

# DISCLOSING GENETIC TEST RESULTS TO THE PATIENT'S RELATIVES: HOW DOES THE LAW INFLUENCE CLINICAL PRACTICE?

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## Abstract

*Disclosure of genetic test results to relatives is the subject of extensive scholarly debate and empirical research. This is because genetic test results may have serious implications not only for the patient but also for the relatives. However, the patient's legal right to confidentiality makes disclosure to relatives problematic if the patient refuses disclosure. One aspect which has not yet received sufficient scholarly attention is how clinicians deal with the legal framework within which they operate. This Article aims to fill this gap by presenting findings from a qualitative study conducted with Israeli clinicians who provide counseling and treatment to healthy women undergoing BRCA1/2 testing. The findings indicate that clinicians follow the law. They respect their duty of confidentiality and generally refrain from informing the relatives without the patient's consent. However, the findings also indicate that they find the law restrictive when patients explicitly refuse to inform their relatives. Furthermore, the law does not help clinicians to resolve the difficulties regarding patients' passive non-disclosure, namely when the patient agrees to inform the relatives in the encounter with the clinician but refrains from doing so after leaving the clinician's office. In addition, the law does not help clinicians to overcome the practical difficulties of tracking relatives when patients are not cooperative and refuse to provide contact details. These findings lead to a discussion about methods that could overcome the difficulties regarding disclosure to relatives, including the option of imposing a legal duty on clinicians to inform the relatives. The position expressed in this Article is that the law should leave it to the discretion of the clinicians to decide whether or not to initiate a process of disclosure without the patient's consent. In tort law terminology, a legal duty to the relatives should be recognized, but the question of whether and how to initiate a process of disclosure without consent should remain at the discretion of clinicians. Such a legal rule, which shifts the discussion from the duty stage*

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*to the breach-of-duty stage, would require clinicians to dedicate more thought to the criteria justifying disclosure without consent. In addition, it would require clinicians to change their underlying attitude to confidentiality and disclosure and consider them with equal moral and legal weight.*

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#### I. INTRODUCTION

Disclosure of genetic test results to relatives is the subject of extensive scholarly debate (both in bioethics and law)<sup>1</sup> and empirical research<sup>2</sup> since a patient's genetic test results may have serious implications for the relatives' health. For example, a diagnosis of a female breast cancer patient as a carrier of a mutation in the BRCA1/2 genes suggests that her daughters, mother, and

1. E.g., Anneke Lucassen & Roy Gilbar, *Alerting Relatives About Heritable Risks: The Limits of Confidentiality*, 361 BRIT. MED. J. k1409 (Apr. 5, 2018) [hereinafter Lucassen & Gilbar I], <https://www.bmj.com/content/361/bmj.k1409> (discussing when disclosing family history of heritable disease may be appropriate); Edward S. Dove, *ABC v St George's Healthcare NHS Trust and Others: Should There be a Right to be Informed About a Family Member's Genetic Disorder?*, 44 L. HUM. GENOME REV. 91 (2016) (discussing a case regarding a daughter's claim against her father's clinicians for failure to inform). We use the term relatives and family members interchangeably.

2. Sandi Dheensa et al., *Health-care Professionals' Responsibility to Patients' Relatives in Genetic Medicine: A Systematic Review and Synthesis of Empirical Research*, 18 GENETICS IN MED. 290, 296 (2016) [hereinafter Dheensa I].

sisters are at an increased risk of developing breast cancer. Informing the patient's relatives of the diagnosis in this case could help them reduce the risk of onset of the disease, by, for example, maintaining close surveillance or undergoing a prophylactic operation.<sup>3</sup> However, clinicians have to respect the fact that patients have a legal right to confidentiality.<sup>4</sup> Thus, when a patient insists on his/her right to confidentiality and requests that the relatives not be informed, disclosure becomes legally and bioethically problematic.<sup>5</sup> In this context, assuming relatives want to reduce their increased risk, a question in law and bioethics arises as to whether a clinician can approach the relatives and raise their awareness of their increased risk. This issue is particularly pressing as genetic technologies for diagnosing diseases become cheaper, quicker and more extensive, and enter mainstream medical practice, as well as being readily available to consumers commercially.<sup>6</sup>

From a bioethical perspective, a major theme in the current discourse revolves around the scope of the clinicians' duty of confidentiality to the patient who undergoes genetic testing, and the justifications for disclosure of the results to relatives without the patient's consent.<sup>7</sup> There are two main bioethical approaches in this context—liberal-individualistic and relational.<sup>8</sup> A liberal-individualistic approach perceives the individual as essentially separate from others, thus supporting a strict right to confidentiality, even when the information has significant implications for the individual's relatives.<sup>9</sup> In contrast, a relational approach stresses that the individual lives within a web of social relationships so that a right to confidentiality, particularly when the information has implications for others, should be more flexible.<sup>10</sup>

From a legal perspective, one aspect which has not yet received sufficient attention is how clinicians deal with the legal framework within which they operate, or in other words, how the law influences clinical practice. Although research that examines how clinicians perceive their duty of confidentiality in genetics and what they think about disclosure to relatives without patients' consent has been published,<sup>11</sup> there is little research about the impact of existing legal rules on clinical practice. This Article aims to fill these gaps by presenting

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3. Andrea Eisen et al., *Breast Cancer Risk Following Bilateral Oophorectomy in BRCA1 and BRCA2 Mutation Carriers: An International Case-Control Study*, 23(30) J. CLINICAL ONCOLOGY 7491 (2005); Judith Balmana et al., *BRCA in Breast Cancer: ESMO Clinical Practice Guidelines*, 22 (supp. 6) ANNOTATED ONCOLOGY vi31–vi34 (2011).

4. Lucassen & Gilbar I, *supra* note 1.

5. *Id.*

6. See Sandi Dheensa et al., *Limitations and Pitfalls of Using Family Letters to Communicate Genetic Risk: A Qualitative Study with Patients and Healthcare Professionals*, 27 J. GENETIC COUNSELING 689, 698–99 (2018) [hereinafter Dheensa II] (describing how the ease of obtaining this information has inspired conversations regarding how to most effectively communicate to patient families).

7. TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS*, 323–24 (Oxford U. Press, 7th ed. 2013) [hereinafter BEAUCHAMP & CHILDRESS]. We use the term clinicians because in clinical genetics both genetic counselors and geneticists provide services to patients.

8. John Christman, *Relational Autonomy, Liberal Individualism, and the Social Constitution of Selves*, 117 PHIL. STUD. 143 (2004).

9. *Id.*

10. See *infra* Part II (providing an extended bioethical analysis of these approaches).

11. See generally Dheensa I, *supra* note 2 (discussing empirical studies of health care providers' thoughts regarding disclosure to relatives).

findings from a qualitative study conducted with clinicians who provide counseling and treatment to healthy women who undergo BRCA1/2 testing.<sup>12</sup> The findings will allow us to analyze and develop the current bioethical discourse regarding the scope of medical confidentiality but also to conclude whether the legal framework—which is similar in many Western countries— influences clinical practice in genetics. In addition, the findings will inform the discussion on how to protect patients' rights to autonomy, privacy, and confidentiality while promoting public interest in avoiding the onset of heritable diseases.

The analysis will show that the law has a substantial influence on the practice of clinicians in genetics. Generally, clinicians follow the law and respect the duty of confidentiality.<sup>13</sup> However, they hold the view that the law restricts them when patients explicitly refuse to inform the relatives.<sup>14</sup> Moreover, the analysis will show that the law does not help clinicians to resolve the difficulties that arise in the following cases: when patients agree during the consultation with the clinician to inform their relatives but refrain from doing so when leaving the clinician's office;<sup>15</sup> when clinicians want to locate relatives to inform them but the patient is not cooperative; and when clinicians are reluctant to intervene in familial relationships. Finally, the analysis will show that clinicians in genetics do not use the legal tools available to them to resolve cases of patients' explicit non-disclosure to relatives.

The discussion in this Article has implications for jurisdictions that regulate this area. In this Article we focus on the legal position in the U.S., the U.K., and Israel. The gaps detected between law and practice in this study and the methods clinicians adopt when dealing with disclosure to relatives within a legal framework, that limits their practice and personal preferences, raise questions law-makers in many jurisdictions face. Namely, whether they should strive to minimize these gaps and what methods they should use to deal with them.

In light of this introduction, the structure of this Article will be as follows. Part II of the Article discusses the bioethical framework as it influences both clinical practice and law, while Part III will present a literature review summarizing the findings from empirical work on the issues discussed in this article. Part IV will provide a comparison of the legal framework in the U.S., the U.K., and Israel—where the empirical study was conducted. In Parts V and VI, we describe our study and present its findings, and in the final part we analyze the findings and discuss their implications.

## II. BIOETHICAL FRAMEWORK

The familial aspects of communicating genetic information have initiated a heated debate in bioethics. Some scholars do not make a distinction between

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12. The test reveals whether one carries a mutation which increases the risk of developing breast and ovarian cancer.

13. Dheensa I, *supra* note 2, at 296.

14. *Id.*

15. This phenomenon is also known as passive non-disclosure. See *infra* note 83 (providing further discussion).

genetic information<sup>16</sup> and any other type of medical information,<sup>17</sup> while others argue that genetic information is exceptional, highlighting its predictive and familial characteristics.<sup>18</sup> This discussion relates to the bioethical debate concerning the access of relatives to medical genetic information.<sup>19</sup> Overall, it is possible to identify two main approaches.

One approach is patient-centered. It highlights the liberal-individualistic conceptions of autonomy, privacy, and confidentiality.<sup>20</sup> It stresses that patients have a private sphere, which includes information about their health and is inviolate without their permission.<sup>21</sup> In addition, this approach emphasizes that the individual patient is autonomous in the sense that s/he has the right to make his/her own decisions regarding the dissemination of information that concerns his/her health.<sup>22</sup> Such an attitude reflects the desire people have to lead their life as they wish and to control the level of external social influences when they make decisions about their health. Thus, according to this approach, patients should have the ultimate authority to regulate the flow of genetic information to others, including their relatives, where the information stems from medical tests physically performed on them.

A utilitarian mechanism of cost-benefit evaluation is also in operation in this context. The general working assumption is that patients may be more likely to disclose all relevant information to their clinicians and therefore receive accurate diagnosis and treatment, if they are assured that the information communicated in the consultation room is kept in confidence.<sup>23</sup> According to this utilitarian approach, disclosure without the patient's knowledge or consent is morally justified in exceptional circumstances, when it can substantially benefit others.<sup>24</sup> This may occur when a patient's refusal to inform his/her relatives poses them a risk of serious harm.<sup>25</sup> When disclosure to relatives can prevent or reduce the risk of the onset of hereditary disease, an adequate moral decision, according to this utilitarian approach, might be to inform the relatives

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16. We adopt the legal definition of genetic information stated in the Israeli Genetic Information Act 2000 discussed in detail below. See *infra* note 134 (defining genetic information as "information stemming from genetic testing." Genetic testing is defined as "the testing of the DNA sample of a person in order to characterize and compare DNA sequences.").

17. Lawrence Gostin & James G. Hodge Jr., *Genetic Privacy and the Law: An End to Genetics Exceptionalism*, 40(1) JURIMETRICS 21–58 (1999); Dean Bell & Belinda Bennett, *Genetic Secrets and the Family*, 9(2) MED. L. R. 130 (2001) [hereinafter Bell & Bennett]; NEIL C. MANSON & ONORA O'NEILL, *RETHINKING INFORMED CONSENT IN BIOETHICS* (Cambridge U. Press, 2007).

18. Loane Skene, *Patients' Rights or Family Responsibilities*, 6(1) MED. L. REV. 1 (1998) [hereinafter Skene]; Roy Gilbar, *Communicating Genetic Information in the Family: The Familial Relationship as the Forgotten Factor*, 33(7) J. MED. ETHICS 390 (2007) [hereinafter Gilbar I]; Michael Parker & Anneke Lucassen, *Using Genetic Test Results in the Care of Family Members: How does the Duty of Confidentiality Apply?*, 26 EUR. J. HUM. GENETICS 959 (2018) [hereinafter Lucassen & Parker I].

19. GRAEME LAURIE, *GENETIC PRIVACY: A CHALLENGE TO MEDICO-LEGAL NORMS* (Cambridge U. Press, 2002).

20. See Bell & Bennett, *supra* note 17 (defending individual autonomy theories).

21. LAURIE, *supra* note 19, at 6–8.

22. Bell & Bennett, *supra* note 17, at 158.

23. BEAUCHAMP & CHILDRESS, *supra* note 7, at 319.

24. Christopher Jones, *The Utilitarian Argument for Medical Confidentiality: A Pilot Study of Patients' Views*, 29 J. MED. ETHICS 348, 348 (2003).

25. *Id.*

without the patient's consent.<sup>26</sup> However, it must be stressed that according to this patient-centered approach, disclosure in these circumstances is the exception and not the rule.<sup>27</sup>

Another approach is relational. It holds that relatives should have independent access to familial genetic information when it becomes available, or alternatively that they should be informed of an increased genetic risk running in their family.<sup>28</sup> There are two immediate implications of such a strategy. First, the patient may be morally compelled to raise the awareness of relatives to the familial genetic risk (although they may not necessarily be required to reveal their own identity as the source of the information).<sup>29</sup> Second, it may introduce flexibility into the clinicians' duty of confidentiality to allow them to raise relatives' awareness of their familial genetic risk despite patients' refusal.<sup>30</sup>

The grounds for this approach can be found in communitarian and feminist perceptions of patient autonomy. These perceptions stress that the patient has a moral responsibility to take the relatives' interests into account when making decisions which have implications for their lives.<sup>31</sup> Feminists and particularly proponents of ethics-of-care, argue that the essence of a familial relationship, which is based on intimacy, care, and mutual respect, produces a sense of moral responsibility among family members.<sup>32</sup> This sense of moral responsibility, which is based on close familial relationships, should lead patients to inform their relatives of the increased genetic risk to which the relatives are exposed.<sup>33</sup> From an ethics-of-care perspective, it would also require clinicians to take into consideration, not only the clinical aspects of the seriousness of the disease, the chances of onset, and the means to prevent or treat, but also to consider the likely reaction of the relatives if informed and the impact of any decision—either to inform the relatives or not—on the patient-relatives relationship.<sup>34</sup>

Communitarians highlight the values of solidarity and an individual's moral obligations to those whose lives are affected by his/her decisions

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26. BEAUCHAMP & CHILDRESS, *supra* note 7, at 321–23.

27. See generally Roy Gilbar, *The Passive Patient and Disclosure of Genetic Information: Can English Tort Law Protect the Relatives' Right to Know?*, 30(1) INT. J. L. POL'Y FAM. 79, 81 (2016) [hereinafter Gilbar II] (noting that patients typically opt to disclose their medical information to family members, and the motivations, both practical and ethical, for doing so).

28. See Lucassen & Gilbar I, *supra* note 1 (explaining the relational model, and its implications for law and professional responsibilities).

29. Gilbar II, *supra* note 27.

30. See Lucassen & Gilbar I, *supra* note 1, at 3 (“English law, like professional guidelines, imposes a duty of confidentiality on clinicians and grants discretion to warn relatives.”).

31. Anne Donchin, *Autonomy and Interdependence: Quandaries in Genetic Decision-Making*, in RELATIONAL AUTONOMY: FEMINIST PERSPECTIVES ON AUTONOMY, AGENCY AND THE SOCIAL SELF 236–58 (Catriona Mackenzie C & Natalie Stoljar eds., 2000).

