

## Chapter 28 Patients' Duties: The Missing Element in European Healthcare Law

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notes 1-2 deleted (will be included in bios)

### 1. Introduction: Plenty on Patients' Rights, but Very Little on Patients' Duties

The gradual development of the concept of patients' rights in Europe in the second half of the 20th Century gave way to rapid acceleration in its final decade. A raft of European countries passed patients' rights legislation or promulgated patients' charters, whilst the WHO Regional Office for Europe focused on the promotion of the rights of patients through research and reporting,<sup>1</sup> and through the organization of conferences, which led to the production of such notable patients' rights documents as the 'Declaration of Amsterdam' in 1994.<sup>2</sup> In 1996 the Council of Europe completed work on the Oviedo Convention,<sup>3</sup> which provided a general statement of the rights of patients in Europe.<sup>4</sup> The Convention was subsequently incorporated into the national legal systems of several countries. Later, in 2000, as part of the proceedings which produced the Treaty of Nice in December of that year, all the institutions of the EU variously agreed to, signed, or proclaimed the Charter of the Fundamental Rights of the European Union,<sup>5</sup> which contains a provision concerning access to and quality of health services, and a number of other provisions relevant to the rights of patients. Meanwhile, in a number of significant decisions,<sup>6</sup> the European Court of Justice developed the cross-border rights of patients within the EU.

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<sup>1</sup> See for example H.J.J. Leenen, J.K.M. Gevers, G. Pinet, *The rights of patients in Europe a comparative study* (Kluwer Law and Taxation 1993); D. Iliev and M. Vienonen, *Patients' rights development in Europe* (WHO Regional Office for Europe 1998).

<sup>2</sup> WHO Regional Office for Europe, 'A Declaration on the Promotion of Patients' Rights in Europe' (The 'Declaration of Amsterdam'), 1994.

<sup>3</sup> Council of Europe, Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, 1997.

<sup>4</sup> See H.D.C. Roscam Abbing, 'The Convention on Human Rights and Biomedicine: An Appraisal of the Council of Europe Convention' (1998) 5 EJHL 377-387 at 380. See, generally, H.D.C. Roscam Abbing, 'Human Rights and Medicine: A Council of Europe Convention' (1996) 3 EJHL 201-205.

<sup>5</sup> European Union (2010) Charter of Fundamental Rights of the European Union (updating the 2000 Charter).

<sup>6</sup> Beginning with C-120/95 *Decker v Caisse de Maladie des Employés Privés* [1998] ECR 1998 I-01831; (C-158/96) *Kohll v Union des Caisses de Maladie* [1998] ECR 1998 I-01931.

Activity has continued into the new Millennium. The Active Citizen Network (ACN) produced its Charter on the Rights of European Patients in 2002 and commitment to the Charter was reaffirmed in 2009.<sup>7</sup> In 2011, Directive 2011/24/EU systematized the cross-border rights of patients within the EU, and the ACN took this as an opportunity to campaign for the right of European citizens to make an informed choice regarding their healthcare.<sup>8</sup> The WHO regional office remains active in producing research and campaigning for better implementation of patients' rights.<sup>9</sup> Many other developments and initiatives have occurred, both internationally and nationally, designed to give tangible reality to the rhetoric of patients' rights.

What is striking about these developments, however, is the relative dearth of discussion of any notion of patients' duties. We suspect that at least part of the explanation for this is that, conceptually, 'patients' duties' have been impeded by an inheritance of some of the main juridical features of fundamental duties in European countries' constitutional law. In political terms, the concept of a duty owed by the citizen to the state is coloured by the history of 20th century Europe. For many, 'citizens' duties' are still a symbol of dictatorial communist regimes and their constitutions, or a reminder of the dark effects of the 'national duty' so cherished by the Third Reich.<sup>10</sup> Portugal is unusual in that it does have a number of patients' legal duties.<sup>11</sup> Yet the reason for this is illuminating. These duties were adapted from the Hospital Statute (Decree Law 48 357, of the 27th April, Art. 81), which dates from 1968, when Portugal was still not a democracy. This gives force to the view that duties are connoted as juridical features of dictatorial regimes.<sup>12</sup>

In consequence, there is little express recognition of the existence of fundamental duties in the majority of European constitutions, and when there is, those duties mentioned are seen as limits upon fundamental rights and freedoms, or as a natural part of the 'socially integrated

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<sup>7</sup> Available at <http://ec.europa.eu/>. **PLEASE INSERT SOME KEYWORDS INSTEAD OF THE ENTIRE WEBSITE...IDEM** ...health/ph\_overview/co\_operation/mobility/docs/health\_services\_co108\_en.pdf

<sup>8</sup> Available at <http://www.activecitizenship.net/.....IDEM> patients-rights/29-news/116-manifesto-for-the-implementation-of-the-right-of-european-patients-to-make-an-informed-choice.html

<sup>9</sup> WHO Regional Office for Europe, 'Patient Safety and Rights: Developing tools to support consumer health literacy' (WHO Regional Office for Europe 2010).

<sup>10</sup> B. Holzmagel, 'Function and interpretation of fundamental rights' in A. Weber (ed), (2001) *Fundamental Rights in Europe and North America* (Kluwer Law International 2001) (at **GER81-98**): **WHAT'S THIS?**

<sup>11</sup> Portuguese Health Bases Law (Law 84/90, of the 24<sup>th</sup> of August), Base XIV, §2.

<sup>12</sup> The 1990 reform of the law deleted the Article of the 1968 law that placed a legal obligation on patients to comply with the medical prescriptions and therapeutics prescribed to them. However the 1968 Law was never explicitly derogated, and this duty seems nowadays to be against the self-determination principle and informed consent rules. See further P. Lobato de Faria, *Medical Law in Portugal* (Kluwer Law International 2010) 3.45-3.56.

individual’, rather than as independently existing and enforceable duties.<sup>13</sup> That is, what in jurisprudential terms are known as fundamental duties are seen not as an independent source of individual obligation, but instead as an implicit corollary of an unwritten rule of responsibility that all citizens should have regarding the use of their rights and freedoms. One might speculate on this basis that the absence of ‘patients’ duties’ in European health laws follows the general tendency of avoiding a written recognition of citizens’ duties.

