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Informing relatives of their genetic risk: an examination of the Belgian legal context

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Findings from genomic sequencing can have important implications for patients and relatives. For this reason, most professional guidelines support that patients have an ethical duty to inform relatives and, when disclosure does not occur, most guidelines allow health-care professionals (HCPs) to breach confidentiality. Translating the ethical duties to respect the patient's confidentiality and prevent harm in at-risk relatives into legislation is a complex issue due to the both personal and familial nature of genetic information. In many countries there is no specific guideline or law addressing family communication of genetic information and thus it is unclear what duties patients and HCPs have towards at-risk relatives. Using Belgium as an example for countries in which this is the case, we examined the existing Belgian legislation in relation to three central topics: (1) patients' duties to family members, (2) respect for patient confidentiality and privacy, and (3) HCPs' duties to family members. We then investigated international legal frameworks and compared it with the Belgian context to see to what degree international precedent could aid in the interpretation of Belgian law. Based on our review of the legislation, we make recommendations for the interpretation of current law and examine whether there is sufficient legal precedent to answer the questions central to family communication of genetic information. Although we focus on the specific Belgian legislation, the discussions are relevant for many other countries that have similar legislative approaches.

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INTRODUCTION

Genetic information is unique in that it is personal, predictive, and familial. Findings from genetic sequencing may have implications for not only the patient, but also their family members. Such information may indicate that a family member is at risk of developing the condition or passing the condition on to their children, and thus informing relatives may play a key role in initiating diagnosis, treatment, or access to reproductive screening technologies.

For this reason, communicating findings to family members can be very important, and in fact, many guidelines support that in cases where the genetic condition is both serious and actionable patients have a duty to share this information with at-risk relatives [1, 2]. Defining severity and actionability in this context can be challenging, and given the complex inheritance, penetrance, and expression of genetic conditions this judgment is inherently probabilistic. Empirical research demonstrates that many patients struggle to inform their family members of their genetic risk [3]. Patients may already be coping with their own diagnosis and may be reluctant to share information that could cause distress for their relatives [3]. These challenges are further amplified in families with pre-existing relational strains.

While guidelines primarily place the responsibility of informing family members on patients [2], when patients fail to do this, health-care professionals (HCPs) may have a duty to inform at-risk relatives. In this situation, HCPs must balance their duty to prevent harm in the at-risk relatives with their duty to preserve the patient's right to the confidentiality of their genetic information. Most professional guidelines allow for breaches in patient confidentiality in cases where the disclosure of genetic information could prevent serious harm for at-risk relatives [2].

At the legal level, the disclosure of genetic information to at-risk relatives without the consent of the patient is a complex issue, which varies considerably depending on the jurisdiction. For example, in Australia, there is legislation permitting HCPs to breach patient confidentiality to inform family members [4] and in the UK, the recent court case *ABC v St George's NHS Trust* ruled that HCPs have a duty to balance the interests of the patient and their relatives [5]. Contrastingly, in France, legislation imposes a legal duty on patients to inform relatives, either directly or indirectly through the HCP, about genetic risks relevant for their health [6]. However, many other countries lack specific regulation regarding family communication of genetic information [7, 8] so there is a need to clarify the legal situation regarding issues around family communication. This is the case in Belgium where there is no specific law or professional guideline adjudicating the permissibility of disclosure without patient consent [9]. Nevertheless,

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existing legal frameworks might apply by analogy, a point which has not been investigated previously.

To address this gap, we examined the existing Belgian legislation in relation to applicable international frameworks regarding three central topics: (1) patients' duties to family members, (2) respect for patient confidentiality and privacy, and (3) HCPs' duties to family members. Based on our review of the legislation, we make recommendations for the interpretation of current law and examine whether there is sufficient legal precedent to answer the questions central to family communication of genetic information. Although we focus on the specific Belgian legislation, the discussions are relevant for many other countries that have similar legislative approaches.

