Healthcare professionals' responsibility for informing relatives at risk of hereditary disease

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ABSTRACT

Advances in genetic diagnostics lead to more patients being diagnosed with hereditary conditions. These findings are often relevant to patients' relatives. For example, the success of targeted cancer prevention is dependent on effective disclosure to relatives at risk. Without clear information, individuals cannot take advantage of predictive testing and preventive measures. Against this background, we argue that healthcare professionals have a duty to make actionable genetic information available to their patients' at-risk relatives. We do not try to settle the difficult question of how this duty should be balanced against other duties, such as the duty of confidentiality and a possible duty not to know one's genetic predisposition. Instead, we argue for the importance of recognising a general responsibility towards at-risk relatives, to be discharged as well as possible within the limits set by conflicting duties and practical considerations. According to a traditional and still dominant perspective, it is the patient's duty to inform his or her relatives, while healthcare professionals are only obliged to support their patients in discharging this duty. We argue that this perspective is a mistake and an anomaly. Healthcare professionals do not have a duty to ensure that their patients promote the health of third parties. It is often effective and desirable to engage patients in disseminating information to their relatives. However, healthcare professionals should not thereby deflect their own moral responsibility.

INTRODUCTION

We know that inherited genetic alterations contribute to the development of many diseases. When such variants are identified in a patient, the patient's genetic relatives may also be at risk. For some of these inherited conditions, such as an increased risk of developing certain types of cancer, effective preventive options are available both for the patient and for relatives at risk. Medically warranted risk-reducing surgery and/or surveillance programmes reduce both cancer incidence and mortality in, for example, families with hereditary breast and ovarian cancer and Lynch syndrome.[1 2]

It is widely assumed that in these circumstances, it is the duty of the patient to inform his or her genetic 'at-risk relatives'. The task of healthcare professionals (henceforth 'HCPs') is typically taken to be to support the patient in fulfilling this duty. In this article, we argue that this perspective amounts to a moral failure on the part of HCPs, as a collective, to take responsibility for the protection and promotion of population health, including the health of particular, identified or identifiable individuals.

We propose that, in most circumstances, if a patient's genetic data reveal a pathogenic variant in a high-penetrant disease-causing gene, and if effective preventive measures are available, then an HCP with this information at hand has a moral duty to investigate whether the patient has any genetic at-risk relatives, and, if so, to make sure the information becomes available to those at-risk relatives that may benefit from it. In order to avoid direct conflict with at-risk relatives' possible right not to know, as well as to avoid implausibly demanding requirements, we propose that the duty is only to make information available, not to actually ensure, or control, that the recipients/relatives are informed. However, we will refer to the duty, for short, as a 'duty to inform'.

We believe that the duty to inform is based on the HCPs' more general duty to promote and protect population health, as well as on a duty to empower particular individuals to protect their own health. Typically, HCPs work in groups and the duty may then be collective in nature.

We believe that the current focus among both practitioners and academics on patients' responsibility and duty to inform at-risk relatives is inappropriate and has caused an unfortunate distortion of the debate. What is relevant for HCPs is their own responsibility and their own duties. The relationship to patients must be managed respectfully and constructively, of course, and so confidentiality and trust should be given a high priority when they are at stake. However, the relationship should not include insistence on the part of HCPs that patients inform their at-risk relatives, or behave morally in other ways.

In the following, we will first consider current practice for dissemination of medically relevant genetic information to people at risk. We will also note some main strategies employed for promoting uptake of preventive measures in at-risk families. Against this background, we move on to analyse the strong focus on patients' responsibility, before we develop our proposal to change focus to the responsibility of HCPs. This responsibility is consistent with conflicting values or duties, as we go on to explain. Finally, we consider some practical consequences of the shift of focus, before we conclude.

CURRENT PRACTICE AND PROBLEMS

The effectiveness of cancer prevention in high-risk families mainly depends on the number of at-risk relatives reached and included in surveillance programmes.[3] Uptake of predictive testing for hereditary cancer syndrome has been reported to vary widely (from 15% to 94% in different studies),

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with several studies reporting that less than half of eligible at-risk relatives are being tested.[4 5]

In most countries, current clinical practice is to encourage family-mediated information spreading of a patient's genetic test results. Written information about the investigation and about recommended preventive measures is sometimes provided by HCPs in order to facilitate the spread of information.

