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## **One Size Fits All? On Patient Autonomy, Informed Consent and the Impact of Culture**

### **Abstract**

While both medical law and medical ethics have developed in a way that has sought to prioritise patient autonomy, it is less clear whether it has done so in a way that enhances the self-determination of some patients, particularly but not exclusively from non-Western backgrounds. In this article we consider the desire of such patients for family involvement in decision-making and argue that this desire is not catered for effectively in either medical law or medical ethics. We examine an alternative approach based on relational autonomy that might serve both to allow such patients to exercise their self-determination while still allowing them to include family members in the decision-making process.

**Key Words: Medical Law; Autonomy; Family; Relational Autonomy; Consent; Culture**

## I. Introduction

The development of relational autonomy as an emerging concept in law and bioethics can be seen as a reaction to the failure of these two disciplines to address the social context of the doctor-patient relationship.<sup>1</sup> In this article we argue that the emergence of relational autonomy has not yet yielded a meaningful legal response to the impact of the patient's cultural background on the decision-making process, thus creating difficulties for clinicians and some patients to make decisions about treatment. Indeed, the discussion in medical law and bioethics has over the last few decades focused on a very individualistic form of patient autonomy. The underlying notion has been that competent adult patients should be capable of making the decisions they want without the controlling influences of others.<sup>2</sup> For this purpose, the patient must receive information, understand it and voluntarily express her preferences about the options available to her (hereafter: disclosure, understanding and independence). More recently, however, the scholarly discussion has shifted from this individualistic perception of patient autonomy to a relational approach where the patient's social context is taken into account when making decisions.<sup>3</sup> This shift has led some scholars to suggest that law and bioethics should provide mechanisms that allow for the inclusion of the family in the process.<sup>4</sup>

Interestingly, the emergence of relational autonomy did not yield a comprehensive legal discussion about the impact of the patient's cultural background on the medical decision-making process. Despite evidence suggesting that people are influenced by their cultural backgrounds when making decisions about their health,<sup>5</sup> this issue has been scarcely discussed so far in English medical law.

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<sup>1</sup> S. Wolf, 'Erasing Difference: Race, Ethnicity and Gender in Bioethics' in A. Donchin and M. Purdy (eds), *Embodying Bioethics: Recent Feminist Advances* (Lanham: Rowman & Littlefield, 1999).

<sup>2</sup> E.g.: I. Kennedy, *Treat Me Right: Essays in Medical Law and Ethics* (Oxford: Clarendon Press, 1991).

<sup>3</sup> S. McLean, *Autonomy, Consent and the Law* (London: Routledge-Cavendish, 2010).

<sup>4</sup> R. Gilbar, 'Asset or Burden? Informed Consent and the Role of the Family: Law and Practice' (2012) 32(4) *Legal Studies* 525.

<sup>5</sup> F. Moazam, 'Families, Patients and Physicians in Medical Decisionmaking: A Pakistani Perspective' (2000) 30(6) *Hastings Center Report* 28.

Consequently, it is not clear whether English law provides an adequate framework for decision-making for patients who do not subscribe to the bioethical approach it adopts. However, this is an important issue because patients from various cultural backgrounds receive medical treatment in the NHS under English medical law.

This article proposes to examine these issues and to critically evaluate whether English law accommodates cultural variations and whether, in the eyes of the law, respect for autonomy includes respect for the cultural values patients bring to the consultation room.<sup>6</sup> To fulfil this aim we will start our discussion by presenting empirical evidence on how some patients, particularly from non-Western backgrounds, make decisions. We mention non-Western backgrounds because such patients have been the subject of empirical research, as we discuss below. However, we would emphasise that these issues do not pertain solely to them and apply equally to patients of all backgrounds. This will lead us to examine whether relational autonomy can accommodate community-based, family-dominated approaches to medical decision-making and whether English law is sensitive to cultural variations. Arriving at the conclusion that the current position is unsatisfactory, we will conclude by pointing to the future direction the law should take in our view. It should also be noted that we do so without taking a position on this decision-making model itself. Rather, our position is that English law is not sensitive to the needs of collectivist approaches. To this end, we argue that patients should be able to choose to participate in either approach – and a relational autonomy approach, despite its limitations, might be a realistic way of achieving this. However, a key to this exercising of autonomy is of course the proviso that the choice is freely made, and indeed that the patient is free to reject the use of family involvement - which if unwelcome would become a limit to autonomy rather than an enhancement of it.

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<sup>6</sup> L. Blackhall, et al., 'Ethnicity and Attitudes toward Patient Autonomy' (1995) 274(10) *JAMA* 820.

## II. The role of ethnicity and culture in health

Culture has various meanings. It can be defined as a set of shared attitudes, values, beliefs, language, rituals and practices that distinguish a particular social group,<sup>7</sup> or as a set of guidelines that people inherit as members of a particular community, that guide them how to view the world and how to behave in relation to other people.<sup>8</sup> These cultural values influence the way that people conduct themselves in the health care system and they provide patients a set of ethical priorities when making decisions about diagnosis and treatment. As we argue below, studies have been indicated that whereas people from a Western background may prioritise self-determination, rights and open communication with clinicians, people from non-Western cultural backgrounds may be more likely to be guided by family-determination, moral responsibility to others, and limited disclosure. The question posed in this article is whether it is possible to reconcile these two approaches when they meet.

## III. The empirical background

Over the last two decades there has been a growing number of studies which indicate that patient independence and disclosure of information are perceived differently in Western and non-Western societies. A key factor in these two aspects relates to role of the patient's family.

### (i) Independence

In some non-Western societies the family has a dominant role in decision-making. For example, Fan points out that a key difference between the Anglo-American and the East Asian bioethical approaches is that the East Asian approach provides the family rather than the individual patient the

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<sup>7</sup> J. F. Gubrium and J.A. Holstein, *The New Language of Qualitative Method* (Oxford: Oxford University Press, 1997).

<sup>8</sup> C. Helman, *Culture, Health and Illness* (5<sup>th</sup> edn., Abingdon: Hodder Arnold, 2007).

authority in medical decision making.<sup>9</sup> This derives from the significance Confucianism attaches to the family and the belief that one's life is inseparable from those of their family. Care and harmonious dependence are common and influential features in the decision-making process in many East Asian families.<sup>10</sup>

The dominance of the family is also reflected in South-Asian societies. Describing the decision-making process in Pakistan, Moazam states that '*you are your family and your family is you*'.<sup>11</sup> Moazam and other writers explain that religion has an influence on people's decision-making and that in Islam the family is perceived as a source of strength and protection.<sup>12</sup> This view is also shared in Hinduism and Sikhism<sup>13</sup> Harmonious family life is a moral imperative only second in importance to the will of God. In many families decision-making is generally based on a strong sense of moral responsibility to one's family, so making decisions about illness is a project undertaken by the family unit as a whole.<sup>14</sup>

Arguably, the family is important to patients in many respects regardless of their cultural background. However, the level of dominance of the family when the patient faces important decisions differs. Whereas English medical law imagines that the individual patient in general has the final say, in Middle-Eastern, North-African and South-Asian societies, the family is more likely to be hierarchical and male member(s) have a dominant role in decision-making, often more than

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<sup>9</sup> Fan R., 'Self-determination vs. Family-determination: Two Incommensurable Principles of Autonomy' (1997) 11(3) *Bioethics* 309.

<sup>10</sup> *Ibid.*, at p. 318.

<sup>11</sup> See Moazam, above n. 5, at page 30 (italics in original).

<sup>12</sup> C. O'Kelly, C. Urch and E. Brown, 'The Impact of Culture and Religion on Truth Telling at the End of Life' (2011) 26(12) *Nephrology, Dialysis, Transplantation* 3838.

<sup>13</sup> H. Coward and T. Sidhu, 'Bioethics for Clinicians: Hinduism and Sikhism' (2000) 163(9) *Canadian Medical Association Journal* 1167.

<sup>14</sup> *Ibid.*

the patient.<sup>15</sup> Thus, when treatment decisions have to be made, the spouse, male parent or eldest son will have the decision-making authority with an input from the patient and other relatives.<sup>16</sup>

Indeed, studies from the Indian sub-continent show that relatives meet clinicians independently and provide consent to treatment on the patient's behalf.<sup>17</sup> When emigrating to a new country, relatives act as translators and thus possess substantial control over the decision-making process.<sup>18</sup> This suggests that decision-making is led by the clinician together with the family, and certainly not by the clinician and the individual patient as imagined by English law.<sup>19</sup> However, the relatives' acts may be perceived as acts of care rather than oppression.<sup>20</sup>

(ii) Disclosure and truth-telling

The Anglo-American process of obtaining consent to treatment requires the clinician to provide detailed information to the individual patient. This is promoted by the imposition of the moral duty to tell the patient the truth about their illness.<sup>21</sup>

However, a reluctance to receive bad news has been noted in East Asian,<sup>22</sup> South-Asian<sup>23</sup> and Middle Eastern societies<sup>24</sup> where relatives act as the recipients of the information, especially when

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<sup>15</sup> Moazam, above n. 5; V. Moghadam, 'Patriarchy in Transition: Women and the Changing Family in the Middle East' (2004) *Journal of Comparative Family Studies* 137.