PATIENTS' DUTIES TO INFORM FAMILY MEMBERS

While there is a consensus in the ethics literature and guidelines [2] in support of the moral duty of patients to inform their family members of their genetic risk, it is not clear whether in Belgium this moral duty has a legal backing. The Belgian Penal Code may provide insight into whether patients have a legal responsibility to inform their family members about their genetic risk. Article 422*bis* of the Penal Code states (own translation) that "those who fail to give or provide assistance to someone who is in great danger" and who was "able to help without serious danger to themself or others" could be held legally liable of culpable negligence [10]. On these grounds, patients may have a legal responsibility to inform family members of genetic risk information in circumstances where this knowledge is key to the prevention of harm in family members.

Currently there is no ruling as to whether the legal duty of assistance is applicable in the context of communication about genetic risk. Notably, the duty of assistance has been applied in the context of infectious disease, with regards to communication about HIV seropositivity. A seropositive person who fails to inform their partner breaches their legal duty of assistance by knowingly subjecting their partner to a serious and actual danger [11]. While genetic conditions are not contagious (like infectious diseases), they are still transmissible. However, unlike HIV, the transmission of genetic diseases only occurs between generations, so it is not clear to what degree judgments regarding infectious disease can be applied in the context of genetics. The question remains whether a patient who fails to inform family members of their genetic risk similarly breaches their duty of assistance. If the nondisclosure of genetic risk poses a serious and actual danger to the patient's family member, the case could be made that the patient could be liable under the Penal Code. It is important to note that to justify the claim of culpable negligence against the patient, the danger faced by the family member must be caused by nondisclosure of genetic risk information rather than by the genetic disease itself. The patient is not responsible for the harm caused by the genetic disease, but if the relative suffers harm that could have been avoided had they been informed of their genetic risk earlier then the patient could be found to be at fault.

To better understand whether the legal duty of assistance could apply in the genetics context, consider the case of a patient who is unwilling to inform a family member of their risk of developing Lynch syndrome. Lynch syndrome, also known as hereditary nonpolyposis colorectal cancer, can have serious health consequences and if left untreated can be life threatening [12]. Taking the severity into consideration, the family member could have a legal claim against their relative who failed to inform them, backed by the Penal Code. This is because if not informed, the family member may otherwise remain unaware of their risk of developing Lynch syndrome, at least until the condition had developed to such an extent as to exhibit detectable symptoms. If informed, the family member could have taken steps to prevent the condition from developing, such as regular colon screening or even prophylactic surgery, that would result in substantially improved health outcomes. Notably, in Belgium there is a screening program for citizens fifty and older that includes screening for Lynch syndrome [13]. For relatives at or approaching the age of screening, the importance of disclosure would be diminished in light of this screening program. However, for younger relatives, communication would still be important due to the possibility of an early onset of colorectal cancer that would not be detected in time by the screening program [12]. Lynch syndrome exhibits a dominant inheritance pattern and is highly penetrant. For genetic conditions where the risk to relatives may be lower or harder to predict, it is harder to establish a patient's duty to inform their relatives. Although each case would need to be evaluated individually, in some cases, due to the severity of the harm that could be prevented by disclosure of genetic risk information, the patient may have a legal duty to provide assistance according to the Penal Code.

In the example above, the application of the legal duty of assistance is justified by the key role that genetic information could play in preventing harm to family members. There may also be grounds to apply this duty in cases where the genetic condition in question is not clinically actionable (meaning there are no prevention or treatment options available) but where knowledge of the genetic risk could have important implications for decision making. In some cases, knowledge of a genetic risk can enable family members to make more informed reproductive decisions. This is evident in the case of Huntington's disease that causes severe movement, cognitive, and psychiatric disorders. Currently, no treatment is available for this neurodegenerative disease, however, it is possible to utilize reproductive technologies to avoid passing the condition down to offspring. If an individual knew that their relative was at risk of having Huntington's and was considering having a child, they may have a duty to inform their relative for whom this information could be essential in preventing having an affected child. Furthermore, genetic risk information can also have important implications for financial and career planning.

RESPECTING PATIENT'S CONFIDENTIALITY AND PRIVACY

Patient's right to privacy

All persons under the Belgian Constitution have a "right to the respect of their private and family life, except in cases and conditions determined by the law" [14]. As a patient, one is also entitled to the right to privacy, as established by Article 10 of the Belgian Patients' Rights Act. The Act states (own translation) that "patients have the right to protection of their privacy whenever the professional intervenes, in particular with regards to information relating to their health" and "no interference shall be permitted in the exercise of this right except in so far as it is provided for by law and is necessary for the protection of public health or for the protection of the rights and freedoms of others" [15]. Based on this Act, the patient is owed the right to privacy, however, this right is not absolute and must be balanced with the right to protection owed to others.

