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Genetic Risks, Disclosure and Foreseeable Harm: An unanswered question after *ABC v St George's Healthcare*

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ABSTRACT

ABC v St George's Healthcare NHS Trust was a missed opportunity. The case was a first opportunity for the UK courts to engage with a duty to disclose genetic risks to patients' relatives, but Nicol J's judgment focused on whether a duty was fair, just and reasonable and ignored issues of harm and proximity. This paper offers an answer to what the foreseeable harm, or gist damage, is in a claim of genetic nondisclosure. It considers intangible harms such as autonomy, dignity and preparedness but rejects these as formulations of harm as they fail to sufficiently recognise physical burdens of genetic conditions. The paper also explores tangible harms drawn from existing principles of tort. Loss of a chance is discussed and rejected because of the difficulties of the all or nothing approach on a balance of probabilities. It is instead proposed that eventuating genetic conditions are the gist of the action and an argument is put forward as to why it is not fatal to a negligence claim that defendants do not directly cause genetic diseases.

INTRODUCTION

ABC v St George's Healthcare gave the the High Court an opportunity to consider a duty to disclose genetic risks to patients' relatives.[1] The duty was rejected as not fair, just and reasonable; *ABC* is therefore an opportunity missed. The court's focus on whether a duty was fair, just and reasonable sidestepped issues of foreseeable harm and proximity, leaving important questions unanswered. One such question is what is the foreseeable harm in claims for genetic nondisclosure? With *ABC* due for appeal in March 2017, this paper will propose a definition of harm consistent with established interests in negligence.

ABC involved a diagnosis of Huntington's disease. The claimant's father was convicted of the manslaughter of his wife (her mother) on grounds of diminished responsibility and sentenced to a hospital order under the Mental Health Act 1983. He was diagnosed with Huntington's disease two years later but refused to allow this information to be communicated to his daughter, who was pregnant at the time. The claimant argued

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[1] [2015] EWHC 1394 (QB).

nondisclosure was negligent; had her father's condition been disclosed she would have undergone testing and, after receiving a positive result, aborted her pregnancy.

For the strike out applications, the defendants were prepared to proceed on the basis the claimant could demonstrate foreseeable injury and proximity at trial. Thus foreseeable harm and proximity were not considered by Nicol J. The discussion of proximity and a patient's relatives in *ABC* has been dealt with elsewhere,[2] and the focus of this article is on another element of negligence – foreseeable harm – which was not discussed in *ABC*. The time is ripe therefore to analyse this.

Negligence is actionable upon proof of harm; it is the gist of claims[3] and 'completes the cause of action'.[4] The first question in establishing a new duty is what foreseeable harm a defendant should owe a duty against? Harm can take the form of a setback to a variety of interest, common examples in negligence including physical, psychiatric and financial. At the duty stage, foreseeability of harm is important as a threshold concept, for 'without it there is no need to go further because no duty of care will be owed'.[5] Injury must therefore surpass a minimum threshold; Stapleton labels this minimum 'gist damage'.[6] Recovery is not restricted to the gist damage but it forms the nub of the action. Thus physical injury may be gist damage – i.e. a broken leg – but consequential financial losses and mental and emotional trauma are also compensable.

Harm is fundamental in proving liability, but 'is by far the least developed' of the fundamental concepts of negligence.[7] Physical injuries – the mainstay of negligence – are axiomatic and require minimal analysis. But when difficulties arise regarding definition and categorisation of harms, the courts do not address harm as a concept in its own right but repackage it as either a question of duty or causation. To a certain extent it does 'not matter under which heading the courts address questions of this kind', but a 'lack of conceptual clarity may adversely affect the way in which these questions are formulated and dealt with.'[8]

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[2] M. Fay, 'Genetic Risks, Families and Negligence: A Duty to Disclose Actionable Risks' (forthcoming, *Medical Law International*); M. Fay, 'Informing the Family: A Geneticist's Duty of Care to Disclose Genetic Risks to Relatives of the Proband' (2011) 27(2) Professional Negligence 97.

[3] Stapleton, J., 'The gist of negligence' (1988) 104 LQR 213; Chico, V., *Genomic Negligence: an interest in autonomy as the basis for novel negligence claims generated by genetic technology* (Routledge-Cavendish, London: 2011). *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] AC 871 per Lord Scarman at p883.

[4] Nolan, D., 'New forms of damage in Negligence' (2007) 70(1) MLR 59-88, 59.

[5] C. Whitting, *Street on* Torts 14th ed. (OUP, Oxford: 2015) p37.

[6] Stapleton, n3, 'Gist of Negligence'.

[7] Deakin, S., et al, *Markesinis & Deakin's Tort Law*, 7th ed. (OUP, Oxford: 2007), p. 106.

[8] Deakin, n7, p. 107. Markesinis and Deakin highlight the issue of loss of a chance as an example of this conceptual difficulty. By relying on a balance of probabilities approach in *Hotson v East Berkshire Area Health Authority* [1987] AC 750, the court eschewed the question of whether '"loss of a chance" fell within the definition of compensatable damage.'

Stapleton contends a coherent doctrine is necessary as harm is a word 'bandied about in a number of different contexts, usually without clear definition yet equally without apparent awareness of the importance of precision in its use.'[9] Clarity and precision are important because a fundamental question of scope is 'what damage is or could be recognised as constituting the minimum for an actionable claim.'[10]

Harm is an underdeveloped, nebulous concept within negligence.[11] This paper seeks to address what the foreseeable harm is in cases involving nondisclosure of genetic risk. Commentators have advanced definitions of harm relevant to a variety of genetic torts; Chico has proposed an interference with autonomy as the gist of a negligence action;[12] Brownsword proposes human dignity as a potential basis for claims.[13] This paper begins by analysing these proposed harms. An objection to autonomy and dignity is they focus on self-determination over the physical burdens of genetic conditions. Damages awarded in recognition of frustrated autonomy may not recognise the burdens of a medically actionable condition. The eventuating disease is ostensibly more damaging than a restriction of choice. This paper will also explore harm as a lack of preparedness, exposing the frailties of this approach. It will then consider harm as a loss of a chance to avoid a genetic condition and, alternately, a loss of a chance to obtain medical treatment. The all-or-nothing approach of the balance of probabilities and judicial resistance to loss of a chance in personal injury means such definitions are problematic.

Finally, this paper will propose that eventuating genetic conditions could form the gist of a negligence action. The central objection to this is defendants do not cause genetic disease, but caselaw indicates it is not necessary to directly cause injury in negligence. This interpretation is supported by cases from the US. American tort law has ostensibly conceptualised foreseeable harm as the eventuating genetic condition, relying on cases involving undisclosed risks of infection, contagion, and physical violence. Accepting the genetic condition as foreseeable harm would represent an extension to protection for physical integrity, an interest well recognised in negligence.[14]

AN INTANGIBLE HARM?

[9] Stapleton, n3, p213.
[10] Stapleton, n3, p213.
[11] A discussion of the broader philosophies of harm in tort is beyond the scope of this paper, but has been discussed elsewhere, see Stapleton, n3, Nolan, n4.
[12] Chico, n3.
[13] Brownsword, R., 'An interest in human dignity as the basis for Genomic Torts' (2000) 42 *Washburn Law Journal* 413.
[14] *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, per Lady Hale, 102.

It is axiomatic that genetic information can 'be extremely useful in making significant life decisions'.[15] Research indicates people 'like to make decisions based on relevant information',[16] with 88-94 per cent of people estimated to want to know about medically actionable genetic conditions and circa 60 per cent about non-preventable conditions.[17] When a genetic risk is not disclosed, an individual 'may feel harmed by this failure';[18] this harm take the form of a frustration of the ability to lead an autonomous life, alternately it may be mental trauma resulting for an inability to prepare for the onset of a genetic condition. Both of these interpretations are possible on the facts in *ABC*: on the one hand, the claim relates to reproductive autonomy,[19] on the other it is alleged the claimant has suffered psychiatric harm. The aspect of the claim relating to the additional expenses the claimant alleges she will incur if her (untested) daughter does have the condition is problematic and runs afoul of wrongful birth caselaw which has traditionally not awarded damages for the birth of a healthy baby.[20] This part of the claim is problematic because (i) it is not clear whether deleterious genetic traits would constitute a disability under previous caselaw (a fact complicated by the lack of infant testing for late onset disorders), and (ii) it is a moot point whether the claimant will actually suffer economic loss if her daughter does develop Huntington's because it is a late onset condition. This element of the claim will not be considered in depth here because the focus of this piece is on harm to the claimant herself.