32. See HILDE LINDEMANN-NELSON & JAMES LINDEMANN-NELSON, *THE PATIENT IN THE FAMILY: AN ETHICS OF MEDICINE AND FAMILIES* (Routledge, 1995) (examining the way that feminism and ethics of care approach medical issues within familial relationships).

33. See Gilbar II, *supra* note 27, at 81 (noting the varied motivations that patients have, for disclosing medical information to family members, including the “belief that it is their responsibility to protect the relatives' health”).

34. See Gilbar I, *supra* note 18, at 391 (providing a list of factors for clinicians to consider, when confronted with the question of whether to inform relatives).

regardless of whether they share intimate relationships.<sup>35</sup> Therefore, in the context of genetics, if a patient holds information that has implications for the physical and mental health of his/her relatives, communitarians would stress the patient's moral responsibility to share this information because the aim is to promote the common good of the family as a community.<sup>36</sup> A communitarian perspective would also highlight the importance of protecting the health of the family and society more generally, through a relaxation of the clinicians' duty of confidentiality. According to this approach, promoting the common good of the patient's family should require clinicians, to raise the awareness of family members to the increased risks they might face.<sup>37</sup>

Bioethical discussions about the limits of confidentiality and the scope of disclosure of genetic information to relatives have generated models that deal with these issues. Highlighting the fact that the patient and the biological relatives share the same gene pool has led scholars to argue that a patient's claim for exclusive control over the access to his/her genetic test results should be dismissed.<sup>38</sup> Rather, as Parker and Lucassen argue, genetic information should be viewed as a joint bank account with all account holders having equal access to the information.<sup>39</sup> A similar approach highlights a distinction between *personal* genetic information, which identifies a particular individual (the patient) as a carrier of a particular disease, and *familial* genetic information which indicates that there is an increased risk of developing a particular heritable disease in a certain family.<sup>40</sup> Lucassen and Gilbar argue that disclosure of familial genetic information without the patient's knowledge or consent is not considered a breach of the clinician's duty of confidentiality if the anonymity of the source of the information (i.e., the patient) and his/her privacy, are maintained.<sup>41</sup> Similarly, in a recent article, Parker and Lucassen argued that in

35. AMITAI ETZIONI, *THE SPIRIT OF COMMUNITY* (Fontana Press, 1995); see also Barbara Prainsack, *The "We" in the "Me": Solidarity and Healthcare in the Era of Personalized Medicine*, 43(1) SCI. TECH. & HUM. VALUES 21, 86 (2018) (providing a recent account on solidarity and its relevance in health care and bioethics).

36. Rosamond Rhodes, *Genetic Links, Family Ties and Social Bonds: Rights and Responsibilities in the Face of Genetic Knowledge*, 23(1) J. MED. PHIL. 10 (1998); Ann Sommerville & Veronica English., *Genetic Privacy: Orthodoxy or Oxymoron?*, 25 J. MED. ETHICS 144 (1999).

37. ROY GILBAR, *THE STATUS OF THE FAMILY IN LAW AND BIOETHICS: THE GENETIC CONTEXT* 104–07 (Ashgate, 2005).

38. See Skene, *supra* note 18, 40–41 (discussing alternative models of disclosing genetic information); Barbara Knoppers, *Genetic Information and the Family: Are We Our Brother's Keeper?*, 20 TRENDS IN BIOTECHNOLOGY 85, 85 (2002) (arguing that "genetic information is necessarily familial and the needs and interests of other family members cannot be ignored."); Anneke Lucassen & Michael Parker, *Confidentiality and Sharing Genetic Information With Relatives*, 375 LANCET 1507 (2010) (arguing that there should be an exception to non-disclosure regimes surrounding genetic testing results, for familial genetic factors).

39. Michael Parker & Anneke Lucassen, *Genetic Information: A Joint Account*, 329 BRIT. MED. J. 165 (2004). Another model developed in the literature is forming a family covenant. See David J. Doukas & Jessica W. Berg, *Family Covenant and Genetic Testing*, 1(3) AM. J. BIOETHICS 3 (2001) (discussing the features of a family covenant, and the ways that it serves the interests of the physician, patient, and family in genetic testing scenarios).

40. Such a distinction is acknowledged by patients: Rebecca D. Pentz et al., *Hereditary Nonpolyposis Colorectal Cancer Family Members' Perceptions About the Duty to Inform and Health Professionals' Role in Disseminating Genetic Information*, 9(3) GENETIC TESTING 261 (2005).

41. See Lucassen & Gilbar I, *supra* note 1, at 2 (noting the motivations that patients have to disclose the results of genetic testing to their family members); Anneke Lucassen & Roy Gilbar, *Disclosure of Genetic Information to Relatives: Balancing Confidentiality and Relatives' Interests*, 55(4) J. MED. GENETIC 285 (2017)

circumstances where medical genetic information can potentially benefit the relatives, and where clinicians can use familial information without identifying the patient (who was the first in the family to undergo the genetic test), then “the duty to use it in the care of others outweighs a duty of confidentiality.”<sup>42</sup> Parker and Lucassen emphasized that in these circumstances the clinical information about the patient should be kept confidential but that “information about the heritable predisposition that led to it should be available for health professionals to use in the care of family members.”<sup>43</sup> Their view is convincing because it protects both the interests of the individual patient in maintaining his/her anonymity and the relatives’ interests in receiving significant information about their health. Not only does it enable relatives to make informed decisions about their health and take measures to prevent or reduce the chances of the onset of the relevant disease,<sup>44</sup> but it also takes into consideration the impact of the decision on familial relationships, which are crucial to the ability to act autonomously.

A significant issue to arise from this discussion about the distinction between personal and familial information, is how we define confidential information. In this context, it can be argued that information should be confidential if it is personal or private and there is a reasonable expectation that it would be kept in confidence.<sup>45</sup> Thus, for example, it can be argued that it is reasonable to expect that information which reveals personal details about the patient or exposes his/her vulnerability would be kept in confidence by the clinician who is party to this information. In addition, it can be argued that information, which stems from a close and intimate relationship, would be considered confidential by the parties involved.<sup>46</sup> Finally, it can be argued that two or more individuals can agree that information communicated between them is confidential and will not be shared with others without consent.<sup>47</sup>

Applying these conceptions to our context, it can be argued that alerting relatives—without the patient’s consent or knowledge—that they are exposed to

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[hereinafter Lucassen & Gilbar II] (arguing that distancing the disclosure of the familial trait, from the patient that it was discovered in, might not implicate the clinicians’ duty of confidentiality).

42. Lucassen & Parker I, *supra* note 18, at 965.

43. *Id.* at 966.

44. See Lucassen & Gilbar II, *supra* note 41, at 286 (discussing the benefits that accrue to family members who are informed about a familial factor, as a motivation for disclosing such information, when performing genetic testing).

45. This was recognized, for example, by the British House of Lords in *Campbell v. MGN* [2004] UKHL 22, per Lord Nicholls at para. 21 [hereinafter *Campbell*]. For analysis see JONATHAN HERRING, *MEDICAL LAW AND ETHICS* 231–32 (Oxford U. Press, 7th ed. 2018) (discussing *Campbell* in the context of concerns regarding a reasonable expectation in the clinician keeping the patient’s test results in confidence). Similarly, in the U.S., the RESTATEMENT (SECOND) OF TORTS 652D (1977) describes it as disclosure of a matter which “would be highly offensive to a reasonable person.”

46. LAWRENCE O. GOSTIN, *PUBLIC HEALTH LAW: POWER, DUTY AND RESTRAINT* 128–29 (U. Cal. Press, 2001); see also Roy Gilbar, *Medical Confidentiality and Communication With the Patient’s Relatives: Legal and Practical Perspectives*, 24(2) *CHILD FAM. L. Q.* 199, 201 (2012) [hereinafter Gilbar III] (“[T]hus, being selective in communicating personal information to others and having the discretion to set different levels of disclosure to different people is an important aspect of an intimate relationship”). This view was acknowledged in *Campbell*, *supra* note 45, at para. 13.

47. See HERRING, *supra* note 45, at 230 (stating that this may be relevant when the patient is treated privately).

an increased risk of developing genetic disease does not amount to disclosure of confidential information. If the source of information is not disclosed to the relatives, then the familial information communicated does not reveal personal details about the particular patient, particularly if the information is based on familial common knowledge.<sup>48</sup> Similarly, it does not reveal anything that exposes the vulnerability of the patient simply because the identity of the patient is not revealed. Furthermore, in these circumstances, when clinicians communicate familial genetic information to relatives there can be no expectation to keep this piece of information in confidence because it is based on family history known to many relatives in the family.<sup>49</sup> For example, if several female relatives are known to have been diagnosed with breast cancer in the past, informing all family members that they may have an increased risk of developing heritable breast cancer is not a breach of confidentiality because this knowledge was not kept in confidence by the female relatives who have already been diagnosed with the disease.<sup>50</sup> The information is already in the family's public domain and therefore raising the awareness of other family members to the increased risk of developing heritable breast cancer is not considered disclosure of confidential information.<sup>51</sup>

Examining the definition of confidential information, the British Medical Association, for example, states that identifiable patient information, "whether written, computerized, visual or audio recorded, or simply held in the memory of health professionals is subject to the duty of confidentiality."<sup>52</sup> This includes clinical information about a patient's diagnosis or treatment and the details of the clinician and the clinics attended by the patient.<sup>53</sup> Legally, the English Data Protection Act 1998 defines personal data as that "relating to a living individual who can be identified by those data," or by those data together with other information held by the data controller (e.g., a clinician).<sup>54</sup> The Act considers

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48. This may occur when relatives are aware that several female family members were diagnosed with breast cancer.

49. See generally Gilbar III, *supra* note 46, at 202 (discussing the intimacy of family relations, the implications that this has for privacy within those relationships, and whether or not one can opt to ignore those privacy regimes at will).

50. This indeed requires the clinician to collect information about the patient's wider family, and their medical history. For example, if the patient has only one relative, then informing him/her would immediately reveal the patient's identity. However, when a patient has many first-degree and second-degree relatives, informing them that there is a familial risk of developing breast cancer does not reveal the specific patient's identity. Nevertheless, one can argue that a clinician might not be able to determine in advance whether disclosure to relatives will have an adverse impact or even an ambivalent, non-helpful effect. This is because clinician who does not know the relatives personally cannot know whether they would wish to be informed. In addition, the clinician may struggle to assess the impact such a disclosure would have on the relationships within the family. Nevertheless, we argue here that if the societal aim is to decrease genetic risks in families, then raising relatives' awareness without revealing the patient's identity is justifiable.

51. However, arguably, the knowledge that medical genetic information from genetic tests may be communicated to their relatives without their consent could potentially have dangerous consequences. Patients might refuse helpful, even life-enhancing genetic testing. We wish to thank the reviewer for making this insightful comment.

52. *Confidentiality*, BRIT. MED. ASS., <https://www.bma.org.uk/advice/employment/ethics/medical-students-ethics-toolkit/9-confidentiality> (last visited Feb. 23, 2019).

53. *Id.*

54. *The Data Protection Act 1998*, PARADIGM, <http://www.paradigm.ac.uk/workbook/legal-issues/dpa.html> (last visited Feb. 23, 2019).

health records as “sensitive personal data” that can be disclosed only if certain conditions are met (such as patient consent).<sup>55</sup> The European General Data Protection Regulation defines personal data as “any information relating to an identified or identifiable person,” and perceives genetic information as sensitive personal data.<sup>56</sup>

From our perspective, these statements do not explicitly reject the contention made above. Lucassen and Gilbar explain that since 99.9% of the DNA sequence is common to all individuals, medical genetic information cannot be considered “sensitive”.<sup>57</sup> It is the (0.1%) difference in the genome that leads to potential sensitivity.<sup>58</sup> In the context of disclosure to relatives, biological family members share an even greater proportion of their DNA, so a particular BRCA1 mutation, for example, may not identify an individual but rather a group of related individuals who have a family history of breast cancer.<sup>59</sup> Therefore, arguably, alerting relatives that they are exposed to an increased risk of developing heritable breast cancer without the patient’s consent or knowledge does not breach confidentiality because no identifiable information is communicated in such a statement, even if genetic findings in one family member led to that conclusion.

The discussion about the definition of confidential information in a clinical setting brings to the fore the bioethical justifications for the existence of confidentiality as a rule that influences the clinician-patient relationship.<sup>60</sup> There are at least two main justifications here. First, confidentiality reflects one aspect of the principle of patient autonomy.<sup>61</sup> According to this justification, the patient controls the flow of information to others and this maintains his/her right to make independent decisions about information related to his/her health.<sup>62</sup> Invoking a utilitarian justification, a confidential environment may encourage a patient to reveal all the relevant information needed for the clinician to provide accurate diagnosis and treatment. As a corollary, if a patient knows that the information communicated in the consultation room is not fully confidential,

55. *Id.*

56. Dr. Detlev Gabel, *Chapter 5: Key Definitions—Unlocking the EU General Data Protection Regulation*, WHITE & CASE (Sept. 13, 2017), <https://www.whitecase.com/publications/article/chapter-5-key-definitions-unlocking-eu-general-data-protection-regulation>; *What is Personal Data?*, EUR. COMM’N, [https://ec.europa.eu/info/law/law-topic/data-protection/reform/what-personal-data\\_en](https://ec.europa.eu/info/law/law-topic/data-protection/reform/what-personal-data_en) (last visited Feb. 23, 2019). These regulations came into force in May 2018.

57. Lucassen & Gilbar I, *supra* note 1, at 2.

58. *Id.*; see *Frequently Asked Questions About Genetic and Genomic Science*, NAT’L HUM. GENOME RES. INST., <https://www.genome.gov/19016904/faq-about-genetic-and-genomic-science> (last visited Feb. 23, 2019) (“All human beings are 99.9 percent identical in their genetic makeup. Differences in the remaining 0.1 percent hold important clues about the causes of diseases.”).

59. See *BRCA Mutations: Cancer Risk and Genetic Testing*, NAT’L CANCER INST., <https://www.cancer.gov/about-cancer/causes-prevention/genetics/brca-fact-sheet> (last visited Feb. 23, 2019) (“[A] positive test result cannot tell whether or when an individual will actually develop cancer . . . [but a] positive test result may also have important implications for family members.”).

60. See Jessica Wilen Berg, *Patient Confidentiality: Privacy and Public Health*, THE DOCTOR WILL SEE YOU NOW (Aug. 17, 2011), <http://www.thedoctorwillseeounow.com/content/bioethics/art3401.html> (“Ethical theories provide many different ways to view confidentiality laws.”).

61. See Jukka Varelius, *The Value of Autonomy in Medical Ethics*, 9 J. MED. HEALTH CARE PHILOS. 377, 377 (2016) (“It is plausible that autonomous persons are often in the best position to determine what would be good and bad for them . . .”).

62. See HERRING, *supra* note 45, at 271 (discussing ethical issues).

they might hesitate to reveal important information and thereby compromise their chances of receiving accurate and effective treatment.<sup>63</sup> This, in a wider sense, may engender a breach of trust between patients and clinicians.

