Patients’ Rights

PATIENTS’ RIGHT TO PRIVACY AND PUBLIC INTEREST

David A. Frenkel* and David M. Wood**

Abstract: The relationship between public interest and privacy is complex, particularly in healthcare. If public interest overrides the right to privacy, medical staff may be forced to break confidentiality beyond what is permitted by law. Should politicians be excluded from the definition of “patients” when confidentiality is concerned? Should that “exclusion” be broadened to include judges and other public figures, for example, leaders of industry? Would it not be reasonable to entrust a medical team, who may assess their health state and inform the public of their assessment without divulging private medical data? Nothing will prevent any person from revealing their own medical state to the public; nonetheless, it should be at their discretion. Once a person dies, his right to privacy of health information should be with his heirs. Voyeurism should not be elevated to become a tool for legalising violations of health confidentiality.

Keywords: Confidentiality; Medical Data; Privacy; Public Interest; Public Health; Employment; Healthcare.

INTRODUCTION

Medical and health confidentiality is deeply rooted in our society. It is one of the first recorded professional legal and ethical duties a member of the medical professions should obey and follow as part of the Hippocratic Oath. Maintaining the confidentiality of medical information is one of the few universally accepted ethical rules. The leaking of private information can change lives. There is an uneasy relationship between the concept of public

* L.L.D., FRSPH, Emeritus Professor, Faculty of Business and Management, Ben-Gurion University of the Negev, Beer-Sheva, and Professor, School of Law, Carmel Academic Centre, Haifa, Israel. E-mail: dfrenkel@som.bgu.ac.il.

** Ph.D., SRPharmS, Department of Pharmacy, King’s College London, UK.

*** This is a revised version of a presentation given at the 6th International Conference on Information Law and Ethics (Thessaloniki, Greece, May 30-31, 2014).
interest and notions of privacy. Intrusion into a person’s private life, including private health information, is often justified in terms of serving the “public interest”.

PRIVACY AND CONFIDENTIALITY

While it is often difficult to define, there are legal definitions of infringements of privacy. In France, for example, Article 226-13 of the Code Pénal, declares breach of professional secrecy an offence. Article L. 1110-4 of the Code de la santé publique recognises the patients’ rights to medical secrecy and imposes the duty of confidentiality also on all health providers and staff members of health care institutions. Article 4 of the Code de déontologie medicale makes it binding as an ethical rule.

The Netherlands introduced the Heilwesengesetz (New Dutch Medical Services Act) (WGBO) in 1995, which has been incorporated into the Bürgerliches Gesetzbuch (Civil Code). As discussed by Stolker and Slabbers the Dutch legislature treats the doctor-patient relationship as a civil law relationship. Article 7:457 of the Civil Code imposes the duty to observe professional secrecy on the medical profession.

In Italy, breach of professional secrecy is an offence (Article 622 of the Criminal Code) while patient rights, including professional confidentiality, are regulated by the Code on Medical Ethics which, while not legally binding, is followed and respected by the medical profession.

Health information and medical data in Poland are protected by the Medical Professions Act of 1996 and the Patients’ Rights Act of 2008, not directly through privacy but through doctor-patient confidentiality.

In Israel, section 1 of the Protection of Privacy Law of 1981 states that, “no person shall infringe upon the privacy of another person without the other’s consent”. Section 2 defines that infringement of privacy includes “publishing of any matter relating to his intimacy, including [...] his health condition

[...]” The Patients’ Rights Law imposes a specific duty of confidentiality on all medical personnel. The right of privacy in Israel has been elevated to the level of a constitutional basic right in Basic Law: Human Dignity and Liberty.

Though many countries have legislation to protect privacy in general, not all countries have clear legislation to protect privacy of health information.