At the European level, the right to privacy is a human right laid down in Article 8 of the European Convention on Human Rights. The European Convention on Human Rights is designed to protect citizens against state action but can also have horizontal effects between individuals. In addition to establishing the right to privacy, Article 8 also outlines possible exceptions to this right as follows: a) when created by law or when necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, b) for the prevention of disorder or crime, for the protection of health or morals, or c) for the protection of the rights and freedoms of others [16]. The privacy of the patient's information is protected at the European level by the General Data Protection Regulation (GDPR), which

regulates the processing of personal data [17]. Genetic data is considered as a kind of personal data, which due to its sensitive nature warrants additional protections under GDPR. For genetic data to be shared, certain conditions must be met, for example: the processing is necessary (a) to protect the vital interest of the data subject or of another natural person where the data subject is physically or legally incapable of giving consent, (b) for reasons of substantial public interest, (c) for the purposes of preventive or occupational medicine, or (d) for the public interest in the area of public health. The question can be asked whether the rights of the family members can be seen as a "vital interest" (Article 9(2)(c)) or a "public interest in the area of public health, on the basis of Union or Member State law" (Article 9(2)(g)). Considering that the patient's genetic information also has implications for the health of family members, it is worth considering whether there is a legal backing for the construction of genetic information as familial or shared rather than merely individual. When collecting or disclosing certain genetic information about a patient, the HCP is processing data as defined in Article 4(2) GDPR. The question is whether, in the case of the processing of genetic data, the "data subject" is defined as only the patient from whom the genetic data is derived from, or if the family members can also be considered data subjects. Due to the fact that genetic data may be seen as shared and that it may have direct implications for the family members, they might also be able to be considered as "data subjects" with all the rights that follow from this [9].

Professional secrecy

In Belgium, HCPs have a legal duty to maintain patient confidentiality. This duty is established by Article 25 of the Code of Medical Deontology [18] and Article 458 of the Penal Code regarding professional secrecy [10]:

> Medical doctors, surgeons, health officers, pharmacists, midwives, and all other persons who, by virtue of their state or profession, have knowledge of secrets entrusted to them, and disclose them outside the case that they are called to testify in court or before a parliamentary committee of inquiry… (Article 458 Penal Code; own translation)

Applied to the context of family disclosure of genetic information, Article 458 indicates that it is generally not permissible for a HCP to share genetic information with those other than the patient. However, Belgian jurisprudence has established that there may be exceptional situations in which the duty of professional secrecy would no longer be applicable [19–21]. The conditions for the exception to professional secrecy require that there be a serious, imminent, and actual threat. They also state there must be a balance of interests such that the legal interest to be protected must have a greater value than the legal right or interest that is being overruled. This means that the superseding duty or interest must have a higher legal value than the duty of professional secrecy in order for an exception to professional secrecy to be justifiable. Lastly, the breach of professional secrecy must meet the principle of subsidiarity—it must be the only way to prevent harm.

The question then is whether the exception to the duty of professional secrecy could be applied in the context of family disclosure of genetic information if there was a serious, imminent, and actual threat to the health of a family member. Many genetic conditions could be considered to present a threat to the health of the family member, but whether a particular condition is sufficiently serious and imminent to warrant a breach of professional secrecy depends on the specifics of the condition in question as well as the family history. In conditions where a genetic mutation has a high penetrance, expressivity, and severity, it could meet the grounds for a breach of professional secrecy. For example, a finding of the autosomal dominant *BRCA1* mutation in a patient indicates that other family members are very likely to be carriers. Although a *BRCA1* mutation does not guarantee that carriers will develop cancer, it has been found that female carriers have a 60–80% chance of developing breast cancer and are more likely to develop ovarian cancer, while male carriers face an increased likelihood of developing prostate cancer [22].