However, communicating *familial* genetic information to relatives does not necessarily compromise patient autonomy, nor should it lead to breach of trust between patients and their clinicians. Raising relatives' awareness to an increased genetic risk they share does not affect the patient's right to control the flow of his/her personal medical information to others. Under these circumstances, the patient still retains the authority to decide whether or not s/he shares the news about his/her health status with relatives. Furthermore, as Parker and Lucassen argue, trust between patients and clinicians would not be compromised if the clinicians were to explain to the patient that his/hers anonymity and private sphere are protected when familial genetic information is shared with the relatives.<sup>64</sup> Being open and transparent that familial genetic information may be shared with other relatives will contribute to trust, which is imperative for a positive clinician-patient relationship.<sup>65</sup> The underlying assumption here is that the identity of the first family member to undergo genetic testing cannot be revealed by the clinicians' disclosure of the familial information.<sup>66</sup>

Another important point in this discussion, which relates to the relatives' right to autonomy and privacy, is whether the relatives want to know that they are exposed to an increased genetic risk which may affect their health. In short, in our context, the question is how influential is the interest relatives might have in not receiving the information. Providing a thorough bioethical analysis of the right not to know is beyond the scope of this Article,<sup>67</sup> but it should be noted that some support the contention that there should be no legal obligation for clinicians to inform relatives.<sup>68</sup> According to this view, clinicians should have the discretion to decide whether in a particular situation, they think that disclosure should be preferred to confidentiality or vice versa. We will deal with the issue of a legal duty to inform the relatives below, but at this point we argue that notifying family members of an increased risk of developing a heritable disease does not infringe their right not to know if it is based on already known information. Thus, informing relatives that they have an increased risk of developing heritable breast cancer will not come as a surprise if they already know that several family members have already been diagnosed with the disease. Furthermore, even if they are unaware of the family's medical history, we argue

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63. *Id.* at 270–71.

64. See Lucassen & Parker I, *supra* note 18, at 962 (“[W]e believe that if these protections are made explicit, many patients would want to see genetic information used in the care of family members, and would agree that where real benefits to family members are possible, these ought to be provided.”).

65. Nevertheless, an opposite view does exist. *Id.*

66. However, this assumption may be refuted in practice, for example, when the patient has only one relative. In this situation, if the relative is informed she/he will easily identify who the source of the information is.

67. See RUTH CHADWICK, MAIRI LEVITT & DARREN SHICKLE (Eds.), *THE RIGHT TO KNOW AND THE RIGHT TO NOT KNOW: GENETIC PRIVACY AND RESPONSIBILITY* (Cambridge U. Press 2nd ed., 2014) (providing further detail).

68. See LAURIE, *supra* note 19, at 267–72 (advocating for a greater role for privacy).

that it is one thing to inform an individual that her mother was diagnosed with heritable breast cancer and therefore she (the daughter) has X percent chance of developing the disease herself, and another thing to tell the daughter that she, like other first and second degree relatives, is exposed to a familial genetic risk of developing breast cancer. Our view is that the former contains personal genetic information and the latter provides familial genetic information. The second statement is thus less intrusive than the first in terms of the expected harm such a disclosure could inflict.<sup>69</sup>

Summing up the bioethical discussion, the relational approach challenges the patient-centered approach by emphasizing that the balance between confidentiality and disclosure should not always (or in most cases) be weighted towards the protection of patient confidentiality. As Dove and his colleagues wrote, the relational approach encourages clinicians “to see their patients as embedded in a network of others, to critically reflect, together with their patients, on the needs and interests of these others, and to prominently consider values such as reciprocity and interdependence.”<sup>70</sup> Thus, clinicians should provide equal weight to considerations which support patient’s confidentiality and those that support disclosure to relatives. In making a distinction between personal and familial genetic information, the relational approach considers the autonomy of both patient and relatives in the social context within which they live. Whether this is the approach clinicians and patients adopt in clinical genetics is discussed next.

### III. LITERATURE REVIEW

Empirical studies in clinical genetics to date have examined clinicians’ attitude regarding genetic information, the duty of confidentiality, and disclosure to relatives.<sup>71</sup> Studies have also examined the rate of patients’ non-disclosure to relatives and the means that clinicians use to raise relatives’ awareness of their increased risk.<sup>72</sup> Still other studies have investigated the views and conduct of clinicians regarding professional ethical guidelines.<sup>73</sup> This Section will review the existing research on these topics.

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69. However, this view might not be agreed by all. See, e.g., *Cambell*, *supra* note 45 (discussing cases where disclosure of personal genetic information to relatives was viewed to be “offensive to a reasonable person”).

70. Edward Dove et al., *Beyond Individualism: Is There a Place for Relational Autonomy in Clinical Practice and Research?*, 12(3) *CLINICAL ETHICS* 150, 157 (2017).

71. *Id.*; see Sandra Petronio, *Navigating Ethics of Physician-Patient Confidentiality: A Communication Privacy Management Analysis*, 16(4) *PERMANENTE J.* 41, 41 (2012), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3523934> (“This model depends on the communication privacy management (CPM) perspective that emerged from a 35-year research program investigating how people regulate and control information they consider private and confidential.”).

72. Roy Gilbar & Sivia Barnoy, *Disclosure of Genetic Information to Relatives in Israel: Between Privacy and Familial Responsibility*, 31(4) *NEW GENETICS SOC’Y.* 391 (2012); Mary S. McCabe, *When the Family Requests Withholding the Diagnosis: Who Owns the Truth*, 6(2) *J. ONCOLOGY PRAC.* 94 (2010).

73. See Dheensa I, *supra* note 2, at 290 (“Our systematic review and synthesis of 17 studies explored the attitudes of HCPs, patients, and the public regarding the extent of HCPs’ responsibility to relatives with respect to disclosure.”).

Studies indicate that clinicians perceive genetic information as both personal and familial.<sup>74</sup> Nevertheless, in the clinic, most clinicians relate to genetic information as private and confidential.<sup>75</sup> At the same time, they feel responsible for the relatives, and make efforts to convey relevant genetic information to affected relatives through the patient.<sup>76</sup> This behavior reflects the clinicians' view that the main responsibility for informing the relatives lies with the patient. While most patients declare their intention to inform their relatives, there is evidence that explicit refusal to disclose does occur. A study among patients tested for hereditary cancer that examined the intention to disclose genetic test results to relatives reported a 3% rate of nondisclosure.<sup>77</sup> Another French study reported that 8.6% of women visiting genetic cancer clinics for the first time did not intend to disclose test results.<sup>78</sup> A study, conducted in Israel among healthy Ashkenazi Jews, reported a rate of 88% of actual disclosure of BRCA1/2 test results to family members.<sup>79</sup> The conclusion of this study was that improving the testing experience might encourage disclosure.<sup>80</sup>

While clinicians claim that explicit refusal to inform the relatives is rare, most have encountered cases of non-disclosure.<sup>81</sup> In addition to explicit non-disclosure, where patients declare openly that they will not share the information with their relatives,<sup>82</sup> there is a more common phenomenon of passive non-disclosure, where patients agree to inform their relatives but refrain from doing so once they have left the clinicians' office.<sup>83</sup> It is difficult to measure the rate of passive non-disclosure, but it is possible to infer from existing studies that it is quite common. For example, one study found that only 36% of patients' relatives approached genetic clinics to test for hereditary breast and colon cancer.<sup>84</sup> Another study found that 23% of patients' relatives received genetic

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74. Sandi Dheensa et al., *Approaching Confidentiality at a Familial Level in Genomic Medicine: a Focus Group Study with Healthcare Professionals*, 7(2) BRIT. MED. J. e012443 (2017) [hereinafter Dheensa III]; David J. Doukas, *Genetics Providers and the Family Covenant: Connecting Individuals with their Families*, 7(4) GENETIC TESTING 315 (2003).

75. See Dheensa I, *supra* note 2, at 294 (discussing the clinical practice norms).

76. See *id.* at 290 (noting the implications of genetic test results on family members of the patients); Beth R. Dugan et al., *Duty to Warn At-Risk Relatives for Genetic Disease: Genetic Counselors' Clinical Experience*, 18 AM. J. MED. GENETICS PART C. SEMINARS GENOMICS 27 (2016) (providing statistics on genetic counselors reporting to patients' relatives).

77. Gilbar & Barnoy, *supra* note 72.

78. Claire Julian-Reynier et al., *Disclosure to the Family of Breast/Ovarian Cancer Genetic Test Results: Patient's Willingness and Associated Factors*, 94 AM. J. MED. GENETICS 13, 16 (2000).

79. Sari Lieberman et al., *Familial Communication and Cascade Testing Among Relatives of BRCA Population Screening Participants*, 20 AM. COLL. MED. GENETICS GENOMICS 1446, 1452 (2018).

80. *Id.* at 1446.

81. Angus Clarke et al., *Genetic Professionals' Reports of Nondisclosure of Genetic Risk Information within Families*, 13 EUR. J. HUM. GENETICS 556, 557 (2005).

82. See Dheensa I, *supra* note 2, at 296 (noting the frequency of patients who feel no obligation to disclose).

83. See Clara Gaff & Jan Hodgson, *A Genetic Counseling Intervention to Facilitate Family Communication about Inherited Conditions*, 23 J. GENETICS COUNS. 814 (2014) (discussing a counseling procedure to overcome this issue).

84. Laura E. Forrest et al., *Increased Genetic Counseling Support Improves Communication of Genetic Information in Families*, 10 GENETICS. MED. 167, 169 (2008) [hereinafter Forrest].

counseling for hereditary cancers.<sup>85</sup> Although it is possible to argue that some of the informed relatives chose not to seek genetic counseling and undergo genetic testing, there are indications that the rate of applications to genetic clinics for testing and counseling increases if clinicians take active steps to directly inform the relatives (and do not rely solely on patient-relayed information).<sup>86</sup> Studies examining the source of patients' refusal to share genetic information with their relatives indicate that the reasons include having poor or no relationships with relatives, protecting relatives from bad news, the relative's right not to know, and patients' feelings of guilt and blame.<sup>87</sup>

Similar studies examining the reasons for clinicians' reluctance to inform relatives indicate their reluctance to interfere in familial relationships,<sup>88</sup> and damage patients' trust in the healthcare system.<sup>89</sup> However, at the same time, clinicians feel morally responsible for the relatives' health,<sup>90</sup> so they seek ways to facilitate disclosure, possibly, by emphasizing the familial aspect of genetic information.<sup>91</sup> A suggestion by the U.K. Joint Committee on Genomics in Medicine (JCGM) recommends asking patients to sign an informed consent form that includes the following statement: "I acknowledge that my results may sometimes be used to inform the appropriate healthcare of members of my family."<sup>92</sup> Interestingly, a recent study reported that most genetic clinics in the U.K. did not adopt this recommendation.<sup>93</sup>

Additional studies indicate that rates of disclosure to relatives can be increased if clinicians take active steps by providing patients with family letters to give to relatives.<sup>94</sup> These letters highlight the genetic risk to which the relatives are exposed and offer them to seek genetic counseling.<sup>95</sup> A similar method involves sending family letters directly from the clinician to the relatives subject to the patient's consent.<sup>96</sup> Studies show that this method is even more

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85. Graeme K. Suthers et al., *Letting the Family Know: Balancing Ethics and Effectiveness when Notifying Relatives about Genetic Testing for a Familial Disorder*, 43 J. MED. GENETICS 665, 665 (2005) [hereinafter Suthers].

86. For example, in Forrest's study, *supra* note 84, at 171, the rate of relatives who approached genetic clinics rose from 36% to 61% and in Suthers' study, *supra* note 85, at 665, the rate of relatives' attendance in genetic clinics rose from 23% to 40%. These findings suggest that patients passively refrain from informing relatives.

87. Michael Arribas-Ayllon et al., *The Practical Ethics of Genetic Responsibility: Non-Disclosure and the Autonomy of Affect*, 9 SOC. THEORY HEALTH 3 (2011); see Dheensa I, *supra* note 2, at 290 (noting the results of research studying disclosure of genetic testing results).

88. Dheensa III, *supra* note 74, at 5.

89. *Id.* at 6.

90. See Dheensa I, *supra* note 2, at 296 (describing how multiple studies suggest HCPs feel morally responsible to relatives).

91. See Dheensa III, *supra* note 74, at 4 (showing ways that clinicians seek to facilitate disclosure of genetic health to information to patient's family members).

92. THE ROYAL COLLEGE OF PHYSICIANS, CONSENT AND CONFIDENTIALITY IN CLINICAL GENETIC PRACTICE: GUIDANCE ON GENETIC TESTING AND SHARING GENETIC INFORMATION 36 (Royal College of Physicians, 2d ed. 2011) [hereinafter ROYAL C.], <https://www.rcpath.org/resourceLibrary/consent-and-confidentiality-in-genetic-practice.html>.

93. Sandi Dheensa et al., *How do Clinical Genetics Consent Forms Address the Familial Approach to Confidentiality and Incidental Findings? A Mixed-Methods Study*, 17 FAMILIAL CANCER 155 (2018).

94. See Dheensa I, *supra* note 2, at 291 (explaining that when HCPs take active steps to ensure that information has been communicated, disclosure increases).

95. *Id.*

96. *Id.*

successful in increasing the number of relatives who approach genetic clinics and seek genetic counseling.<sup>97</sup> One of the reasons for the difference between giving the letter to patients to disseminate to relatives and sending relatives the letter directly from the clinic is that some patients find it emotionally difficult to send the letter to their relatives.<sup>98</sup>

In conclusion, this review demonstrates that one aspect that has so far not received sufficient attention is how the legal framework, within which the clinicians operate, affects their views and the way they conduct their practice. Another important aspect that deserves examination is what clinicians think about the existing legal position and whether they think it is helpful. However, before addressing these aspects it is necessary to provide a legal background. The descriptions of the legal position in the U.K. and the U.S. are followed by a discussion of the legal position in Israel where the empirical study was conducted.

#### IV. LEGAL BACKGROUND

##### A. *The Position in the U.K. and the U.S.*

Generally, Anglo-American law imposes a duty of confidentiality on clinicians as a rule and allows disclosure of medical information without the patient's consent as an exception in order to avoid serious harm to the relatives.<sup>99</sup> However, there are some differences between American and English law.

In the U.K., disclosure of genetic test results to relatives is not governed by the legislator.<sup>100</sup> Rather, English law imposes a general duty of confidentiality on clinicians regarding all type of medical information.<sup>101</sup> Disclosure of genetic information to relatives is addressed specifically by professional ethical guidelines that provide clinicians the discretion to decide, according to the circumstances of a particular case, whether the benefit of disclosure to relatives outweighs a patient's right to confidentiality.<sup>102</sup> So far, courts in the U.K. have not created an *explicit* legal rule regarding clinicians' responsibility in clinical genetics.<sup>103</sup> In response to a claim filed by the daughter of a patient diagnosed with Huntington's disease, against her father's physicians for not informing her, the Court of Appeal recently ruled that clinicians may in principle owe a duty to

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97. See Suthers, *supra* note 85, at 665 (noting results of a study); Gareth D. Evans et al., *Comparison of Proactive and Usual Approaches to Offering Predictive Testing for BRCA1/2 Mutations in Unaffected Relatives*, 75 CLINICAL GENETICS 124 (2009) (noting results of a testing study).

98. See Dheensa II, *supra* note 6, at 695–96 (noting the emotional distress involved).

99. Rebecca Branum & Susan M. Wolf, *International Policies on Sharing Genomic Research Results with Relatives: Approaches to Balancing Privacy with Access*, 43 J. L. MED. & ETHICS 576, 580–82 (2015).

100. See GENERAL MEDICAL COUNCIL, CONFIDENTIALITY: GOOD PRACTICE IN HANDLING PATIENT INFORMATION 73–76 (Gen. Med. Council 2017) (noting English law professional guidelines).