The European Convention on Human Rights, for example, does not refer to health privacy. Article 8.1 of the Convention, whose title is “Right to respect for private and family life” states: “Everyone has the right to respect for his private and family life, his home and his correspondence.” However, this is not a right to privacy. Furthermore, Article 8 must be balanced with Article 10 which guarantees freedom of expression. As stated by instructors at the Open University in UK, this is significant when the press is alleged to have breached an individual’s right to privacy.³

Even after the Human Rights Act 1998, there is no right to privacy in the UK’s law. Though, the doctrine of breach of confidence has been developed by the courts and provided limited right to privacy. The Calcutt Committee in the United Kingdom stated that, “nowhere have we found a wholly satisfactory statutory definition of privacy”.⁴ However, the Committee added that it would be possible to give privacy a legal definition and further adopted such a definition in its first report on privacy: “The right of the individual to be protected against intrusion into his personal life or affairs, or those of his family, by direct physical means or by publication of information”.⁵ Among the duties of a doctor registered with them, the General Medical Council in the UK stated the duty “to respect patients’ right to confidentiality”, and to “never abuse your patients’ trust in you or the public’s trust in the profession”.⁶

In general, legislators, as well as medical professionals, accept the principle that the duty of confidentiality regarding health information is not absolute. They agree that there may be exceptions and even confidential information may be disclosed in three cases:

- a) When the patient, if legally capable, consented to or asked for the disclosure, or the information is disclosed to health professionals involved in providing treatment to the patient;
- b) It is required by law or by international conventions, e.g. creating or processing a health data registry, provided the individual’s rights to privacy are protected;
- c) For the sake of public interest, e.g. disclosing reportable infectious diseases to the appropriate health authorities and in cases of alleged criminal acts (though legal regulations may demand specific permission by authorities, such as the court or the district attorney).

PUBLIC INTEREST

What “public interest” is must also be defined. Not everything that interests the public or individuals in the public is necessarily in the public interest. There is a difference between the public interest and the interest of the public. 7

As stated by Laurie et al, “it is a public interest to protect individuals’ rights to privacy and confidentiality. Public interest is different from interests of the public or communities or groups, large or small, which are part of the public. Interests of such groups are more likely to infringe upon individual rights to privacy, confidentiality, and dignity. Public interest may encompass contradicting attitudes. Public interest is not an absolute one”.

Powers has phrased it by stating that “A commitment to privacy rights does not entail a commitment to absolute rights”.

Ashcroft has exemplified the possible contradictions by writing: “there is a public interest in the effective […] administration of […] criminal justice; but there is also a public interest in restraining undue […] surveillance of our personal lives.”

What is, therefore, public interest, and what exactly constitutes public interest? Is it necessary to find out how many want to know or how many may benefit from or would be affected by the information? What is the degree to which the ends of the individual members of society should be the ends of their society? Should public interest be identical to, or should it be connected to the idea of human rights? Häyry and Takala stated, “Public interest is a diffuse matter and respect for it can mean many things. Some of which cannot always co-exist peacefully”.

According to Cathcart, “Two distinct meanings of the word ‘interest’ are at issue: in one we give our attention to something because it has the potential to do us good or harm; in the other, we are merely curious. The distinction is explicit in the difference between the negatives: ‘disinterested’ and ‘uninterested’. For journalists there are subjects which are in the public interest but which the public doesn’t find interesting. […] And equally there are stories which interest the public but have no potential to make the reader better or worse off in any meaningful way […]”.

We should define public interest as a relative concept of a private or individual interest, and not as an absolute interest. Some acts, as public interest, may be

---


good for some individuals and bad for others. By that we will be able to hold constant private interests in order to determine those interests that are unique to our society. Krasner\textsuperscript{14} tried to analyse cases in order to identify national interests when no corporate interests were found in the US foreign policy. Different approaches may lead to various definitions. It seems that it would be impossible to draft an undisputable definition of public interest, which will be accepted by everyone, or perhaps there is no need for it to be defined. However, broadly speaking, public interest should include acts or conduct which further society's best interests as well as protection of the general public from harm.\textsuperscript{15} It is also possible to state that it should include promotion of collective interests.\textsuperscript{16} However, we should be very careful when speaking of collective interests. They may lead to interests of groups in society, especially in non-liberal communities, who are willing to stigmatise groups, either because of their origin, race and ethnicity, their culture, behavioural preferences or views. It is important to guarantee that people will not be discriminated against on the basis of their genetic profile and that one's right to full medical insurance will not be lessened. We should try, therefore, to limit the meaning of public interest in order to safeguard the individual rights to privacy and confidentiality.\textsuperscript{17}