The first possible conception of foreseeable harm in nondisclosure claim is as an intangible injury, a frustration of the claimant's interests as opposed to physical trauma. Three possible ways gist damage might be conceived are as an injury to autonomy, an interference with human dignity or a lack of preparedness.

Autonomy

Chico proposes '[w]hatever the implications of not knowing … the individual might feel that a failure to inform her of the personal genetic risk is an interference with her autonomy'.[21] To act autonomously, individuals require relevant information and it may be injurious to autonomy to withhold information pertinent to decision making. This is the rationale in cases

[15] R. Gilbar, 'The Passive Patient and Disclosure of Genetic Information: Can English Tort Law Protect the Relatives' Right to Know?' (2016) 0 *International Journal of Law, Policy and The Family* 1
[16] T. Heaton, V. Chico, 'Attitudes towards the sharing of genetic information with at-risk relatives: results of a quantitative survey' Hum Genet (2016) 135: 109.
[17] Heaton, Chico, n16, pp114-115.
[18] Chico, n3, p141.
[19] *ABC*, n1, 2.
[20] *McFarlane v Tayside Health Board* [2000] 2 AC 59.
[21] Chico, n3, p. 146.

concerning patients' consent and the disclosure of risks in medical treatments. The argument here is: '[y]ou did not inform me of the risk which has eventuated; but for your failure I would not have consented to the procedure … [and] sustained injury.'[22] A duty to disclose risks to patients is premised on respect for personal autonomy and requires communication of relevant risks 'before she consents to a medical intervention.'[23] The purpose of disclosure is to facilitate informed decision making and the same point may be argued about the disclosure of genetic information. The foreseeable harm in nondisclosure claims may therefore be an injury to autonomy because relevant information is withheld and informed decision making inhibited. Considering autonomy from an intrinsic perspective,[24] Chico argues it may be irrelevant whether a genetic disease manifests or 'the extent to which it can be prevented.'[25] A claim would exist because relevant information is withheld. When a claimant discovers nondisclosure they may feel aggrieved because 'it amounts to a failure to treat her as … able to cope with knowing information about her own genetic risks.'[26]

Knowing 'relevant information is ... important in being an autonomous person',[27] but an intrinsic perspective of autonomy may be difficult to reconcile with the focus of negligence on adverse consequences. It is difficult to argue harm occurs 'irrespective of whether further adverse consequences flow from the failure to respect autonomy'.[28] Though torts like battery are actionable per se, negligence recognises and remedies harms. An injury to autonomy from an intrinsic perspective would set the bar low in terms of gist damage, it is also doubted whether such could be reconciled with traditional principles of tort. While it is acknowledged autonomy can be restricted by withholding information per se, it is doubted such restriction is sufficient to constitute gist damage. Harm has to meet a minimum threshold to be subject to a negligence claim: physical injuries must be negative physiological changes and cannot be benign;[29] psychiatric harm requires a recognised psychiatric disorder.[30] If nondisclosure is harmful because it restricts autonomy per se and not because it causes an adverse outcome

[22] G.T. Laurie, J.K. Mason, *Mason & McCall-Smith's Law and Medical Ethics*, 9th ed. (OUP: Oxford, 2013), p116.
[23] Chico, n3, p147. On this point, see particularly *Chester v Afshar* [2005], also *Birch v University College London NHS Trust* [2008] EWHC 2237.
[24] I.e. that being autonomous is a good thing per se.
[25] Chico, n3, p147.
[26] Chico, n3, p147.
[27] Chico, n3, p146.
[28] Chico, n3, p148.
[29] *Grieves v FT Everard* [2007] UKHL 39.
[30] *Alcock v Chief Constable of South Yorkshire Police* [1990] 2 AC 310.

(such as denying the opportunity to seek preventative treatment), it is argued as inconsistent with established principles of negligence.[31]

If the courts did accept any restriction of autonomy is deleterious, they could adopt an approach similar to *Rees v Darlington Memorial Hospital NHS Trust* and award a conventional sum in recognition of the interference.[32] However, the approach in *Rees* has not subsequently been extended beyond claims for wrongful pregnancy and birth. It has also been widely criticised,[33] the low compensatory award in the House of Lords leading to the impression it 'is given as a consolation prize when the claimant does not succeed in proving her claim for a tangible harm … and not as a new type of harm.'[34] Even if injury to autonomy was compensable in nondisclosure cases, without adverse consequences compensation is unlikely to be significant (and could even be paltry), which would act as a disincentive to claimants. A duty must be realistically enforceable otherwise it is a hollow obligation. Another (potentially facetious and contentious) distinction between intrinsic autonomy in genetic nondisclosure and wrongful pregnancy is an adverse outcome exists in the latter. Claimants endure the pain, suffering and discomfort of pregnancy and childbirth[35] (but not the birth of a healthy child).[36]

An intrinsic perspective of autonomy must therefore be rejected as a conception of harm. An alternative definition which may align better with the focus in negligence on adverse consequences is what autonomy 'might have made possible rather than the value of experiencing autonomy per se.'[37] Patients' relatives could argue disclosure is required to 'enable them to choose how to deal with the chances of developing a disease … and in other cases with reproductive decisions.'[38] Defining autonomy by its instrumental value means foreseeable harm would be a restriction of the ability to choose to obviate or accept risks. This is analogous to the duty 'English negligence law recognises with respect to nondisclosure of medical risks.'[39] Autonomy is important in doctor-patient disclosure cases because

[31] However, not all torts require proof of damage, and a claim for injury to autonomy might be viewed as closer to an action for battery than negligence. As the focus of this paper is negligence, other potential tortious avenues will not be discussed.
[32] [2003] UKHL 52.
[33] N. Priaulx, 'Damages for the "Unwanted" Child: Time for a Rethink?' (2005) 74(3) *Medico-Legal Journal* 152.
[34] Gilbar, n15, p18.
[35] *McFarlane v Tayside Health Board* [2000] 2 AC 59. Lord Millett (at 114) believed such was inconsistent with the dismissal of the parents' claim for the financial costs of raising an unwanted child. Since pregnancy is a natural process and not an adverse physical change, the '*McFarlane* view' has been suggested as widening the concept of personal injury: see C. Whitting, 'Physical Damage in Negligence' (2002) 61(01) CLJ 189. A contrary view is given by Conaghan, J., 'Tort Law and Feminist Critique' Current Legal Problems 56 (2003) pp. 190–191; Nolan, n4, and Hale LJ (as she then was) in *Parkinson v. St James and Seacroft University Hospital NHS Trust* [2002] QB 266.
[36] Which amounts to pure economic loss.
[37] Chico, n3, p148.
[38] Gilbar, n15, p17.
[39] Chico, n3, p148.

disclosure of risks enables patients to meaningfully choose whether to undergo a procedure, precluding or accepting a risk of bodily interference.[40] But while *Montgomery* reaffirmed patients' interests in making informed decisions, the Supreme Court has not recognised autonomy as a head of damage.[41] Furthermore, the essence of doctor-patient caselaw is physical harm, and Lady Hale has suggested autonomy is wrapped up with physical integrity,[42] an interdependence which raises questions about autonomy forming the gist of a claim without concurrent physical injury.

If frustration of autonomy's instrumental value can constitute gist damage, injury would occur when nondisclosure of a medically actionable risk restricts an individual's ability to choose intervention over inaction. Since 'gist' damage does not define the limits of recovery, eventuating conditions would be consequential to the injury to autonomy (in that the injury prevented preventative/mitigating action), and thus compensable. *Chester v Afshar* can be used as an illustration.[43] The claimant was not forewarned of a statistically low risk of spinal injury during the procedure she was to undergo. The risk was inherent in the operation and independent of negligence, thus an analogy may be drawn with with genetic risks which are inherent in a person's genome and also independent of negligence. The critical question for the House of Lords was whether nondisclosure was causative of the claimant's injury, but of interest here is the nature of the harm compensated.