<sup>16</sup> Jafarey and A. Farooqui, 'Informed Consent in the Pakistani Milieu: The Physician's Perspective' (2005) 31 *Journal of Medical Ethics* 93; F. Aslam, O. Aftab and N.J. Janjua, 'Medical Decision Making: The Family-Doctor-Patient Triad' (2005) 2(6) *PLoS Medicine* e129; K. Hawthorne, J. Rahman and P. Roisin, 'Working with Bangladeshi Patients in Britain: Perspectives from Primary Health Care' (2003) 23(2) *Family Practice* 185.

<sup>17</sup> U. Senarath and N. S. Gunawardena, 'Women's Autonomy in Decision-Making for Health Care in South Asia' (2009) 21(2) *Asia-Pacific Journal of Public Health* 137; A. Humayun et al., 'Patients' Perception and Actual Practice of Informed Consent, Privacy and Confidentiality in General Medical Outpatient Departments of Two Tertiary Care Hospitals of Lahore' (2008) 9 *BMC Medical Ethics* 14.

<sup>18</sup> See Hawthorne, Rahman and Roisin, above n. 16.

<sup>19</sup> J. Samanta and A. Samanta, 'Exploring Cultural Values that Underpin the Ethical and Legal Framework of End-of-Life Care: a Focus Group Study of South Asians' (2013) 1(1) *Journal of Medical Law & Ethics* 63.

<sup>20</sup> See Moazam, above n. 5, at p. 30.

<sup>21</sup> Surbone A., 'Telling the Truth to Patients with Cancer: What is the Truth?' (2006) 7 *Lancet Oncology* 944.

<sup>22</sup> Turoldo F., 'Relational Autonomy and Multiculturalism' (2010) 19 *Cambridge Quarterly of Healthcare Ethics* 542.

<sup>23</sup> See Moazam, above n. 5.

<sup>24</sup> Mobeireek, AF., et al. 'Information Disclosure and Decision-Making: The Middle East versus the Far East and the West' (2008) 34(4) *Journal of Medical Ethics* 225.

the diagnosis and prognosis are poor.<sup>25</sup> This approach remains influential when people from these backgrounds immigrate to countries that promote truth-telling.<sup>26</sup> Relatives' requests to conceal bad news from the patient is based on mutual care and commitment in the family,<sup>27</sup> and on the conviction that remaining in the bliss of ignorance sustains hope.<sup>28</sup>

The differences between the patient-centred and the family-oriented approaches is relevant to patients in the UK. Recent studies recorded some of the challenges English clinicians face when treating patients from minority backgrounds.<sup>29</sup> With respect to *independence*, the participant doctors noted that, particularly in cases involving female patients, the patient may be passive and the relative more dominant. As for *disclosure*, the participant doctors struggled when approached by relatives who asked them not to deliver bad news to the patient. In relation to *understanding*, challenges arose when a relative attended consultations to interpret for the patient because the doctors could not ascertain whether the relative delivered all the information to the patient and whether the patient understood it.

Indicating that cultural background influences patient and family involvement in medical decision-making can be contested by the argument that people are generally influenced by various factors, which not only include culture and ethnicity but also, gender, age, dynamics in their particular family and, perhaps most pertinently in our context, the level of exposure to the common ethical principles of the society they live in.<sup>30</sup> Therefore, it might be too simplistic to make generalisations about the impact of the patient's cultural background on the medical decision-making process.

Nevertheless, in this article we focus on this topic in light of the different perceived attitudes of

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<sup>25</sup> S. Chaturvedi et al., 'Communication with Relatives and Collusion in Palliative Care: A Cross-Culture Perspective' (2009) 15(1) *Indian Journal of Palliative Care* 2.

<sup>26</sup> J. Kai et al., 'Challenges of Mediated Communication, Disclosure and Patient Autonomy in Cross-Cultural Cancer Care' (2011) 105 *British Journal of Cancer* 918.

<sup>27</sup> Moazam, above n. 5, at p. 32.

<sup>28</sup> O'Kelly, above n. 12.

<sup>29</sup> Kai, above n. 26.

<sup>30</sup> I. Hyun, 'Waiver of Informed Consent, Cultural Sensitivity, and the Problem of Unjust Families and Traditions' (2002) 32(5) *Hastings Center Report* 14.



Western and non-Western societies regarding patient autonomy and family involvement. However, when discussing these issues we will address the reality of patients who are influenced simultaneously by a family-oriented approach in their private sphere and by a patient-centred approach in the public sphere. To address these issues we will start our discussion by analysing the conception of relational autonomy, which principally takes into account the social context of the individual and the relationship with their significant others.

#### **IV. Relational autonomy**

In large part, relational autonomy has been developed by feminists who realised that a comprehensive account of the autonomous individual must address not just the individual's inner self but also their social relationship with others. Relational autonomy theorists attempt to combine the reality that social relationships constitute an important part of the individual's identity with the prominence given in Western society to freedom and liberty. The result was a relational approach which considers the impact of social influences on the individual's decision-making capacity.<sup>31</sup>

Relational autonomy, as the discussion in this part indicates, is a contested conception. Ethics-of-care writers highlight the importance of care and inter-dependence for the capacity to act autonomously.<sup>32</sup> Accepting that people make decisions in a dialogue with significant others<sup>33</sup> led ethics-of-care feminists to emphasise that social relationships develop and nurture one's capacity to be autonomous.<sup>34</sup> Donchin, for example, argues that decision-making involves a dynamic relationship among people who are closely involved in each others' lives.<sup>35</sup> Nedelsky adds that

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<sup>31</sup> C. Mackenzie and N. Stoljar, 'Autonomy Refigured' in C Mackenzie and N Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (Oxford: Oxford University Press, 2000).

<sup>32</sup> Chodorow N. *The Reproduction of Mothering* (Berkeley; University of California Press, 1978).

<sup>33</sup> C. Taylor, *The Ethics of Authenticity* (Cambridge, Massachusetts: Harvard University Press, 1991).

<sup>34</sup> J. Nedelsky, 'Reconceiving Autonomy: Sources, Thoughts and Possibilities' (1989) 1 *Yale Journal of Law & Feminism* 7.

<sup>35</sup> A. Donchin, 'Autonomy and Interdependence: Quandaries in Genetic Decision-Making', in Mackenzie and Stoljar, above n. 31, pp. 236-258.

personal autonomy can be appreciated through reference to shared social norms and values,<sup>36</sup> thus accepting that culture and ethnicity are significant in determining one's autonomy. This relational approach accords with societies which prioritize interconnectedness and interrelationships.<sup>37</sup>

The ethics-of-care approach corresponds with procedural theorists who also value intimate relationships of care and dependence. Procedural theorists also accept that the capacity to act autonomously and to critically assess available options is the product of social influences.<sup>38</sup> However, procedural theorists will agree with substantive theorists that the individual must distance herself from others when embarking on the process of decision-making, though substantive theorists also argue that some conditions should be in place for the capacity to act autonomously.<sup>39</sup>

Ultimately, it seems that the disagreement among the various streams of relational autonomy relates to the perception of identity. Herring recently admitted that the ethics-of-care perception of identity as essentially found in relationship with others raises the risk of it being open to 'appalling misuse.'<sup>40</sup> Indeed, a significant part of the debate among relational theorists derives from the realisation that close relationships can be detrimental to the development of autonomy. This part of the debate is important here in light of the dominant position of the family in some cultures and the empirical studies reviewed above, suggesting that in some societies the patient has a limited say in medical decision-making.

A central question is how to perceive individuals who live in hierarchical communities. This debate divides substantive and procedural theorists into two camps. Substantive theorists, such as Oshana, are aware that others can assist the individual to execute her life plans, but Oshana also requires the

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<sup>36</sup> J. Nedelsky, *Law's Relations: A Relational Theory of Self, Autonomy and Law* (Oxford: Oxford University Press, 2011).

<sup>37</sup> K. Bowman, 'What are the Limits of Bioethics in Culturally Pluralistic Society?' (2004) 32(4) *Journal of Law, Medicine & Ethics* 664.

<sup>38</sup> Stoljar N., 'Autonomy and the Feminist Intuition' in Mackenzie and Stoljar, above n. 31, pp. 94-95.