CONFIDENTIALITY v. THE PUBLIC RIGHT TO KNOW

As we noted, medical confidentiality is not absolute. It is generally accepted that public health needs, and threats to other people, may lawfully override the patients' right to confidentiality. However, President Ronald Reagan initiated a change in this matter. Early in his presidency he decided to go public regarding his wearing a small hearing aid. A few months after he had been re-elected for his second term as President, he made public that he was going to undergo surgery to remove cancerous polyps from his colon and all through his second term as President he made public all the operations and treatments he underwent. All these health problems and surgeries did not prevent him from


continuing his presidency in full. A question might be raised – would he have been elected or re-elected had he publicly announced his health problems before the elections? By publicising his health problems, Reagan made them a part of the “public right to know”.

President Reagan created a new situation for politicians, which has become standardised across the developed world. His idea to confront the conflict between individual privacy and the public right-to-know was well thought out, and he revealed the information only when he knew he would be legally unable to be re-elected. Until then, all of the presidents’ medical and health issues were kept secret and confidential. The extent of President Reagan’s health problems during his first term, excluding the hearing problem, was made public only after he completed his second term.

The conflict between the right to privacy and the public right to know is heightened when a political figure seeks office. People may be concerned if candidates cannot finish their terms. This was not the view of President Clinton during his election campaign, when he promised to open his medical records, should he be elected. However, he promised to make medical information available to the press immediately only a day after The New York Times published that a physician reporter, L. Altman, wrote that “Mr. Clinton has been less forthcoming about his health than any Presidential nominee in the last 20 years”.

Politicians already elected to their office, are not always happy when their medical information is released, even when they have authorised disclosure of

18. There are many examples of poor health being a factor in a politician’s downfall and failure to be elected. Other examples show the opposite and politicians with poor health continuing their political careers. See Tossell EJ, Goldman J. President Health: Do we have a Right to Know? (1 April 2004) iHealth Beat, available at: http://www.ihealthbeat.org/perspectives/2004/presidential-health-do-we-have-a-right-to-know?view=print (Accessed 24 October 2014).
their medical state. President Reagan was very disappointed for many years, after one of the NIH’s doctors reported - after the removal of cancerous polyps from his colon during the colonoscopy, which everyone was invited to watch over the surgeon’s shoulder on TV - that “The President has cancer” instead of saying “the President had cancer”.23

It is not easy for a politician to go public with personal health information. However, is every citizen capable of understanding and evaluating the medical information delivered in the press, which may or may not be objective?

One of the results of President Reagan making politicians’ health matters part of the people’s “right to know” has been that divulging medical information by a politician is considered as a matter of honesty. However, being honest can potentially be a ‘lose-lose’ situation for a politician.24

As people may disapprove of their capabilities, as interpreted by their competitors, politicians who disclose their medical matters, may lose their election. If they lie about their health or capabilities, and then the deception is discovered, voters might no longer respect them, due to their dishonesty. Politicians who hide their health matters and refuse to release information would be treated as persons who have things to hide and, thereby, as being dishonest. A report from CNN.com stated: “In today’s political environment, saying no is tantamount to admitting there is something to hide and so many candidates have taken to releasing sometimes voluminous medical records in an effort to answer questions and thwart further digging.”25

Should the health of politicians be public domain, and politicians be excluded from the definition of “patients”, where is confidentiality concerned? The health of board members of industry may have an effect on their ability to run the company and consequently the share prices and investments of private

individuals. Should that “exclusion” be broadened to include judges and other public figures, for example, leaders of industry, sports or television? Should public figures be entitled to protection of their privacy, in matters of health? If public interest overrides the right to privacy, medical staff may be forced to break their ethical and legal duty to confidentiality beyond protection of public health, public security and serious social public interests.

The guidelines published by the Council on Ethics and Judicial affairs of the American Medical Association instruct physicians to “cooperate with the press to insure that medical news are available more promptly and more accurately than would be possible without their assistance”, provided that their patients have authorised them to disclose their medical information. Should the patient disagree, the American Medical Association advises physicians not to release any information? The view of the American College of Healthcare is that “society’s need for information rarely outweighs the right of patients to confidentiality”. The US National Institute of Health (NIH) recommends that “if a patient attracts media attention”, NIH will consult with the patient “on what information, other than the fact of hospitalization or condition, may be released in response to a media’s request”.