101. GRAEME T. LAURIE, SHAWN HARMON AND GERARD PORTER, MASON & MCCALL SMITH'S LAW & MEDICAL ETHICS 179 (10th ed. 2016).

102. GENERAL MEDICAL COUNCIL, *supra* note 100, at ¶¶ 73–76.

103. Roy Gilbar & Charles Foster, *It's Arrived! Relational Autonomy Comes to Court*, 26 MED. L. REV. 125 (2018) [hereinafter Gilbar & Foster].

directly warn a patient's relatives of an increased familial risk.<sup>104</sup> In *ABC v. St. George's Healthcare NHS Trust*, the claimant argued that had she known of her father's diagnosis when she was pregnant, she would have undergone testing, and had she found out she was a carrier of Huntington's, she would have terminated the pregnancy.<sup>105</sup> The Court of Appeal rejected the clinicians' request to strike out the claim, holding that the case can go to a full trial, where questions of breach of duty and causation can be discussed.<sup>106</sup> The Court of Appeal's decision was supported by scholars who adopted a relational approach because the judges acknowledged, *inter alia*, the familial aspects of genetics and the relatives' right to autonomy.<sup>107</sup>

A similar clinicians' duty of confidentiality exists in American law, and disclosure of genetic information to relatives is subject to a patient's consent.<sup>108</sup> Disclosure without consent to relatives is allowed as an exception.<sup>109</sup> There are states whose legislation addresses disclosure of genetic information to relatives.<sup>110</sup> In addition, there were two court decisions, one delivered in Florida<sup>111</sup> and one in New Jersey<sup>112</sup> which directly addressed this issue. While there was agreement in both courts that clinical geneticists owe a duty of care to the relatives, there was no agreement regarding how the clinicians should fulfill this duty. Whereas the Florida court held that clinicians merely need to inform the patient about the implications of his/her genetic condition for the relatives,<sup>113</sup> the New Jersey court held that there might be circumstances where clinicians would owe a direct duty to the relatives.<sup>114</sup> A third decision, which essentially relates to wrongful conception type of cases, was given by the Minnesota Supreme Court.<sup>115</sup> The court held that clinicians may owe a duty to a third-party who is not their patient, stating that in the case in question, the claim could be based on the physicians' failure to warn the patient's mother of her risk of giving birth to another child with fragile X syndrome.<sup>116</sup>

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104. *ABC v. St. George's Healthcare NHS Trust* [2017] EWCA Civ 336, [2015] EWHC 1394 (QB) (Eng.) [hereinafter *ABC*].

105. *Id.*

106. *Id.*

107. See Gilbar & Foster, *supra* note 103 (discussing 'need access'); Colin Mitchel et al., *Exploring the Potential Duty of Care in Clinical Genomics Under UK Law*, 17 *MED. LAW INT'L* 158, 176 (2017) (discussing the Court of Appeal decision). Others oppose the court's position; see Dove, *supra* note 1 (discussing why *ABC* may have been wrongly decided).

108. See Branum & Wolf, *supra* note 99, at 578 (discussing the need for consent); Mark Rothstein, *Reconsidering the Duty to Warn Genetically At-Risk Relatives*, 20 *GENETICS MED.* 285 (2018) [hereinafter Rothstein] (discussing duties in American law).

109. Susan M. Wolf et al., *Returning a Research Participant's Genomic Results to Relatives: Analysis and Recommendations*, 43 *J. LAW MED. ETHICS* 440, 453 (2015).

110. NAT'L CONFERENCE OF STATE LEGISLATORS, *GENETIC EMPLOYMENT LAWS* (2008), <http://www.ncsl.org/research/health/genetic-privacy-laws.aspx>. New Jersey is such a state. See Rothstein, *supra* note 108, at 286 (discussing New Jersey law).

111. *Pate v. Threlkel*, 661 So. 2d 278 (Fla. 1995).

112. *Safer v. Estate of Pack*, 677 A.2d 1188 (N.J. Super. Ct. App. Div. 1996).

113. *Pate*, 661 So. 2d at 282.

114. *Safer*, 677 A.2d at 1193.

115. *Molloy v. Meier*, 679 N.W.2d 711 (Minn. 2004).

116. *Id.* at 720.

On a federal level, disclosure of genetic information is addressed by the Privacy Act,<sup>117</sup> and regulations issued by the federal Office of Civil Rights under the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule.<sup>118</sup> The Privacy Act addresses disclosure of personal information held by federal agencies, including the Department of Health and Human Services. According to the Act, federal agencies cannot disclose medical information without the patient's consent unless it is made "pursuant to a showing of compelling circumstances affecting the health or safety of an individual."<sup>119</sup> The Privacy Act applies to medical test results that present "compelling circumstances affecting the health or safety of an individual."<sup>120</sup> Although it is possible to argue that a clinician's duty to warn should be owed to relatives when medical information is clinically actionable, the guidelines of the Department of Justice indicate that "compelling circumstances" refer to emergency situations.<sup>121</sup> Thus, it is not clear whether disclosure of genetic information to relatives would constitute an emergency, which justifies disclosure without consent.

The HIPAA Privacy Rule protects the privacy of health information, which includes genetic information.<sup>122</sup> The regulations allow clinicians to disclose protected health information to their colleagues for the purposes of diagnosis and treatment of another patient, who can be the patient's relatives.<sup>123</sup> The Department of Health and Human Services' Office of Civil Rights issued its interpretation to the Privacy Rule. This states that "health care providers may share genetic information about an individual with providers treating family members of the individual who are seeking to identify their own genetic risks, provided that the individual has not agreed to restriction on such disclosure."<sup>124</sup> According to this interpretation, patients may ask their clinicians not to reveal their medical information, but the latter do not have to respect such a request.<sup>125</sup> As Rothstein concludes, these guidelines would apply either when the patient was not informed of an intended disclosure to relatives, or when the patient asked that his/her medical information would not be disclosed to others, but the

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117. 5 U.S.C. § 552a(b)(8) (2018); U.S. DEP'T OF JUSTICE, OVERVIEW OF THE PRIVACY ACT OF 1974 (2015) [hereinafter DEPT. OF JUSTICE], <http://www.justice.gov/opcl/introduction>.

118. 45 C.F.R. § 160 (2018); 45 C.F.R. § 164 (2018); *Summary of the HIPAA Privacy Rule*, OFF. FOR CIVIL RIGHTS, U.S. DEP'T HEALTH HUM. SERV. (2013) [hereinafter *HIPAA Privacy Rule*], <https://www.hhs.gov/sites/default/files/privacysummary.pdf>.

119. 5 U.S.C. § 552a(b)(8) (2018).

120. *Id.*

121. U.S. DEP'T OF JUSTICE, OVERVIEW OF THE PRIVACY ACT – CONDITIONS OF DISCLOSURE TO THIRD PARTIES (2015), <http://www.justice.gov/opcl/conditions-disclosure-third-parties#health>.

122. 45 C.F.R. § 164.501 (1)–(2) (2018).

123. 45 C.F.R. § 164.502(a)(1)(ii) (2018); *FAQ: Under the HIPAA Privacy Rule, May a Health Care Provider Disclose Protected Health Information About an Individual to Another Provider, When Such Information Is Requested for the Treatment of a Family Member of the Individual?*, OFFICE OF CIVIL RIGHTS, U.S. DEP'T OF HEALTH AND HUMAN SERV. (Jan. 13, 2009), [http://www.hhs.gov/ocr/privacy/hipaa/faq/disclosures\\_to\\_friends\\_and\\_family/512.html](http://www.hhs.gov/ocr/privacy/hipaa/faq/disclosures_to_friends_and_family/512.html).

124. Department of Health and Human Services, Modifications to the HIPAA Privacy, Security, Enforcement and Breach Notification Rules under the Health Information Technology and Economic and Clinical Health Act and the Genetic Information Nondiscrimination Act; Other modifications to the HIPAA Rules, 78 Fed. Reg. 5566–5702, 5668 (Jan. 25, 2013) (codified at 45 C.F.R. Pts. 160, 164).

125. *Id.*

clinician did not respect his/her request. It should be noted that, according to this interpretation, clinicians are under no duty to inform the relatives and if they do decide to inform them, they can provide the information to their colleagues and not address the relatives directly.<sup>126</sup>

Guidelines set by American professional organizations are more restrictive. In its 1998 guidelines, the American Society of Human Genetics (ASHG) stated that “disclosure [without the patient’s consent] should be permissible where attempts to encourage disclosure on the part of the patient have failed; where the harm is highly likely to occur and is serious and foreseeable; where [the] at risk relative(s) is identifiable; and where either the disease is preventable/treatable or medically accepted standards indicate that early monitoring will reduce the genetic risk.”<sup>127</sup> The guidelines add that “the harm that may result from failure to disclose should outweigh the harm that may result from disclosure.”<sup>128</sup>

These guidelines look stricter than those issued by professional bodies in the U.K.<sup>129</sup> The U.K.’s Joint Committee states that “it may be sufficient to acknowledge that a familial mutation exists and provide its details without naming the person in whom it was found. If such a statement inevitably points to one particular person, then the harms and benefits of proceeding without further consent need to be carefully assessed.”<sup>130</sup> This statement reflects a relational approach, and it acknowledges the distinction made in Part II between personal and familial genetic information. This statement supports our view that disclosure of familial genetic information should be allowed as it is not considered a breach of patient confidentiality.

A relational approach is evidenced in the response of the Joint Committee to clinicians serving a patient who denies disclosure to relatives.<sup>131</sup> The Joint Committee stresses that it is important to weigh up the harms of breaching confidentiality with the potential benefits to relatives of so doing, but it reminds clinicians that the rule of confidentiality is not absolute.<sup>132</sup> In special circumstances, it may be justified to breach confidentiality in order to avoid serious harm. The Joint Committee’s guidelines add that before breaching the confidentiality of a patient who explicitly refuses disclosure to relatives, the clinicians should “(a) attempt to obtain consent to disclosure from the patient in question, (b) have discussed the case with experienced professional colleagues, (c) tell the patient that they intend to breach this confidence and why, (d) keep any disclosure to that which is strictly necessary for the communication of risk, and (e) document discussions with the reasons for disclosure without consent.”<sup>133</sup>

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126. See DEPT. OF JUSTICE, *supra* note 117 (providing a background of the Privacy Act of 1974).

127. American Society of Human Genetics, *Professional Disclosure of Familial Genetic Information*, 62 AM. J. HUM. GENETICS 474, 474 (1998).

128. *Id.*

129. See ROYAL C., *supra* note 92, at 21–22 (describing five steps that the practitioner should consider before releasing information without consent).

130. *Id.* at 21.

131. See *id.* at 21–22 (suggesting how to weigh harms and benefits to the patient and public when the patient denies disclosure).

132. *Id.* at 21.

133. *Id.*

Although one can argue that overall, professional bodies in the U.S. and the U.K. speak in one voice when adopting a utilitarian cost-benefit mechanism, it is clear when reading the guidelines carefully that the U.K. guidelines provide the clinicians more opportunity for disclosure to relatives than the U.S. guidelines, or at least provide more discretion to clinicians to alert relatives to their genetic risks. This, for example, is evident in the U.K. guidelines which allow disclosure of familial genetic information, an option the American guidelines do not mention.

This short review suggests that the Anglo-American legal framework places confidentiality as the rule in genetics, and disclosure with the patient's knowledge or consent as an exception. The law does not impose a legal duty on clinicians to directly inform the relatives but neither, in principle, does it bar relatives from suing the patient's clinicians for non-disclosure. In addition, the law addresses the rather rare phenomenon of explicit non-disclosure but does not deal with the more common phenomenon of passive non-disclosure where the patient refrains from informing the relatives after leaving the clinician's office. Such a legal regime may create difficulties for clinicians, who possess information that has health implications for the relatives. Very few studies have addressed this issue empirically; thus, it is important to examine how clinicians working in clinical genetics deal with the legal framework. To this end, we conducted an empirical examination in several medical centers in Israel, where specific legislation and several court decisions regulate the communication of genetic test results to relatives.

#### B. *The Legal Position in Israel*

There are no professional guidelines dealing specifically with the disclosure of genetic information to relatives in Israel, although the *Genetic Information Act 2000* and the courts address this issue.<sup>134</sup>

The declared aim of the Act is to regulate genetic counseling and protect the patient's right to privacy with respect to identifiable genetic information without compromising the promotion of public health.<sup>135</sup> The Act imposes a duty on clinicians to inform patients about the implications of undergoing genetic testing, both for them and for their relatives.<sup>136</sup> This suggests that the legislator sees the patient as the main source of information for the relatives. If the genetic test results indicate that the patient is a carrier, the legislator expects them to inform their genetically at-risk relatives. The Act also imposes a duty of confidentiality on clinicians.<sup>137</sup> Disclosure to relatives is subject to patient consent and disclosure to relatives without consent is an exception and must fulfill the following criteria.<sup>138</sup> Clinicians can communicate genetic information to the relatives' clinician (and not directly to the relatives) unless the patient

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134. Genetic Information Law, 5761-2000, § 1 (Isr.) [hereinafter Israel Genetic Information Act].

135. *Id.* § 1.

136. *Id.* § 12.

137. *Id.* § 18.

138. *Id.* § 20.

objects.<sup>139</sup> However, despite this objection, the patient's clinician can inform the relatives' clinician if after hearing the patient, an ethics committee<sup>140</sup> is convinced of the following: (1) communicating the information is necessary to protect the relatives' health, improve their health, or prevent death, disease, or serious disability;<sup>141</sup> (2) disclosure is the only way to achieve these goals; (3) the benefit to the relatives from communicating the information to their treating clinician supersedes the harm caused to the patient, or the patient's reasons for refusing disclosure are unreasonable.<sup>142</sup> In addition, efforts should be made to protect the patient's anonymity in this process.<sup>143</sup>

Overall, like the American and English legal positions, the Israeli Act highlights the individualistic aspects of autonomy and confidentiality and does not adopt a relational approach.<sup>144</sup> The protection of patients' privacy is set as its main goal and the individual patient is given the authority to decide whether or not to inform their relatives.<sup>145</sup> The Act adopts a utilitarian mechanism only if the patient refuses disclosure.<sup>146</sup> Only then can the clinician start a process of disclosure without consent, which can be approved if the benefit is considered to outweigh the harm to the patient.<sup>147</sup> Genetic information is perceived by the Act primarily as personal and private without reference to the existence of mutual moral duties between family members.<sup>148</sup> It does not oblige the patient to inform relatives and does not give the relatives an independent access to the patient's genetic test results.<sup>149</sup> Moreover, although the provision of an ethics committee with the authority to resolve cases of explicit non-disclosure reflects a communitarian perspective (where members of the community have the authority to resolve a conflict), the Act does not highlight solidarity, mutual commitment, or ethics of care, which form the pillars of familial relationships. By restricting the communication of information to clinicians (patient's clinician to relatives' clinician), the Act allows the patient to remain passive.<sup>150</sup> However, by insisting that clinicians do not reveal the patient's identity when communicating genetic information to the relatives' clinicians, the Act

139. *Id.*

140. Ethics committees are established by the Israeli Patient Rights Act 1996. The Patient Rights Act, 5756-1996, SH No. 327 (Isr.) [hereinafter Israeli Patient Rights Act]. They include a senior lawyer who acts as the committee's chair, 2 doctors, a nurse, a social worker/psychologist and a clergy man. The purpose is to resolve disagreements through a process of deliberation without reaching the courts.

141. Disclosure can also be approved by the ethics committee to prevent harm to the fetus (i.e., the patient's prospective relative). In practice, it allows disclosure to a pregnant relative.