Patients typically recognise that they have a responsibility to share information with relatives.[6] Still, because of various factors associated with blocking the information, such as personal feelings of guilt, lost contact and concerns about the relative's reaction, the number of relatives who are informed is limited.[7] In addition, studies show that family-mediated information is often misunderstood or distorted.[8] Jacobs *et al* found that relatives who were informed by patients recalled significantly less accurate information than relatives informed directly by genetics health professionals.[9]

HCPs seem less prone to recognise a responsibility to inform at-risk relatives. One reason may be the unclear legal situations in many countries, where traditional patient confidentiality conflicts with a looser obligation to inform relatives at risk of a severe medical condition. Such situations expose HCPs to the threat of legal sanctions. However, this threat does not fully explain HCPs' reluctance to inform. Consider France, where patients are legally required (Public Health Code: L.1131-1-2) to either inform at-risk relatives themselves, or else request that their physician does so on their behalf. The law mandates that HCPs ask patients to make their choice in writing. This legal framework is explicitly designed to clarify the legal responsibilities and to facilitate the dissemination of information. However, there are many challenges to implementing this new practice.[10–12] A recent report observed that the French legal framework does not remove resistance among HCPs to inform patients' relatives themselves.[13] To the contrary, the report concludes that, with regard to the patients' option of requesting that physicians inform at-risk relatives, 'all effort is made to dissuade the proband [patient] from choosing it'.

ESTABLISHED INTERVENTION STRATEGIES

Most interventions aiming to increase uptake of predictive testing have focused on assisting patients in their communication with their at-risk relatives. Methods include psychoeducational guidance and various information aids. Such extended genetic counselling improves patient's knowledge, reduces anxiety and increases intention to inform at-risk relatives, but its effect on uptake of predictive testing has rarely been evaluated.[14]

An alternative to family-mediated information is healthcare-mediated information to at-risk relatives (from HCPs). Three studies have compared these two alternatives within the field of hereditary cancer.[15–17] The overall conclusion is that uptake of genetic testing increases when at-risk relatives are contacted by HCPs (up to doubling the uptake). Furthermore, this alternative has no identified adverse psychological effects.

In Denmark, a healthcare-mediated approach was officially granted to the national hereditary non-polyposis colorectal cancer registry in 1997. This enables healthcare providers to send unsolicited letters, with information and an invitation to genetic counselling, to members of families with familial and hereditary colorectal cancer. A follow-up study of this service showed that 78% of those receiving direct letters thought it was 'generally okay' to be notified in this manner.[18] Though about half preferred to be notified in some way prior to receiving the letter, 64% reported that it was acceptable to receive a letter also without prior notification. Ninety per cent preferred the unsolicited letter to receiving no information at all, and 66% preferred to be informed by the healthcare system rather than a distant relative. In the USA, a study by Frey *et al* evaluated an initiative of healthcare-mediated information to at-risk relatives by telephone.[19] Among 114 identified at-risk relatives, 92 (81%) underwent telephone genetic counselling and 66 (58%) completed genetic testing. The contacted relatives (with the limitation of a response rate of only 41%) showed low levels of anxiety and distress and high levels of satisfaction with the genetic testing.

Another strategy for increasing uptake of predictive testing in relatives is to put increased pressure on patients to inform relatives. This is one point of the legal requirement in France, mentioned above, which was introduced in 2011. Patients who receive a genetic diagnosis for a serious condition that allows preventive measures are now legally bound to either inform relatives at risk, or to authorise an HCP to do it for them. Patients who fail to comply become liable and can be fined by a judge for the damage caused. HCPs are, meanwhile, legally prevented from communicating genetic information to relatives without the patient's consent.[10 11] As previously mentioned, physicians are reportedly reluctant to inform relatives and seem to consider family-mediated information a strong default.[13]

FOCUS (AND PRESSURE) ON THE PATIENT

Discussion about the dissemination of genetic information in medicine and in medical ethics has focused on two issues: (1) how HCPs should support patients in informing relatives and (2) the potential conflict between patient confidentiality and a duty to warn relatives of severe medical risk. It is generally taken for granted that direct information from HCPs to at-risk relatives is only ever at issue after patients have refused or otherwise failed to inform them. One quality contribution proposes 'shared responsibility' between HCPs and patients and endorses the nudging of patients to inform, but falls back on tradition in claiming that 'it should be clear that [an offer by HCPs to contact relatives] is a means to satisfy a patient's responsibility, not a transfer of responsibilities to the professional'.[20] The assumption is that only patients are responsible for informing at-risk relatives. If HCPs were to be considered responsible, this would be a 'transfer of responsibilities'. Another recent quality contribution proposes the creation of a legal duty of care for third parties (relatives), to complement and balance the legal duty of confidentiality. This duty of care, however, will only 'come to the fore' when 'patients say they refuse to notify their at-risk relatives'.[21]