This is not to say that there is no recognition of the concept of patients’ duties, but such interest in the topic as there is can be described, as English<sup>14</sup> puts it, as ‘growing though modest’. This may, however, soon be set to change. Research commissioned by the European Commission<sup>15</sup> has found that the language of patients’ rights remains too abstract and does not deliver what patients actually want or require from their interactions with medical professionals. In addition, in the current and foreseeable socio-economic climate healthcare will soon, without political intervention, become unmanageably burdensome for national governments.<sup>16</sup> The World Bank has estimated that public expenditure on healthcare in the EU, running at 8% in 2000, could increase to 14% by 2030. The European healthcare sector is, so it has been said by the Economist Intelligence Unit, heading for ‘financial meltdown’.<sup>17</sup> The growth of patients’ rights, and the increasing frequency with which patients sue their healthcare providers, has arguably become part of the problem, as much as it has also been part of the solution to the medical paternalism of the past.

In this chapter we do not argue that the concept of patient’s duties is a panacea which alone can solve these problems, but we do argue, first, that that consideration of the neglected aspect of rights jurisprudence - the duties of patients – offers a better philosophical and practical starting point for conceptualizing patient-professional interactions, and secondly, that such an approach may, in comparison to a rights-based approach, offer both a more satisfactory practical framework for patient-professional interaction and better contextualize

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<sup>13</sup> It seems to be the general opinion of the authors from 11 European countries that contributed to the chapter on fundamental duties in Weber (note 10).

<sup>14</sup> D.C. English, ‘Moral obligations of patients: a clinical view’ (2005) 2 J Med Philos 139-152.

<sup>15</sup> European Commission, Directorate for health and consumer safety, ‘Eurobarometer Qualitative Study Patient Involvement: Aggregate Report May 2012’ (European Commission 2012).

<sup>16</sup> For some jurisdictions within the EU, this is already the situation: see V. Notara and others, ‘Economic crisis and the challenges for the Greek healthcare system: the emergent role of nursing management’ (2010) 5 J Nurs Manage 401-504.

<sup>17</sup> Economist Intelligence Unit, ‘The future of healthcare in Europe, London: Economist Intelligence Unit’ (2011) 1.

<sup>17</sup> Most vigorously and influentially argued by R. Dworkin, *Taking Rights Seriously* (2<sup>nd</sup> impression with corrections, Duckworth 1978).

such interactions in the climate of finite healthcare resources. We start by considering the underpinning jurisprudence of patients' rights and patients' duties, as represented by the work of Ronald Dworkin and Joseph Raz respectively, before arguing in favour of a notion of 'covenant', embracing notions both of rights and of duties. Having done that, we briefly sketch and analyze some of the most important of these 'missing' duties.

## 2. A Jurisprudence of Normative Duties

### 2.1 The necessity of thinking that patients have duties

The political dominance of rights discourse is mirrored in jurisprudence and constitutional theory.<sup>18</sup> Nonetheless, there is agreement at least on the following: rights and duties imply each other. The jurisprudential problem is not whether one can have rights without duties but rather, whether a theory of their interrelationship should be rights-based or duty-based. As Ronald Dworkin explains:

... rights and duties may be correlated, as opposite sides of the same coin... In many cases, however, corresponding rights and duties are not correlative, but one is derivative from the other and it makes a difference which is derivative from which... In the first case I justify a duty by calling attention to a right; if I intend any further justification it is the right that I must justify, and I cannot do so by calling attention to the duty. In the second case it is the other way around. The difference is importance because... a theory which takes rights as fundamental is a theory of a different character from that which takes duties as fundamental.<sup>19</sup>

We shall return to the specifics of Dworkin's claims below. The point for present purposes is that in a very general sense, the conclusion of jurisprudence on this question is that rights and duties have a symbiotic relationship, of mutual implication, whether 'correlative' or 'derivative'. So, clearly, the rights of patients imply the correlative duties of healthcare providers: the patient's right to informed consent is also the professional's duty to provide the necessary information to enable the patient to make an informed decision, and the patient's right to confidentiality implies the professional duty of secrecy, for example. On that point, we assume, all would agree. But we also argue that the rights of patients imply the duties of patients, in a relation which is both, in Dworkin's terminology, 'correlative' and 'derivative'.

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<sup>18</sup> *ibid.*

<sup>19</sup> *ibid.* at 171.

This is not merely a logical or deductive point. It is also a cultural and political one. These discourses – in particular that of human rights, of which the discourse of patients’ rights is a subset – are constructive and visionary, even utopian. They are part of a project to put in place a vision of state and citizenry that we find articulated at various local, national and international levels, not least in the Treaty on European Union. This vision balances rights and duties, individual freedom and respect for difference, the interests of the individual against those of the State and of the society. The model citizen, who underpins the EU, is both a free agent and a morally responsible agent. He or she is aware of the rights of his or her neighbours to pursue the same general goal, of personal fulfilment, albeit in different articulations and by different means, and is concerned to respect those differences. In addition, he or she is aware of the mutual dependency of the relationships between strangers in such a society, in which individuals benefit from the efforts and contributions of society as a whole.<sup>20</sup>

Compared to this model citizen, however, we find that the patient constructed by patients’ rights discourse is at present little more than a caricature. This patient is a person with very many entitlements but very few responsibilities. Yet, our ethics or jurisprudence should inform us that freedom without responsibility is an illusion. Moreover, although it may be unfair to hold law to blame for the inherent power imbalance between professionals and patients, nevertheless the current construction of the patient by law - as a person with rights but no duties - reinforces that prior-existing power imbalance by casting the patient in an essentially reactive role. The care-provider, under a series of duties, must be proactive in his or her dealings; a patient, with a series of rights, can only be reactive. To ‘stand on one’s rights’ is not to set the agenda. Thus the doctrine of patients’ rights subtly reinforces the power of the professional, and infantilizes patients.