142. Israel Genetic Information Act, *supra* note 134, § 20.

143. *Id.* § 21.

144. *See id.* §§ 18–22 (specifying the circumstances where genetic information may be disclosed and requirements for waiver of confidentiality).

145. *See id.* § 1 (“The purpose of this Law is . . . to protect the right to privacy of the person . . . in respect of identified genetic information.”).

146. *See id.* § 20 (showing how to weigh out benefits and harms to the public and the patient when the patient denies to disclose).

147. *See id.* § 20 (“Notwithstanding the objection of the subject, the information may be transmitted . . . if the Ethics Committee . . . is convinced . . .”).

148. *See id.* § 20 (failing to mention mutual moral duties between family members as a factor in the process of the patient's genetic information disclosure).

149. *See id.* § 20 (stating that the patient can independently choose not to disclose to relatives).

150. *See Gilbar II, supra* note 27, at 83 (describing how allowing the patient to control disclosure of their genetic information gives the patient the ability to remain passive).

implicitly recognizes the distinction between personal and familial genetic information.<sup>151</sup>

Aside from the Act, Israeli magistrate and district courts have addressed the issue of disclosure to relatives in four cases.<sup>152</sup> The cases did not reach the Israeli Supreme Court, so the decisions given by these courts do not set a legal precedent.<sup>153</sup> Nevertheless, they send a clear message regarding the tension between confidentiality and disclosure to relatives in genetics.<sup>154</sup> The courts delivered their decisions at a preliminary stage where the clinicians asked the court to strike out the relatives' claim before trial, arguing that they do not owe a duty to inform the relatives because they owe a duty of confidentiality to the patient.<sup>155</sup> Imposing a legal duty to inform the relatives, the clinicians argued, would be considered a breach of their duty of confidentiality to their patients.<sup>156</sup> The Court dismissed this argument, holding that, in principle, clinicians in genetics owe a duty of care to the relatives, since the patient's genetic test results may have implications for the relatives' health.<sup>157</sup> The courts relied on clinical practice in genetic counseling where clinicians discuss the implications of the test results for the relatives with patients before and after testing, and ask their patients to share any information with their relatives.<sup>158</sup> However, the courts also held that the clinicians' duty can be fulfilled by requesting the patient to inform relatives.<sup>159</sup> One court explicitly held that clinicians have no duty to contact the relatives directly to warn them, highlighting the practical difficulties involved.<sup>160</sup> In short, the courts explicitly held that the responsibility to inform the relatives lies with the individual patient and not with the clinician.<sup>161</sup> In this context, the position of the Israeli courts is similar to the position of the Florida court in the U.S.<sup>162</sup> They did not adopt the approach that the English Court of Appeal took in *ABC*.<sup>163</sup>

In light of this legal background, the purpose of the present study was to examine how, if at all, the legal position affects the practice of clinicians in genetics and whether it provides them with an adequate tool to deal with the inherent tension between confidentiality and disclosure.

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151. See Israel Genetic Information Act, *supra* note 134, § 20 (highlighting how the Act distinguishes these entities).

152. See generally Roy Gilbar, *Genetic Testing of Children for Familial Cancers: A Comparative Legal Perspective on Consent, Communication of Information and Confidentiality*, SPRINGER SCI. BUS. MEDIA B.V. (2009) (discussing the Israeli district court and magistrate court cases that discuss the issue of disclosure).

153. *Id.*

154. *Id.*

155. *Id.*

156. CA(HI) 11951-08-12 AA v. Prof. Rivka Carmi (2013) (Isr.).

157. *Id.*

158. CA(HI) 35160-12-12 Mishori-Deri v. Alhuashla (2013) (Isr.).

159. *Id.*

160. *Id.*

161. CA(CT) 3512-08-08 Abu Sablan v. Prof. Shohat (2009) (Isr.); see also (CA)(TA) 244-05-12 M v. Ministry of Health, paras 185–86 (2016) (Isr.) (addressing individual patients' responsibility to inform relatives).

162. See *Pate v. Threlkel*, 661 So. 2d 278, 280–81 (Fla. 1995) (discussing the physician's duty to inform).

163. See *ABC*, *supra* note 104 (explaining the difference between the approach of the English Courts and the Israeli Courts).

## V. THE STUDY

### A. *Methods*

To fulfill our aim, we conducted a qualitative-based study comprising semi-structured, face-to-face interviews with clinicians who work in the area of inherited breast cancer. The decision to focus on inherited breast cancer was based on several reasons. First, women who are referred to genetic services usually have a family history of the disease.<sup>164</sup> In such cases, diagnosis and treatment of inherited breast cancer become a familial issue, which raises the topic of dissemination of genetic information within the family.<sup>165</sup> Second, much of the services that genetic clinics provide are in the field of onco-genetics generally and in inherited breast cancer specifically.<sup>166</sup> Third, there are several specialized clinics in Israel where healthy BRCA1/2 carriers have bi-annual check-ups, discuss preventative treatment options with clinicians in various specialties (geneticists, oncologists), and consider the issue of disclosure to relatives.<sup>167</sup> The existence of these specialized clinics in Israel derives from the relatively high rate of heritable breast cancer in the Jewish population.<sup>168</sup>

The study was conducted in six medical centers across Israel that provide diagnostic and treatment services in the area of inherited breast cancer. The inclusion criteria for the study were clinicians who provide services to individuals with a family history of inherited breast cancer.

The study was based on a framework analysis approach, which suits studies that have specific questions, a limited time frame, a pre-designed sample (e.g. clinicians) and *a priori* issues that merit close investigation. This was an appropriate model since the central concern of a framework analysis approach is to describe and interpret the practice of a particular setting,<sup>169</sup> which in this case was how clinicians deal with legal rules regarding confidentiality in genetics and disclosure to relatives. For practical reasons, the study had a limited time frame and the study population comprised a pre-designed sample of clinicians who work in genetics.

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164. See generally Mary-Claire King et al., *Breast and Ovarian Cancer Risks Due to Inherited Mutations in BRCA1 and BRCA2*, 302 AM. ASSOC. FOR ADV. SCI. 643 (2003) (discussing how Israeli women diagnosed with breast and ovarian cancer carry a familial genetic mutation).

165. See Karin Henriksson et al., *The Need for Oncogenetic Counseling: Ten Years' Experience of a Regional Oncogenetic Clinic*, 43 ACTA ONCOLOGICA 637, 640 (2004) ("If additional information on tumor disorders in the family are necessary . . . the proband has to obtain forms for informed consent from relatives . . .").

166. *Genetic Testing for Hereditary Cancer Syndromes*, NAT'L CANCER INST. (Apr. 11, 2013), <https://www.cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet> (mentioning that hereditary breast cancer is one of the most common types of inherited cancer syndromes).

167. See Yael Laitman, *Rates of Risk-Reducing Surgery in Israeli BRCA1 and BRCA2 Mutation Carriers*, 85(1) CLINICAL GENETICS 68 (2013) (discussing how Israeli clinics conduct oncogenetic testing of women after receiving consent).

168. Benjamin B. Roa et al., *Ashkenazi Jewish Population Frequencies for Common Mutations in BRCA1 and BRCA2*, 14(2) NAT. GENETICS 185 (1996).

169. Jane Ritchie & Liz Spencer, *Qualitative Data Analysis for Applied Policy Research*, in ANALYZING QUALITATIVE DATA 173 (Alan Bryman and Robert G. Burgess eds., 1994); Aashish Srivastava & S. Bruce Thomson, *Framework Analysis: A Qualitative Methodology for Applied Policy Research*, 4(2) JOAAG 72, 73 (2009).

An interview guide was developed for the study and included questions about the conduct of clinicians when they face patients who explicitly refuse disclosure, or who passively refrain from informing relatives. The participants were also asked about their views regarding professional responsibilities to patients and relatives in light of the legal mechanisms set by the Act.

### B. Study Population

The study included 28 participants in three main groups. The reason for including these groups is that they accompany the patient throughout the process of diagnosis and treatment, before and after genetic testing. The largest group comprised 15 participants (12 female genetic counselors (GC) and 3 female geneticists (G)) who meet patients before and after testing. The second group comprised 7 participants (6 female nurses (GN) and a female social worker (SW)) who run special clinics for healthy BRCA1/2 carriers and provide moral and informational support to them before and after testing. The last group included 6 physicians (5 oncologists (OG) and a surgeon (SG)) who discuss the implications of the test results and treatment options with BRCA1/2 carriers. Appendix A describes the characteristics of the study participants.

### C. Data Collection

Following the receipt of an ethics approval for the study, clinicians who met the inclusion criteria were sent an invitation to participate in the study, together with background information. Those who agreed to participate were then contacted by email/phone to arrange a date for an interview. The interviews were conducted in the participants' office, lasted up to one hour, and were audio-recorded.

### D. Data Analysis

A framework analysis approach was used to analyze the data.<sup>170</sup> The analysis included five stages.<sup>171</sup> First, the researchers became familiar with the data by listening to the audio recordings and reading the transcripts. Second, the researchers identified the main themes. In accordance with the framework analysis approach, and since this study examines particular pre-determined issues, some of these themes were selected in advance (e.g., clinicians' general attitudes to their legal duty of confidentiality), while some were identified during data analysis (e.g., the clinicians' family letters to relatives). These themes were used as the grounds for a thematic analysis. In the third stage, each interview was read thoroughly and coded. Each sentence or participant's comment/response was marked as a separate segment based on the selected and identified themes. In the fourth stage, the segments were sorted and grouped together in sub-categories under the main themes. This process was dynamic,

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170. See Srivastava & Thomson, *supra* note 169 (explaining framework analysis).

171. See Ritchie & Spencer, *supra* note 169, at 178 (explaining the five stages of the framework analysis).

and additional sub-categories were identified and created during the analysis. This process facilitated the understanding of various findings in the interviews. In the last stage, the researchers discussed the findings and their implications. Disagreements were discussed and resolved. Theoretical, bioethical, and legal interpretations were assigned to the findings.

## VI. FINDINGS

The participants raised issues which address the legal framework within which they work.

### A. *Genetic Information as Personal and Familial*

As already described, the Israeli Act perceives genetic information as personal and private information that belongs primarily to the individual patient.<sup>172</sup> In contrast to this position, the study participants perceived genetic information as belonging not only to the individual but also to the family. GC10, a genetic counselor, stated: “Undoubtedly, it is familial. It is both [personal and familial] . . . I do try and emphasize [to patients] that because I think that it does not belong only to the individual himself, it is familial.” GN3, a nurse who sees BRCA mutation carriers and supervises students, stated: “I tell my students that being a carrier is not a personal thing, it’s a familial issue. It has familial aspects. It’s not something personal.”

This approach reflects the belief of the participants that genetics is a family-based area of practice. GC9, a genetic counselor, stated: “Genetics is a familial area. Each genetic test that an individual undergoes influences others . . . If an orthopedist addresses the back, an ophthalmologist addresses the eyes . . . a genetic counselor addresses the entire family.”

This led participants to admit that they feel responsible for the relatives. GC12, a genetic counselor, added: “In principle, in genetics we also have a responsibility to the family. I explain in the pre-testing consultation that this test is familial.” SW1, a social worker who runs a clinic for healthy BRCA mutation carriers, stated that in genetics there is a “message” that patients need to pass on the information to relatives because they are responsible once they receive the information from the clinicians. She added: “You [the patient] and us [the clinicians] are responsible. I mean, we, the genetic department, are responsible [for the relatives] through you.”

### B. *Confidentiality*

Israeli law places confidentiality as a central duty imposed on clinicians in genetics vis-à-vis their patients.<sup>173</sup> In accordance with this view, the study participants stated that their duty of confidentiality is an important principle in

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172. See Israel Genetic Information Act, *supra* note 134, § 20 (illustrating that the subject patient has primary preference over their genetic information).

173. *Id.*

their relationships with patients. GC11, a genetic counselor, stated: “I do think that confidentiality is highly important, and I believe that the individual definitely has the option not to tell.” GN1, a nurse who runs a clinic for healthy BRCA mutation carriers, stated: “Personally, I think that confidentiality is highly important [to the patient]. It is something which is his. It’s private. It’s the only thing that is private actually... The fact that she wants to keep it to herself, it’s her right.” OG1, an oncologist who sees healthy BRCA mutation carriers, was very explicit: “There is nothing to argue about here. The patient’s right to privacy is something I hold more dear than anything else.” GN3, a nurse who sees BRCA carriers, commented that confidentiality “is the patient’s right, and it is a human right” adding that “our job is to protect the patients, to protect them and their confidentiality.”

Furthermore, the study participants believed that the legal duty of confidentiality helps to sustain a good clinician-patient relationship, protect patients and give them a sense of security. GC6, a genetic counselor, stated: “I will tell you an anecdote. I met my neighbors here, so the first thing I tell them, ‘we are neighbors but nothing gets out from here.’ They should know this, so they could be calm, and it gives [them] a sense of security.” GC7, another genetic counselor, stated: “I think it protects the patient in front of me. I mean, the patient would not undergo testing if [confidentiality] did not exist.” G2, a geneticist, stated: “I do relate to confidentiality. Very much so. This is what I would expect [from clinicians] on a personal level, when it concerns myself and my relatives. So, it is very easy to activate it regarding people I am committed to. If you ask me, at the end of the day, theoretically and philosophically I think that the law [on confidentiality] is right in this context. I think that the individual’s interests supersede all others.” Similarly, GC11, a genetic counselor, replied when asked whether she would prefer her duty of confidentiality to be more flexible: “I would not make it more flexible. I think it is a very important principle.”

However, study participants also stated that the legal duty of confidentiality in clinical genetics restricts their practice, particularly when patients refuse disclosure to relatives. GC5, a genetic counselor, stated: “There is a problem with confidentiality when it concerns genetics because genetics is [about] a familial disease and a personal disease.” GC7, another genetic counselor, who highly values confidentiality stated: “It is a bit too restrictive . . . A solution should be found because it is a bit too restrictive.” Similarly, G2, a geneticist, stated: “It is restrictive in the very specific situation where family members explicitly refuse to share the information with their relatives and do not let me share the information with their relatives.” Similarly, when asked whether it would have been easier to talk to the patient’s relatives, had a duty of confidentiality not existed GC4, a genetic counselor, said “yes, obviously” adding that “it is true for any genetic area, not just in cancer.” She then explained: “Let’s say, they told you that the [patient’s] sister has a son with I don’t know what. So on the one hand, I cannot approach the sister and talk to her because I don’t want her to know that her sister was here . . . In that sense, you know, it is restrictive. But on the other hand, you must follow the law.”

### C. Disclosure

As already discussed, Israeli law allows disclosure to relatives, subject to the patient's consent.<sup>174</sup> The Israeli Act imposes a duty on clinicians to explain to the patient the implications of the test results for the relatives,<sup>175</sup> implicitly tasking the patient with the job of informing the relatives.<sup>176</sup> The Act states that disclosure to relatives—through their clinicians—without the patient's consent is subject to specific conditions, mainly when disclosure can prevent serious harm.<sup>177</sup>

The responses of the study participants reflected this position—conveying the message that communication of genetic information to the patient's relatives is crucial to help relatives avoid heritable cancer. Their comments indicate that they work with their patients and rely on them to inform their relatives. GC2, a genetic counselor, stated: "If a person sits in my office, I tell him 'actually this test has virtually no meaning for you, it does not have a therapeutic meaning for you. Actually, [with your help] what I do is to inform your first-degree relatives, brothers, sisters, children, parents if there are any, who would need testing.' I mean, this is, from my perspective, the purpose of the test, and therefore it comes up in the pre-testing consultation and it obviously comes up in the post-testing consultation."<sup>178</sup> GC7, a genetic counselor, said: "I use the same family member who approached me, telling him how important it is [to inform] and I hope it would help." In addition, GC3, a genetic counselor, stated: "I stress to [patients] the importance of telling [their relatives] and I say, I raise the point that it won't be nice if eventually [a relative] was not informed and did not undergo testing because she was not told she was at risk." Similarly, when asked about the way a relative could be informed about her genetic risk, GN3, a nurse who sees BRCA mutation carriers, said that, in her view, the only way genetic information can reach the relative is through the patient.