The strong focus on the patients' duty to inform their relatives probably has several explanations. One is, undoubtedly, that the genetic information obtained by testing a patient is considered to belong to that patient. Indeed, those few who propose direct communication from HCPs to relatives tend to do so on the grounds that the information shared does not belong exclusively to patients, but is collective or 'familial' in nature.[22 23]

In addition, the focus on patients' duties to inform very likely has a historical explanation. As healthcare started to consider suspected inherited conditions, these were often related to syndromes with a clinical diagnosis (without molecular confirmation). Later, the advances in cytogenetic techniques enabled karyotyping revealing chromosomal aberrations, but these findings rarely related to actionable and preventive possibilities (with the exception of family planning and prenatal analyses). HCPs are of course typically focused on the patient in front of

them rather than on the patient's relatives. Thus, during the first decades of genetic medicine, it was more natural for HCPs to discuss with their patients if, how and when genetic information should be shared with relatives, rather than consider warning at-risk relatives directly.[24]

Recent advances in gene sequencing techniques, and identification of disease-causing pathogenic genetic variants for late-onset diseases where preventive options are available have changed the premises within clinical genetics and public health genomics. The genetic information now received may be both actionable and life-saving for at-risk relatives, giving a new dimension to such information. These developments seem to have had little impact on HCPs' attitude to making genetic information available to at-risk relatives. The focus is still on supporting or influencing their patients to disseminate information.[25]

This state of affairs, natural as it is from a historical perspective, is unfortunate. In general, it is *not* the task of HCPs to make patients fulfil their moral duties. A physician who learns that a patient is cheating on her partner or with her taxes is under no professional obligation to try make that patient better her ways. Nor is there a special professional duty to make patients behave morally when this affects other people's health in particular. A physician who learns that her patient is advocating non-adherence to recommended vaccination programmes, for example, at her workplace or in public, is under no professional obligation to stop this. Indeed, pressuring the patient to cease this activity may undermine the relationship with the patient, which is supposed to be focused on the patient's health. HCPs have a duty to protect and promote the health of others, but not a duty to make their patients do so.[i]

SHIFTING FOCUS TO HCPS

We have argued that HCPs have a moral duty to make actionable medical information available to those it concerns, that is, genetic at-risk relatives. We have also argued that it is not the role of HCPs to ensure that their patients behave morally, whether or not the behaviour concerns dissemination of medical information to third parties. The appropriate question for HCPs to ask themselves is not 'how should I support the patient in sharing information with her relatives?' Instead, the relevant question is 'how should I ensure that information is made available to relatives?'

To our minds, the duty of HCPs is based on a more general duty to protect and promote population health. It is possible, as some have done, to describe this duty as a duty to warn, being an instance of the more general duty to rescue.[20] If so, however, we believe that the duty to rescue is itself based on the duty to protect and promote population health.

It is not plausible to base HCPs' duty to inform on a general duty of so-called 'easy rescue', that is, the alleged duty of all moral agents to prevent serious harm at minimal cost to themselves.[26] We accept that there may be such a duty. We also accept that this duty may imply a duty of HCPs to rescue or warn in cases of very serious genetic conditions, where preventive options are available. However, the overwhelming majority of cases of hereditary risk of disease are not sufficiently serious or sufficiently immanent that the general duty of easy rescue will be activated.[27] If a private person, even an off-duty physician, overhears a stranger saying that they have a relative who has an increased lifetime risk of developing cancer, but that the specific relative is not aware of this fact, there is arguably no moral duty to confront the stranger and offer assistance in informing the relative. It may be permissible to do so, but not obligatory.

The duty to inform should be understood as a collective and institutional duty to aid a particular population, within priorities set by costs, benefits and, possibly, need.[28] Ultimately, the duty bearer is society and its elected representatives in government. However, professionals can be appointed to fulfil this collective duty. They can also volunteer to do so by accepting a code of professional ethics.