In this, and similar cases, the severity and high likelihood of serious health consequences indicated by the presence of a pathogenic variant indicate that a breach in professional secrecy in order to inform at risk family members could be justified. Belgium has a screening program for breast cancer but only for those 50–69 years old, which is later than what is recommended for those with a family history [23]. Thus, when assessing the importance of disclosure, the age of the relatives would have to be taken into account. Furthermore, genetic inheritance and penetrance are complex and in cases where a pathogenic variant indicates a low likelihood of a serious condition developing, the breach of professional secrecy to inform a family member would likely not be justified. If an exception to the duty of professional secrecy were to be allowed in the context of genetics, whether a particular case warranted said breach would have to be adjudicated by health-care professionals based on the particular condition and family history. In summary, Belgian legislation stipulates that HCPs owe patients a duty of professional secrecy, but this duty is not absolute and in the context of genetics, one may argue that in some cases disclosing genetic results without patient consent may be permissible in certain circumstances.

This interpretation of what qualifies for an exception to professional secrecy is supported by recent Belgian legal scholarship. Cornelis acknowledges that while the HCP has a duty to respect the patient's confidentiality, the HCP also has a duty to warn third parties (in this case the family members) of their genetic risk [24]. She argues that when the genetic condition in question is serious and treatable, and the HCP is aware that the patient has not informed their family members, the HCP's duty to provide assistance and their duty to warn supersede their obligation of professional secrecy.

Communication between health-care professionals

While patient-led disclosure is the preferred method for informing family members of their genetic risk, in an ongoing interview study with Belgian HCPs [2], several mentioned the possibility of contacting a family member's clinician to inform them that a genetic condition was identified in the family as an alternative means of informing relatives. This solution to the limits of patient confidentiality is based in the shared professional secrecy of HCPs that is recognized by the legal literature, case law and legislation in Belgium [20, 25–27]. When the persons concerned are both bound by a professional secrecy and they act in the same health-care context, they can share the necessary information to each other with the expressed or implied consent by the patient or within its interest. The shared professional secrecy is also introduced in articles 36-40 of the Belgian Act on the Quality of Health Care Practices ("Quality Act") [28]. The question can be asked whether a HCP can invoke shared professional secrecy to inform a colleague involved in care of a relative who then can inform that relative of their genetic risk. For instance, could a clinical geneticist inform the family member's general practitioner that a genetic condition had been found in the family?

Drawing on shared professional secrecy in such cases is problematic. Firstly, shared professional secrecy requires that both health-care professionals be involved in the diagnosis or treatment of the patient and not of another family member. Secondly, there is the issue of whether genetic information can be shared under the Quality Act or principle of shared professional secrecy when the patient themselves has not given consent. Under the Quality Act (which goes into effect July 1, 2022), the

prior informed consent of the patient is a requirement to gain access to health data [28]. Under the requirements for shared professional secrecy, information can be shared without consent but only when it is in the interest of the patient themselves. Since "patient" is defined as "the natural person to whom health-care is provided, at his or her own request or not", it does not appear that the definition could include a family member for whom the HCP does not provide health-care.

HEALTH-CARE PROFESSIONAL'S DUTIES TO FAMILY MEMBERS

When a patient does not inform their relatives of their genetic risk, it is unclear whether according to Belgian law the HCP may have a responsibility to disclose the information. To answer this, it must be determined whether HCPs owe family members any duties, and whether these duties could supersede the duty of confidentiality owed to the patient.

Duty of assistance

The Belgian Penal Code states that those who knowingly or willingly fail to provide or seek assistance for persons faced with serious and actual danger fail to meet the general commitment to solidarity and are thus liable of culpable negligence. Like the patient, the HCP may also owe the family members a duty of assistance under Article 422*bis* of the Belgian Penal Code [10]. It is accepted that the duty of assistance can, under certain circumstances, be considered as having a higher value than the right to privacy as enshrined in the professional secrecy [20, 29–34]. The reasoning for this has already been established in the context of communication about HIV, both in legal literature and by the National Council of the Order of Medicines. It is unclear whether in the context of genetic medicine, the duty of assistance to the family members can take precedence over the duty of professional secrecy owed to the patient. However, when a genetic condition is severe and actionable (whether through prevention, treatment, or reproductive options), it seems justifiable that the duty of assistance would trump the duty of professional secrecy. It could also be the case that the Penal Code, in outlining the duty of assistance, creates a legal exception to professional secrecy. In this case, the Penal Code would thereby either permit or require HCPs to inform the at-risk family members if it could be established that the family member faced a serious and actual threat.