### D. Confidentiality vs. Disclosure

Most participants stated that they have encountered BRCA mutation carriers who do not want to inform their relatives about the increased genetic risk they face. GC11, a genetic counselor, replied to the interviewer's question as to whether she had experienced a case where a patient explicitly refused to inform his relatives: "Yes, there were many cases like this." GN1, a nurse who runs a clinic for healthy BRCA mutation carriers, stated that there are women who share the information with their spouse but do not want to inform their mother or aunts. GC2, a genetic counselor, stated: "The cases that I define as 'pathologic' are those of a female [patient] who tells [me] 'I don't care about my family, I am not going to tell them.'" SW1, a social worker who runs a clinic

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174. Israel Genetic Information Act, *supra* note 134, § 20(1)–(3).

175. *Id.* § 12.

176. *Id.*

177. *Id.* § 20.

178. This is obviously relevant when the patient has already been diagnosed with the disease and then underwent genetic testing. It is not the case when healthy women are tested for BRCA, for example.

for healthy BRCA mutation carriers, related a case where she experienced the outcome of a patient's refusal to inform the relatives: "I saw someone whose mother underwent genetic testing and did not tell her, and then the daughter got ill. I knew the daughter. The daughter told me [about it]."

However, the study participants did not agree on the magnitude of patients' refusal to share information with their relatives. While there were participants like GC11 above, who stated that there are "many cases" of explicit refusal to share information, other participants, such as GC8, a genetic counselor, stated that there are hardly any cases where patients explicitly refuse to inform the relatives. Some, like GC6, stated that it does happen and that she had several patients who refused to inform their relatives.

Significantly, in this context, some participants stated that patients who do not intend to inform their relatives do not express this intention during the consultation with the clinician. Although such a passive non-disclosure phenomenon (discussed above)<sup>179</sup> is not addressed by the Israeli Act or the courts, the participants stated that it does happen in practice. GC10, a genetic counselor, stated: "I do think that generally people tend not to involve me so much about their decision not to inform the family. I mean... in the sense of sitting in front of me, telling me 'I don't intend [to inform], this is not something they will tell [me]. It is not something they will be proud of.'" When asked by the interviewer whether patients kept silent after she told them that it is advisable to inform their relatives, GC10 replied that the patient "would either be silent, or he would nod, 'yeah, yeah' . . . They will not express an objection." GC11, a genetic counselor, stated: "I think that many [patients] understand that they do not need to tell me [that they do not intend to inform their relatives]. That it is unreasonable to tell me that . . . We see families that suddenly the daughter shows up, and we know that her mother was tested and did not tell [her]. We do see these cases." She then added: "I think that many people . . . come with an agenda from home, and if they do not want to tell, they will not tell."

This type of experience led participants (such as G2 and GC9) to emphasize that in these situations, they do not know whether the patient would eventually inform the relatives. Moreover, GC8, a genetic counselor, provided the following case she described as "traumatic," which reflects the outcome of passive non-disclosure: "A 40-year-old lady came to see me. She was diagnosed with breast cancer. It was not an early stage. It was an advanced stage. It was awful. Well, I did the counseling and she was a [BRCA] carrier. Before giving her the test results, my head of department noticed that it is a family we already know. She identified the family by their names. It was known that there is a mutation in that family. Do you get it? Her sister, who was already diagnosed as a carrier, did not tell her . . . [The sister] knew and did not tell [my patient] who was then diagnosed with breast cancer and did not know about the mutation."

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179. See Gaff & Hodgson, *supra* note 83, at 821 (noting patients who agree to inform their relatives but refrain from doing so once they have left the clinician's office).

GC6, a genetic counselor, provided the following case which indicates that certain patients who do not explicitly refuse disclosure in the consultation actually do refrain from telling their relatives: “There is a family, they have a genetic mutation. Anyone who carries it can develop Lynch. Lynch is colon cancer above the age of 20, but if the parents are blood relatives and they have a child who inherits both [mutant] copies, the child will die at the age of 5–6 from many tumors. I have a big family. I examined several relatives, and several children in this family died, and I have this information and I say, ‘God, how can I help this family to prevent this thing?’ And I say to this female patient several times, ‘tell all your siblings.’ I tell her husband to tell all his siblings. . . [And] they don’t tell.”

A reason most participants cited for patients’ refusal to inform their relatives is lack of good familial relationships or lack of contact with their relatives. GC12, a genetic counselor, stated: “Most families who sit in my office [tell me that] this [family member] does not talk to that [family member]. It is like an inherent part in the relationships between people apparently . . . it happens in almost all families.” G3, a geneticist, stated: “[T]here is lots of anger [between family members], and detachment.” A similar response was given by GC10, a genetic counselor: “I hear, here and there, ‘with this branch of the family there is no contact, to this [relative] I will not approach and ask for information.’ So, there are people who are willing to pay an enormous price to avoid talking to their family.”

For most study participants a patient’s refusal to inform their relatives presents a major difficulty. When asked what she does when patients say they do not want anyone to know about their genetic test results, GC5, a genetic counselor, replied that “it is highly problematic.” When asked what she does in these situations, she replied with great frustration: “I don’t know, I don’t know. It is a problem.” Similarly, when GC7, a genetic counselor, was asked what she does when her patients do not want to inform their relatives, she said that she is “trapped.”

In the participants’ eyes, patients’ non-disclosure to relatives is problematic because it requires them to strike an adequate balance between two principles that they hold dear—protecting patient confidentiality and preventing harm to relatives. The participants felt that striking a balance in this context is a difficult task. GC11, a genetic counselor, stated: “We do see women, sisters and daughters of female carriers, who come ill, and we say ‘wow, we knew,’ but I don’t have a practical and a conceptual solution. I do think that [confidentiality and disclosure are] two principles that contradict each other and I don’t know how we can find [the right] balance.” GC1, a genetic counselor, commented: “I won’t betray the confidentiality of the patient who came to see me. But I do think that we need to think creatively how to do it, and not just to say ‘I can’t tell, so I am not telling, [or] I am not allowed to do it, so I won’t do it.’ Fine, you don’t do what you are not allowed to do, obviously. But you can think that it is important [to tell] especially in genetics . . . I do think that it is something that requires a solution.”

However, despite these expressions of concern from participants who search for solutions or tools, which would allow them to warn the relatives while maintaining confidentiality, there were also participants who focused more closely on patient-centered considerations and raised concerns about their involvement in disclosure to relatives. G1, a geneticist, who was asked whether she would have contacted relatives had a duty of confidentiality not existed replied: “It is highly complicated, highly complicated. I think that I need to give my patients the right to decide what to do.” GC12, a genetic counselor, stated: “Even if theoretically I could [inform relatives], I keep telling myself that eventually I need to trust people, and to rely on the fact that I clarified things [in the consultations] . . . Would I go to [relatives], approach them and tell them something if the law [on confidentiality] did not exist? I do not know.” In addition, when asked whether she would like to have more freedom to inform the relatives GC6, a genetic counselor, said that “freedom means that there is a duty.” When the interviewer asked if she would like the law to give her the discretion to decide whether to inform genetically at-risk relatives, she highlighted the negative aspects, saying, “so they would say why I haven’t decided to inform [the relatives] at that moment.” When asked by the interviewer whether she would prefer the legal position to remain as it is, she said: “No, but I don’t know what the solution is, if there is one.”

Interestingly, participants who were concerned about the negative implications of disclosure to relatives talked about the relatives’ interests in not knowing the patient’s genetic test results. G1, a geneticist, stated: “Just assume that tomorrow someone calls you, saying to you ‘listen, come to our clinic’ . . . the question is whether the relative wants to know that. It is his right and his right to choose either to know or not to know.” She then added: “How do I know what the person wants to hear? There are people who do not want to know, and they have a right not to know.” GC3, a genetic counselor, stated that “it seems to me impossible to start approaching people who did not come to see me, I don’t know them, to invade their privacy, and suddenly telling them things they didn’t ask me about, they might not want to know.”

Participants who raised concerns about informing relatives directly also stated that they do not want to intervene in family dynamics. When asked what she would do if she did not have a duty of confidentiality, GC12, a genetic counselor, stated: “Will I approach them and inform them? I do not know because I think that you need to know their familial situation.” Similarly, GC2, a genetic counselor, stated: “I have a family, and one of them came to see me two weeks ago, and the family name was familiar to me. I tried to get from him whether he knows something about family members who already got tested. I saw that he knows nothing. . . . As long as they do not tell me that they are family, I keep their files separately. Well, I put a note to myself so I know what genetic mutation the family has, but I do not force a family to communicate information they do not want to share . . . who am I to intrude on the family?”

Similarly, GN1, a nurse who runs a clinic for healthy BRCA mutation carriers, provided the following case: “There is someone here, a divorced lady and her niece. [My patient] has a few nieces who reached the age that it is

important they know. Now, their mother is a carrier, I mean the sister of [my divorced patient] does not want to tell her daughter (my patient's niece). The mother does not want her daughter to know, and [the patient] tried to find a way. The niece's mother, the sister of my patient, does not come to see me. I do not see her. Everything is through the [patient]. So, the [patient] wanted that I would make up a story. I would lie and invite [the patient's sister] to see me. I told her, 'I am not making lies. I am not willing to make up a story. You can do whatever you want.' I told her, 'don't involve me in this. I can't, it's a lie.'"

On a practical level, some participants stated that it is very difficult to locate relatives of patients who refuse to pass on the test information. GC5, a genetic counselor, stated: "I tried not to think about it so much, about this responsibility [to inform the relatives], because I do not know what to do with it. Because I think that the means available to me are very limited. I do not talk about the law. Let's assume that the law would have forced me to [inform relatives]. I do not know what I would have done . . . I do not know what I would have done in practice. We have no option in terms of time, in terms of other resources, to start tracing family members. We do not have this option, other than telling the patient in the consultation, 'listen, it is imperative,' and then he tells me, 'I do not have a relationship [with them],' and then I say, 'I understand you do not have a relationship but it is critical.' I do not know what more I can do." GC12, another genetic counselor stated: "To verify that [patients] do it in practice? In most cases I cannot do it. As much as they can sue me, I do not have the option of getting to all these people in the family, practically." GC11, a genetic counselor, stated: "Technically, it is impossible. There was a lawyer in a conference, and someone asked him how we can find these people, so he said, 'if these people had owed you money you would have found them.' You have a female patient, particularly women who do not keep their maiden name. You do not have a clue who their sister is . . . to me, it is problematic to start looking for her doctor."

#### *E. Whose Responsibility?*

As already discussed, Israeli law perceives the patient as the party who has the main responsibility to directly inform their relatives.<sup>180</sup> Similarly, the study participants stated that ultimately, the patient holds the responsibility to directly communicate the information to the relatives. GC12, a genetic counselor, stated: "I tell them up front that it is their moral duty if, God forbid, she will have cancer because you did not tell her." G1, a geneticist, explained: "In the consultation, we explain to the family that it is their responsibility to inform the other relatives." She then added: "My responsibility to him is to explain and ensure that . . . he understands that his responsibility now—similar to my responsibility to him—is his responsibility to his relatives." GC7, a genetic counselor, stated: "it happens when I say, 'look if you are a carrier then it is your responsibility to

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180. See Israel Genetic Information Act, *supra* note 134, § 12 (stating that the Genetic Information Act only imposes the duty upon clinicians to explain to the patient the implications of their test results for their relatives, not the duty to tell the patient's relatives themselves).

inform your family because I can't, I need to protect your confidentiality . . . it is in your hands.” GC4, a genetic counselor, stated: “We are communicating the message explicitly that ‘it is your responsibility towards your siblings.’”

#### F. Practical Methods of Disclosure

As explained above, the legal mechanism set by the Israeli Act is for clinicians to ask the patient for permission to inform the relatives' clinicians.<sup>181</sup> If the patient refuses, the clinicians have to approach the ethics committee in their medical center and ask its approval to pass the information on to the relative's clinicians.<sup>182</sup> The study participants talked about various ways they adopt to ensure that information will reach the relatives. Only three participants (GC8, GC11, and GN3) talked about approaching the medical center's ethics committee as an option to resolve situations where patients explicitly refuse to inform their relatives. In this context, GC8 stated that this option is unhelpful: “Even if I convene an ethics committee, which will approve it, I don't know [the patient's] brothers and sisters. I don't have their details. I don't have the details of their doctors.” GC11 stated that she had no knowledge of an ethics committee ever being convened in this context.<sup>183</sup>

One method study participants adopt is to make repeated attempts to convince the patient to inform their relatives. G1, a geneticist, confirmed that there are cases where patients explicitly state that they do not want to inform relatives. In these cases, G1 stated that, “we try to explain why it is very important, to convince that it is important to inform [the relatives].” GC12, a genetic counselor, stated: “On a practical level, I sit with people and convince them 20,000 times . . . talking with them time and again . . . In most cases people will cooperate.” GC7, a genetic counselor, tries to convince the patient to pass on the information and she also offers assistance: “I first try to convince how important it is [to inform the relatives] and I volunteer to help.” She then added: “I tell her, you do not need to say you are ill, you can say you did the test due to family history and you are a carrier. Here you do not expose your health status but you do help. . . I always say I am willing to help.” GC3, a genetic counselor, also stated: “. . . [I]f [someone] comes to see me I will tell him, ‘listen, you are now my voice, or messenger, so go and tell your family because I can't do it for you.’” GN4, a nurse who runs a clinic for healthy BRCA mutation carriers, added: “[O]ne of the things that I try to explain to people is that your daughter is old enough, let her decide if she wants to know or does not want to know. She

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181. *Id.* § 20.

182. *Id.*

183. Three lawyers who act as chairs of one third of all ethics committees in Israeli medical centers told the authors that ethics committees are seldom convened to resolve this type of case. Thus, two of the three senior lawyers told the authors that they had never dealt with a case of a patient's explicit refusal to disclose genetic information to relatives. The third lawyer told the authors that she receives one or two cases a year. The Israeli Ministry of Health, which did a survey about the activity and conduct of ethics committees in 2015, communicated informally to the authors that, out of 50–60 cases that reached the ethics committees, only 5 cases (8%–10%) concerned patients' refusal to inform relatives. The vast majority of cases that the ethics committees dealt with in 2015 concerned disagreements between patients and clinicians regarding patients' refusal to receive curative treatment.

might say ‘no, I don’t care. I will get married and then I will do it.’ This is one of the things we say here, meaning, ‘you gave her life, you raised her, you have some rights over her, but she is old enough, so she can be told and decide; if you feel it is difficult to tell her, bring her over here and we’ll tell her, we’ll help. We’ll do it gently.’”