<sup>39</sup> *Ibid.*

<sup>40</sup> J. Herring, *Caring and the Law* (Oxford: Hart, 2013), 77-78.

individual to meet her goals without depending on the judgment of others and without taking any responsibility for others' needs. Oshana believes that autonomy requires control over external circumstances. Thus, once the individual possesses adequate information, critically reflects on the events that shaped her desires, and decides to delegate the decision-making authority to others, she is no longer autonomous even when she is happy and content with her life. Oshana explains that she 'fails to be autonomous not because she wants to be subservient, but because she is subservient.'<sup>41</sup>

Christman argues that Oshana's view is liberal-individualistic because she expects the individual to rationally transcend the social context within which she lives. Indeed, Oshana believes that the individual must maintain the ability to 'pursue goals different from those who have influence and authority over her.'<sup>42</sup> Christman notes that such a view stand in contrast to the relational approach which recognises that social relationships constitute the individual's identity and that in reality people's lives are interconnected.<sup>43</sup>

In contrast, procedural theorists like Christman promote the idea that '*independence of the mind*' is sufficient for autonomy.<sup>44</sup> This means that the individual must possess the capacity to critically reflect on the values that guide her life. Based on this process of critical reflection the individual would formulate her preferences and decisions.<sup>45</sup> Christman adds that an adequate critical reflection requires two components: (1) *competency*, which includes minimal rationality, self-control, the ability to access and understand information, a motivation to act, and the capacity for care, intimacy and social cooperation; and (2) *authenticity*, which accepts that a process of critical reflection is shaped by social influences.<sup>46</sup>

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<sup>41</sup> M. Oshana, 'Personal Autonomy and Society' (1998) 29(1) *Journal of Social Philosophy* 81.

<sup>42</sup> *Ibid.*

<sup>43</sup> J. Christman, 'Relational Autonomy, Liberal Individualism, and the Social Constitution of Selves' (2004) 117 *Philosophical Studies* 143.

<sup>44</sup> See Stoljar, above n. 38, pp. 94-111

<sup>45</sup> *Ibid.*

<sup>46</sup> See Christman, above n. 43.

Elaborating on the *authenticity* component, Christman believes that an individual who lives in oppressive circumstances is autonomous if ‘she is able to realistically imagine choosing otherwise were she is in a position to value sincerely that alternative option.’<sup>47</sup> Adequate reflection, Christman explains, ‘requires that a person can see herself doing otherwise, under at least some imaginable conditions; otherwise she is not manifesting a true capacity to consider her own internal states.’<sup>48</sup> This is undoubtedly requires others to give the individual the opportunity to distance herself from her social context and conduct critical reflection without ‘distorting factors’.<sup>49</sup> However, Christman’s requirement to endorse cultural values carries the risk of losing autonomy altogether because he defines endorsement as a ‘failure to be deeply alienated from social values.’<sup>50</sup>

For others, elements such as self-trust, self-confidence and self-esteem are also important for one’s capacity to be autonomous.<sup>51</sup> They realise that those who are close to the individual have a substantial effect on the development of these personal qualities. McLeod and Sherwin argue that if one is deprived, from a young age, of the opportunity to experience situations where her choices are respected, she may lack self-trust and passively delegate the authority to make important decisions to men who possess this capacity.<sup>52</sup>

Building on this, Mackenzie argues that a weak substantive approach is needed to secure autonomy in oppressive relationships. Mackenzie explains that the individual can claim authority over her life only if she perceives herself as a legitimate source of that authority. To achieve this, she has to be situated in a web of norms which hold individuals as legally and morally accountable for their actions, and by receiving the recognition from others that she has the authority over her life. Indeed, this account highlights the importance of social relationships.

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<sup>47</sup> *Ibid*, at p. 154.

<sup>48</sup> *Ibid*.

<sup>49</sup> *Ibid*, at p. 153.

<sup>50</sup> *Ibid*, at p. 153-154.

<sup>51</sup> See Stoljar, above n. 38.

<sup>52</sup> C. McLeod and S. Sherwin, ‘Relational Autonomy, Self Trust and Health Care for Patients who are Oppressed’ in Mackenzie and Stolzar, above n. 31, pp. 259-279.

Mackenzie requires society to secure the conditions which will enable the individual to trust her authority. Thus, the state should not let social structures and relationships to undermine the individual's capacities necessary for autonomy.<sup>53</sup> Therefore, autonomy is meaningless without the promotion of equality and justice in the private and the public spheres.<sup>54</sup>

Summing up, the discussion on autonomy shows that there are similarities between the liberal approach and the relational approach.<sup>55</sup> The aim is to secure the capacity of individuals to make decisions which help them to live flourishing lives from their own unique perspective. The focal point is the individual. The community is not perceived as a unit of its own but as a group of individuals with different personal interest and desires. The differences between the theoretical approaches revolves around the psychological appreciation that a person needs to have a separate private sphere but also needs to belong and have relationships to shape the person she is.<sup>56</sup> The discussion mainly focuses on how to strike the balance between the two.<sup>57</sup> Thus, we are back to the starting point: social relationships can both promote and compromise the capacity to be autonomous.<sup>58</sup>

In our view, the approach taken by Mackenzie strikes the best balance. As feminists stress, autonomy is a matter of degree.<sup>59</sup> In reality, people – whether in hierarchal communities or not – act autonomously in some respects and submissively in others.<sup>60</sup> Some of the communities, of which the individual is a member, provide her a sense of security and guidance even when the society she lives in is essentially oppressive.<sup>61</sup> As Kuczewski and McCrudden argue, the Western scholars who

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<sup>53</sup> C. Mackenzie, 'Relational Autonomy, Normative Authority and Perfectionism' (2008) 39(4) *Journal of Social Philosophy* 512.

<sup>54</sup> M., Friedman, 'Autonomy and Male Dominance' (2004) 87 (1-2) *Soundings* 175.

<sup>55</sup> Christman, above n. 43.

<sup>56</sup> S. Minuchin, *Families and Family Therapy* (Cambridge, MA: Harvard University Press, 1974).

<sup>57</sup> D. Meyers, 'Intersectional Identity and the Authentic Self?: Opposites Attract!' in Mackenzie and Stoljar, above n. 31, pp. 151-180

<sup>58</sup> M., Friedman, 'Autonomy, Social Disruption, and Women' in Mackenzie and Stoljar, above n. 31, pp. 35-51.

<sup>59</sup> See Friedman, above n. 58 and Meyers, above n. 57.

<sup>60</sup> See Mackenzie, above n. 53.

<sup>61</sup> See Meyers, above n. 57.

write on the autonomy of people who live in collectivist societies are ‘outsiders’. They cannot assess adequately the complexities and variations the individual who lives in these societies experiences as an ‘insider’. The reality is that societies are not one-dimensional and static, but rather their members ‘pick and choose from its beliefs.’<sup>62</sup> This is particularly true in our context, where patients from some backgrounds may be influenced by the cultural values of their origin *and* the values of the society they live in.

Thus, in our view, a patient who allows her male relative(s) to receive distressing news and make decisions on her behalf acts autonomously if she is given the opportunity to: (1) develop self-confidence in her judgment; (2) critically reflect on the values of her culture of origin, (3) evaluate her desires, and (4) endorse or reject the suggested course of action in a way which is not unduly coercive.<sup>63</sup> This, as ethics-of-care and substantive theorists argue, should be supported by a sense of justice in the private sphere of the family and in society in general.<sup>64</sup>

Ultimately, though, a practical difficulty remains: How can we ascertain whether a patient’s delegation of decision-making authority to her relatives is based on a sense of self-trust and a process of critical reflection? How can we be sure that her decision is ‘*authentically*’ hers?

## **V. Relational autonomy in bioethics**

Bioethics is based on Western moral philosophy with an emphasis on individualism, rights and personal autonomy.<sup>65</sup> However, it has gradually moved from a universal and context-free perspective of the doctor-patient relationship to a context-based approach where autonomy is

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<sup>62</sup> M. Kuczewski and P. McCrudden, ‘Informed Consent: Does it Take a Village? The Problem of Culture and Truth Telling (2001) 10 *Cambridge Quarterly of Healthcare Ethics* 34.

<sup>63</sup> See Friedman, above n. 58, at p. 47.

<sup>64</sup> Herring, above n. 40, at 79.

<sup>65</sup> See Bowman, above n. 37.

defined in relation to others.<sup>66</sup> In this section we will examine several relational autonomy accounts in bioethics in the context of independence, disclosure of information and understanding.

### (i) Independence

Traditional Western bioethics treats social influences with suspicion.<sup>67</sup> To exercise their decision-making capacity competent adult patients should be free - as far as possible - from controlling influences by others.<sup>68</sup> Yet some proponents of relational autonomy in bioethics appreciate the benefits of social influences and the involvement of the family in the decision-making process.<sup>69</sup> However, there is disagreement regarding the extent of social influences on the patient's freedom to make decisions independently.