In consequence, patients’ rights as currently understood are potentially counter-productive both for individuals and in terms of the common good. As is noted in the Declaration of Amsterdam

Patients should be aware of the practical contribution they can make to the optimum functioning of the health system. Their active participation in the diagnosis and treatment process is often desirable and sometimes indispensable... The patient has an essential role, the

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<sup>20</sup> In M. Ignatieff, *The needs of strangers* (Vintage-Random House 1994) the author explores this subject. He opposes the current dominant “language of rights” to a more desirable “language of the good” (ibid. at 14).

reciprocal of the provider's, in ensuring that the dialogue between them is carried out in good faith... the role patients play in the appropriate delivery of health care should be underlined, especially in today's complex health systems which are largely supported by collective financial mechanisms and where the economic and equitable use of resources allocated to health care is an objective which can be shared by health professionals and patients alike.<sup>21</sup>

We agree absolutely with these comments. But we disagree with the orthodox view of the mechanics of their realization. The drafters of the Declaration of Amsterdam, for example, made 'the basic assumption... that the articulation of patients' rights will in turn make people more conscious of their responsibilities'.<sup>22</sup> This is vague at best and hopelessly optimistic at worst. This was recognized by medical professionals soon after the publication of the Amsterdam Declaration.<sup>23</sup> In 1996 the European Forum of Medical Associations issued its Statement on the 'Declaration of Amsterdam' in which it suggested that 'reference should be made in the Declaration to the other important responsibilities which complement the rights referred to in the Introduction to the document, the acceptance of which is essential if patients' rights are to be adequately implemented'.<sup>24</sup> For us, this hits the nail on the head: the truth is that reciprocity cannot be engendered by rights alone. If we want real reciprocity, we have first to attempt to articulate it. A language of patients' rights, without an accompanying language of patients' duties, simply does not allow us to do this.

## 2.2 A model of reciprocity

As Dworkin indicates, the introduction of patients' duties into the equation raises the question of whether our model, based on a concept of the ideal patient or consumer of healthcare services, should be understood as rights-based or duty-based. Our argument in this paper is not merely that patients (should) have duties, but also that it is important that our theories (and practices) are duty-based in Dworkin's sense, i.e. in the sense that duties are seen as being more fundamental than rights, or that rights are derived from duties. As such, we are required to confront Dworkin's own position. This is because Dworkin's argument is that what he calls 'rights-based deep theory' is to be preferred. His preference is underpinned by two specific claims. First, in his view, reasoning which begins with rights carries no positive

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<sup>21</sup> WHO (note 2) 7, 8.

<sup>22</sup> *ibid.* at 7.

<sup>23</sup> (1996) 3 *International Digest of Health Legislation* 410-411.

<sup>24</sup> *ibid.* §11.

moral implications, as rights are ‘concerned with the independence rather than the conformity of individual action’.<sup>25</sup> Rights-based strategies, like duty-based strategies, may make use of rules that are clearly moral in character, but rights, unlike duties, have ‘no essential value in themselves’.<sup>26</sup> They are instrumental; they enable people to be free (in some sense) but do not specify the positive content of that freedom. That is a matter for the right-holder.

Secondly, thinking of rights as fundamental allows one to specify limitations that should be placed on the powers of the State and social institutions in order to respect those fundamental rights. Duty-based deep theories, Dworkin argues, are by contrast morally prescriptive or illiberal. They ‘are concerned with the moral quality of ... acts, because they suppose, without more, that it is wrong for an individual to fail to meet certain standards of behaviour’.<sup>27</sup> In addition, ‘A theory that takes some duty or duties to be fundamental offers no ground to suppose that just institutions are those seen to be in everyone’s self-interest under some description’,<sup>28</sup> and so are unable to specify which individual freedoms, or rights, should be fundamentally protected. In essence, his argument is that a theory based on the fundamentality of certain rights better enables freedoms to be maximized than does a theory based on the fundamentality of certain duties, as it does not impose a priori a moral code or set of morally underwritten limitations on human freedom.

We cannot accept this. First and foremost, we do not accept Dworkin’s claim that rights-based deep theory is value-free in moral terms. In our view, he admits as much when he explains that ‘The basic idea of a rights-based theory is that distinct individuals have interests that they are entitled to protect if they so wish’.<sup>29</sup> What is this if it is not a moral-political preference? At least, it is no more morality-free than is a preference for the prioritization of collective interests and responsibilities. As such, the claim of rights-based theory - that it starts from some morally value-free point - is not sustainable. Nor, therefore, does this provide a point of distinction between rights-based and duty-based theories. Dworkin seems to subscribe to the view that the deeper one digs, the more likely one is to find ‘pure’ theory, unadulterated by questions of the social and surface politics. The fallacy in this view is that it

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<sup>25</sup> Dworkin (note 17) 172.

<sup>26</sup> *ibid.*

<sup>27</sup> *ibid.*

<sup>28</sup> *ibid.* at 175.

<sup>29</sup> *ibid.* at 176.

uses the wrong paradigm of theorization, which Dworkin sees as akin to archaeology, whereas the more appropriate metaphor is construction. Theories are built not discovered. There can be no pure, morality-free, starting point for theory, for the simple reason that all theorists are human beings and as such are socially, psychologically and morally situated.

As far as Dworkin's second point is concerned, we agree that some rights – in particular the right to bodily autonomy and integrity in all its various manifestations – are fundamental, in the specific sense that, when they are pertinent, they are (all things being equal) more important than any competing rights or related duties. But it does not follow, as Dworkin claims, that these rights cannot be derived from a duty-based theory. Indeed, we would turn the point around, and argue that any talk of rights is simply not relevant to, in his terminology, 'deep level' theory. This is because rights discourse operationalizes a conflict-based model of human relations. Rights are relational or interpersonal, and 'the interpersonal aspect of rights is a major barrier to any attempt to regard them as foundational'.<sup>30</sup> 'Rights talk' ties us to the surface politics of human relations and so also prohibits us from moving below that surface to some 'deep' level. Rights talk is the language of promises broken or of expectations that have not been fulfilled, of prior-existing duties that have been breached. In our view, the very concept of rights necessarily implies underpinning duty-based, presumptively consensual, normative human relations.<sup>31</sup>

In addition, despite the orthodox view that rights and duties necessarily imply each other, there is in fact an asymmetry between the two which does seem to indicate that rights are derived from duties. The point is that although there can be no rights without duties, there can be duties without rights. Joseph Raz for example discusses so-called common goods; that part of the wealth of society that is under collective ownership for collective benefit. Public spaces or parks are one example. A national health service is another. As Raz points out, 'Typically individuals do not have rights to common goods'. The reason for this is that, although the value of a common good to an individual can be greater than the value of individual possessions<sup>32</sup> 'their value depends on the cumulative contribution of many, sometimes most, members of the community. However great their value to a single

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<sup>30</sup> J. Raz, 'Liberating Duties' (1989) 1 *Law and Philosophy* 3-21, at 11.