The majority believed *Chester* was 'essentially concerned with protecting the patient's right to choose – that is, her autonomy.'[44] But full compensation for the spinal injury was awarded, a point of contention in the literature.[45] One possible explanation is that since the physical injury was consequential to the injury to autonomy (because a chance to obviate or accept a risk was denied), full compensation was justified. Thus autonomy's instrumental value may enable claimants to recover for physical burdens of a genetic condition where nondisclosure has prevented access to medical intervention. The gist of the action would be the frustration of choice, the eventuating condition consequential to the injury to autonomy.

Chico further argues that harm is the 'inability to be able to choose to avoid the risk … as opposed to the genetic condition itself,'[46] thus compensatory awards should reflect the injury to autonomy, not the physical aspects of a condition. In addition, autonomy may be

[40] See *Chester v Afshar* [2004] UKHL 41.
[41] Gilbar, n15, p18; J. Miola, 'Autonomy rued OK?' (2006) Med Law Rev 14(1) 108.
[42] *Montgomery*, n13, 102.
[43] [2004] UKHL 41.
[44] Laurie, Mason, n22, p129.
[45] T. Keren-Paz, 'Compensating Injury to Autonomy: A Conceptual and Normative Analysis' (forthcoming); T. Keren-Paz, 'Compensating Injury to Autonomy: Three Sets of Confusions' (forthcoming).
[46] Chico, n3, p150.

instrumentally valuable to claimants because of the options it represents, and these options may not prevent a genetic condition. People 'can make rational decisions to undergo treatments or undertake avoidance measures even though they know that the chance they will make any difference to the manifestation of the risk is low'.[47] The instrumental value of autonomy could even be described as the ability to make informed choices about one's life and thus be prepared for the onset of a genetic condition. A person could choose to circumnavigate the globe in 80 days while able; equally, someone may be able to take steps to help them come to terms with future, non-preventable ill health. A person's autonomy may be instrumentally valuable even when nothing curative can be done, or when one has no desire to seek treatment. The injury may therefore be the withholding of relevant information about one's life.[48]

A broad appreciation of autonomy's instrumental value is, however, problematic. If a condition is not medically actionable it is difficult to reconcile with the negligence's requirement of adverse consequences. Where autonomy is not respected and deleterious consequences follow (i.e. a preventable condition eventuates), negligence could facilitate recovery for both frustrations of autonomy and consequential physical harm. But if injury to autonomy is only actionable when it leads to physical or mental harm it is not independent of physical integrity. Despite rhetoric to the contrary, the gist damage would not be injury to autonomy. Protection of autonomy would be indirect, the basis of the action is physical or mental harm.[49]

If autonomy was independent of physical and mental integrity and focused on general decision-making, it is debatable it could form the gist of a negligence claim. The scope of autonomy means accurately and consistently defining minimum actionable damage would be difficult. A claimant could argue nondisclosure injured their autonomy because they would not have had children;[50] another might claim injury to autonomy because they would have lived their life differently, circumnavigating the globe in 80 days. Both claimants can demonstrate injury to autonomy but neither are linked with avoiding or mitigating disease. The instrumental value of autonomy in these scenarios is not doubted, but whether one or both claims are worthy of compensation is debatable. If restriction of general choice was

[47] Chico, n3, p150.
[48] Chico, n3, p150.
[49] C. Purshouse, 'Liability for Lost Autonomy in Negligence: Undermining the Coherence of Tort Law?' (2015) 22 TLJ 226, p229.
[50] I.e. *ABC*.

harm (something tort law does not protect)[51] both may have a claim, but such a broad cause of action means any restriction of autonomy (i.e. picking a different career, diet, lifestyle etc. based on genetic risks) would theoretically create a claim. Defining *de minimus* might become a search for the Holy Grail. It is necessary to keep negligence within the bounds of practicability,[52] limitations are thus essential. The moot point is where these should be drawn. Chico proposes a threshold of 'important decisions'[53] and Keren-Paz 'significant choice',[54] but the question is important/significant to whom? What is important to an individual may substantially differ from another or social and cultural norms.[55] This is somewhat recognised in a doctor's duty to disclose material risks to patients. Material risks are risks a reasonable person in the patient's position would likely attach significance to, or ones a doctor ought to know his particular patient 'would be likely to attach significance to'.[56] This subjectivity is reliant on doctor-patient relations, which make patients' wishes ascertainable.[57] If the claimant is a non-patient third party personal views are difficult to canvass. Chico recognises this point in respect of unwanted disclosures, observing autonomy cannot form a basis for arguing individuals are harmed by disclosure of unknown unknowns (i.e. information lacking foreshadowing) where they 'made no express request not to know the information'.[58] An objective assessment of instrumental value is feasible. Levels of uptake of various tests would be a crude means of measuring what a majority may want to know,[59] but research does indicate approximately 90 per cent of people want to know about preventable conditions,[60] and approximately 60 per cent about non-preventable conditions, though this number decreases to 30 per cent for fatal, non-preventable conditions.[61]

Therefore a reasonable person may not want to know about a diagnosis of Huntington's disease.[62] An interrogative approach would be necessary to recognises subjective views on genetic information, but such is problematic. Individual views could be difficult to canvass because clinicians may not engage with patients' relatives. The

[51] Gilbar, n15, p18; Chico, n3.
[52] *Caparo v Dickman* [1990] , per Lord Oliver at 633A.
[53] Chico, n3, p152.
[54] Keren-Paz, n45.
[55] Gilbar, R., Miola, J., 'One size fits all? On patient autonomy, medical decision making and the impact of culture' (2015) 23(3) Med Law Rev 375; Atkins, K., 'Autonomy and the Subjective Character of Experience' (2000) 17 Journal of Applied Philosophy 71.
[56] *Montgomery*, n13, 87.
[57] For example, see *Rogers v Whittaker* [1992] HCA 58, where the claimant's concern about blindness was explicit.
[58] Chico, n3, p172.
[59] Chico, n3, p176.
[60] Heaton, Chico, n16, p114.
[61] Heaton, Chico, n16, p115.
[62] Reflecting a relatively low uptake of predictive testing for Huntington's disease in the UK: Hayden, M.R., 'Predictive testing for Huntingdon's disease: the Calm After the Storm' (2000) 356 *The Lancet* 1944.

preliminary enquiry would also 'make the existence and essential character of the information known', potentially infringing an individual's autonomy if they did not want to know.[63] Thus respecting individuals' general autonomy is difficult without a preexisting relationship as a conduit to knowledge about that specific person. It may be argued nondisclosure injures autonomy because a person could not circumnavigate the globe in 80 days, but recognising such as harm would risk exposing clinicians to claims flowing from unknowable and unpredictable individual perceptions.

But if instrumental autonomy did constitute the gist of an action and was independent of negative infractions of physical and mental integrity, the problem becomes recognition. Autonomy has influenced certain judicial decisions[64] and there is recognition (and emphasis) in the courts of a 'growth in autonomy-based arguments over the last 20 years'.[65] But 'despite the Supreme Court's efforts to promote patients' right to make informed decisions (*Montgomery*) the courts have still not recognized (sic) harm to choice as a new head of damage'.[66] Thus requiring a new head of damage is an additional barrier to establishing injury to autonomy as foreseeable harm.