Hardwig argues that justice and fairness require the patient to take into account the relatives' concerns. He adds that the relatives should have a role in the decision-making process when decisions affect them and goes further, arguing that when decisions dramatically affect relatives' lives, their interests might prevail.<sup>70</sup> This is because to be a family member 'is to be morally required to make decisions on the basis of thinking about what is best for all concerned, not simply what is best for yourself.'<sup>71</sup> Therefore, 'the interests of patients and family members are morally to be weighed equally.'<sup>72</sup>

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<sup>66</sup> L. Turner, 'Bioethics in a Multicultural World: Medicine and Morality in Pluralistic Settings' (2003) 11(2) *Health Care Analysis* 99.

<sup>67</sup> R. Gilbar, 'Family Involvement, Independence and Patient Autonomy in Practice' (2011) 19(2) *Medical Law Review* 192.

<sup>68</sup> J. K. Mason and G. T. Laurie, *Mason and McCall-Smith's Law and Medical Ethics* (9<sup>th</sup> edn., Oxford: Oxford University Press, 2013); T. Beauchamp and J. Childress, *Principles of Biomedical Ethics* (7<sup>th</sup> edn., Oxford: Oxford University Press, 2013).

<sup>69</sup> J. Lindemann-Nelson, 'Taking Families Seriously' (1992) 22 *Hastings Center Report* 6; J. Blustein, 'The Family in Medical Decisionmaking' (1993) 23 *Hastings Center Report* 6.

<sup>70</sup> J. Hardwig, 'What About the Family?' In J. Hardwig, *Is There a Duty to Die? And Other Essays in Medical Ethics* (London: Routledge, 2000), pp. 29-44.

<sup>71</sup> *Ibid.*, at p. 31.

<sup>72</sup> *Ibid.*, at p. 35.

Hardwig's view accords to a certain extent with the dominant role the family has in some non-Western cultures, since both emphasize the value of moral responsibility, which provides the relatives substantial influence in decision-making. However, Hardwig's starting point in imposing responsibility on the patient is the freedom of the individual to make decisions. Hardwig writes that if 'I am morally empowered to make decisions about "my" medical treatment, I am also morally required to shoulder the responsibility of making very difficult moral decisions.'<sup>73</sup> So, the starting point is the individual and not the family as a unit. This does not accord with an approach which perceives the individual and the family as one unit, and therefore includes the latter in decision-making from the beginning. In addition, Hardwig's insistence that justice and equality are the grounds for family involvement in decision-making is not shared by hierarchal communities which provide male family members more decision-making authority than others.

Hardwig is aware that dynamics in the family may be based on resentment, anger, and family dominance. His solution is to conduct family conferences either with or without the clinician, with the aim of hearing all the relevant parties and arriving at a decision which is fair to all. This view, although aims to promote the relatives' interests reflect a substantive approach to autonomy because it requires the patient to be assertive and not subservient.

An ethics-of-care approach is expressed by Hilde and James Lindemann-Nelson, who argue that the love family members express to one another leads them to be considerate of each other's needs and preferences when making decisions. They argue that intimacy produces a sense of responsibility. Thus, just as the relative provides support to the patient when she is ill, the patient should choose the treatment which considers the relatives' concerns. However, they also stress that the patient has

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<sup>73</sup> *Ibid.*, at p. 38.



a greater stake in the decision than anyone else so the relatives' interests cannot supersede the patient's wishes.<sup>74</sup>

Their approach reflects the values many families hold – regardless of their cultural backgrounds – that care and moral support help the patient to enhance their autonomy. However, they also believe that the patient *should* be in the driving seat when decisions are made and that open communication with the clinician should be established. However, this may not reflect the dynamics of some patients and relatives from non-Western societies who place the family rather than the patient at the centre of the decision-making process.

The Lindemann-Nelsons address the issue of family dominance and suggest that the clinician will act as a mediator: on the one hand she will let relatives express their views, but on the other hand she will bar them from unduly influencing the patient.<sup>75</sup> However, this suggestion assumes that the clinician can distinguish between familial influence which is culturally acceptable and that which is not. To conduct such a delicate assessment requires the clinician to become familiar with the patient, the family, the cultural values they share and their level of acculturation.<sup>76</sup> This is what relational theorists promote.<sup>77</sup> However, it requires substantial resources and time.

The need to equip clinicians with the relevant knowledge about the social background of the patient is discussed by Ho, who suggests that when clinicians believe that the patient is acting under family pressure they should discuss this with the patient in private; inquiring about the patient's goals,

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<sup>74</sup> H. Lindemann-Nelson and J. Lindemann-Nelson, *The Patient in the Family* (London: Routledge, 1995), 114.

<sup>75</sup> *Ibid* at pp. 114-117.

<sup>76</sup> Exposure to Western values varies among people from the same cultural background. See B. Palmer et al., 'Acculturation and the relevance of Pain Amongst South Asian Minority Ethnic Groups in the UK' (2007) 46(6) *Rheumatology* 1009; D. Kelleher and S. Hillier (eds.), *Researching Cultural Differences in Health* (London: Routledge, 1996), pp. 124-159.

<sup>77</sup> N. Stoljar, 'Informed Consent and Relational Conceptions of Autonomy' (2011) 36 *Journal of Medicine and Philosophy* 375; Mackenzie, above n. 53.

family dynamics and the ways the patient reaches their decision. These discussions, Ho argues, will enable the clinician to fulfill the patient's wishes without additional familial tensions.<sup>78</sup>

She believes that the relatives' influence may be tolerated by the patient because they are the only family the patient has, and they are so integral to their identity that distancing them from the decision-making process may cause the patient more distress than their substantial influence. Ho concludes that when 'patients defer decision making to family members, unless there is clear evidence of neglect or abuse [clinicians] should respect the patient's expressed wishes.'<sup>79</sup> Clearly, this approach does not accord with strong substantive theorists who would not perceive such a patient as autonomous. But does Ho's view reflect other relational accounts?

Ho specifically addresses the issue of male dominance in non-Western families. Being aware that the consent of a female patient to allow male relatives to make the decisions for her may not be her own decision but the product of her culture, Ho insists that if the patient expressed her wishes and goals with the clinician privately her decision should be respected.<sup>80</sup> In our view, Ho's approach – more than the suggestion to conduct family conferences offered by Hardwig and the Lindemann-Neslons – reflects and respects the cultural values that some patients bring to the examination room on the one hand the importance of protecting patient independence on the other. Indeed, the difficulty in this situation is in finding an approach that is sensitive both to the patient's cultural values and respectful of their autonomy, including the patient's right to reject their cultural values. Ho's account corresponds with Mackenzie's weak substantive approach and is the closest to achieving this that we have found. Ho perceives the passive patient as potentially having the capacity to make autonomous decisions, based on a process of critical reflection on the one hand

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<sup>78</sup> A. Ho, 'Relational Autonomy or Undue Pressure? Family's Role in Medical Decision-Making' (2008) 22 *Scandinavian Journal of Caring Sciences* 128.

<sup>79</sup> A. Ho, 'Family and Informed Consent in Multicultural Settings' (2006) 6(1) *American Journal of Bioethics* 26.

<sup>80</sup> *Ibid.*, at p. 28.

and the provision of external conditions which allow her the freedom to conduct such a process without familial undue influence.

To sum up, according to our preferable approach, the most important decision the patient should make independently, following a process of critical reflection, without undue influences is the decision to either be an active and informed decision-maker or delegate the authority to a close relative. This, however, may not suit family-oriented approaches of non-Western societies but neither does it reflect strong substantive approaches and liberal-individualistic approaches to autonomy. However, we believe that this approach suits the decision-making process conducted in practice when patients from hierarchal societies and clinicians who were taught and required to respect personal autonomy have to reach medical decisions together.

#### (ii) Disclosure & Understanding

The conventional belief is that disclosure of information is a vital component of patient autonomy.<sup>81</sup> It is said to be beneficial because it enables the patient to understand their position and make choices which reflect their desires and life plans.<sup>82</sup> However, the prominent place information received led some to argue that bioethics does not concentrate on what the particular patient really wants to know but on what they *should* know.<sup>83</sup>

This is a valid point. The empirical studies presented above suggest that patients and relatives from various cultural backgrounds do not believe that information is always beneficial. Rather, some believe that bad news may crush the patient's hopes of surviving the disease, and the patient's

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<sup>81</sup> N. Manson and O. O'Neill, *Rethinking Informed Consent in Bioethics* (Cambridge: Cambridge University Press, 2007).

<sup>82</sup> See McLean, above n. 3, at p. 42.

<sup>83</sup> C. Schneider, *The Practice of Autonomy: Patients, Doctors and Medical Decisions* (Oxford: Oxford University Press, 1998).

emotional state is seen as more important than knowing the details of their condition. This is the focus of discussion in this part. The question is whether the current Western debate about autonomy can accommodate a request not to deliver bad news to the patient. To answer this question, we analyse the main themes in the current bioethical discourse on disclosure.