<sup>31</sup> It is for this reason that we cannot agree with M. Kangasniemi and others, 'Duties of the patient: A tentative model based on metasynthesis' (2012) 1 *Nursing Ethics* 58-67, at 64, that we should think in terms of 'right-based duties'. For us, 'duty-based rights' is preferable.

<sup>32</sup> For example, an individual's need for healthcare may be more important, at least at the time of need, than his or her personal possessions, career or leisure pursuits.



individual, it does not justify the imposition of a duty on the many'.<sup>33</sup> Nevertheless, and this is the important point, 'the nonexistence of individual rights is, of course, compatible with the existence of duties to provide and preserve them'.<sup>34</sup>

For Raz, this is a matter both of logic and of recognizing the social and cultural importance of duties.<sup>35</sup> For him, duties are constitutive of human beings qua human beings in a way that rights cannot be. Raz's strategy, in essence, is to turn Dworkin's position on its head. We saw above that Dworkin claims that it is a strength of rights theory that it does not in any a priori way constrain the freedoms of the right-holder. For Raz, what this means is that 'we are passive regarding our rights, we are recipients as far as they are concerned'.<sup>36</sup> By contrast, 'Duties are reasons for action. They can shape our view of our options even when we do not deliberate... rights are less intimately engaged with our lives. Our duties define our identities more profoundly than do our rights'.<sup>37</sup> Raz gives the example of friendship. Friendship is an intrinsic social good. It is good to have friends. But friendship cannot be defined without reference to the duties that are thereby implied, duties of aid and support.<sup>38</sup> Although it is not true to say that if you are not my friend I owe you no duty, it is true to say that if you are my friend those duties are of a different, more intimate, order. As these duties are part of the internality of friendship – they are what makes friendship what it is – duties are an intrinsic constituent of what makes human life what it is. Rights, by contrast, could never enable friendship. That is not what rights attempt to do. Fundamental aspects of the human condition are not conditioned by prior-existing rights. Rather, rights come into operation when conflicts in that prior-existing, duty-based, condition or situation emerge.

It is interesting, and apposite, that Raz uses the idea of friendship through which to elaborate his theory. It underlines the fact that a duty-based theory begins from the assumption of consensus and co-operation rather than conflict. Moreover, these notions of friendship and duty allow us to situate the doctor-patient relationship within the context of finite healthcare resources. In other words, we argue that a duty-based approach is to be preferred, both because it provides a sounder base for constructing the doctor-patient relationship in law, and because it allows us to think beyond that relationship, and provides a moral basis for the view

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<sup>33</sup> Raz (note 30) 10.

<sup>34</sup> *ibid.*

<sup>35</sup> On this, see further F.H. Moghaddam and others, 'Towards a Cultural theory of duties' (2000) 3 *Culture and Psychology* 275-302.

<sup>36</sup> J. Raz, *Value, Respect and Attachment* (CUP 2001) 21.

<sup>37</sup> *ibid.* at 21-22.

<sup>38</sup> Raz (note 30) 19.

that, as patients, we owe duties to other users or potential users of healthcare services, to use those limited resources as efficiently as possible, so as not to deprive others of the treatments which they have a right - the same right as us – to access.<sup>39</sup>

Hence, we need a jurisprudence of normative duties, which clearly establish norms in terms of consensus not conflict if we are ever to have in healthcare the standards of human dignity and equity to which we all aspire. This is not an argument against patients' rights, nor is the implication that patients should have any fewer rights than they currently enjoy. Rather, it is an insistence that, given that we have a choice, it is preferable for us to conceptualize from a duty-based and consensus-based position. For us, then, one's rights as a citizen (with entitlements) flow from one's situation, as a member of a society (with mutual and reciprocal obligations).

Having argued that we are mandated in theoretical terms to construct a model of the patient that is grounded in a preference for duties rather than rights, the question arises of the form that that model should take. We have found the work of Glenna M. Crooks<sup>40</sup> extremely useful on this question. Crooks' argues that modern healthcare delivery<sup>41</sup> has lost touch with its historical basis, which is not the conventional norm - contract - but covenant. There are various reasons for this. Chief amongst them are; the immense changes in size and form of healthcare services: the exponential increase in demand for treatments and the limits that must in consequence be placed on access to finite medical resources; the regulation of healthcare through the application of free market principles which lean towards short-termism; and the corresponding splintering of service provision such that many – health service procurers and managers, or private companies that manufacture medical products, for example – do not even see their role as being that of 'healer'. Contract as a model emphasizes the short term and defines (and limits) obligations precisely. Covenants by contrast

(...) by their very nature, involve more fundamental elements of relationships. They are mutual, binding and alter the life and the life-course of any party who enters into them in significant ways. Covenants are typically created between greater and lesser parties – as in the

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<sup>39</sup> See H.M. Evans, 'Do patients have duties?' (2007) 33 *Journal of Medical Ethics* 689-694. *In fine* this is a corollary of the famed "responsibility principle", see: H. Jonas, *The imperative of Responsibility: in search of an Ethics for the Technological Age* (The University of Chicago Press 1984).

<sup>40</sup> G.M. Crooks, *Creating Covenants: Healing Health Care in the New Millennium* (Medical Vision Press 2000). Crooks builds on the work done on covenants in healthcare by, amongst others, W. May: see W.F. May, *The Physician's Covenant: Images of Healer in Medical Ethics* (Westminster Press 1983).

<sup>41</sup> Her argument concerns the situation in America, which is clearly different from that of Europe in a number of significant ways, but for our purposes these differences of focus are immaterial.

grant of property between father and son. They reflect the dependency of the weaker party on the stronger party and the superiority of the stronger party over the weaker one... they are binding and they cannot be reversed... In contrast to contracts, covenants are for ever. As a result, they transform the identity of the parties. Covenants are not highly detailed. They do not anticipate each of the possible aspects of the relationship over time; to do so within a covenant would not be possible<sup>42</sup>

A covenant, on this definition, is what an English Equity lawyer would recognize as an equitable duty in the old-fashioned sense:<sup>43</sup> a duty defined not by precise positive terms but by the conscience of the person who is under the duty in question, i.e. a duty to do the 'right thing'. Such a duty, applied equally to the provider and the recipient of medical treatment, seems to us to be a good place from which to start to reconceptualize the manner in which the patient is constructed by law.

