial desires or wishes but in accordance with universal rational laws. Downie is quite direct in his criticism of 'consumer autonomy'. He contends that a degree of paternalism is inherent within a professional relationship whereby the principles of beneficence and non-maleficence may on occasion take precedence over respect for individual autonomy. This certainly supports Holm's account of 'protective responsibility' while also echoing O'Neill's 'principled autonomy' as outlined above.

In specific reference to patient autonomy and the clinical relationship Olsen (2003, p.705) refers to "the ethical use of influence" within a patient/clinician context. Similar to Downie above Olsen proposes that influence is not only 'intrinsic' but 'desirable' within the clinical relationship. Olsen's

discussion centres on the process of coercion in mental health practice whereby the use of coercion is justified on the basis of a rights-based approach. In accordance with this approach the patient is seen as an autonomous self-governing agent who has the right to act free from interference. In this context coercion is justified only if the patient lacks capacity to make a judgement or may cause harm to himself, or others. Olsen offers an alternative relational approach whereby influence is seen as a constant feature of the clinical relationship and treatment decisions are continuous and subjective. The relational approach demands that every action of influence, despite its magnitude, is assessed for its ethical suitability. Therefore, respect for patients is paramount throughout and the power relationships are continuously acknowledged. This perspective is coherent with the principles of relationality, responsibility and care outlined in this paper. It provides another example of professional care superseding autonomy in a clinical context.

Gillon's (2003) specific adherence to autonomy as a paramount principle in healthcare practice, which promotes the other bioethical principles, has been rejected by Callahan (2003) in favour of communitarianism and by Dawson and Garrard (2006) on the basis that it rejects the prima facia nature of the principles. The latter argument is significant here as it essentially asserts that the professional duty to care demands that one move beyond mere respect for autonomy in favour of acknowledging other ethical principles when the context requires it. Dawson and Garrard (2006) take issue with Gillon's position that autonomy is 'first among equals' in the context of the four ethical principles outlined by Beauchamp and Childress (2001). They refute Gillon's argument on a number of levels, but particularly with regard to the manner in which his standpoint rejects the Rossian perspective of prima facie, as opposed to, absolute principles. In accordance with an ethic of prima facie duties (Ross 1967) one principle might triumph over the others in accordance with specific situations.

Dawson and Garrard (2006) suggest that justice will take precedence over autonomy in resource allocation issues and that the principles of autonomy and non-maleficence can often be in conflict in a

healthcare context. The authors also add that in suggesting that autonomy promotes the other principles Gillon actually exalts their relevance as opposed to rendering them less important. In accordance with Dawson and Garrard's perspective accepting Gillon's position would result in a return to "moral absolutism and its demand that we regard some principles as exceptionless" (p.201). The acceptance of autonomy as the 'first' principle could have negative consequences for patient care as outlined above. There are numerous other accounts in the literature which suggest that an over-zealous adherence to patient autonomy may allow individuals to be disadvantaged by their own choices, create unnecessary confusion and provide a means whereby healthcare professionals abdicate, either intentionally or otherwise, their own professional and caring responsibilities (Holm, 1997; Scott et al., 2003a; Kapp, 2007; Whitney and McCullough, 2007, Harnett and Greaney, 2008).

The empirical literature also provides some evidence for the proposal that patients value the role others take in the decision-making process during their time of vulnerability (Scott et al., 2003b; Levinson et al., 2005; Doherty and Doherty, 2005; Hamann et al.,2007). A large-scale survey design in Toronto investigated patients' preferences for participation in decision-making at three levels: seeking information, discussing options and making the final decision (Levinson et al., 2005). The sample was stratified to ensure representation from the wider population. Results showed that while 96% of patients surveyed preferred to be offered choices and asked their opinions, 52% displayed a preference for leaving the final decision to their doctors. This echoes Berlin's assertion that "individual freedom is not everyone's need" (1969, p.40).

Therefore, it appears that a model of autonomy based on freedom to choose does not always meet the requirements of care as articulated by patients and healthcare professionals. We propose that the interdependent concepts of relationality, responsibility and care are essential components of healthcare. An account of patient autonomy which focuses on the absence of constraints may deny their existence or minimise their importance.

**Summary of argument and conclusion**

Patient autonomy is widely acclaimed as the new orthodoxy or ethic for healthcare delivery. This is problematic for a number of reasons. Firstly, this perception of autonomy is often equated with free choice which does not reflect the more positive sense of liberty associated with autonomy. In this view self-determination and mastery have greater significance than the absence of constraints.

Furthermore, autonomous choices do not involve acting solely on one's individual desires in a vacuum but encompass a critical, relational, reflexive review of one's initial wants and an appreciation of the impact of choices on others. Misinterpretation and subsequent inappropriate application of Kantian philosophy has sometimes contributed to an account of autonomy in healthcare which is less than complete and possibly misleading. Finally, a model of autonomy based on freedom to choose, which fails to consider the notions of relationality, responsibility and care does not provide the best means for increasing human potential. We suggest therefore that the combined arguments outlined above provide a platform to question current healthcare policy and rhetoric regarding increased patient autonomy and propose that it should be reviewed or at least accepted with caution.