First, there is an understanding that the level of disclosure to the patient should fit their particular informational needs.<sup>84</sup> These needs are influenced by the patient's cultural background and values.<sup>85</sup> This cultural variation, Beauchamp and Childress argue, strengthens the duty to secure the patient's right to choose either to accept or refuse information. They stress that clinicians should always ask their patients whether they wish to receive information.<sup>86</sup> They also conclude that clinicians should never make assumptions about the patient's informational need based on their cultural background. Based on this approach, the wishes of patients not to receive parts of the information should be respected.

Second, there is a gradual realization that respect for autonomy can be achieved by a rather limited scope of disclosure. Walker, for example, argues that to respect autonomy patients must only know 'what in general terms is to be done to them.'<sup>87</sup> While this requires clinicians to explain to the patient what they propose to do to improve her condition, it does not require them to disclose the risks and benefits involved in the proposed treatment. This may suit patients whose cultural values do not support full disclosure. It would allow clinicians not to tell the patient that the disease is terminal.<sup>88</sup>

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<sup>84</sup> See Hyun above n. 30.

<sup>85</sup> L. Candib, 'Truth Telling and Advance Planning at the End of Life: Problems with Autonomy in a Multicultural World' (2002) 20 *Families, Systems & Health* 213.

<sup>86</sup> Beauchamp and Childress, above n. 68, at p. 110.

<sup>87</sup> T. Walker, 'Respecting Autonomy without Disclosing Information' (2013) 27(7) *Bioethics* 388.

<sup>88</sup> The issue of truth-telling raises the bioethical discussion about the right not to know, which is conducted mainly in the context of genetics. It is beyond the scope of this article to deal with the right not to know. Here we discuss the issue of partial disclosure and the relatives' request that the patient should not be told. For a recent discussion about the right not to know see: J. Herring, C. Foster, 'Please Don't Tell Me: The Right Not To Know' (2012) 21 *Cambridge Quarterly of Healthcare Ethics* 20.

Walker's position raises the following question: can the patient act autonomously if he does not have information about the personal, familial and social implications of the treatment options? Walker argues that to respect autonomy, the clinician cannot determine in advance that all patients would like to receive detailed information about the risks of the proposed treatment, its success rates and the like. Rather, respecting the patient's capacity to make decisions requires the clinician to let the patient decide whether they want to receive more detailed information about the medical condition or not.<sup>89</sup>

Walker's approach does not reflect the strong substantive approach that requires the individual to be an active decision-maker regardless of her social circumstances. Walker expresses a weak substantive approach when he requires the patient to receive at least basic information about her condition. However, requiring clinicians to respect the wishes of patients *not* to know their prognosis reflects an approach which perceives patients as autonomous provided the patient was given the opportunity to critically reflect on her personal preferences and cultural values. This can be achieved by finding out in advance *what* the particular patient really wants to know and how involved the patient wants to be in the decision-making process in light of her request to receive only part of the information. However, the problem is practical: the clinician may find it difficult to meet the patient alone to discover her true wishes regarding disclosure, particularly if the family asks the clinician not to communicate bad news to the patient. Furthermore, when they do meet in private, will the patient be able to go against her cultural convictions and request detailed information?

Acknowledging that autonomy can be fulfilled by a limited amount of information is also evident in Maclean's account.<sup>90</sup> He argues that the clinician and the patient must embark upon a process of

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<sup>89</sup> See Walker, above n. 87.

<sup>90</sup> A. Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge: Cambridge University Press, 2009).

open and honest communication, and that the patient should have the authority to control the flow of information delivered to them.<sup>91</sup> Maclean adds that the patient does not need to have information which will enable her to actually make the decision. Instead, she must possess sufficient information to decide whether to delegate the decision-making authority to others or keep it. Maclean concludes that if the patient knows that more information is available she can freely waive their right to be informed.<sup>92</sup>

According to Maclean, the only information the patient *cannot* refuse is whether they need an operation or other form of treatment to improve their condition.<sup>93</sup> This satisfies the requirement that there is a proposed medical treatment and there is a need to make a decision about it. This information does not include any details about the type of disease and the prognosis but it gives the patient the option of making a decision about the level of knowledge they require.

Yet, as much as this model respects the informational needs and personal values of the particular patient, it also focuses on the individual patient and their independence. The responsibility to communicate with the clinician is imposed explicitly on the patient whose personal goals are the centre of attention.<sup>94</sup> This view clearly stands in contrast to the collectivist approaches which provide the family the authority to determine the flow of information to the patient.

A third critique of the bioethical approach to information disclosure comes from feminist theorists. Dodds argues that providing extensive information carries the risk of compromising the capacity of the individual to exercise autonomy. It is more important, Dodds argues, to promote the patient's level of understanding. This should be done by providing the patient support mechanisms.<sup>95</sup> The main support, Donchin asserts, comes from the family because making an autonomous decision is a

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<sup>91</sup> *Ibid*, at p. 232.

<sup>92</sup> *Ibid*, at p. 243.

<sup>93</sup> *Ibid*, at p. 251.

<sup>94</sup> *Ibid*, at pp. 244-247.

<sup>95</sup> S. Dodds, 'Choice and Control in Feminist Bioethics' in Mackenzie & Stoljar, above n. 31, pp 213-235.

dynamic collaborative process conducted with the patient's significant others.<sup>96</sup> In addition, Stoljar argues that the provision of medical information to patients should not only include the medical details but also information about the personal, familial and social implications of the treatment options. Thus, when clinicians provide information to the patient, they must be aware of the family dynamics and the cultural background, which may affect the patient's capacity to give consent.<sup>97</sup>

It thus appears that Western bioethics *can* accommodate a request not to receive detailed information.<sup>98</sup> However, we believe that such a request should come from the patient and not from the relatives. We acknowledge that practically it might be difficult for clinicians to find out whether the patient would like to be actively involved in the decision-making process and whether she would like to receive the full picture about her condition. However, we do believe, like other liberal and relational scholars, that in a society based on equality, it is the informational needs and decision-making preferences of the individual patient that should be respected. The next question we need now to examine is whether English law shares this view.

## **VI. Legal background**

In this section we revisit the issues of independence and disclosure and understanding from the last section, but this time from a legal perspective. The law relating both of the issues has seen much change in recent times, particularly that relating to disclosure and understanding but, as we argue in this section, its deliberate shift towards a greater prioritisation of the principle of autonomy neither offers help to patients who may wish to practice a more relational form of autonomy, nor even constitutes a successful transition on its own terms. Moreover, the suspicion with which Western bioethics treats family involvement is replicated in the legal context. This is most often the case

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<sup>96</sup> See Donchin, above n. 35.

<sup>97</sup> See Stoljar, above n. 77, at p. 383.

<sup>98</sup> See Herring and Foster, above n. 88 for the view that autonomy includes the right not to know.

when it prevents the doctor from acting in what she considers to be the patient's best interests rather than when it is supportive of the proposed medical intervention.

(i) Independence

English medical law treats the involvement of others with suspicion and as something of an impediment to the patient's ability to exercise her autonomy. To this end, the principle of voluntariness requires that the patient is not unduly influenced or coerced into making a decision. In the event of such unwelcome interference, the law will consider any consent provided to be vitiated. Equally, a refusal of consent may also be invalidated. The distinction between coercion and undue influence is a subtle one, but it is important for our purposes here. Coercion necessarily involves acts that go beyond mere persuasion and instead constitute an overbearing of the patient's will by another, or a dominance that effectively negates the ability of the patient to make her own decision rather than defer to that of the coercer.<sup>99</sup> Needless to say, violence or even the threat of violence will constitute coercion.<sup>100</sup> However, coercion may take alternative forms. Alongside the threat of violence, there may also be others such as 'economic threats (such as the threat of losing a job, eviction from a home, or threats to property), threats to a person's social standing, and even threats of leaving a partner'.<sup>101</sup> Equally the coercive conduct does not even need to be in the form of a threat, and the patient's autonomy may be infringed if it comes in the form of an inducement or, critically for our purposes, the mere existence of an imbalance of power or hierarchical relationship.<sup>102</sup> In these circumstances, the threat or inducement may not even need to be objectively realistic, so long as it is subjectively felt to be so by the victim. The criminal law relating to consent to sexual intercourse does recognise this by referring to 'improper' pressure

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<sup>99</sup> See, for example, *Mrs U v Centre for Reproductive Medicine* [2002] Lloyds Rep Med 259 and *A Local Authority v Mrs A and Mr A* [2010] EWHC 1549 (Fam).

<sup>100</sup> *R v Olugboja* [1982] QB 320.

<sup>101</sup> S. Knight, 'Libertarian Critiques of Consent in Sexual Offences' (2012) *UCL Journal of Law and Jurisprudence* 137, 143.

<sup>102</sup> *Ibid* at 144.



(implying that some pressure might be ‘proper’), while maintaining that consent should carry its ordinary meaning.<sup>103</sup> Clearly, the key is whether the victim’s decision was affected, rather than the reality of the threat.