Autonomy is important in cases concerning doctor-patient disclosure,[67] but these are concerned with protecting physical integrity and only indirectly protect autonomy. It is doubted injury to autonomy is gist damage if it is only actionable when adverse physical or mental consequences occur. An argument that negligence should recognise interferences with general decision making – whether or not defined by nebulous caveats like 'significant' or 'important' – is objectionable on two counts. First, it will not represent the injury concerning the claimant. It is acknowledged the autonomy of relatives is restricted by nondisclosure because they cannot act autonomously without full information, but if nondisclosure comes to light when the phenotype manifests the primary injury will be physical. The American judgment of *Safer v Estate of Pack* is a case in point;[68] the claimant discovered nondisclosure after her cancer eventuated. The complaint was articulated as physical injury, not injury to autonomy. If, as Chico argues, the loss is 'the interference with autonomy … as opposed to the genetic condition'[69] and damages do not reflect the physical

[63] Chico, n3, p171. Discussion of the interest in not knowing is beyond the scope of this paper. For further discussion see Chico, n3, pp171-191.
[64] *Rees v Darlington Memorial Hospital NHS Trust* [2004] 1 AC 309; *Chester v Afshar* [2005] 1 AC 134.
[65] Laurie, Mason, n22, p129; Mason, J.K., *The Troubled Pregnancy* (Cambridge University Press: Cambridge, 2007).
[66] Gilbar, n15, p18; Miola n41; Chico, n3. For a detailed discussion of the conceptual and philosophical basis of autonomy and how these could be shaped into as a new head of damage in tort, see Chico, n3, pp37-71.
[67] See *Montgomery v Lanarkshire Health Board* [2015] UKSC.
[68] 677 A 2d 1188 (New Jersey Superior Court Appellate Division 1996).
[69] Chico, n3, p150.

burdens of the condition, then the consequences of the doctor's negligence become an elephant in the room.

Second, if the damages for injury to autonomy do not reflect the physical burdens of a disease, claimants could be discouraged from enforcing a duty, emptying an obligation to disclose of content because there is no prospect of enforcement. If a claimant with an intractable condition has a negligence claim because she could not undertake an global circumnavigation in 80 days, this is overly litigious. The value of bringing a claim for injury to autonomy would be in the vindication of the interest in self-determination, but if damages would be tantamount to a consolation prize a successful claim would be a pyrrhic victory. Allowing claims based on a restriction of choice may enable a wider range of claimants to seek redress in negligence, as it would not depend on a genetic risk eventuating. But disclosure in absence of treatment is itself contentious and may cause harm.[70]

Human Dignity

Foreseeable harm caused by nondisclosure of genetic risks may alternatively be an interference with human dignity. The concept is closely related to autonomy as 'the failure to treat an individual as an autonomous person could interfere with her sense of self respect and dignity';[71] dignity and autonomy therefore share similarities in their application to negligence. However, dignity is a broader concept and could encompass situations where claimants do not have an important or significant, choice (providing these caveats are considered applicable restrictions to injury to autonomy). Dignity is a complex concept and here lies one of the key objections to dignity as harm, to which this paper will return.

Human dignity is proposed as the basis of claims arising from genetic technologies by Brownsword,[72] who argues the general principle 'offers a real prospect of novel claims at least being brought forward and given serious consideration.'[73] He suggests 'the flexibility of such a cause of action gives it some chance of staying connected to rapid technological development.'[74] Kuhse is more sceptical, arguing human dignity has 'a very dubious role in contemporary bioethical discourse' and 'is a slippery and inherently speciesist notion …[that] has a tendency to stifle argument and debate and encourages the drawing of moral

[70] See discussion of preparedness below.
[71] Chico, n3, p148.
[72] R. Brownsword, 'An interest in human dignity as the basis for Genomic Torts' (2000) 42 *Washburn Law Journal* 413.
[73] Brownsword, n72, p486.
[74] Brownsword, n72, p486.

boundaries in the wrong places.'[75] Brownsword recognises human dignity is 'an elusive concept, used in many senses by moral and political philosophers.'[76] However, he notes that '[i]n modern debates … it regularly appears in two very different roles, in the one case acting in support of individual autonomy … in the other case, acting as a constraint on autonomy'.[77] He identifies these two 'roles' as human dignity as empowerment and human dignity as constraint. Brownsword's argument relies on human dignity as empowerment, so only this interpretation is considered here.[78]

The conception of human dignity as empowerment 'is very closely linked with modern human rights thinking.'[79] Human dignity is one of the foundational ideas of the Universal Declaration of Human Rights (1948), the preamble providing 'recognition of the inherent dignity … of all members of the human family'. The Convention on Human Rights and Biomedicine acknowledges dignity, Art 1 stating signatories 'shall protect the dignity and identity of all human beings'. The Human Genetics Commission also incorporated dignity in the fundamental principles it applied to personal genetic information, stating '[r]espect for persons affirms the equal value, dignity and moral rights of each individual.'[80] Brownsword submits these as evidence it is recognised each and every human being has inherent dignity. He explains inherent dignity is the foundation of the possession of inalienable human rights and posits 'a regime of tort law *self-consciously and explicitly* equipped with such a conception of human dignity' could respond to perceived wrongs generated by genetic technologies.[81] In nondisclosure cases, a failure to disclosure deleterious traits could be characterised as an interference with relatives' dignity, as the are unble to act autonomously because information significant to their choices is withheld.

Whether human dignity is conceived as empowerment or constraint, application to negligence immediately begs the question why is it necessary to recognise an interest in human dignity, if – in the modern context – dignity appears to be synonymous with autonomy? Dignity as empowerment ostensibly enables individuals to lead autonomous lives; thus a negligence claim based on empowerment-dignity would vindicate autonomy. As Laurie

[75] Kuhse, H., 'Is there a tension between autonomy and dignity?' in Kemp, P., et al (ed.), *Bioethics and Biolaw Volume II: Four Ethical Principles* (Rhodos International: Copenhagen, 2000), p. 74.
[76] Brownsword, above, n72, p419.
[77] Brownsword, above, n72, p419.
[78] For a discussion of human dignity as constraint, see Brownsword, n72, pp420-427.
[79] R. Brownsword, 'Bioethics Today, Bioethics Tomorrow: Stem Cell Research and the "Dignitarian Alliance"' (2003) 17 *Notre Dame Journal of Law, Ethics and Public Policy* 15, p. 21.
[80] Human Genetics Comission (HGC), *Inside Information: Balancing Interests in the use of Personal Genetic Information* (London, 2002), paragraph 2.20.
[81] HGC, n80, p427 (emphasis in original). Brownsword discusses claims based on human dignity in relation to pregnancy and designer babies, control of the outward flow of genetic information by the proband, a right not to know, property in the human body and genetic discrimination.

writes, privacy, liberty and autonomy 'prescribe the way in which individuals are to be treated in Western society … [and] these constructs are all adjuncts to a view of human dignity that is prevalent in our society.'[82] It may be argued it is preferable to protect the concepts encapsulated by 'dignity' on an individual basis rather than through recognition of a broad cause of action which may fall prey to a lack of certainty.[83] An 'obvious problem with such a generalised principle or open-ended cause of action … is that it leaves too much to interpretation.'[84] Achieving judicial consistency may prove problematic and a piecemeal approach is liable to create conceptual and practical difficulties.[85] If an interest protected by a tort is not definable with a degree of certainty, it becomes difficult for defendants to effectively discharge the corresponding duty.