Civil liability

If a HCP decides not to inform family members about the risk of having a genetic disease, the HCP may not only face liability under the penal code, but may also be subject to civil claims by the family members. In the Belgian legal context, civil liability is outlined by Article 1382 of the Civil Code [35], which states (own translation) that, "any act by a human being which causes damage to another person obliges the person by whose fault the damage was caused to compensate the latter." Article 1383 of the Civil Code states (own translation) that, "everyone is liable not only for the damage caused by their actions, but also for that which they cause by their negligence or recklessness." Together these two articles establish accountability for negligence or imprudence. The civil liability by a person requires the presence of the following conditions: a fault, intentional or not, made by the person; damage suffered by the victim; and a causal link between the fault and damage.

If family members are to bring criminal charges against the HCP, it will be important that it can be proven that Article 422*bis* Penal Code (see above) has been violated or that there has been a breach of Article 418 of the Penal Code. Article 418 sanctions a person who is guilty of unintentionally killing or unintentionally wounding a person, who causes the harm by lack of prudence or precaution, but without the intention of assaulting the person. In a civil case the family members will additionally have to prove a fault of the HCP, damage, and causation. When determining whether a HCP can be said to be at fault, the decisions undertaken by the HCP must be compared with the expectations of a normal and careful HCP placed in the same circumstances. It should be noted that while the standard of "normal and careful" are used to assess whether the HCP is at fault, these concepts are not always easy to define. If the judge decides that a normal and careful HCP in the same circumstances would have informed the family, they will be found to be at fault. If a patient promises to tell relatives and then does not, and the HCP could not reasonably be expected to know this, then the HCP would be unlikely to be found liable. Regarding the condition of damage, the family's current situation must be compared with the hypothetical situation had the family been informed. Here, it is important to note that the family members cannot invoke the damages caused by the genetic disease itself, but rather only the damages caused by nondisclosure. Lastly, the causal link requires the fact that without the fault, there would be no damage for the family.

INTERNATIONAL PRECEDENT FOR INTERPRETATING BELGIAN LAW

In Belgium, it is still unclear whether patients or HCPs have a duty to disclose genetic information to family members at risk or a duty of care. While existing Belgian legislation establishes a duty to provide assistance to those at risk, the question remains whether this duty can be applied in the context of communication about genetic risk. Case law and legal literature from other countries can help to give some insights on this issue.

Patient disclosure

Currently there is no ruling in Belgium as to whether the legal duty of assistance is applicable to patients in the context of communication about genetic risk. In contrast, legislation in France explicitly imposes a duty on patients to inform their family members of their genetic risk when there are prevention or treatment options available [6]. Delineating in which cases this would be required is difficult due to the challenges of predicting risk, as well as defining severity and actionability (notably, the French parliament's revision of the law considers genetic counseling as a preventative measure). In France, the HCP is legally obliged to inform the patient beforehand about the risks of not disclosing a serious genetic disorder to family members. The patient then must either inform their at-risk family members themselves (direct disclosure) or provide the contact information of their family members so that the HCP can contact their at-risk relatives (indirect disclosure). Patients who fail to inform their relatives cannot be criminally sanctioned but may be held liable under civil law.

Considering that such a law obliging patients to inform their family members of their genetic risk does not exist in Belgium, this obligation must be deduced from a non-contractual liability of a patient under articles 1382-1383 of the Civil Code. Similarly, Gilbar examined existing English tort law to see whether there were sufficient grounds for a patient's legal duty to inform their family members of their genetic risk [36]. The English tort of negligence works with the same conditions as Belgian non-contractual liability, namely: duty of care, breach, harm and causation. Gilbar argues that all of these conditions are met in the context of a patient's nondisclosure of genetic risk to their family members. With regards to the first condition of the duty of care, Gilbar cites the foreseeability and proximity posed by a genetic condition if risk information is not communicated to establish that the patient has a duty of care to their family members. If a reasonable person in their position would have informed their relatives of their genetic risk, then the patient can be found to be in breach of this duty according to English tort law. This is notable because Belgian