Obviously, if an individual is coerced to act then it is absolutely right and proper that the law should intervene and not allow the coerced decision to stand. No matter what approach to autonomy one holds this is not a situation where the patient act autonomously. The patient has been subjugated and requires the law’s protection. It should also be reiterated that, in this scenario, coercion does not have to take the form of physical domination, but can instead include a significantly overbearing character. Indeed, we would argue that it is possible under this definition to go even further so as to include a family structure where the hierarchy is so rigid and the (usually) paternalistic influence so pervasive that the ability of the patient to act autonomously is completely removed from her.

The concept of undue influence is equally problematic, not least because the line between influence that is legitimately applied and that which can be considered ‘undue’ is a particularly fine one. Both the sense and the weaknesses in the application of the concept are highlighted by the most commonly cited case of *Re T*.<sup>104</sup> Repetition of the full facts is not necessary. For our purposes it is sufficient to say that the patient had stated that she was a former Jehovah’s Witness (who still held to some tenets of the religion) but only mentioned a refusal of blood transfusions ‘out of the blue’ following a conversation with her mother, who was a practicing member of the faith. One of the questions for the Court of Appeal was whether the mother had exerted undue influence on Ms T, and thus whether her refusal was vitiated. The case provides a useful summary of the law, not least because Lord Donaldson MR had to decide it on principles rather than facts as Ms T’s mother did not give evidence. He thus noted that mere influence by a family member is not sufficient to vitiate the patient’s decision, and that that more was required for it to be defined as *undue*:

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<sup>103</sup> See *R v McAllister* [1997] Crim LR 233 and *R v Olugboja*, above n.94 respectively.

<sup>104</sup> *Re T (Adult: Refusal of Medical Treatment)* [1992] EWCA Civ 18.

It is wholly acceptable that the patient should have been persuaded by others of the merits of such a decision and have decided accordingly. It matters not how strong the persuasion was, so long as it did not overbear the independence of the patient's decision. The real question in each such case is 'Does the patient really mean what he says or is he merely saying it for a quiet life, to satisfy someone else or because the advice and persuasion to which he has been subjected is such that he can no longer think and decide for himself?' In other words 'Is it a decision expressed in form only, not in reality?'<sup>105</sup>

Clearly, Lord Donaldson expresses a relational approach when he acknowledges the influence of significant others on the patient's decisions. In principle, he does not object to that. However, Lord Donaldson raises the question which, as we saw above, troubles many theorists and bioethicists: how do we know whether the patient *authentically* means what she says?

Lord Donaldson is cautious. He holds that the nature of the relationship between family members, as well as the significance of religious beliefs, may make it more likely that the line has been crossed and autonomy vitiated:

The influence of parents on their children or of one spouse on the other can be, but is by no means necessarily, much stronger than would be the case in other relationships. Persuasion based upon religious belief can also be much more compelling and the fact that arguments based upon religious beliefs are being deployed by someone in a very close relationship with the patient will give them added force and should alert the doctors to the possibility - no more - that the patient's capacity or will to decide has been overborne. In other words the patient may not mean what he says.<sup>106</sup>

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<sup>105</sup> *Ibid* at para 31.

<sup>106</sup> *Ibid* at para 32. See generally: C. Stewart and A. Lynch, 'Undue Influence, Consent and Medical Treatment' (2003) 96(12) *J Roy Soc Med* 598.

As we mention above, the case highlights both the positive and negative aspects of relational autonomy. From a positive perspective, we can see that, in theory at least, the participation of relatives in the decision-making process is both anticipated and if not welcomed then at least understood. However, from a negative perspective, the fact that the person influencing the patient is a relative is seen by Lord Donaldson as making it *more* likely that the influence is undue – thus making it more of an impediment than assistance to the patient exercising her autonomy.

Butler-Sloss LJ went further in her judgment and referred to situations where one family member may hold a position of dominance over another.<sup>107</sup> This is essentially the situation we discussed above. The danger is that family involvement can be used by judges to negate the patient's decision, even if the patient welcomes it, particularly if the final decision is contrary to the doctor's own advice or the patient's medical interests. In such a scenario this will have the effect of overriding the patient's autonomous decision:

[F]amily and friends are precisely the people whose opinions a patient may find important, and religious convictions can be a source of comfort to many. There is a danger that, if they are discarded, decision-making will become too medicalised, in the sense that doctors on the whole could seek to persuade legally, and that will mostly be in the direction of suggesting that the patient accepts the treatment offered. Moreover, it is interesting to think whether the question of undue influence would have been raised successfully if T's mother had persuaded her to *accept* the treatment rather than reject it. We would speculate that it would not.<sup>108</sup>

Indeed, such an application of the principle can be seen in the *Re T* case itself. Despite Ms T not having discussed the issue of blood transfusions with the medical staff before her mother's arrival, and despite there being no indication of what was said between mother and daughter when they

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<sup>107</sup> *Re T*, above n. 104, at para 50.

<sup>108</sup> N. Hoppe and J. Miola, *Medical Law and Medical Ethics* (Cambridge: Cambridge University Press, 2014).

were alone, both Lord Donaldson and Butler-Sloss LJ still found that the influence exerted by the mother was undue, mainly due to her religious beliefs and mere relationship with her daughter. This was made abundantly clear by Butler-Sloss LJ:

[I]t has long been recognised that an influence may be subtle, insidious, pervasive and where religious beliefs are involved especially powerful. It may also be powerful between close relatives where one may be in a dominant position vis a vis the other. In this case Miss T. had been during her childhood subjected to the religious beliefs of her mother and in her weakened medical condition, in pain, and under the influence of the drugs administered to assist her, the pressure from her mother was likely to have a considerably enhanced effect.<sup>109</sup>

What we can therefore see is a situation where, *in theory*, the law perceives family involvement positively and values the contribution of family members – so long as it is welcomed by the patient herself. However, *in practice* we see that not only are such contributions treated with suspicion, they can actually be used as evidence supporting the vitiation of the consent or refusal based on it. As we see in *Re T*, the courts do appear to require little in the way of evidence of undue influence to apply the concept. Needless to say, this potentially causes problems for some patients who actively seek and value family involvement. While we fully support the curtailing of any influence that is not welcomed by the patient – or has its genesis in dominance – the law does appear somewhat reluctant to accept that some familial interventions may be autonomy enhancing rather than a threat to the patient’s ability to make decisions for herself.

Ultimately, the judges in *Re T* were convinced that the mother had compromised the patient’s right to critically reflect on her personal desires, the values of the community she had once belonged to, and the values of the social network she now belongs to. The patient’s decision immediately after

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<sup>109</sup> *Re T*, above n. 104, at para 50.

her meeting with the mother may indeed suggest that the mother mitigated the patient's self-confidence which is essential for the capacity to act autonomously. The judges believed that the mother had led the patient into a position where she could not alienate herself from the culture she had once belonged to. This, according to the various relational accounts we reviewed, cannot be considered as an autonomous act. Yet, the judges did not have any direct evidence to suggest that this indeed was the case. Therefore, their approach is, in our view, more liberal-individualistic than relational.

#### (ii) Disclosure and Understanding

We have already demonstrated that according to some bioethicists it is sufficient for patients to be made aware of the generalities of their condition and know that they have the option of requesting more information should they wish to receive it. In this way, there can also be assumed to be a right *not* to know – particularly if it is prospectively requested. However, problems may arise if the patient wishes to be provided *some* information, as the doctor will face a difficult issue in deciding at what point the flow should stop. It is even more problematic if a family member has requested that certain information not be communicated to the patient. These issues are dealt with below, but it is important to note at the outset that such cases would be well outside the usually imagined information disclosure scenarios, which tend to deal with unsought information regarding material risks and potential alternatives.

The questions of how much information to give a patient, and whether it is justifiable to withhold disclosure of selected information from a family member may be dealt with jointly. Some elements, however, are simpler than others. Essentially, if the patient at the beginning of the consultation specifically requests that she only wishes to be informed of risks and alternatives that the family member thinks appropriate, or if she states that she does not wish to be informed of

anything at all, then there is nothing in the legal rules that should prevent such wishes being respected – even if it would make the consultation more difficult on a practical level, including the doctor being satisfied that this is really what the patient wants. However, complexities arise if this is not discussed beforehand, because the doctor is then under a common law duty to inform the patient of all material risks and reasonable alternatives to the treatment proposed. Moreover, the law appears somewhat unclear regarding the specific nature of that duty. Thus, we know that there is a duty to inform of risks and, at the very least, reasonable alternatives.<sup>110</sup> However, what is less clear is whether a doctor would be failing in her duty if she failed to mention a risk to the patient on the advice of a family member. Before discussing this, however, it is first necessary to consider the situation regarding the materiality of risk.