The approach of the judiciary to extending the duty of care is also cautious and a concept as broad as human dignity will likely be viewed sceptically. The prospect of judicial scepticism is supported by the reservations of the Court of Appeal towards a generalised tort for breach of privacy in *Wainwright v Home Office*, where Mummery LJ explained:

> 'I foresee serious definitional difficulties and conceptual problems in the judicial development of a "blockbuster" tort vaguely embracing such a potentially wide range of situations … the creation of a new tort … could give rise to as many problems as it sought to solve.'[86]

Judicial attitudes to extending duty are circumspect and rely on incremental analogy, as noted in *ABC*.[87] Combined with an aversion to broad concepts, recognition of harm as an interference with human dignity is unrealistic. Brownsword contends that because a dignity-based tort would be 'very closely related to existing notions of human rights and the importance of individual autonomy … [it] would not represent major changes of direction for either English or American tort law.'[88] This point holds some water yet the

[82] G.T. Laurie, *Genetic Privacy: a challenge to medico-legal norms* (Cambridge University Press: Cambridge, 2002), p. 84.
[83] For example, in the UK, equality is protected by Discrimination Law, while the common law and statue protect autonomy (e.g. the patchy coverage of negligence and the Mental Capacity Act), liberty (e.g. false imprisonment and the Human Rights Act) and privacy (e.g. the Human Rights Act, confidentiality, and the Data Protection Act).
[84] Brownsword, n72, p486.
[85] The law relating to psychiatric injury is one such example of this difficulty and the courts themselves have acknowledged that the search for principle has been abandoned.
[86] [2002] QB 1334, at 60.
[87] *ABC*, n1,
[88] Brownsword, n72, p486.

compartmentalised nature of UK law means elements of dignity (autonomy, equality etc.) are defined and protected separately.[89]

Defining harm as an interference with human dignity also raises the same objection as autonomy: it does not reflect the injury that claimants will experience. Like autonomy, if gist damage is an interference with human dignity (and the underlying ability to exercise free choice) and not the eventuating condition, damages would reflect the infringement of dignity (which in itself would raise an issue of quantum – what is sufficient compensation?) and not the physical burdens of the disease. The deleterious phenotype could be consequential damage, but if harm is an interference with human dignity it is not certain physical injury will be as consequential. An infringement of empowerment-dignity may solely limit the claimant's ability to choose, which may not be restricted to the choice of preventative treatment. Thus human dignity may not recognise the physical burdens of disease. This may limit clinicians' culpability to the restriction of free choice, absolving responsibility for the main consequences of their negligence – the manifestation of a medically actionable genetic risk.

Preparedness

The foreseeable harm genetic nondisclosure may cause could also be characterised as be as a lack of preparedness. This broad conception of injury would essentially focus on claimants' inability to prepare for the onset of their condition. There is overlap with autonomy and dignity here, as a lack of preparedness may interfere with people's ability to live autonomous lives and make informed choices (for example, regarding the timing of circumnavigating the globe in 80 days). A lack of preparedness might also be portrayed as preventing a claimant from coming to terms with future manifestation of their condition and may lead to psychiatric harm. The claim in *ABC* might encapsulate both points. The claimant experienced psychiatric injury; she was also unable to make informed choices about whether to bring her pregnancy to term.[90]

Yet a lack of preparedness as harm is objectionable on two counts. First, the benefits of disclosing intractable conditions are debatable. Literature both supports and refutes the benefits of disclosing to facilitate preparedness,[91] but there is a notable risk of disclosure

[89] See n83.
[90] *ABC*, n1, 2
[91] Tarini, B., *et al*, 'Parents' interest in Predictive Genetic Testing for their Children when a Disease has no Treatment' (2012) *Pediatrics* 129(2), 290-298; Buxton, J., Pembrey, M., 'The New Genetics: What the Public Wants to Know' (1996) 4 *European Journal of Human Genetics (Suppl.)* 153; Hietala, M., *et al*, 'Attitudes towards genetic testing among the general population and relatives of patients with a severe genetic disease: a survey from Finland' (1995) 56 *American Journal of Human Genetics* 1493. Almqvist, E., *et al*, 'Risk of Reversal in Predictive Testing for

negatively affecting individuals where it is made in absence of therapeutic intervention. The high rate of suicide among persons diagnosed with Huntington's disease highlights the potentially extreme reactions attempts to engender 'preparedness' may elicit.[92] The Danish Council of Bioethics has also warned of the possible dangers of 'morbidification'.[93] It is inescapable that 'if disclosure is made to avoid ancillary harm such as psychological upset there is less of a guarantee that the harm in question will, de facto, be avoided.'[94] The inherent uncertainty regarding the actual benefits of disclosure facilitating preparedness casts doubt as to whether it is appropriate that such a temperamental concept be advanced as the gist of an action in negligence.

Second, from a legal perspective conceptualising harm as a lack of preparedness is undesirable because of the uncertainty it introduces. Defining sensible (and fair) boundaries would prove difficult and the breadth of potential harms would expose the medical profession to a plethora of claims arising from claimants' individual (and largely unpredictable) responses and values. Preparedness, like significance and importance, is a subjective concept and the values and benefits individuals attach to being informed will vary. Thus a claimant might argue nondisclosure caused them injury because they were not prepared psychologically for the onset of the condition. Another, however, may contend harm because their life plans would have been better informed if their deleterious genetic heritage was disclosed; preparedness would have enabled them to undertake activities prohibited following the onset of their condition. The claimants in both examples have suffered harm due to insufficient preparedness, but should both interferences lead to valid claims? A claimant suffering psychological upset may be viewed more favourably than someone prevented from undertaking certain activities, but the inability to, for example, circumnavigate the globe in 80 days, is arguably no less injurious and could also lead to psychological upset. The obvious question is whether being upset about being unable to fulfil a dream is equally valuable to being mentally prepared for a condition. In fact it may be that these are indistinguishable because living life to the full is part of being mentally prepared. Certainly where claimants experience psychological upset this may be reconciled with the interest in mental integrity, providing upset amounts to a recognised psychiatric disorder.

Huntington's Disease' (1997) 61 *American Journal of Human Genetics* 945; Wexler, N., 'Genetic Jeopardy and the New Clairvoyance' (1985) 6 *Progress in Medical Genetics* 227.

[92] Almqvist, E., *et al*, 'A worldwide assessment of the frequency of suicide, suicide attempts, or psychiatric hospitalisation after predictive testing for Huntington's deisease' (1999) 64 *American Journal of Human Genetics* 1293

[93] Danish Council of Bioethics, *Ethics and Mapping the Human Genome* (Copenhagen, 1993), p60.

[94] Laurie, n82, p122.

Yet even if it is possible to link preparedness to protected interests, its subjective nature is problematic. Whether an individual feels sufficiently prepared will be influenced by their personal values and perceptions; if harm were articulated in this manner, it would create a broad cause of action, which was a reason dignity was considered unfavourably. This may have the effect of making disclosure the default position but disclosure in absence of medical intervention could itself be harmful. Subjectivity of perception is not something readily embraced by the courts in all scenarios and though it is integrated into doctor-patient disclosure cases, in circumstances involving psychiatric harms individual variations increasing the impact of shocking events actually prohibit liability unless an objective threshold can be met, which is foreseeably problematic if preparedness is linked with the interest in mental integrity.[95] Though one might make a case for preparedness based on what is objectively reasonable, an attempt to draw acceptable boundaries will likely be insufficiently representative of the spectrum of claimants' grievances.

TANGIBLE HARMS

It is 'well recognised that the interest which the law of negligence protects is a person's interest in their own physical and psychiatric integrity'.[96] A duty to guard against harms to these recognised interests has a greater chance of success than one based on a new head of damage. The question is what physical or psychiatric harm is the gist of a nondisclosure claim. The claimant in *ABC* argued wrongful birth, psychiatric injury and economic loss in the event her daughter had Huntington's disease. This paper will not consider economic loss. In relation to wrongful birth, the authorities show the birth of a healthy child is not harm,[97] although an award can be made in recognition of the frustration of reproductive autonomy.[98] The question is whether a child with a late onset disorder could possibly fall within the scope of caselaw on the birth of unhealthy children.[99] The problem with such is children are not routinely tested for late onset disorders. Thus a claimant must show harm to herself.

Loss of a Chance

[95] *Alcock v Chief Constable of South Yorkshire Police* [1991] 1 AC 310.
[96] *Montgomery*, per Lady Hale, 108. Lady Hale also noted 'an important feature of [a person's physical integrity] … is their autonomy, their freedom to decide what shall and shall not be done with their body', suggesting autonomy is not necessarily a freestanding interest but incorporated into the established interest in physical integrity.
[97] *McFarlane v Tayside Health Board* [2000] 2 AC 59.
[98] *Rees v Darlington Memorial Hospital NHS Trust* [2003] UKHL 52.
[99] *Farraj and Another v King's College NHS Trust and Another* [2009] EWCA Civ 1203.

If autonomy, dignity and preparedness are rejected as the gist of the action, focus must turn to harms with a foundation in negligence. One such possibility is defining harm as a loss of a chance of avoiding a genetic condition; if a greater than 50 per cent chance exists that 'the claimant could have avoided the particular condition if she had known about the risk, she could argue that the manifestation of the genetic condition itself constitutes harm.'[100] Loss of a chance is a harm repackaged as a causative problem, thus in this area harm and causation overlap. The focus here is gist damage, so causation will only be briefly mentioned.