This might seem at first glance like a case of 'old wine in new bottles'. What is new about the idea of a covenant? After all, the Hippocratic Oath itself is a covenant. Or rather, and this is the point, it is two covenants. By the first, the entrant to the profession of physician covenants to treat his or her peers as equals, and to act to the mutual good. This is a covenant of mutual obligation. It may not be an agreement between equals – the medical professions are heavily hierarchical – but it is an agreement between peers. By the second, the entrant promises to treat patients to the best of his or her ability and always to keep their secrets. This is a covenant of grant. The obligations it imposes are one-sided. A covenant of grant is in the form of a gift, an obligation imposed or detriment suffered without expectation of reciprocity. Under such a covenant

The physician [acts] to relieve the symptoms or treat the disease. The weaker party – the patient – is under no obligation whatsoever. He may choose whether or not to arrive at the appointed time for the visit, whether or not to give the physician complete clinical information, consent to diagnostic tests, take the prescription or to abide by the advice given.... the patient does not need to promise anything<sup>44</sup>

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<sup>42</sup> Crooks (note 40) 26.

<sup>43</sup> These days, equitable covenants are usually fairly heavily prescribed, either by the operation of law or by the legal instrument creating the covenant.

<sup>44</sup> Crooks (note 40) 29.

The modus operandi of patients' rights strategists has been to conceptualize patients' rights in the form of an additional protocol, parasitic on the discourse of professional obligation based on the Hippocratic Oath. We would argue that this strategy is flawed, precisely because the conception of the professional-patient relation that is embedded in that professional code is an uneven one, based around a covenant of grant, when what is preferable is that the mutuality of that relationship be emphasized, in the form of a covenant of obligation. Again, we would underscore, this does not mean that patients should not have the rights that they do, nor does it mean that, when there is conflict, those rights should not be determinative of the outcome, but it does mean that those rights should be grounded by an underpinning relation of mutual obligation.

There is one final objection that we must respond to before being in a position fully to defend this model based on reciprocity. This comes, perhaps surprisingly as we have relied above on his arguments, from Raz. He is opposed to a duty-based model of reciprocity because

An ethic of reciprocity appears ... unduly restrictive, and insensitive, to those who believe that we have duties to future generations (who cannot have reciprocal duties towards us), to members of other animal species, and towards the environment, or aspects of it<sup>45</sup>

We accept the scope of the duty that Raz argues for. There seems to be no plausible reason why we should owe any greater duty to those currently alive but unknown to us personally than to those yet to be born. Our actions have the potential to affect members of both or either group. But does this mean that we have to abandon reciprocity as a model, given that the yet-to-be-born cannot reciprocate? We would argue not, for the following reason. The mutual covenant of obligation, properly understood, is not exclusively opposed to the covenant of grant in an either/or relation. Rather, the covenant of obligation merely mutualizes the covenant of grant. The latter is a subset of the former. The covenant of grant is the promise of a gift (in the Hippocratic Oath the sacred gift of healing), to be given, without expectation of reciprocation, to strangers. The covenant of obligation is a mutual promise to give gifts in this spirit. The covenant is not broken by the non-performance of one party. The obligation of the other to give remains; it was never contingent on the performance of the other in the first place. Raz's error is that he interprets reciprocity to mean some sort of exchange of equivalents.

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<sup>45</sup> Raz (note 36) 125.

This does not merely answer Raz's theoretical point: it also has important ramifications for practice. It contains, for example, the seeds of an answer to the question: what should a healthcare professional do if a patient breaches this or that duty? Clearly, any answer must start from the proposition that he or she must continue to act in accordance with the covenant of obligation that he or she has made, to continue, that is, to offer the gift that he or she has covenanted to offer.

### **2.3** The duties of patients and their interrelationship with the rights and duties of others

If patients have duties, how do these interact with the rights of those patients, the rights and duties of healthcare providers, and the rights and duties of other patients/citizens? One immediate consequence of the paucity of consideration that has been given to the question of whether patients' have legal duties is that these interrelationships have also been woefully neglected and constitutes a lacuna in our theoretical understanding of the ethical dynamics that underpin the delivery of healthcare services. Moreover, this 'theoretical' question is directly relevant to the practical question of the appropriate manner of implementation of patients' rights. Part of that project is, necessarily in light of finite resources and a politicized arena for the delivery of healthcare services, not so much to specify patients' rights as to specify their reach – and their limitations. In summary, it is our contention that there is a pressing need, first, to systematize the duties of patients and, secondly, to open a debate on the question of how patients' rights might be mitigated, as they have developed so far and may continue to develop in the future, by patients' duties.

### **3. ANALYSIS: The Duties of Patients**

Although in the law of many European countries there is nothing to be found that refers to the duties of patients, in others there is some recognition of the concept. For example Article 452 of the Netherlands' Civil Code, introduced along with the rights of patients by the Medical Contract Law (1994), requests that patients co-operate to the best of their knowledge with their healthcare providers. Also, base xiv, §2, of the Portuguese Health Bases Law (Law 84/90, of the 24th of August) includes the duty of patients to collaborate with health professionals in relation to their own health; the duties to observe the rules of the organization and functioning of health services and institutions, and to use the services in

accordance with those rules, and the duty to respect the rights of other users. In France, the law on the rights of patients and the quality of the health system (Loi n°2002-2003 du 4 mars relative aux droits des maladies et à la qualité du système de santé)<sup>46</sup> made some modifications to the French Code de la Santé Publique, requiring that patients contribute, along with the other actors in healthcare, to the ‘development of prevention, to the guarantee of equal access of each person to the healthcare they need, and to assuring the continuity of healthcare provision and to the best sanitary security possible’ (Art. L1110-1, of the Code de la Santé Publique).<sup>47</sup> What we do not find in any European legal system, however, is any sort of systematic exposition of the duties of patients, and it is to this task that we now turn.