*Conclusion: Towards a new model of patient autonomy*

Having raised significant problems with the manner in which autonomy is currently presented in healthcare the discussion would not be complete without providing at least some possible solutions. It is important note that nothing in this paper should be construed as suggesting that patient autonomy is not worthy of consideration. What is suggested rather is that patient involvement in healthcare should be underpinned by a sound philosophical understanding of what it means to be autonomous and an appreciation that autonomy is not necessarily related to the range of options available, of established intrinsic value, or always desired by those it seeks to liberate. The proposals outlined below require another paper to delineate how they may work together but it is important to refer to them here to close the current argument.

O’Neill’s (1992) proposal for judging the value of autonomy could be usefully applied to the healthcare setting. In this model autonomy is neither revered nor dismissed but rather viewed in context. She suggests that social independence should not necessarily be desired nor dependence automatically condemned. Rather independence or dependence should be judged on the basis of overall contribution to autonomy and other ‘goods’. As O’Neill (1992) suggests we may do well to return to a true Kantian account of autonomy which does not necessarily rebuke interdependence.

Wilson (2007) concurs with much of O’Neill’s perspective and suggests that we should value an individual’s capacity for autonomy as a fundamental way of respecting autonomy as opposed to necessarily respecting autonomous choices. This echoes Seedhouse’s (1998) position that it is essential to differentiate between respecting and creating autonomy and that the latter may not necessarily involve granting individuals all their choices. Both positions offer alternative perspectives for understanding patient autonomy. O’Neill’s (2002) ‘principled autonomy’ with a focus on obligation, Mol’s ‘logic of care’ (2008) and Holm’s ‘protective responsibility’ (1997) collectively provide an interconnected labyrinth in which to consider autonomy questions in healthcare. The interdependent nature of autonomy within the healthcare setting is central to all these perspectives.

Finally, we propose that Meyers’ (1989) account of relational autonomy, as presented above, which is both practical and reflexive presents an overarching framework which could encompass the other proposals outlined, and provide a means whereby patient autonomy can be respected as a socially constructed, non-isolated, concept. It is timely that we question to what extent patient autonomy should permeate healthcare policy, rhetoric and ethics and how we can reconcile respect for autonomy with a professional duty of care. We propose that further philosophical and empirical review, in the context of diagnostic self-testing and other fields, is required to answer these questions.

**Notes**

1. The impetus for this paper arose from an exploration of the meanings ascribed to autonomy in the philosophical literature. A review of key seminal works revealed an incompatibility with the prevailing understanding of autonomy in healthcare and prompted the particular focus of this paper.
2. The use of the word 'definition' has particular significance in philosophy. Downie encourages the writer to look beyond 'lexical' or 'word-word' dictionary definitions which merely report the common usage of terms. He advocates replacing such *nominal* definitions with more *essential* definitions. The latter, he contends, can be arrived at through classification and analysis. (Downie, R.S. 1994. *Definition*. *Journal of Medical Ethics* 20: 181-184.)
3. The terms liberty and freedom are used interchangeably here as reflected in the work of Berlin (1969) and Dworkin (1988).
4. It is important to note that this genealogy of autonomy is primarily rooted in western liberal-democratic and liberal-humanistic thought. Therefore, it is important to appreciate the specific cultural context of this discussion. See Pennycook, A (1997) Cultural alternatives and autonomy. In *Autonomy and Independence in Language Learning*, ed. P. Benson and P. Voller, 35-53. London: Longmans
5. The term bioethics is described by O'Neill (2002) as a meeting ground for those who debate the legal, social and ethical implications of new advances in medicine, science and bio-technology. A detailed account of the 'birth' of bioethics is beyond the scope of this paper but a comprehensive historical account is found in Reich W.T. (1994) The word bioethics; its birth and legacies of those who shaped it. *Journal of Medical Ethics* 4: 319-335.
6. This example was constructed following a review of Kim Atkins' paper which is discussed later in this section.
7. Holroyd maintains that while agents may be relational entities autonomy cannot be. See Holroyd, J. 2009 Relational autonomy and Paternalistic Interventions. *Res Publica*, 15:321-

336. Christman, within his account of relational autonomy, raises a concern that a purely relational approach to autonomy may lend itself to an "overarching paternalism" (2004 p.158).

8. A recent "Liberating the NHS" (2010) white paper proposal, announced by the Secretary for State for Health in the UK, suggests a greater role for doctors in managing budgets at a local level through primary care consortia. See *British Doctors to take charge of spending*, www.ama-assn.org/amednews/2010/08/16/gvsb0816.htm (Accessed 4th April 2011)

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