The at-risk relatives to whom the duty to inform is owed are not merely potential future victims of disease. They are individuals who are identified or else can easily be identified. This may make the duty stronger. It is controversial among philosophers whether people who are identifiable should be given priority over people who are merely statistical, when it comes to avoiding risk or harm. For example, whether we should rescue one person trapped in a well, or rather secure wells to avoid similar trappings in the future, and so benefit a larger number of people, assuming we can only do one of these. There are good reasons on both sides, both consequentialist and deontological.[29] However, there is clearly a widespread expectation that there should be some priority for identifiable people, and the healthcare system in general adheres to this expectation.

That HCPs have a duty to inform relatives does not mean that patients do not have the same duty. Duty and responsibility is not a zero-sum game; two parties may both be responsible for the same thing (three people seeing a fourth person fall in public may all be equally responsible for helping her, and so on). We arguably have greater moral duties to help our relatives than to help just anyone. This in combination with a general duty of easy rescue may give rise to a strong duty to inform on the part of patients. However, as already noted, to what extent patients have a responsibility to inform their relatives has no direct bearing on the appropriate behaviour of HCPs.

The duty of HCPs to inform relatives is not unconditional. It is conditional on costs: larger costs are acceptable if larger risks can be mitigated. This means that the strength of the duty to inform relatives varies with the health risk they face (which depends on the severity and the inheritance pattern of the disease) and also on the degree to which the condition is modifiable (ie, what preventive options are available). It is also conditional on appropriate balancing against other moral duties, most obviously the duty of confidentiality, the duty to uphold the trust of patients and public and the duty to respect the right not to know about one's genetic predisposition. These moral duties will be briefly discussed in the next section. Because of the conditional nature of the duty to inform, it may be better to say that HCPs are *responsible* for making information available, in the sense that they should include this as one of their tasks, set priorities among these tasks and act accordingly.

CONFIDENTIALITY, TRUST AND THE RIGHT NOT TO KNOW

In addition to the unavoidable constraint set by the available resources, there are at least three values that may come in conflict with the HCP's conditional duty to inform relatives. First, the patient may have a legal and moral right to control the

[i]HCPs have both a moral and, in most jurisdictions, a legal duty to prevent their patients from actively harming others due to, for example, being psychotic. Indeed, in some situations, patients may even be detained. HCPs also have a legal duty to trace contacts and warn others if their patient is diagnosed with an infectious disease defined to be a public health hazard. However, this duty to prevent patients from causing harm to others arguably does not extend to patients with a hereditary condition who merely omit to tell their relatives about an actionable finding.

information and so to stop its further dissemination. The standard legal protection for this moral right is the HCP's duty of confidentiality. Laws vary from country to country, but this duty is typically strong. In the UK and Sweden, for example, there is no legal basis for disclosure to others without the patient's consent, even if blocked information could leave others at risk of death or serious harm.

Second, if the patient believes that she has the right to control the information, whether or not this is true, then disclosure of information to relatives, possibly even the suggestion of disclosure, may for some patients damage their trust in the HCPs, or more generally in the healthcare system. Other people who also believe that the patient has the right to control information may react similarly. On the other hand, people with an interest in the information may lose trust in HCPs if respect for the patient's right to control information leads to them not being informed (until later).

Both of these values—confidentiality and trust—can weigh against making information available. When they are negatively affected some sort of balancing or priority must be made. We will not try to resolve how this should be done, except to say that, legally speaking, there should be predictable rules in play to allow HCPs to fulfil, as best they can and within clear limits, their duty to inform, without facing legal complications.

Importantly, what the correct view is on the ownership of genetic information does not affect our position that HCPs are responsible for making information available to relatives, within the constraints set by other moral duties. Suppose that patients own the relevant genetic information, so that it cannot be made available to relatives without patient consent. This does not mean that patients are morally responsible for sharing the information, nor that others cannot be morally responsible for disseminating it further, within the moral constraints set by other moral duties. Consider an analogy. It is the responsibility of the government to build roads. Sometimes, roads must be built over privately owned land. Government employees must then negotiate with landowners, and may in some cases have the right to appropriate land unilaterally. The government does not consider, however, whether or not landowners have a moral duty to give up their land (or build the road) out of the goodness of their hearts, in order to promote or protect the interests of other people. Unilateral appropriation is not based on the possible moral duties of landowners, but on the interest of society (which may in turn also influence the moral duties of landowners). We propose that HCPs should treat the dissemination of genetic information to individuals at risk as the government treats road building. It is their responsibility to carry out this task, with appropriate regard for other moral values.