### 3.1 Duties in the context of treatment

#### *The duty of disclosure*

Accurate diagnosis is essential if optimum treatment outcomes are to be achieved. Accurate diagnosis, in turn, relies on full and accurate information about the patient’s condition and factors which affect it. This seems to imply a duty placed on patients to make a full and frank disclosure of information relevant to this. The research evidence, however, is that patients frequently withhold information from or lie to their treatment providers.<sup>48</sup> The patient has a privacy right in that information which may justify non-disclosure, but the weight of that right seems to depend on the justification for the imposition of a duty to tell the truth. If it is that truth-telling optimizes the chances of the best outcome of an episode of treatment for the benefit of that patient, the choice to withhold information seems to be a matter solely for the patient concerned, but if it is that it optimizes the chances that finite health resources will be used most effectively, then the interests or wishes of the individual patient is not such a good reason for non-disclosure.

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<sup>46</sup> In *Journal Officiel*, number 54, of the 5th March 2002, at 41118.

<sup>47</sup> Article L1110-1 of the *Code de la Santé Publique*: (Loi no 2002-303 du 4 mars 2002 - art. 3 JORF 5 mars 2002: “Le droit fondamental à la protection de la santé doit être mis en oeuvre par tous moyens disponibles au bénéfice de toute personne. Les professionnels, les établissements et réseaux de santé, les organismes d’assurance maladie ou tous autres organismes participant à la prévention et aux soins, et les autorités sanitaires contribuent, avec les usagers, à développer la prévention, garantir l’égal accès de chaque personne aux soins nécessités par son état de santé et assurer la continuité des soins et la meilleure sécurité sanitaire possible.”

<sup>48</sup> See A. Laur, ‘Patients’ responsibilities for their own health’ (2013) 3 *Medico-Legal Journal* 119-123 and the references cited therein.

Considerations such as this complicate discussion of the nature and extent of the duty in question. So too does the particular context. For example, if the treatment of others – perhaps, relatives of the patient who may suffer from the same hereditary illness or disease as the patient – are at stake, the duty to tell the truth is greater than would otherwise be the case. In France, the Cour de cassation held in January 2011<sup>49</sup> that a woman who had failed to disclose that she had AIDS to those attending to her whilst pregnant was not entitled to sue her treatment providers when the child she was carrying was born HIV+. Although not conceptualized explicitly as a breach of the patients’ duty to tell the truth, this was the underlying rationale for the court’s decision.

### *The duty to comply with a treatment plan*

As with the duty to tell the truth, the duty to comply with a treatment plan can be justified either on the grounds of the interests of the particular patient or on the grounds that a patient should not misuse resources, the opportunity cost of which is borne by others. And again, the impact of that duty seems to depend on the reason for having it. The patient may make decisions which impact solely on his or her own health on the basis of autonomy, but if the interests of others are at stake, autonomy must be balanced against obligation. There is a duty to respect the health rights of third parties. For instance, if the patient suffers from an infectious disease, the interests of others are clearly relevant,<sup>50</sup> and this is recognized by the criminal law in many countries.<sup>51</sup>

Care must be taken, however, to ensure that this duty is not understood simply as a duty to do what one is told by one’s treatment provider. In our understanding of the covenant which binds patient and treatment provider, the former is not conceptualized as the passive recipient of care associated, for example, with the work of Talcott Parsons.<sup>52</sup> Rather, the duty arises because the patient and provider have negotiated a treatment plan in the context of a relationship of mutuality. Michael Bury<sup>53</sup> contrasts the ‘consensus model’ associated with Parsons (whereby the role of the patient is merely to comply with the instructions of his or her physician) with the ‘conflict model’ (in which provider and patient are in conflict over proposed treatment: this is the role most closely associated with the concept of patients’ rights) and the ‘negotiation model’ (in which healthcare decisions are made jointly by professional and patient in a climate of mutual respect). For us, the duty to comply with a

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<sup>49</sup> C. Cass. civ.1, Section: Responsabilité médicalé. Pourvoi, No. 09-68042, 20 January 2011.

<sup>50</sup> M. Brazier, ‘Do no harm - do patients have responsibilities too?’ (2006) 2 Cambridge Law Journal 397-422.

<sup>51</sup> See for example M. Wait, ‘The Criminalisation of HIV Exposure and Transmission: A Global Review’, Working Paper prepared for the Third Meeting of the Technical Advisory Group, Global Commission on HIV and the Law, 7-9 July 2011.

<sup>52</sup> T. Parsons, *The Social System* (Routledge 1951).

<sup>53</sup> M. Bury, ‘Doctors, patients and interaction in healthcare’ in M. Bury, *Health and Illness in a Changing Society* (Routledge 1997). PLEASE CHECK

treatment plan arises because the patient had an input into formulating that plan. As Kangasniemi and colleagues have recently argued,<sup>54</sup> free will is a pre-requisite for the imposition of patients' duties.

### 3.2 Duties arising out of access to health care resources

For present purposes we limit our consideration to publicly funded healthcare. The issues are different if the patient is paying privately for his or her treatment, but even in the context of privately purchased healthcare, some of the following duties will be in play.

#### *Duties arising out of access*

Healthcare is a finite resource and the rights of an individual to access it are in principle no greater than those of any other person. This entails a duty with various aspects to it: an individual has duty to; wait their turn for non-urgent treatment; not to misuse services (particularly emergency services) or request a home visit if able to attend the surgery or hospital in question; to attend appointments or give adequate notice of inability to attend; and generally, to not waste resources. These duties clearly overlap with the duty to comply with a treatment plan, discussed above. More generally, there is a duty not to profit out of one's treatment. Fraud has been reported to be an issue in some insurance-based healthcare systems,<sup>55</sup> but even in the absence of fraud, in such a system a patient has a duty not to accept reimbursement at a rate greater than the actual cost of treatment.<sup>56</sup> We do not argue, as a matter of principle, for a duty to pay for the costs of one's treatment, partly because we believe that such a duty is financially regressive and produces a bias in favour of the wealthy which we see as unethical, and partly because in a number of European healthcare systems - typically, those funded out of central taxation - there is no such duty. We recognize that in some European countries at least, this duty is written into positive law.<sup>57</sup> However, in such a situation the obligation to pay stems from contract law rather than the specific medical context, and so cannot be said to constitute a general duty of patients.

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<sup>54</sup> Kangasniemi and others (note 31) 62.

<sup>55</sup> H. Lie, 'Should patients have obligations?' (2011) 16 *Tidsskrift for Den norske legeforening* 2347-51.