A similar though, more interventional, method that study participants reported adopting is using what they call emotional blackmail. For example, they ask the patient how she would feel if a close relative developed breast cancer, which could have been avoided if she had been informed of the risk. G3, a geneticist, stated: “As for disclosure, I do something, which is on the verge of emotional blackmail, and when she said that she does not want [to inform her relatives], I tell her that if, God forbid, she would hear that someone [in her family] got sick and that she could have prevented it, I believe it would be very difficult for her to sleep at night.” GC12, a genetic counselor, stated: “I had cases where I had to put substantial pressure, to give them several options, even to ask [their permission] to call [the relatives]. There were a few cases like this.” G2, a geneticist, stated: “I take the positive side, I say, ‘look, your relatives completely depend on you, I cannot pick up the phone and tell them to come and see me.’” Then, she added: “I do not hesitate to do things I believe in, things which sounds manipulative. But I say ‘look, you would feel uncomfortable with yourself if you know that your niece, age 19, got breast cancer because they did not know in the family that they should undergo testing.’ And for many women it does something.” G2 also commented: “I make it a highly personal issue, very concrete.” GC4, a genetic counselor, related that she tells her patients: “‘I imagine that you do not want to have a sick child.’ When you transfer the message like this, somewhat rudely, and this is the truth, they do communicate the information.”

Another method most participants use in this context is to provide family letters to the patient, which [s]he can then send to the relatives without revealing his or her own identity. The letter offers the relatives the opportunity to approach a genetic clinic in light of an increased risk of heritable cancer found in the family. G1, a geneticist, explains: “The option that we have regarding malignant diseases is we have an unnamed letter, saying that [an increased risk] was found in the family and it is recommended to seek genetic counseling . . . .” GC2, a genetic counselor, added: “We also offer [patients] a letter, which is anonymous, [to give to] the family members that states that, recently [a genetic mutation] was found in the family, and patients will give it.” G2, a geneticist, stated: “You probably heard about the anonymous letter that we created here that people use . . . I think they send it [to their relatives] by mail because we saw relatives coming here [to the clinic].”

GC1, a genetic counselor, explained that they offer to send these family letters directly to the relatives: “What we offer women is that if you do not want to tell [your relatives], we offer (subject to your consent) to write an anonymous letter [to relatives] that a genetic mutation was found in your family.” When asked to whom she sends it, GC1 replied: “To at-risk family members

personally. [The patient] has to give me their postal addresses . . . I do not tell the family members who came to see me, who [in their family] did the test.”

Some participants stated that they saw relatives coming to their clinic holding such a letter. This led them to appreciate the benefits of using this method. GC12, a genetic counselor, stated: “Yes, I think that this is a winning format . . . I saw people who came [to see me] with these letters.” G3, a geneticist, explained what led her to use this method: “The reason I started [giving letters] is because many people who approach [the clinic] came to me with these letters, from other places . . . It works particularly well in places where you do not want to tell.” G2, a geneticist, also acknowledged the positive aspects of the letters: “We did not invent this technique. The credit is not ours. I think it is a brilliant idea. For many people it is very helpful.”

GC2, a genetic counselor, explained that such a letter can be particularly helpful in close-knit communities where people do not want to reveal their health status because it might compromise their chances of finding a spouse: “[The letter] is very helpful for ultra-orthodox Jewish families. There, there is a policy of concealment, so from their perspective, if the information is disseminated, they do not know who did what, but [the patients] will not be the ones to initiate and push [their relatives to undergo testing], because if they push, it would be clear that [the information] comes from them.”

In contrast, a minority of the study participants saw very few relatives coming to them with such a letter. GC10, a genetic counselor, stated: “I hardly see these letters; our letters, or letters from other places. I hardly see [relatives] coming with these letters.” GC7, a genetic counselor, stated: “There are places where an anonymous letter is given to the patient. He sends it to his relatives. It has not become the practice here.”

In addition, a minority of the study participants raised concerns about this type of letter. GC3, a genetic counselor, stated: “There was a time I objected to it, particularly when I heard that they do it anonymously, meaning that [the letter] comes from the medical center . . . . It seems to me something to which I object. There is a place where they know something about my family that I do not know?! So, to me, it was discouraging.” GC11, a genetic counselor, highlighted other negative aspects: “Many people like this option and I can see why. I think about the person who receives such a letter . . . suddenly you receive a letter in the post, it sounds like a bomb falling from the sky. . . . You know it is [directed] to relatives, it is anonymous . . . . And there were people who told me ‘hold on a minute’ . . . they would start interrogating [me]. There are people who came here [saying] we received the letter, but who was here to see you? My cousin?”

## VII. DISCUSSION

### A. *A Short Summary*

The study sheds light on the attitudes of clinicians towards the legal framework within which they operate. It also sheds light on the influence of the

legal position on clinicians' conduct when facing situations involving disclosure of genetic information to relatives. The findings show that the clinicians' approach reflects both relational and patient-centered perspectives. The study participants perceived genetic information as personal and private on one hand and as familial information on the other. In general, they follow the rule of confidentiality and do not inform relatives without consent, explaining that it protects the clinician-patient relationship and the interests of the individual patient. However, they also believed that disclosure of genetic information to at-risk relatives is crucial to avert the onset of a heritable disease or at least reduce the chance of onset. Although the familial aspect of genetics made the study participants feel morally responsible for the relatives, there was a general consensus that the responsibility to directly inform the relatives lies with the patient.

However, in situations where patients explicitly refused disclosure to relatives, many participants expressed the feeling that the legal duty of confidentiality restricts their practice and prevents them from helping the relatives. In addition, study participants described their frustration when they face patients who passively refrain from informing the relatives. When the patients do not share their reluctance, the clinicians do not know whether or not the information reaches the relatives. Some participants used strong words to describe their exasperation when patients who were diagnosed with heritable cancer came to see them not knowing that their family members had already been tested.

Like clinicians in other studies,<sup>184</sup> our study participants discussed several issues regarding the scope of their responsibilities to the relatives. They raised the issue of the relatives' right not to know and their own reluctance to intervene in the relationships between the patient and their relatives. However, the most influential concern the study participants raised was the practical difficulties of tracing the relevant relatives when the patient does not cooperate and explicitly refuses disclosure. The study participants said that they have no resources to trace relatives and contact them or their clinicians.

Finally, the study participants discussed the solutions they adopt to promote disclosure to relatives. One option was to make repeated attempts to convince the patient to convey the information to their relatives, using what some called "emotional blackmail." Another approach was to offer relatives to disseminate family letters, which alert relatives to their increased genetic risk and invite them to seek genetic counseling. Only three participants discussed the option employed by the Israeli Act, of approaching an ethics committee. No participant reported having used this option when his or her patient refused disclosure.

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184. *See supra* Part III (discussing previous studies where clinicians discussed the scope of their responsibilities to the relatives).

### B. *The Implications*

The findings indicate that clinicians follow the law. They respect their duty of confidentiality and generally refrain from informing the relatives or their clinicians without the patient's consent or knowledge.<sup>185</sup> However, the findings also indicate that the law has an impact on clinicians' conduct. They admit that it restricts them when patients explicitly refuse to inform the relatives.

Furthermore, in our view, the findings suggest that the law does not help clinicians resolve the difficulties they face. First, the law does not address the phenomenon that study participants described regarding patients' passive non-disclosure, namely when the patient explicitly or implicitly agrees to inform the relatives in the encounter with the clinician but refrains from doing so after leaving the clinicians' office. The participants expressed their frustration with this situation but, the law is silent. In Israel, the mechanism of informing relatives is based on patient consent and the only provision for the relatively rare situation in which a patient explicitly refuses to inform relatives is to offer clinicians to approach the medical center's ethics committee.<sup>186</sup> As we have seen in the U.K. and the U.S., the discretion is given to the clinicians.<sup>187</sup>

Second, the fact that the study participants described methods they had developed to resolve the issue of explicit non-disclosure instead of employing the legal mechanism of approaching ethics committees, indicates that clinicians do not believe that this legal tool can help them in this context. The very few study participants who mentioned the option of approaching ethics committees negated this route, an opinion supported by the findings that although cases of explicit non-disclosure do occur in practice, only a very small number reach an ethics committee.

Third, the law does not help clinicians overcome the practical difficulties of tracing relatives when a patient is not cooperative and refuses to provide details about the relatives. The law is silent in this context.<sup>188</sup> It simply does not address the situation where the ethics committee approves disclosure to relatives but the patient is not willing to provide contact details of the relatives or their clinicians.<sup>189</sup> Thus, if the aim is to assist relatives, or society more generally, to avoid heritable diseases, then the law fails to further this aim.

Fourth, the law is blind to the potential interests of relatives who do not wish to receive genetic information.<sup>190</sup> In other words, the Israeli Act does not

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185. See Dheensa III, *supra* note 74 (explaining that most clinicians consider genetic information private and confidential so, they consider it the responsibility of the patient to inform their relatives).

186. See *supra* note 140 (explaining the requirements by which an Israeli ethics committee will allow a clinician to inform their patient's relatives).

187. GENERAL MEDICAL COUNCIL, *supra* note 100, at 10–11; *HIPAA Privacy Rule*, *supra* note 118.

188. See generally Israel Genetic Information Act, *supra* note 134 (illustrating that the Genetic Information Act does not mention the situation in which a patient is uncooperative and refuses to provide details to their relatives).

189. Currently, in the Israeli public health care system, it is technically impossible for the patient's clinician to trace the relatives' clinicians without the cooperation of the patient.

190. See generally Israel Genetic Information Act, *supra* note 134 (illustrating that the Genetic Information Act does not mention the situation in which relatives do not wish to receive genetic information).

address the right not to know.<sup>191</sup> Once the ethics committee approves disclosure, the patient's clinician will approach the relative's clinician who can then contact the relatives with the news. The relative's clinician has no duty to find out whether the relative indeed wishes to know.<sup>192</sup> This is a concern the study participants raised, and one we consider that the law should address explicitly.

Finally, the law does not explicitly address the participants' reluctance to intervene in family dynamics when the patient refuses disclosure.<sup>193</sup> As previous studies show,<sup>194</sup> a central difficulty in informing relatives is having poor or no contact between the patient and the relatives. The study participants had experienced such scenarios, and this led to their reluctance to directly inform the relatives. When examining the Act, Section 20 states that the ethics committee can approve disclosure to the relatives' clinicians either when the benefit from disclosure outweighs the harm to the patient from disclosure, *or* when the patient's reasons for his or her refusal are unreasonable given the specific circumstances.<sup>195</sup>

However, if the members of the ethics committee hear from the patient that s/he refuses disclosure because s/he has a poor or no relationship with his or her relatives, can this be defined as unreasonable according to section 20 of the Act? A few points should be highlighted in this context. The ethics committee is tasked with discovering *why* the patient refuses disclosure.<sup>196</sup> For this purpose, the members of the ethics committee can discuss with the patient his or her relationship with the relevant relative(s).<sup>197</sup> This indeed resolves part of the clinicians' concern regarding intervention in familial relationships. However, if committee members reach the conclusion that it is reasonable for the patient to refuse disclosure when s/he has a poor, or no, relationship with the relatives, they implicitly decide that they are not willing to intervene in the patient-relatives relationship. Such a response does not resolve the reluctance of the study to intervene in family dynamics. Ultimately, the relatives will remain unaware of the increased genetic risk to which they might be exposed.

In contrast, if the ethics committee members reach the conclusion that having poor or no familial relationships is an unconscionable reason for patients' non-disclosure to relatives, and if they consequently approve disclosure to relatives without consent, the clinicians' reluctance to intervene in familial relationships is thus resolved. However, it should be appreciated that a decision

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191. Interestingly, the Israeli Patient Rights Act, *supra* note 140, which is the main piece of legislation that regulates the doctor-patient relationship in Israel, does not recognize the patient's right not to know and not to receive information from the doctor when the doctor fulfills his or her duty of obtaining informed consent from the patient.

192. In our view, this is not a major concern. Our assumption is that on the whole, individuals (and the society in which they live) wish to avoid serious heritable diseases.

193. *See generally* Israel Genetic Information Act, *supra* note 134 (noting the Genetic Information Act does not discuss the reluctance of clinicians to interfere in family matters when patients refuse disclosure).

194. *See Dheensa I, supra* note 2 (noting poor familial relationships as one of the difficulties of disclosure).

195. Israel Genetic Information Act, *supra* note 134, § 20.

196. *Id.*

197. *See id.* § 20(1) (stating that the Ethics Committee needs to inquire whether "communication of the genetic information regarding the subject is required for the maintenance of the health of a relative or to improve such person's health, and for the prevention of death, illness, or serious disability of such relative . . .").

by an ethics committee to inform the relatives in this context (despite the patient's refusal) will not necessarily have a positive influence on the familial relationships and might well complicate them further.<sup>198</sup> Thus, in our view, the legal mechanism in Section 20 of the Act does not provide an adequate solution to the difficulty raised by the study participants regarding their reluctance to intervene in the patient-relative relationship. One might argue that making strenuous efforts to convince the patient that the relevant genetic information must reach the relatives, or offering the patient help in communicating the information to the relatives are better ways than the legal tool set in Section 20 of the Act.

Concluding that the existing legal tools are unhelpful in disseminating genetic information to relatives is not the end of the discussion. The study participants discussed three methods to overcome the difficulties of patients' reluctance to inform the relatives. Focusing first on family letters, studies show that when they are sent directly by clinicians to relatives, it increases the rate of participation by relatives in genetic testing.<sup>199</sup> Furthermore, family letters given to patients to send to their relatives has become a standard practice in genetic counseling in European countries.<sup>200</sup> In this context, our study indicates that family letters have become common practice in Israel.<sup>201</sup> The majority of study participants stated that they use this method and believe it is "brilliant." However, we need to examine its advantages and disadvantages in light of the legal position and the bioethical principles it promotes.

From a legal perspective, using family letters with the patient's consent cannot be considered a breach of confidentiality.<sup>202</sup> In our study, the participants obtained the patients' consent and therefore did not breach their legal duties. Thus, the letters serve to resolve the negative impact of passive non-disclosure because they allow the patients to remain passive while enabling clinicians to disseminate the information to the relatives (when the patient gives his permission to send the letters to them). However, it does not resolve the difficulty if the patients do not intend to disseminate the letters to their relatives and/or forbid the clinicians to send the letters directly to the relatives.

In our view, sending family letters directly to relatives or to their clinicians without the patient's consent is not a breach of confidentiality if the letter does not identify the patient. As explained in Part II, medical information which does

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198. See Dheensa II, *supra* note 6, at 695 (describing some patients' feelings about the letters as causing more familial problems).

199. See Suthers, *supra* note 85, at 667–68 (discussing results of relatives undergoing genetic testing); Evans, *supra* note 97 (explaining that when clinicians send letters to the relatives, it increases the number of relatives who seek genetic counseling).

200. HELENA KÄÄRIÄINEN ET AL., EUROGENEST, RECOMMENDATIONS FOR GENETIC COUNSELLING RELATED TO GENETIC TESTING (FINAL VERSION) (2009), <http://www.eurogentest.org/index.php?id=674>.

201. It is another issue whether family letters have become a recommended standard for clinical practice in Israel. As we saw there were several clinicians who expressed their reluctance to use family letters. However, this issue may become important in a relatives' claim against the patient's clinicians. If sending family letters reflects a recommended clinical practice, failing to send letters may be perceived as a breach of the clinician's duty of care.

202. See Dheensa II, *supra* note 6, at 692 (discussing how patient consents allow physicians leeway to distribute necessary information).

not identify the patient cannot be regarded as personal information, which merits the legal protection of the right to confidentiality.<sup>203</sup> Furthermore, the Israeli Act defines identifiable genetic information as “any genetic information relating to a particular subject where an identifying detail appears . . . .”<sup>204</sup> Thus, we believe that a clinician who sends family letters without the explicit consent of the patient does not breach confidentiality if the information included in the letter does not identify him/her.<sup>205</sup> Sending these letters promotes the autonomy of the relatives. It enables them to make informed decisions about their health.<sup>206</sup> However, the next question in this context is whether clinicians owe a legal duty to send family letters without the patient’s consent. We will deal with this question below.