liability law also determines fault using the standard of what a reasonable person would have done in the given circumstances. Thus, there is support for an interpretation of the Belgian law that would hold patients legally accountable for informing their relatives. Regarding the conditions of harm and causation, Gilbar argues that the harm posed by nondisclosure consists of both the physical harm to the family member's health as well as the harm to their ability to make informed and autonomous decisions. Based on parallels with English tort law, there is support for a broader interpretation of the legal duty of assistance that would also apply in the context of genetics.

HCP disclosure

Belgian law establishes the duty of HCPs to maintain patient confidentiality, but the question remains whether current legislation provides sufficient grounds to establish the HCP's duty to inform relatives, or whether they could at least be permitted to do so. The HCP's duty to inform relatives has recently been recognized in the pivotal UK court case *ABC v. St. George's NHS Trust* [5]. The court ruled that HCPs have a duty to balance the interests of the patient and their relatives and found in this particular case that the harm that could have been prevented had the family member of the patient been informed outweighed the concerns for the patient's privacy. Notably though, this case was concerned with communication about Huntington's disease that is highly penetrant. While the court ruled that HCPs have a duty to balance the interests of patients and relatives, whether the scale would tip in the direction of patients or their relatives is dependent on the predicted risk, severity, and actionability of the particular case. As already outlined, even in the Belgian legal context a case-by-case analysis must be made between the duty of care owed to the family members and the duty of confidentiality owed to the patient. If it could be established that HCPs in some circumstances could be obliged to inform a patient's family members, it would need to be clarified to what lengths a HCP would have to go to try to fulfill this duty.

It is also possible that communication about genetic risk could meet the conditions for an exception to the legal duty of professional secrecy that HCPs owe patients. Belgian jurisprudence has already developed justification for an exception to professional secrecy in the context of infectious disease, but it has yet to explicitly grant the same treatment of inheritable disease [24]. A comparison between the context of infectious disease and genetics to establish a duty of care for family members has been recognized by the American *Safer v. Estate of Pack* case in which the court explicitly stated, "in terms of foreseeability especially, there is no difference between the genetic threat at issue here and the menace of infection, contagion or a threat of physical harm… the individual or group at risk is easily identified, and substantial future harm may be averted or minimized by a timely and effective warning" [37]. An interpretation of Belgian law that allows for exceptions to the duty of professional secrecy in the context of genetics would also align with legislation in Australia, where an exception to privacy legislation permits HCPs to disclose genetic information to relatives in cases where the HCP reasonably finds disclosure to be necessary to lessen or prevent a serious threat to the life, health, or safety of the relatives [38]. Notably, the Australian law requires that patients be informed by their HCP of this possibility during the informed consent process prior to genetic testing [39]. If in Belgium it could be established that patients have a duty to communicate or there is the possibility for HCPs to breach confidentiality, this should be communicated to patients before testing.

CONCLUSION

Current Belgian legislation coupled, with international precedent, may provide sufficient justification to establish a duty to inform relatives of their genetic risk in some cases. While for patients there is a strong case to be made for a duty to inform, for HCPs this duty must be balanced with the duty to respect patient confidentiality. If HCPs have responsibilities towards patient's relatives, there are still questions around what HCPs must do to fulfill that duty—does informing the patient of familial implications suffice or must they track down family members? In cases where genetic risk information could have a significant impact on relatives' health and reproductive decision making, an exception may be warranted to the legal duty of professional secrecy that HCPs owe patients. Although this analysis focused on legislation in Belgium, the discussions could be relevant for many other countries where similar legislative approaches exist. More research on this topic is needed not only by legal scholars, but also by ethicists and social scientists, in order to better understand the perspectives of patients, families, HCPs, and the public on different policy approaches towards this issue.

DATA AVAILABILITY

Data sharing is not applicable to this article as no datasets were generated or analyzed during the study.

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COMPETING INTERESTS

The authors declare no competing interests.

ETHICAL APPROVAL

Ethical approval was not required for this research since it did not work with human subjects or sensitive data.

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