The third value that may be in conflict with the duty to inform is the right of at-risk relatives not to know about their increased risk.[30] This right is controversial, since some argue as follows: if there is a right not to receive important and actionable information about one's health, its moral basis must be an interest in autonomy. However, important and actionable information about one's own health *strengthens* one's autonomy. Therefore, there can be no autonomy-based right not to know such things.[31] This argument also appears in the more general debate on whether or not we can have good reasons to respect an autonomous choice to become less autonomous. Feinberg has convincingly argued that if the right to autonomy is understood as a right to personal sovereignty, rather than as a good to be promoted, then respect for others' (current) autonomy gives us reason to accept their failing to protect or strengthen their own (future) autonomy.[32] Hence, we believe there can be a right not to know, or at least that people can autonomously choose not to know and that there are then reasons to respect this choice, just like any other choice.

At the same time, the duty to inform relatives is mirrored by their right to receive information. Because the information we are considering is relevant for health and actionable (ie, there are preventive treatments available), we believe the right to know is strong. Since there can be interests and rights on both sides, it is important to consider proportions. If a large majority of the population do not want to be informed about their hereditary risks, then their right not to know may arguably outweigh the right to know of a small minority. As it happens, however, studies from Sweden, Norway, Denmark and the USA indicate that the majority do want to know.[18 33 34] In a fictive situation where a condition is fatal and preventable, another study showed that only 5% would not want to know.[35]

INDIRECT AND DIRECT STRATEGIES

We have argued that HCPs have a duty to make relevant genetic information available to at-risk relatives, or, in other words, that it is the responsibility of HCPs to ensure that information becomes available to them. We have explained that other moral duties may prevent dissemination in some cases, but that this does not undermine the general claim that HCPs should be focused on making information available to at-risk relatives, not on the moral duties of their patients.

If our proposal is accepted, there remain several practical issues concerning how information is best disseminated. Importantly, relatives can be informed either *directly*, by for example, certified mail or phone from HCPs, or *indirectly*, by engaging the patient as a mediator. In both scenarios, the patient will often be needed to identify *who* the relatives are and, sometimes, *how* to reach them, for example, to find their postal addresses or telephone number. Under the indirect strategy, the patient is encouraged to convey the information to the relatives herself, by for example, phone, email or face-to-face meeting. If this strategy is used, HCPs should ensure that their moral responsibility is not inappropriately deflected onto the patient. As noted above, the patient probably has a moral duty of her own to inform her relatives. However, this does not mean that the patient should also relieve HCPs of their duties (that both me and my brother have a moral duty to help our father with some important task does not mean that I can limit my contribution to supporting my brother in fulfilling his duty).

At the same time, that HCPs have an independent duty to inform does not mean that they should not involve patients in fulfilling this duty. To the contrary, patients should be seen as allies and assets. In many cases, the most efficient method by which information can be made available to relatives is to have the patient share it with them. To continue the analogy with road building, there is no general expectation that landowners should contribute to the building of roads, but with some imagination we can conjure up circumstances where their cooperation would be very helpful, or even crucial, such as in an area where the locals have unique knowledge and experience of the terrain and therefore unique abilities to traverse it.

Studies on patients' attitudes to informing relatives at risk of hereditary disease have mainly recruited patients with experience of family-mediated disclosure.[6] These patients often prefer what they have experienced, that is, family-mediated information.[6 36] However, this is not a good indication that future patients and relatives have this preference. For one thing, it is rational to prefer what one has experienced and found satisfactory over

something that one has not experienced and so has not been able to evaluate. We therefore think that a documented appreciation for family-mediated information among people with experience of it should not be our only reference point when deciding on future practice. In fact, preferences among those without personal experience of either strategy may be more relevant. For example, two studies on attitudes in the general population indicate that the majority would prefer healthcare-mediated information over family-mediated information in a fictive situation of being a relative at risk of hereditary colorectal cancer.[18 37]

CONCLUSION

We have argued that when HCPs learn that a particular individual, who is not currently a patient, is at substantial risk of having a hereditary condition, and when there are medically warranted preventive measures available to that individual, then HCPs have a moral duty to make this information available to her.

We have argued further that this duty is conditional on available resources as well as on balancing against other moral duties. However, it is the HCPs who must consider these potentially conflicting duties, set priorities and act accordingly. Though patients may also have a moral duty to inform their relatives, it is not appropriate for HCPs to insist that this duty is fulfilled, just as it is not appropriate more generally to insist that patients fulfil their moral duties. HCPs should encourage patients to be involved in making information available to their relatives because this is an efficient strategy, but not because of the moral duties of the patients.

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