Moving on to the other two methods discussed by the study participants namely, dedicating strenuous efforts to convince patients to inform the relative, and, in exceptional circumstances, to employing emotionally blackmail, it should be noted that these methods accord with the law because they require the patient’s cooperation and consent. As previous studies show, these methods raise the rate of disclosure to relatives,<sup>207</sup> but they do not resolve situations where the patient insists that s/he will not inform the relatives. Although empirical evidence suggests that this is a rare phenomenon,<sup>208</sup> the participants in our study encountered patients who explicitly refused to inform their relatives and had experienced negative consequences. Therefore, the inevitable conclusion is that although the two methods developed by study participants accord with the law, they do not provide a comprehensive solution.

An analysis of the three methods discussed by the study participants leads us to the following conclusions. On the one hand, they expressed a relational view. They voiced the opinion that genetics has substantial familial aspects and that the decision to inform (or not to inform) the relatives influence familial relationship and is influenced by them. On the other hand, the study participants adopt a patient-centered approach. This was demonstrated by their reluctance to confront patients who express explicit refusal or implicit reluctance to inform relatives of their genetic risk. Instead, the clinicians preferred to work with the patients to obtain their cooperation and convince them to inform their relatives using the three methods discussed above. This, to the study participants, was preferable to approaching the medical center’s ethics committee, which may resolve cases of patients’ explicit refusal to inform in an adversarial fashion. Unfortunately, the problem with these three methods is that in some cases, the relatives do not receive the information because of the clinicians’ reluctance to enter into a conflict with their patients.<sup>209</sup> The outcome is breach of the relatives’

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203. K Blightman et al., *Patient Confidentiality: When Can a Breach be Justified?*, 14(2) CONTINUING EDUC. ANESTHESIA CRITICAL CARE & PAIN 52, 55 (2013).

204. Israel Genetic Information Act, *supra* note 134, § 2.

205. We develop this discussion further below.

206. However, as Dheensa II, *supra* note 6, at 695, found, family letters have disadvantages.

207. Jan Hodgson et al., *Outcomes of Randomized Controlled Trial of a Complex Genetic Counselling Intervention to Improve Family Communication*, 24 EUR. J. HUM. GENETICS 356, 358 (2016).

208. See Clarke, *supra* note 81, at 558 (providing empirical evidence focused on rate of disclosure).

209. See *id.* (studying data of relatives not receiving information).

right to autonomy, or in other words, their right to make informed decisions about their health.<sup>210</sup> Ultimately, in our view, the clinicians in the study are closer to the patient-centered approach than to the relational approach.

Assuming that most clinicians indeed adopt the above three methods and some relatives therefore remain uninformed, the next question is whether the law, can resolve such situations via an imposition of a tortious duty of care on clinicians. Although this point was not queried directly in the study, the predominating view of the study participants that the main responsibility lies with the patient suggests that they would not embrace this option. Their comments suggest that despite their awareness of their overall responsibility to the relatives, this obligation is satisfied by asking the patient to inform their relatives. Furthermore, the participants seemed to feel relieved of a direct duty towards the relatives because of the practical difficulties of tracing them without the cooperation of the patient. This was reflected in the statement of one of the study participants who said that convening the ethics committee is not practical when clinicians have no details about the patient's relatives (when the patient does not cooperate).

Thus, we conclude that the position of the study participants reflects the legal position held by the Israeli Act and courts (and that of the Florida court), namely that clinicians in genetics owe a duty to genetically at-risk relatives, which is satisfied by asking the patient to convey the information to them. Notably, the participants' responses did not reflect the decisions of the Court of Appeal in *ABC* and of the New Jersey court.<sup>211</sup> These courts recognized that under certain circumstances clinicians may owe a direct duty to the relatives.<sup>212</sup>

Nevertheless, the question remains whether clinicians should have a legal duty to inform the relatives, and if so, what this duty entails. This question is relevant for all three jurisdictions reviewed in this Article. This question can be considered in the light of the study's findings and the distinction made in Part II between personal genetic information and familial genetic information. In this context, we believe that if the general aim of society is to prevent or reduce the incidence of heritable diseases, then, in principle, clinicians should owe a legal duty to the genetically at-risk relatives. However, as already discussed, the critical question is then what is the nature of this duty.

The clinicians' duty should include the following aspects. First, clinicians must ask the patients to inform relatives who are exposed to an increased genetic risk. Second, clinicians may owe a duty to take active steps to ensure that the information reaches the relatives.<sup>213</sup> In practice, this may mean asking the patient to send family letters to the relatives or obtaining his/her consent to send the letters directly to them. In exceptional cases, this may mean (in Israel) approaching an ethics committee and convincing them that disclosure to

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210. John Coggon & Jose Miola, *Autonomy, Liberty, and Medical Decision-Making*, 70 CAMBRIDGE L.J. 523, 523–24 (2011).

211. *ABC*, *supra* note 104; *Safer v. Estate of Pack*, 677 A.2d 1188, 1192 (N.J. App. 1996).

212. *ABC*, *supra* note 104; *Safer*, 677 A.2d at 1192.

213. See MS Pandit & Shobha Pandit, *Medical Negligence: Coverage of the Profession, Duties, Ethics, Case Law, and Enlightened Defense – A Legal Perspective*, 25 INDIAN J. UROL. 372 (2009) (discussing physicians' legal duties).

relatives' clinicians must be approved.<sup>214</sup> In English and American law, this might require clinicians to contact the relatives or the relatives' clinicians directly (assuming this is feasible).<sup>215</sup> Third, when fulfilling their duty, clinicians should communicate *familial* and not personal genetic information. That is, they should make all efforts to protect the patient's interests with respect to autonomy, privacy, and confidentiality on the one hand while safeguarding the relatives' health on the other. Fourth, clinicians should be involved in determining the scope of the duty, or in other words the circle of people to whom the duty is owed. It is obviously unreasonable to require clinicians to contact distant relatives or even to dedicate efforts to tracing them or their clinicians (when sufficient resources are not provided). However, it is reasonable to require clinicians to contact the patient's first-degree relatives (or their clinicians) particularly when the patient provides their contact details or when it is relatively easy to trace them (or their clinicians). Finally, the clinicians should owe a direct duty to relatives with whom they have direct contact.<sup>216</sup>

Thus, ultimately, our opinion is that the law should leave the discretion to the clinicians to decide whether or not to initiate a process of disclosure without the patient's consent. In tort law terminology, we argue that a principal duty to the relatives should be recognized, but that the question of whether and how to initiate a process of disclosure without consent should remain at the discretion of clinicians. Legally, this means that clinicians who do not inform at-risk relatives (directly or via their clinicians) under circumstances where they should have done so, may be liable if there is a causal link between their failure to inform and incurred harm. Such a legal rule, which shifts the discussion from the duty stage to the breach-of-duty stage, would require clinicians to dedicate more thought to the criteria justifying disclosure without consent and to draft detailed guidelines on the subject. In addition, it would require clinicians to change their underlying attitude to confidentiality and disclosure, providing them equal moral and legal weight.

Like the court in *ABC*, we believe that the imposition of such a duty would not lead to defensive practices or to a breach of trust between clinicians and patients, particularly if clinicians adopt the U.K. Joint Committee's recommendation of offering patients to sign a consent form which allows clinicians to share *familial* genetic information with relatives or their clinicians when the patient can maintain his/her anonymity.<sup>217</sup> This would enable the clinicians and patients to conduct a beneficial discussion about the need to share familial genetic information with relatives and reach an agreement regarding disclosure to them.

We also believe that a clinician's decision to communicate familial genetic information to the relatives should be the last resort. It should only be employed

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214. See generally *id.* (relating disclosures and ethics).

215. See generally *id.* (discussing contacting relatives).

216. This could be the solution under the circumstances occurring in *ABC* where the patient's clinicians knew the patient's daughter (the claimant) and had prior contact with her. They also knew that she was pregnant when the issue of disclosure arose.

217. See *ROYAL C.*, *supra* note 92, at 4 (discussing the sharing of genetic information with relatives).

after dedicating strenuous efforts to convince the patient to inform relatives of their increased risk through family letters or other means. However, in order to enable them to fulfill their duty, it will be necessary to allocate resources to help clinicians in this task. For example, the medical records of all genetic clinics should be accessible to genetic counselors and geneticists so that they can determine whether relatives of their particular patient have undergone genetic counseling and testing. Similarly, genetic departments should be allocated additional staff who can provide ongoing support to patients undertaking the task of informing the relatives after testing. Alternatively, additional staff should be allocated to trace relatives or their clinicians when the patients are less cooperative. These resources will resolve the practical difficulties the study participants raised in the interviews and help clinicians deal with passive non-disclosure.

In our view, our proposal to impose a duty on clinicians to communicate familial genetic information to relatives accords with Section 21 of the Israeli *Genetic Information Act*. This section requires that disclosure to the relatives' clinicians in cases where the patient expresses his/her objection must be conducted in a way that protects his/her anonymity as much as possible. We thus hold the view that when an ethics committee approves disclosure to relatives' clinicians according to the procedure set in Section 20, it should approve disclosure of familial genetic information and not disclosure of personal genetic information. As explained above, our proposal also accords with the Anglo-American legal position.<sup>218</sup>

Ultimately, we believe that imposing a duty on clinicians to communicate familial genetic information directly to the relatives or their clinicians in cases of explicit non-disclosure will lead clinicians to strike a more adequate balance between their duty of confidentiality to patients and the duty of disclosure to the relatives. In our view, the study participants, like their counterparts in other Western countries, prefer that the process of disclosure to the patient's relatives is based on patients' consent and collaboration between clinicians and patients. However, if the aim is to expand the number of people in each family who are aware of their risk of developing a heritable disease, then we need to change clinicians' perceptions regarding confidentiality and disclosure to relatives. As this and other studies show, clinicians in clinical genetics currently value confidentiality more than disclosure.<sup>219</sup> They also feel frustrated by the existing legal framework, not knowing how to resolve the inherent tension between confidentiality and disclosure. We believe that involving clinicians in determining the scope of their legal duty to relatives with respect to genetic information, and exposing them to liability in tort, would force a change in their underlying perceptions. We also believe that detailed professional guidelines about the scope of this duty and about the circumstances in which disclosure is advisable would create clarity for both clinicians and patients.

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218. See generally Pandit & Pandit, *supra* note 213 (discussing physician legal responsibilities).

219. See Dheensa I, *supra* note 2, at 290 (comparing the values of disclosure and confidentiality).

Notably, the English court in *ABC* sent this message, implying that if a particular clinician meets the professional standard regarding confidentiality and disclosure, then it would be difficult for a future court to accept the relatives' claim (when the clinician is sued for not informing the claimant relative).<sup>220</sup> This suggests that the reasonable physician test in tort law would be highly influential in determining the question of whether the defendant clinician in genetics breached his/her duty to the relatives. As discussed above, we support a position, which provides opportunity for clinicians in genetics and their professional bodies to be involved in drafting the scope of this duty, but we argue that the final word in this context belongs obviously to the court and not the clinicians.

### VIII. CONCLUSIONS

Disclosing genetic information to the patient's relatives is an important and complicated aspect of clinical practice in genetics.<sup>221</sup> The existing discourse in law and bioethics is conducted within a framework of two central approaches.<sup>222</sup> One highlights liberal-individualistic considerations, perceiving the patient as essentially separate from others.<sup>223</sup> The other is relational and emphasizes the importance of close relationships and the moral obligations family members owe each other.<sup>224</sup> Within this framework, the law is positioned closer to the individualistic approach and in all three jurisdictions analyzed in this Article the legal rule is confidentiality with the exception being disclosure to relatives without consent.<sup>225</sup> The findings of our study confirm that the approach of clinicians is currently also closer to the individualistic patient-centered approach because they are reluctant to inform relatives without the patient's consent. However, the findings also indicate that the clinicians' approach is more relational than the law because they take active steps to ensure that familial information reaches the relatives when the patient is reluctant to do so.

Significantly, our study highlights several gaps between the legal position and the tools it provides on the one hand, and the views and conduct of clinicians in practice on the other. The inevitable conclusion is that the law does not address all the practical difficulties involved and does not provide effective and comprehensive solutions to clinicians who face the issue of disclosure to relatives. The law thus becomes less influential and relevant in clinical genetics. In order to retain its influence, the law should impose a duty on clinicians to communicate familial genetic information on the rare occasions where patients explicitly refuse disclosure. In light of the increasing significance of genetic information for individuals, families and society, it is time for law-makers to re-

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220. See *ABC*, *supra* note 104, at ¶ 35 (implying the difficulty of future courts dealing with relatives' claims).

221. Hodgson, *supra* note 207, at 356.

222. BEAUCHAMP & CHILDRESS, *supra* note 7, at 323–24; Lucassen & Gilbar I, *supra* note 1, at 361.

223. BEAUCHAMP & CHILDRESS, *supra* note 7, at 323–24.

224. Lucassen & Gilbar I, *supra* note 1, at 361.

225. Dheensa I, *supra* note 2, at 290.

consider the current legal position, fill the existing gaps, and adopt a relational approach.

#### APPENDIX A

##### Genetic Counselors and Geneticists

GC1- Genetic Counselor, Female, Ph.D., Medical Center **A**  
GC2- Genetic Counselor, Female, Medical Center **A**  
GC3- Genetic Counselor, Female, Ph.D., Medical Center **A**  
GC4- Genetic Counselor, Female, Medical Center **B**  
GC5- Genetic Counselor, Female, Ph.D., Medical Center **C**  
GC6- Genetic Counselor, Female, Medical Center **D**  
GC7- Genetic Counselor, Female, Medical Center **A**  
GC8- Genetic Counselor, Female, Medical Center **E**  
GC9- Genetic Counselor, Female, Medical Center **B**  
GC10- Genetic Counselor, Female, Medical Center **B**  
GC11- Genetic Counselor, Female, Medical Center **E**  
GC12- Genetic Counselor, Female, Medical Center **C**  
G1- Geneticist, Female, Medical Center **B** (Department Deputy Head)  
G2- Geneticist, Female, Medical Center **B** (Department Head)  
G3- Geneticist, Female, Medical Center **A**

##### Nurses

GN1- Nurse, Female, Medical Center **E** (Clinic Head of Healthy BRCA1/2 Carriers)  
GN2- Nurse, Female, Medical Center **D** (Breast Cancer Coordinator)  
GN3- Nurse, Female, Ph.D., Medical Center **A** (Breast Cancer Coordinator)  
GN4- Nurse, Female, Medical Center **F** (Clinic Head of Healthy BRCA1/2 Carriers)  
GN5- Nurse, Female, Medical Center **F**, (Breast Cancer Coordinator)  
GN6- Nurse, Female, Hospice Unit  
SW1- Social Work, Female, Ph.D., Medical Center **D** (Clinic Head of Healthy BRCA Carriers)

##### Doctors

OG1- Oncologist, Female, Medical Center **D**  
OG2- Oncologist, Female, Medical Center **D**  
OG3- Oncologist, Male, Medical Center **D** (Unit Head)  
OG4- Oncologist, Male, Medical Center **B**  
OG5- Oncologist, Female, Medical Center **G**  
SG1- Surgeon, Male, Medical Center **E**