One immediate difficulty with arguments reliant on avoiding conditions is that few genetic conditions can currently be avoided.[101] But if the disease itself cannot be harm because 'the HCP in no way causes the condition'[102] it logically follows injury may be the loss of a chance of avoiding the deleterious phenotype. The problem for claimants is that courts are reluctant to accept personal injury claims based for loss of chance of avoiding physical harm.

The leading authority on this point is *Hotson v East Berkshire Health Authority*.[103] The claimant, a young boy, fell from a tree and sustained an injury to his hip, which was subsequently misdiagnosed. The misdiagnosis resulted in treatment being delayed and, by the time he was correctly diagnosed, the claimant suffered necrosis of the hip joint leaving him permanently disabled. The injury caused by the fall had a 75 per cent chance of leading to necrosis; the negligent diagnosis denied a 25 per cent chance of recovery. In other words, he suffered a loss of a one in four chance of avoiding necrosis. The claimant argued the defendants caused him loss and he was entitled to damages proportionate to the lost chance of recovery, but the House of Lords rejected his claim. On the balance of probabilities, the fall was responsible for his injury and not the negligence of the doctor – in their Lordships' opinion the injury was legally (if not medically) inevitable when the claimant fell from the tree. The decision is objectionable in that it disregarded the significance of the claimant's chances of recovery. These were one in four and, in alternate contexts such as gambling, would be viewed as favourable. There is an obvious disconnect in the law here: on the one hand, doctors are expected to disclose risks that are statistically slight (ten per cent risk of a stroke was highlighted by Lord Bridge in *Sidaway*, a one to three per cent risk was the root of the claim in *Chester*), but on the other clinicians are not liable for reducing patients' prospects

[100] Chico, n3, p143.
[101] Chico, n3, p143.
[102] G.T. Laurie, 'Obligations arising from Genetic Information – Negligence and the Protection of Familial Interest' [1999] CFLQ 109.
[103] [1987] 2 All ER 909

of recovery merely these did not pass the point of balance and are therefore not legally certain. The obvious criticism is that there are few certainties in medical treatment and any attempt by the courts to impose such is disingenuous.

Despite criticism from Lords Nicholls and Hope, the House of Lords affirmed *Hotson* as the leading authority on loss of a chance in *Gregg v Scott*.[104] Here doctors negligently failed to diagnose a cancer patient reducing his prospects of recovery from 42 per cent to 25. The claimant argued that their negligence caused him to lose the chance of a cure (which in terms of cancer is characterised as survival for ten years) but the majority rejected the claim because it did not satisfy the balance of probabilities. Baroness Hale, in particular, argued that it would be problematic to permit loss of chance arguments because 'almost any claim for loss of an outcome could be reformulated as a claim for a loss of a chance of that outcome.'[105] This appears the principle objection to loss of a chance, since it might enable claims to succeed in part where they would otherwise fail. A claimant could thus 'recover 100 per cent if he proved on a balance of probabilities the loss of the outcome … [but] would still recover something if he lost that argument but proved he had nonetheless lost some chance of a better outcome.'[106] It could effectively lead to a 'heads you lose everything, tails I win something situation.'[107]

Lords Hope and Nicholls in the minority thought that the claimant had lost something of value and the law ought to recognise the wrong inflicted. Lord Nicholls argued forcefully that to deny recovery 'would be irrational and indefensible.'[108] He explained:

> 'The loss of a 45% prospect of recovery is just as much a real loss for a patient as the loss of a 55% prospect of recovery … He lost something of importance and value. But, it is said, in one case the patient has a remedy, in the other he does not. This would make no sort of sense. It would mean that in the 45% case the doctor's duty would be hollow. The duty would be empty of content.'[109]

His Lordship makes a compelling point that differentiating between chances above and below the point of balance could render a doctor's duty empty of content in particular

[104] [2005] AC 176.
[105] *Gregg*, n104, 233.
[106] S. Maskrey, W. Edis, '*Chester v Afshar* and *Gregg v Scott*: mixed messages for lawyers' (2005) 3 JPI Law 205, p. 213.
[107] Maskrey, Edis, n106, p213.
[108] *Gregg*, above, n104, 177.
[109] *Gregg*, n104, 180.

circumstances. This is because where the claimant's initial chance is less than 50 per cent the law does not regard the deleterious outcome as consequential to the doctor's negligence.[110] He further added that while 'losing a chance of saving a leg is not the same as losing a leg … that is not a reason for declining to value the chance for whose loss the doctor was directly responsible.'[111] Lord Philips in the majority did accept a loss of chance might be recognised in an appropriate case (which he considered *Gregg* not to be), suggesting this avenue is not wholly closed. However, if a lost chance of a cure is not an appropriate case, the question is whether genetic conditions would be treated differently, as avoiding a disease presupposes treatment exists. It is difficult to imagine the courts distinguishing loss of a chance caused by a cancer misdiagnosis with a loss of a chance caused by nondisclosure of a hereditary cancer risk.

The outcomes of *Hotson* and *Gregg* are at odds with the approach to loss of a chance in economic loss, where a lost opportunity to litigate a claim, gain employment and negotiate a more profitable business deal are recoverable. Thus the difficulty 'is not with loss of chance per se, rather something to do with extending this head of damage to personal injury',[112] a point reinforced by Baroness Hale's reticence in *Gregg*. Weir has also argued that while '[l]osing a chance of a gain is a loss like the loss of the gain itself, alike in quality just less in quantity: losing a chance of not losing a leg is not the same thing as losing a leg.'[113] Yet Weir's assessment does not countenance the value of the chance of saving, in his example, the claimant's leg. Considered from the claimant's perspective, an opportunity to save a limb – even where said opportunity has a lower than 51 per cent chance of success – possesses value and denial of that opportunity is harmful.

If a duty to disclose is viewed as protecting the physical integrity of patients' relatives, and thereby their health, an alternative definition of harm may be a loss of a chance to access medical treatment, as opposed to avoiding a condition. This argument might only be relevant when the genetic risk is actionable. For example: a patient undergoes genetic screening and is identified as possessing a mutation on the BRCA1 gene, which increases the chances of them developing breast cancer by 50-80 per cent. Knowledge of the risk means that individual can opt to undergo preventative therapies, such as a mastectomy or chemoprevention. If this information is not disclosed to the patient's relatives, and they go on to develop breast cancer,

[110] This is not to say that the doctor would escape censure, as regulatory bodies such as the General Medical Council or Nursing and Midwifery Council are likely to investigate clinical 'incidents', but it would leave the claimant without compensation for the loss they have endured.
[111] *Gregg*, n104, 185.
[112] Chico, n3, p146.
[113] T. Weir, *Tort Law* (OUP: Oxford, 2002), p76.

the nondisclosure has denied those individuals the opportunity to access appropriate medical interventions. It may be argued that the loss of a chance harms claimants because it prevents mitigation of genetic risk, eventuating phenotypes being consequential to this gist damage because treatment may have reduced the probability of such manifesting. In one sense, this interpretation is simply word play, shifting the onus from avoiding the genetic disease to accessing treatments that might have made avoiding the disease possible. But if harm cannot be the disease itself because 'the HCP in no way causes the condition'[114] it may be advantageous to refrain from characterising harm as a loss of a chance of avoiding a condition. Where nondisclosure denies access to preventative treatment doctors' actions operate in in conjunction with claimants' genes to enable the deleterious outcome. The same logic could be applied to *W & Others v Essex CC.*[115] The council did not inflict the sexual abuse but denied the claimants a chance to mitigating the risk by failing to disclose the risk posed by the perpetrator (a foster child) to the victims' parents.