As mentioned above, the question of how we define the materiality of risk constitutes the vast majority of the informed consent case literature. It is also an area of law that has seen a significant amount of change. It is not necessary in this piece to chart the development of the law, particularly since it has been done elsewhere, but it is sufficient to say that in under 30 years the law has metamorphosed from forcefully defending the definition of a material risk as a clinical judgment to now equally forcefully claiming that such a definition needs to be made by the patient.<sup>111</sup> Therefore, where previously the common law stated that a material risk was one that a reasonable doctor would disclose, it is now seen as one that the reasonable patient in the patient's position would wish to be informed of. In the case of *Pearce* Lord Woolf held that while the amount of information to be disclosed to patients was based on what the reasonable doctor would disclose, the reasonable doctor must disclose what the reasonable patient would wish to be informed of – thus essentially shifting the law from one where the doctor determines what information must be

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<sup>110</sup> *Birch v UCL Foundation Hospital Trust* [2008] EWHC 2237 (QB).

<sup>111</sup> For an account of the development of the law see J. Miola, 'On the Materiality of Risk – Paper Tigers and Panaceas' (2009) 17(1) *Medical Law Review* 76.

disclosed from one that prioritises the right of the patient to decide.<sup>112</sup> The impetus behind what has been a fundamental change has been the principle of autonomy, which the courts have increasingly identified and prioritised in risk disclosure cases. This approach reached its zenith in the case of *Chester v Afshar*, albeit in the context of causation in risk disclosure rather than the materiality of risk, where a majority of the House of Lords were willing to change the law – and admit that they were doing so – in order to find for the claimant.<sup>113</sup> The reason, expressed openly by the majority of their Lordships, was that the purpose of the law relating to information disclosure existed to protect patient autonomy. To this end Lord Steyn noted that:

*[t]he starting point is that every individual of adult years and sound mind has a right to decide what may or may not be done with his or her body. Individuals have a right to make important medical decisions affecting their lives for themselves: they have the right to make decisions which doctors regard as ill advised. Surgery performed without the informed consent of the patient is unlawful.*<sup>114</sup>

Despite the existence of the usual rules of causation that would normally end her claim – Mrs Chester had stated that even had she been informed of the risk of paralysis she would probably have consented to the operation anyway, but perhaps at a later date – Lord Steyn found for her on the basis that despite this her right to autonomy had been infringed as she had not received all of the information required to make her own choice. He therefore held that the ‘right to autonomy and dignity can and ought to be vindicated.’<sup>115</sup> Lord Walker was of a similar view, in the sense that he too felt that a patient making a decision without being put in possession of *all* of the relevant information could not possibly be exercising her self determination:

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<sup>112</sup> See *Pearce v United Bristol Healthcare NHS Trust* [1999] 1 PIQR 53 and *Wyatt v Curtis* [2003] EWCA Civ 1779. See also Miola, above n. 111.

<sup>113</sup> *Chester v Afshar* [2004] UKHL 41.

<sup>114</sup> *Ibid* at para 14, *per* Lord Steyn. Emphasis added.

<sup>115</sup> *Ibid* at para 24, *per* Lord Steyn.

Part of the imbalance between doctor and patient is due to the patient's lack of information, and, on one view, it is the function of the law to redress the imbalance by providing patients with the 'right' to be given that information, or perhaps more accurately imposing a duty on doctors to provide it. There are some within the medical profession who appear to resent the notion that informed consent is part and parcel of 'patient rights'-a patient with rights is a lawsuit waiting to happen. On the other hand, a patient with no rights is a citizen who is stripped of his or her individuality and autonomy, as well as her clothes, as soon as she walks into the surgery or the hospital.<sup>116</sup>

There are two reasons why the current position in English law may be said to be of significance for the sort of patient that we consider in this article. The first lies in the notion expressed by Lord Walker that without all of the relevant information the patient is 'stripped' of her autonomy and individuality. It has been argued elsewhere that this notion of autonomy as the mere transfer of information from doctor to patient is an insufficient requirement for the autonomy of the patient to be respected.<sup>117</sup> Indeed without, for example, understanding on the part of the patient while she may be at *liberty* to make her own decision, she will not be equipped to make an *autonomous* one.<sup>118</sup> In such circumstances her choice will be far from the one that she wanted to make and such an approach risks what Maclean refers to as abandoning patients to their decisions.<sup>119</sup>

In the case of some patients, moreover, such a narrow approach also has the capacity to limit the individual's autonomy by denying her the right to make the decision *in the way that she wants to make it*. If she would prefer that a relative act as an informational filter, then as long as this is her sincere wish and there is no coercion it is difficult to argue that forcing information on to her would

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<sup>116</sup> *Ibid* at 58, *per* Lord Walker quoting M. Jones, 'Informed Consent and Other Fairy Stories' (1999) 7 *Medical Law Review* 103.

<sup>117</sup> See J. Coggon and J. Miola, 'Autonomy, Liberty and Medical Decision-making' (2011) 70(3) *Cambridge Law Journal* 523.

<sup>118</sup> For an example, see: *Al Hamwi v Johnson and Another* [2005] EWHC 206.

<sup>119</sup> A. Maclean, 'Autonomy, Consent and Persuasion' (2006) *European Journal of Health Law* 321.



enhance the autonomous nature of her decision. Indeed, the notion that ‘ignorance is bliss’ is not limited to any single culture.

The second problem for the patients that we consider in this article relates to the idea that in its efforts to enhance autonomy the law has only gone as far as requiring that the information transfer be sufficient to satisfy a *reasonable patient in the patient’s position*. This evaluates and defines the patient’s right not in terms of their own preferences, but rather in relation to the preferences of a hypothetical, objective judicial construct that is the ‘reasonable patient’. As feminist writers have long since identified, what is best reflected is the wishes and desires of the general populace rather than the individual, and at worst such an approach penalises and marginalise anyone who is alternative or ‘other’.<sup>120</sup> Clearly, not all patients constitute a majority or orthodox view. Therefore, the danger for them is that they may not benefit from any of the increased protections of autonomy that the courts have been introducing. Neither will the addendum that the reasonable patient must be *in the patient’s position* help such patients. What the addendum means has been sparsely examined by the courts, and where it has been considered the conclusion seems to be that it relates more to specific physical factors.<sup>121</sup> We would imagine that no court would require that the mode of informed consent required of doctors would change depending on, for example, the patient’s ethnic background or religion, and nor would we support any suggestion that to do so would be appropriate.

The only modification in the law that *would* help to enhance the autonomy of patients who value familial involvement would be to tailor the duty of disclosure to the *individual* patient.<sup>122</sup> This would help patients from all cultural backgrounds to receive information as they wished, but it is

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<sup>120</sup> See, for example, J. Conaghan and W. Mansell, *The Wrongs of Tort* (London: Pluto Press, 1999); L. Bender, ‘A Lawyer’s Primer on Feminist Theory and Tort’, (1988) 38 *Journal of Legal Education* 3 and M. Moran, *Rethinking the Reasonable Person* (Oxford: Oxford University Press, 2003).

<sup>121</sup> See the Canadian case of *Arndt v. Smith* [1997] 2 S.C.R. 539.

<sup>122</sup> See *Rogers v Whitaker* (1992) 175 CLR 479 and *Rosenberg v Percival* [2001] HCA 18.

not currently the law in England, although it has been argued that English law is inching inexorably towards adopting it.<sup>123</sup> Such a test is difficult to implement effectively, and the most frequent criticism of the test is that it is unfair to doctors – who cannot be expected to know what a patient is thinking – and therefore unworkable. However, it should be noted that Australian law has adopted a test for the materiality of risk that incorporates an element of the particular patient test. In *Rogers*, a risk was defined as material if

a reasonable person in the patient’s position, if warned of the risk, would be likely to attach significance to it or *if the medical practitioner is or should be reasonably aware that the particular patient, if warned of the risk, would be likely to attach significance to it.*<sup>124</sup>

A predictable storm of protest ensued.<sup>125</sup> Nevertheless, *Rogers* was reaffirmed by the High Court of Australia in *Rosenberg*, where Callinan J. addressed the disquiet thus: ‘[n]o doubt the manufacturers of bottled drinks viewed the reasoning in the House of Lords in *Donoghue v. Stephenson* in the same way’.<sup>126</sup> Indeed, *Rogers* remains good law in Australia more than 20 years after it was decided, and the law appears to be settled and functioning well. It is clearly not impossible to implement. This is because, in order for the particular patient test to bite, the patient must inform the doctor of her specific needs. There is ultimately less difference than one might imagine between the particular patient test and the other methods of ascertaining materiality.<sup>127</sup>

In order for the autonomy of the patients that we focus on here to be respected, two things need to happen in relation to risk disclosure. The first is that the courts accept that to protect self-determination does not just involve ensuring that information is provided, but also the patient’s

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<sup>123</sup> See, Miola, above n. 111.

<sup>124</sup> *Rogers*, above n 122, at 490. Emphasis added.