<sup>56</sup> Which means, in our view, that the case of *Vanbraekel* (C-368/98 *Vanbraekel and Others v Alliance nationale des mutualites chretiennes* (ANMC) (2001) ECR 2001 I-05363) was wrongly decided by the European Court when it stated that "if the reimbursement of costs incurred on hospital services provided in a member state of stay, calculated under the rules in force in that State, is less than the amount which application of the legislation in force in the member state of registration would afford to a person receiving hospital treatment in that State, additional reimbursement covering that difference must be granted to the insured person by the competent institution".

<sup>57</sup> See for example Base XIV, §2 of the Portuguese Health Bases Law (Law 84/90, of the 24th of August), which provides that consumers of healthcare are under a duty to pay the charges that derived from healthcare provision when due. Nevertheless, these charges under the present constitutional framework should only take the form of "taxas moderadoras" which are symbolic prescription fees and not real payments.



### *The duty to respect the rights of other patients*

The duty to respect the rights of other patients has some fairly straightforward elements to it. For instance, inpatients should respect the privacy rights of other patients.<sup>58</sup> Patients should refrain from acting in a way which impacts negatively on the treatment of others. In extreme situations, when a patient is abusive or violent, the risk posed to the health or well-being of other patients may require treatment providers to break the ethical covenant of gift. In other words, on occasion breach by the patient of this duty will justify a refusal to offer that patient treatment.<sup>59</sup> More generally, the duties arising out of access, discussed above, can be seen as duties owed to other patients.

### *The duty to respect the rights and duties of professionals*

A violent or abusive patient also breaches his or her duty to respect the rights and dignity of their healthcare providers. Beyond that, things are more debatable. The treatment duties identified above may operate in the context of interaction with healthcare provider, but they are first and foremost owed to the system (and through that, to other citizens and to other patients in particular), rather than to the specific individuals who are offering me treatment. In other words, the issue is primarily to do with the efficient use of resources. Nor is it clear that the dignity or professionalism of those providing treatment is necessarily affected by, for example, the patient's failure to provide full disclosure of relevant information or comply with the treatment plan. Nevertheless, we would argue that such things can and should be seen in terms of a duty to respect the rights of professionals, because they are essential terms of the covenant of mutuality which provider and patient should operate under.

But this duty must be carefully circumscribed. The 1997 Oviedo Convention,<sup>60</sup> whilst recognizing the right of patients to refuse treatment, and to withdraw consent at any time, proceeds to suggest,<sup>61</sup> that in the context of an ongoing procedure, this 'does not mean that the withdrawal of a patient's consent during an operation should always be followed. Professional standards and obligations (...) (may oblige the doctor to continue with the operation so as to avoid seriously endangering the health of the patient'. The ethical basis of this view is that the patient, having given consent to allow a procedure to begin, cannot simply demand that it be brought to a halt, if to do so would leave that patient in a

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<sup>58</sup> Evans (note 39) 690.

<sup>59</sup> Department of Health (UK) (2001) 'Withholding Treatment from Violent and Abusive Patients in NHS Trusts' Health Service Circular HSC 2001/18.

<sup>60</sup> Oviedo Convention (note 3).

<sup>61</sup> In paragraph 38 of the accompanying Explanation of the Convention.

position dangerous to their health, because this would compromise the ethical requirement of the professional to ‘do no harm’.

This is a tricky issue: can the patient be required to recognize the professional obligation if to do so requires that the patient’s autonomy be breached? In some cases, this approach is clearly problematic. The English case of Ms. B (2002) provides an example.<sup>62</sup> Here Ms. B, rendered tetraplegic following the hemorrhaging of the spinal column in her neck, which had in turn caused an intramedullary cervical spine cavernoma, wished that life-sustaining treatment be ended. Her treatment providers, however, were insistent that she accept treatment, in the form of a one-way weaning procedure. Eventually, Ms. B went to court, which concluded that ‘the right of the competent patient to request cessation of treatment must prevail over the natural desire of the medical and nursing profession to try to keep her alive’,<sup>63</sup> and that the treatment proposed was ‘an unrealistic and unhelpful programme (...) designed to help the treating clinicians and the other carers and not in any way designed to help Ms B’.<sup>64</sup>

In this case, eventually, the correct decision was made. In other cases, however, the law has failed to recognize that the duties of the professional should not override the rights of the patient. In the French case of Mrs. X (2001), a decision of the Conseil d’État, the court held that it was lawful to override the refusal to accept blood products of Mr. X, a practicing Jehovah’s Witness, who was suffering from renal failure.<sup>65</sup> The reason for this, in the view of the court, was that the professional duty to save the life of the patient overrode the right of the patient to refuse treatment. Here, precisely, is an example of the dangers of deciding patients’ rights by reference to discourses of professional obligation. Let us pose the question in this way: does the patient have a duty to sacrifice his or her bodily autonomy and religious convictions for the sake of integrity of the professional’s adherence to his or her ethical code? The answer to this question must surely be ‘no’: the patient has no such duty. To hold otherwise would be to place the conscience of the treatment provider above that of the patient; and this cannot be right. Thus, the self-determination of patients has to be respected. This is the view of the law in France (see Article L1111-4 of the Code de la Santé Publique) and it has been defended at the court level in Europe, such as in the case Marcos (2002), where the Spanish Constitutional Court decided, against previous criminal courts decisions, to recognize the violation of the appellants fundamental right to religious freedom due to the transfusion procedures undertaken in their 13 year old son Marcos, against both their will and the will of the latter.<sup>66</sup>

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<sup>62</sup> Re B (Consent to Treatment: Capacity) [2002] EWHC 429; [2002] 2 All E.R. 449.

<sup>63</sup> *ibid.*, para. 27.

<sup>64</sup> *ibid.*, para. 99.

<sup>65</sup> Conseil d’Etat, 26 octobre 2001, Mme X (*Refus du patient témoin de Jehovah et urgence transfusionnelle*).

<sup>66</sup> See “*Sentencia 154/2002,18 de julio*” (full text available at: <http://mbarral.webs.ull.es/>). This case was commented in R.F. Marques and P.T. Gonçalves, ‘A recusa da transfusão – da prática à jurisprudência’ (2007) Sub Judge 38.