Articulating harm as a loss of a chance of accessing treatment also limits the scope of the duty: disclosure would not be expected in absence of treatment, because the benefits in these circumstances are debatable.[116] This interpretation is premised on an assumption that prevention (or risk reduction) is preferable to lengthy, invasive therapies, or, alternatively, early intervention is beneficial to claimants who are at risk – a fact starkly demonstrated by poor survival rates for suffers of pancreatic cancer in the UK, who are often diagnosed at a stage when their cancer is inoperable. The starting point would not be whether a claimant's prospects of recovery were beyond the point of balance, thus a 'certain' chance lost, but whether treatment would have been available had the genetic risk been disclosed. The initial enquiry is thus restricted to a 'yes' or 'no' answer. However, thereafter caselaw on loss of a chance suggests that the statistical significance of the treatment would be a relevant consideration for the court. Therefore if a treatment has only a 25 per cent chance of averting the onset of a condition then the chance is below the point of balance and would fail a typical analysis of the issue. Relying on percentage chances to impose legal (as opposed to factual) certainty would ignore that 'there is something valuable in having the opportunity to try all you can to prevent a genetic disease'[117] but it is not anticipated that the courts would move

[114] Laurie, n102.
[115] [2001] 2 AC 592 (HL). The defendant placed a foster child being investigated for rape with a foster family who had young children of their own. The foster parents had expressly told the defendant they would not foster children suspected of sexual offences. The defendant failed to disclose the foster child's history and he proceeded to abuse the biological children.
[116] Almqvist, n91 and n92.
[117] Chico, n3, p150.

away from the all-or-nothing approach of the balance of probabilities. Thus although categorising the harm as a loss of a chance of medical treatment may appear initially sensible, the knotty issue of probability and the necessity of legal certainty mean that it is unlikely to avoid the core problem with losses of chance: the need to surpass a causative point of balance.

Whether there is a sustainable basis for continuing to differentiate between negligence causing an individual to lose a 51 per cent chance and negligence denying a (still statistically significant) 49 per cent chance of recovery remains a moot point and one the Court of Appeal has stated should be left to the Supreme Court.[118] In principle, denying a chance of recovery, treatment or avoiding a risk outright should be compensable harm because a possibility of recovery (such as the 25 per cent chance in *Hotson*) is of value to the claimant. However, Baroness Hale's practical concerns about permitting claims for loss of a chance are not insignificant. As a result, claims concerning nondisclosure, where the chance of avoiding, treating or recovering from a genetic condition are lower than 50 per cent, are unlikely to succeed.

The Genetic Condition

It has been argued a genetic condition is not harm because nondisclosure does not cause the condition, which is instead a product of the claimant's genome. This logic initially appears compelling but it fails to address that foreseeable harm is not necessarily dependant on being caused by a defendant's conduct. Furthermore, whether a defendant causes harm is a question of causation and not an argument on the nature of damage.

A useful analogy can be lifted from the case of *SAAMCO*, where Lord Hoffmann discussed the example of a mountaineer recuperating from an injury to his leg.[119] Imagine a physician negligently fails to disclose a weakness in the mountaineer's leg and he is injured whilst climbing because his leg collapses. If treatment is presumed not to be negligent, it cannot be said the doctor created the weakness in the leg, but the injury sustained as a result of that undisclosed weakness forms the crux of an action in negligence. The eventuating risk that could have been minimised by disclosure constitutes the gist damage. Substituting the weakness for a treatable genetic condition – say, breast cancer – arguably leads to the same conclusion: the doctor does not create the deleterious trait, but nondisclosure allows it to eventuate.[120] *Chester v Afshar*[121] illustrate this point.

[118] *Wright (a child) v Cambridge Medical Group* [2011] EWCA Civ 699.
[119] *South Australia Asset Management Corp v York Montague* [1997] AC 191, 213.
[120] A noteworthy point is that in the example of the mountaineer there is a doctor-patient relationship, but this is a matter of proximity and not foreseeable harm. On proximity between blood relations and the proband's doctor see M.

In *Chester*, the claimant was exposed to a (statistically slight) risk of spinal injury in a non-negligent operation. The risk was not disclosed prior to the procedure; it eventuated, and the claimant successfully recovered for her physical injuries. The House of Lords tried to characterise the foreseeable harm against which a duty was owed as a loss of autonomy, which nondisclosure infringed. There is some merit to this rationale because the purpose of a duty to disclose is 'to enable adult patients of sound mind to make for themselves decisions intimately affecting their own lives and bodies'.[122] The majority might be accused of attempting to make their decision 'more palatable'[123] by defining harm in terms of autonomy, but the reality is few claims presently succeed in absence of physical injury.[124] Lady Hale's comments in *Montgomery* regarding autonomy as part of the enjoyment of physical integrity, cast further doubt on autonomy constituting gist damage. When autonomy is actionable because physical or psychiatric injury occurs it is the tangible injury, not autonomy, that is the gist of the claim.

A genetic disease can thus constitute harm, despite nondisclosure not causing the injury directly. The negligence in *Chester* was the failure to disclose the risk, the gist of the claim the nonconsensual physical injury. Comparable with the spinal injury in *Chester*, genetic diseases are adverse physical outcomes. Where medically treatment is available for a disease, harm can be 'grounded in the deterrence of outcomes injurious to physical integrity, which … [is] uncontroversially protected by the tort of negligence.'[125] Disclosure would have facilitated access to early diagnosis and treatment, allowing the claimant to avoid or mitigate the disease's physical consequences. Where the condition is intractable the claimant could articulate psychiatric injury, but disclosure is absence of therapy is problematic.[126] Furthermore, psychiatric injury from receiving bad news does not typically create liability.[127] A fear of the future argument may be appropriate where the claimant does not know if they have passed a deleterious treat to their children,[128] but such is restrictively provided for.

Fay, *Genetics, Families and Negligence: A Duty to Disclose Actionable Risks* (forthcoming, *Medical Law International*).

[121] [2004] UKHL 41.

[122] *Chester*, n121, per Lord Bingham, 5.

[123] J. Murphy, *Street on Torts* 13th ed., (OUP, Oxford: 2012), p158.

[124] C. Purshouse, 'Judicial Reasoning and the Concept of Damage' (2015) 15(2-3) Med Law Int 155. Cf. Rees; J. Coggon, 'Varied and principled understandings of autonomy in English law' Health Care Analysis 2007 15(3) 235; T. Keren-Paz, n45.

[125] Stapleton, n3, p443.

[126] Almqvist, n92.

[127] *Ravenscroft v Transatlantic* [1991] 3 All ER 73.

[128] *Group B Plaintiffs v Medical Research Council* [2000] Lloyd's Rep Med 161; *Grieves v FT Everard* [2007] UKHL 39.

It is argued here that treatable genetic diseases are the gist of the negligence action. Further support for this interpretation can be drawn from *Birch v University College London Hospital NHS Trust,*[129] where the defendants failed to disclose the risk of a stroke inherent in undergoing a catheter angiogram and the low risk alternative of an MRI. The patient suffered a stroke and successfully sued. Like *Chester*, the claim hinged on an adverse outcome; no claim would likely have arisen without physical injury. Again the gist damage was the eventuating risk, which was inherent in the angiogram, not a result of negligence conduct. The defendants did not cause the stroke, just as they would not cause a genetic disease. Nondisclosure means a claimant cannot avoid or minimise risk, the eventuation of said risk the foreseeable harm against which a duty to disclose guards.