<sup>125</sup> See, for example, N. Olbourne, ‘The Influence of *Rogers v. Whitaker* on the Practice of Cosmetic Plastic Surgery’ (1998) 5 *Journal of Law and Medicine* 334. Indeed, the court in *Rosenberg* (above n109) identified eight common criticisms of *Rogers* (see I. Freckleton, ‘*Rogers v. Whitaker* Reconsidered’ (2001) 9 *Journal of Law and Medicine* 5).

<sup>126</sup> *Rosenberg*, above n 122, at 101.

<sup>127</sup> See Miola, above n 111.

choice regarding *how* this may be achieved, including the use of a relative as a filter if requested. This has not yet been considered by the courts, but if they are serious about prioritising autonomy and that choice is genuine then it is one that we argue should be respected.

Secondly, the limitations of any ‘reasonable patient’ test in relation to minorities need to be acknowledged. Such a test would most likely not achieve a satisfactory result for patients who desire family involvement as, quite simply, it is not designed to cater for minority needs. Just as we argued in relation to independence, the law is set up in such a way as to assume that the interaction is merely between doctor and an active and assertive patient, and it involves at the very least a creative interpretation of the rules to accommodate patients who prefer a relational aspect to the interaction. At the moment, the law does not consider their needs.

Thus, while we fully support the idea of respecting patient autonomy and their right to make independent and informed decisions, we also favour respecting the right of patients from non-Western cultures to make decisions about treatment based on their cultural values and norms, so long as the patient is not unduly influenced. We have also argued that relational autonomy perceives the patient as having the final say (despite taking into account the interests of the family). We believe that the law should secure at least a limited right to make independent decisions about their true wishes: what they *really* want in terms of family involvement, independence, receipt of information and decision-making authority, and that if they prefer to delegate all this to relatives – regardless of their reasons and motives - clinicians should respect it. This is particularly the case given the fact that the law has sought to put patient self-determination at the centre of medical law. Given this, the law should continue to support the principle of respect for autonomy even where it leads to outcomes or modes of interaction that might be different to those expected of patients from a ‘traditional’ Western background.

## VII. Conclusion

Our analysis has argued that legal and bioethical scholars have gradually come to recognise the impact of the patient's social and cultural backgrounds on decision-making. However, it also reveals that English law has so far not addressed this issue comprehensively. It appears to us that the main difficulty of the current legal and bioethical positions in England is dealing with a passive patient who delegates their decision-making authority to dominant relatives. Although this scenario may occur in any family,<sup>128</sup> it may be more evident in the case of patients from whose cultural values inherently provide substantial influence to the family at the expense of the individual patient.

Our analysis further shows that there is a consensus in the Anglo-American legal and bioethical literature that the patient should be capable of making autonomous choices and that a process of direct communication between the clinician and the individual patient is the golden rule. We therefore doubt whether it would be possible to accommodate situations where (male) relatives lead the decision-making process and become the main point of contact for the treating clinician. To accommodate these situations would require Western bioethicists and lawyers to make radical changes in the perception of the doctor-patient relationship, reduce the dominance of the principle of respect for patient autonomy and raise the moral significance of the principle of beneficence. This may be a too big step to take – even if this was what the patient wants. We therefore acknowledge that the starting point of any proposed solutions in this context require some level of individual autonomy and a sense of justice and equality in the family.

### (i) Proposed changes

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<sup>128</sup> See Gilbar, above n. 4.

First, a positive change in this context would be for English law to abandon the reasonable patient test for disclosure of information to patients. While well intentioned, it is neither applicable to patients from some ethnic minority backgrounds in terms of the way that they wish to make decisions, but nor does it even protect autonomy in the way that it assumes that it does. English law should seek to be in line with the current bioethical position and adopt a test where the scope of disclosure is determined by the informational needs and wishes of the particular patient. The Australian experience, as we noted above, has shown that this is a perfectly practical test to use.<sup>129</sup>

This, undoubtedly, will have a huge impact on the way patients prove their claims in informed consent cases, but it would amend the artificial position that currently requires clinicians to meet a standard of disclosure that is not applicable to many of their patients.<sup>130</sup> Nor, it can be argued, does it adequately protect their autonomy in any meaningful sense.<sup>131</sup> The particular patient test for disclosure will be beneficial for patients regardless of their cultural backgrounds because it will require clinicians to dedicate more time and efforts in knowing the patient, their family, their cultural and personal values which guide them in decision-making.

Second, as the theoretical discussion above indicates, to some procedural and ethics-of-care scholars respect for autonomy means respecting the cultural values patients bring to the consultation room. This agreement has led commentators to stress that patients should have the right to make choices regardless of their content. This is a positive development but from the perspective of patients from some cultural backgrounds it does not go all the way. To fully respect the patient's cultural values is to respect the decision-making process they adopt even if it is collectivist, hierarchical and not based on equality in the family. This, of course, assumes that the patient makes this choice after critically reflecting on her personal desires and cultural values, and not through

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<sup>129</sup> See *Rogers v Whitaker* (1992) 175 CLR 479 and *Rosenberg v Percival*, above n. 122. See also: Miola, above n. 110.

<sup>130</sup> See Turner, Above n. 66, at p. 108.

<sup>131</sup> See Coggon and Miola, above n. 117.

coercion or undue influence. A step towards respecting such an approach is to acknowledge that the patient's family is, to some people and cultures, an intrinsic part of their identity and the decision-making process. Currently, the involvement of the relatives depends on the patient, but if more sensitivity is due to patients from non-Western backgrounds then the family's status should be recognised. If anything, the law as it currently stands envisages relatives as being obstacles to proper decision-making rather than aids to be valued – even if the patient values them.

Indeed, fully respecting the patient's cultural values will go against what some might see as the basic tenets of English society. Freedom to make independent choices is fundamental and so is the equality between the sexes. Therefore, asking clinicians to approach the individual patient and find out how informed and involved they want to be in the process would be a reasonable compromise between the Western and collectivist-based approaches to the individual-family relationship. This would be beneficial particularly for patients who through a process of acculturation combine a Western and non-Western approach to decision-making. After all, the level of autonomy of a particular patient depends on the impact of their social, cultural and economic backgrounds.<sup>132</sup> Finding the opportunity to talk to the patient alone without the relatives may not be easy, but possible if it is planned in advance. Indeed, the two authors of this piece do not support a view that provides the family a dominant role in decision-making, particularly and unequivocally so if the patient does not welcome such involvement, but we fully respect the right of others to do so and their freedom to act in that way should they wish to do so. If the law is serious about protecting autonomy, it should seek to do so too.

Finally, we strongly agree that the values which guide the decision-making process of patients must be '*authentically*' their own and not the product relatives' manipulation.<sup>133</sup> We thus agree with

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<sup>132</sup> M. Davies and G. Elwyn, 'Advocating Mandatory Patient 'Autonomy' in Healthcare: Adverse Reactions and Side Effects' (2008) 16 *Health Care Analysis* 315.

<sup>133</sup> See Hyun, above n. 30, at p. 16.

Hyun's proposed mechanism which aims to ensure a just decision-making process: (1) the clinician informs the patient that she has the right to make informed decision and that this right does not exclude family involvement if this is what she wants; (2) the patient clearly expresses her preference to waive completely the right to make informed decisions and is not pressured or 'bullied' into to doing so by her relatives; (3) the patient's wish to delegate the decision-making authority to the relatives is authentic in the sense that the patient did not suffer '*serious deprivations of legitimate alternatives that remain open to others in her community*';<sup>134</sup> (4) the family is psychologically prepared to handle the information about the patient's condition and is willing to make decisions on her behalf; (5) the family aims to promote patient's condition or the family's common good. This, however, as Hyun admits, requires the clinician to know the patient and the family well and it require allocating resources for this purpose.

This article examined whether English law can accommodate a non-Western bioethical approach to decision-making. We concluded that legally more can be done to resolve tensions between NHS clinicians and patients and relatives holding more collectivist views. This is in large part due to the case that the law has not really considered the situation regarding such patients, and cases have not yet arisen that do so. However, we believe that despite its weaknesses promoting a relational approach to autonomy and decision-making may be the first step in the right direction because it strikes an adequate balance between the important values of British society and those of immigrants and their descendents. However, it requires those who adopt a relational approach to give more room to the family in the medical decision-making process.

This article is mainly an exploratory study. It shows that more empirical studies should be conducted to fully appreciate the reality of clinicians, patients from ethnic minority backgrounds and their relatives, so that we can better understand how the law can help such patients to exercise

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<sup>134</sup> Hyun adds that these deprivations must be caused by other people, must be deprivation of choice which is reasonably available to others who are not more able-minded and talented than the patient, and they must not be justly deserved.

their autonomy. This article also indicates that a deeper bioethical evaluation of the principles of respect for autonomy and beneficence in this area is needed.