### 3.3 General duties of citizens regarding health

All duties of patients are potentially controversial when one seeks to apply them in practice, but the duties of citizens regarding health have the greatest potential for controversy. This is because such duties seem to extend beyond the purely medical, to encompass also questions of lifestyle. Starting with what is clear, the duties of patients derived from accessing national health care systems can be seen as a subset of the mutual duties all citizens owe each other. Some would go so far as to argue that this entails a duty to pay one's taxes and only support political parties pledged to uphold, if and when in government, the ideal of publicly provided healthcare.<sup>67</sup> Others, us included, might feel that the link between taxation and political affiliation is too remote from the issue of medical treatment to be properly said to constitute a duty owed by patients. Even in systems funded by insurance or reimbursement, many citizens (children, retired persons, persons in receipt of unemployment, disability or other benefits) are entitled to access the system despite having no personal obligation to contribute to its funding.

To a certain extent, it is merely a logical extension of these ideas about the equitable allocation of finite resources to argue that citizens owe a duty to uphold their own health to the maximum extent possible.<sup>68</sup> But such an extension is problematic, because unlike duties in the context of treatment or duties arising out of access - duties which arise because the particular patient has sought to exercise an entitlement - in this situation the citizen has done nothing, other than being born (which can hardly be described as a positive act) to indicate the acceptance of any such duty. Moreover, the extension of patients' duties into such areas raises, more acutely than elsewhere, the issue of patient autonomy, and the right to follow the lifestyle of one's own choice. And yet, as is well known, habits such as smoking, excessive use of alcohol, over-eating leading to obesity, or engagement in 'risky' sexual activities, have serious consequences for the efficacy of a healthcare system.<sup>69</sup> However, if because of lifestyle choices, a citizen at some point seeks treatment for the consequences of those choices, the issue can then be seen in terms of access and entitlement, as discussed above, and it seems reasonable, as an abstract proposition, that failure to pursue a healthy lifestyle is considered relevant at the point at which treatment is sought, based on the ethical argument that a person who has acted irresponsibly can expect a lesser degree of responsibility to be accepted by his or her healthcare system than a person who has not acted in that way.

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<sup>67</sup> Evans (note 39) 691; Kangasniemi and others (note 31) 63.

<sup>68</sup> J. Goode and others, 'Risk and the responsible health consumer: the problematics of entitlement among callers to NHS direct' (2004) 2 Crit Soc Pol 210-32.

<sup>69</sup> For example, in the UK it has been reported that '£4.2bn is spent on obesity-related issues every year, £2.7bn on illness related to alcohol abuse, up to 10% of the entire NHS budget on type 2 diabetes-related treatment and £1bn on sexually transmitted infections': see E. Hill, and J. Maning, 'Responsibility in healthcare: changing the culture: A 2020health discussion paper' (2010), available at: 2020healthorg.com.

It is not surprising, therefore, to see it argued that citizens owe a duty to desist from such activities and generally maintain a healthy lifestyle.<sup>70</sup> Equally, it is not surprising that it is in respect of such issues that patients frequently lie to healthcare providers.<sup>71</sup> However, the question of whether lifestyle choices should be seen in terms of a healthcare-related duty owed by citizens is, at root, ethical rather than financial. Should our healthcare systems seek actively to mold citizens or should they accept patients' claims for care as valid, based solely on healthcare needs, without judging patients by reference to ideas of causality or responsibility? In practice, this question cannot be imposed in such abstract terms: it is a question of balance – we would accept that there is a duty to others in play here, which sits in tension with the right to make one's own lifestyle choices - but the complexities and permutations involved in providing an answer to the question just posed cannot be engaged with in the limited space available here.

#### **4. Concluding Comments**

Our discussion indicates that patients already have a number of duties which are capable of enforcement in one way or another (although, not, typically, through legal action). The point, then, is not so much that patients' duties do not exist, but more that at present the duties of patients are ill defined – some can be found in an articulated form, others cannot. For example, there is an existent duty to refrain from violence towards or abuse of staff or other patients, but it is commonly understood as a management or security problem rather than as a breach of duty. Even here, however, it is not always clear what constitutes a breach of duty. In *Glass v UK* (2004) 39 EHRR 15, relatives of a physically and mentally disabled young boy intervened physically to revive the child (who had suffered complications following an operation to remove an obstruction from his respiratory tract and been placed on a ventilator) when it became clear that medical staff intended only to offer palliative care. Violence was used by the boy's relatives, who were subsequently arrested for assault. The European Court of Human Rights, however, found that the boy's mother, who had opposed the decision to offer only palliative care, had had her rights to privacy and respect for family life, found in Article 8 of the European Convention on Human Rights, breached by the medical staff. It is interesting to note that in such a life and death situation, and when treatment providers were themselves in breach of their duty to take due account of the wishes of the boy's family, the use of violence on behalf of the patient, can nonetheless be seen as a justifiable act, in an analogy with e.g. self-defence.

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<sup>70</sup> Laur (note 48) 122.

<sup>71</sup> K. Ravn, 'Body of lies: patients aren't 100% honest with doctors' *Los Angeles Times* (Los Angeles, 8 June 2009) cited in Laur (note 48) 120.

This case reminds us that it is one thing to compile, in the abstract, a list of patients' duties, but it is a very different thing and much more complex to understand how those duties operate in practical and dynamically complex situations, and how they interrelate with the rights of the duty-holder and the rights and duties of others. Issues such as the enforceability of duties, knowing that even those who argue strongly for patients' duties tend to concede that 'perhaps none...[are] strictly enforceable'<sup>72</sup> (as is the case with rights: some rights are clearly not enforceable by individuals, such as the 'right' to access healthcare); the question of whether one can owe duties to oneself; the existence or not of a duty to participate in research (here we agree with Kangasniemi that this involves particularly complicated ethical problems).<sup>73</sup> Although aware that these questions remain for future research and discussion, in this paper we have sought to provide a doctrinal and jurisprudential base for a duty-led approach, and to give some indication of which duties are most likely to be in play.

Obviously, we did not intend to compile a definitive list of patient's duties, but we consider that a more elaborated patient's duties legal doctrine is vital if we are ever to move beyond the historical powers imbalances between professionals and patients, based on a construction of the patient as infantized and responsibility-free, and seek to replace this with what we might call the 'covenant' model, grounded in ideas of mutual respect and obligation.

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<sup>72</sup> Evans (note 39) 691.

<sup>73</sup> Kangasniemi and others (note 31) 64.