This line of reasoning finds support in cases concerning physical injuries inflicted by third parties, where the risk of such was not disclosed. In these circumstance the defendants do not cause the harm, but a duty arises because the injuries eventuate from an undisclosed risk. The eventuating risk is again the gist damage. The defendants in *Tarasoff v Regents of the University of California*[130] negligently failed to disclose the risk posed by a patient to his ex-girlfriend. The patient, during therapy, had confessed to his psychiatrist his intention to kill the victim once discharged. Though his threat was severe, the defendants exercised few precautions and, significantly, made no attempt to apprise the ex-girlfriend of the risk. The victim's mother alleged the defendants were negligent in failing to warn her daughter about the risk her ex-boyfriend posed.[131] The Supreme Court of California held a duty of care was owed to the victim. As with *Birch* and *Chester*, it was the eventuating risk that was the foreseeable harm. The patient killed his ex-girlfriend, but nondisclosure meant she could not minimise the danger. Individuals unaware of a genetic risk occupy an analogous position: harm may be 'minimized by a timely and effective warning.'[132]

The failure to warn of the risk posed by a third party was again at issue in *Selwood v Durham County Council*.[133] The claimant was a social worker employed by a local authority involved in close collaboration with two NHS trusts to provide integrated social care and mental health services. The claimant's was assigned to a case involving a young girl whose father suffered from mental health problems and had a history of violent behaviour. The

[129] [2008] EWHC 2237.
[130] 17 Cal. 3d 425 (Cal. 1976).
[131] For example, ibid. at 433 per Tobriner J: 'Poddar [the ex-boyfriend] persuaded Tatiana's brother to share an apartment with him near Tatiana's residence; shortly after her return from Brazil, Poddar went to her residence and killed her.' Had the defendants disclosed the risk posed by the ex-boyfriend it is foreseeable that these accommodation arrangements would not have been made.
[132] *Safer v Estate of Pack* 677 A 2d 1188 (New Jersey Superior Court Appellate Division 1996), 1192.
[133] [2012] PIQR P20.

father was a patient of the NHS trusts and, during treatment, told his doctors that he wished to harm the social worker involved in his daughter's case. He later stated he would 'kill her on the spot' if he saw her. Despite the severity of these threats and the patient's known history of violence, neither the claimant nor her employers were warned of the risk. When the patient was temporarily discharged from hospital, he attacked the claimant with a knife, inflicting serious injuries. The defendants were not the source of the claimants' injuries, but those injuries were the gist of the negligence action. Nondisclosure meant the claimant could not avoid or minimise the risk. Nondisclosures of physical and medical risks are distinguishable in some ways,[134] but the gist damage is consistently the eventuating risk. The adverse outcomes about which claimants could have been forewarned create an action in negligence.

In claims for nondisclosure, foreseeable harm may therefore be the eventuating physical burdens of a medically actionable genetic disease. US jurisprudence appeared to endorse this proposition in *Safer v Estate of Pack*.[135] The claimant was suffering a hereditary cancer which her father had also suffered. It was alleged her father's doctor was required 'to warn those at risk so that they might have the benefits of early examination, monitoring, detection and treatment, that would provide opportunity to avoid the most baneful consequences of the condition.'[136] The court concluded circumstances involving genetic conditions were analogous to litigation involving contagious diseases[137] and *Tarasoff* duties, stating:

> 'In terms of foreseeability especially, there is no essential difference between the type of genetic threat at issue here and the menace of infection, contagion or a threat of physical harm.'[138]

The court did not analyse harm (perhaps reflecting Nolan's point that harm is generally subsumed into either questions of duty or causation[139]) but equating genetic disease with infection, contagion and physical harm is indicative of the eventuating risks being the gist damage. The court's reference to 'substantial future harm'[140] reinforces this point. The complaint was couched in terms of avoiding 'the most baneful consequences of the

[134] Disclosure in *Chester* and *Birch* would have assisted the defendants in securing valid consent, whereas disclosure in *Tarasoff* and *Selwood* would have facilitated the personal safety of the victim.
[135] 677 A 2d 1188 (New Jersey Superior Court Appellate Division 1996).
[136] *Safer*, n135, 623.
[137] E.g. *Skillings v Allen* 143 Minn 323 (1919); *Gammil v United States* 727 F 2d 950 (10th Cir 1984).
[138] *Safer*, n135, 626.
[139] Nolan, n4.
[140] *Safer*, n135, 626.

condition',[141] thus substantial future harm logically means the physical burdens of the condition.

Bradshaw v Daniels[142] further supports this interpretation of harm. A clinician owed a duty to a patient's wife to warn her of the risks of exposure to the source of her husband's disease – Rocky Mountain spotted fever.[143] The disease was non-contagious but the doctor negligently failed to disclose his wife was at the same epidemiological risk; she later died. The doctor in *Bradshaw* did not cause the condition, but he was 'in a position to know of a risk that may not be obvious to others'.[144] Reversing the appellate court's decision, the Supreme Court of Tennessee concluded it was appropriate 'to impose upon a physician an affirmative duty to warn identifiable third parties in the patient's family against foreseeable risks emanating from the patient's illness.'[145]

The case law above demonstrates that eventuating risks can constitute foreseeable harm though the defendant may not directly cause the injury. Eventuating risks have stemmed from third parties such as patients, non-negligent operations, non-negligent exposure, and deleterious genetic traits. Undisclosed risks are foreseeable harm because defendants are 'in a position to know of a risk that may not be obvious to others'.[146] Medically actionable genetic diseases are foreseeable harm against which a duty should guard. Nondisclosure prevents claimants avoiding or minimising the physical (and potentially psychiatric) burdens of the condition. *Safer* found no essential difference between genetic conditions and infection, contagion or threat of physical harm;[147] it is common to these that harm may be 'minimized by a timely and effective warning.'[148] Disclosing a risk of genetic disease protects physical and psychiatric integrity, interests well recognised in tort.

A criticism of foreseeable harm defined as medically actionable genetic conditions is it will restrict the scope of a duty. A claim for injury to autonomy may be advantageous in that it may not require an adverse outcome, only frustration of the ability to choose, enabling recovery in a broader range of situations.[149] This may indirectly promote more widespread disclosure of genetic risks. Having to 'wait' for a genetic condition to develop before a valid

[141] *Safer*, n135, 623.
[142] 854 SW 2d 865 (Tenn. 1993).
[143] A potentially fatal tick borne disease caused by the bacterium *Rickettsia Rickettsii*.
[144] C. Parker, 'Camping trips and family trees: must Tennessee physicians warn their patient's relatives of genetic risks?' (1998) 65 *Tennessee L Rev* 585, p.597.
[145] *Bradshaw*, n142.
[146] C. Parker, 'Camping trips and family trees: must Tennessee physicians warn their patient's relatives of genetic risks?' (1998) 65 *Tennessee L Rev* 585, p.597.
[147] *Safer*, n135, 626.
[148] *Safer*, n135., 1192.
[149] Chico, n3; Keren-Paz, n45.

claim arises restricts the volume of potential cases. Not every genetic risk eventuates, thus blood relations could only litigate in narrow circumstances. But it is necessary to keep negligence within 'the bounds of common sense and practicality'.[150] Obligating disclosure to protect autonomy may meet resistance because of the volume of claims it could create. Disclosures made in absence of therapeutic response also risk causing psychiatric harm. Furthermore, autonomy receives limited recognition in negligence, necessitating a new head of damage. If the eventuating genetic disease is foreseeable harm, gist damage is grounded in physical integrity 'an interest uncontroversially protected by the tort of negligence.'[151]

CONCLUSION

ABC v St George's Healthcare was a first opportunity for the UK courts to engage with a duty to disclose genetic risks to patients' relatives, but it was a missed opportunity. Nicol J focused on whether a duty was fair, just and reasonable and left unanswered important questions about proximity and foreseeable harm. This paper has sought to answer what harm forms the gist of the action in a relative's claim for nondisclosure of genetic risks. Several possible interpretations of harm have been examined and the relative strengths and frailties of these approaches laid bare. Intangible harms such as autonomy, human dignity and a lack of preparedness have been scrutinised and a reconciliation with classic definitions of harm such as loss of a chance considered. These formulations of gist damage have been rejected; it has instead been argued the nub of a nondisclosure claim is the eventuating of a medically actionable genetic risk. This argument draws support from both UK and US caselaw involving undisclosed risks of harm and it is argued that a defendant need not directly inflict harm for liability to accrue in negligence. This approach is argued as appropriate and is reflected in the American decision of *Safer v Estate of Pack*, which involved nondisclosure of a genetic risk. In reaching a conclusion favouring the claimant, the court drew analogies between genetic risks, risks of physical violence and contagious diseases. This interpretation of harm is argued as grounding a duty to disclose in the interest in physical integrity, which is a mainstay of negligence. Thus formulating the harm as an eventuating risk is reconcilable with established principles of tort.

[150] *Caparo v Dickman* [1990] 2 AC 605, per Lord Oliver, 633A.
[151] Stapleton, n3, p.443.