Tossell and Goldman call on professional medical associations to join with the media and consumer advocates in order to create a standard that guides disclosures of potential presidential candidates’ medical records.12 However, if accepted; it may be applied to any candidate to other posts. As a starting point they suggest the following principles:

- Candidates must consent to the release of their medical information before it is made public.
- In most instances, a summary of a candidate’s medical records should be sufficient. This will protect the confidentiality of a provider’s subjective notes.
- A candidate should be able to withhold certain health information from public disclosure if the information is irrelevant to the candidate’s ability to perform the duties of president and would jeopardise one’s willingness to seek and receive certain care.26

RULE OF PROPORTIONALITY

In dealing with such delicate and borderline cases related to a violation of the right to privacy, we propose applying the rule of proportionality in each individual case. Three tests are required in order to meet the rule of proportionality:

- The first is the test of effectiveness: the measure taken should constitute an effective means for the realisation of the aims or targets pursued by that measure.
- The second is the test of fair balance: there should be a fair balance between the aims pursued and the interests harmed.
- Finally, the third is the test of necessity and subsidiarity: the measure taken is necessary to achieve those aims and no alternative which is less intrusive is available.

CONCLUSION

In relation to political candidates, Kahn put out the question: “Worried about fitness or just plain voyeurism?” His answer is: “[…]. It seems that all we really need to know is whether a candidate is physically and psychologically fit to hold office, an assessment most people would be comfortable leaving to trained and unbiased professionals. Once a candidate is pronounced “fit to serve” any digging for further information starts to look more like reality-


based programming than investigative journalism. [...] voyeurism is not a
good enough reason to violate medical privacy".29

We endorse Kahn’s idea. It follows also the view expressed by George Annas
that “the only medical information to which the public should be entitled
is information that indicates, to a reasonable medical probability that a
presidential candidate will not survive a four-year term, or will not be able to
function mentally in a reasonable manner”.30

This approach applies the third test of the rule of proportionality - the test of
necessity and subsidiarity. Is there any alternative which is less intrusive to
achieve the same aims?

The assessment of the health condition of politicians or those in high positions
in business, sports and television, which may seriously affect their ability to
carry out their job to the extent it may affect the entire country or specified
public, may be revealed to the public who may be affected, only in the
event they may become incapable of functioning. It is not the details of the
health problems that should be revealed but only the concluding assessment
regarding the inability or incapability to function, either permanently or only
temporarily. This is the information the public should be entitled to know. In
case that person is unable to function – is it permanently or only temporary?
However, if that person decides to step down or quit, before the assessment has
been produced, no such an assessment should be made public. The reasons for
stepping down or quitting should be left to him, should he decide to give any.

In cases of political functionality, the decision should be laid in the hands of a
statutory pre-nominated medical committee. The members of such a committee
should be appointed and act according to clear and specific regulations set
beforehand. This committee should be empowered to collect all necessary
medical information from the treating physicians and other medical staff, and
submit their conclusions to the appropriate body who would decide how to

October 2014).
30. Cited in Tossell EJ, Goldman J. President Health: Do we have a Right to Know? (1
presidential-health-do-we-have-a-right-to-know?view=print (Accessed 24 October 2014)
and in Annas GJ. The Health of the President and Presidential Candidates. The New
proceed (e.g. transfer powers to deputies, calling for new elections), depending on the medical conclusion, which may be different in case of temporary inability compared to a permanent one.

Whenever medical assessment is needed, the same principle should be applied in all other fields of life, without divulging medical details. Employment relationships may serve as an example. Employees are entitled to health privacy. The assessment of the physician, and when necessary of the occupational doctor, for fitness to work, what kind of work, as well as for sick leaves, should be enough without giving medical details. Here, too, the least intrusive option is used and achieves the aims of effectiveness and fair balance. The doctor-patient confidential relations are least infringed upon.

Nothing will prevent any person from revealing their medical state to the public - as this is their right, even if it is only to create empathy and better public relations. However, it should be at their discretion.

The same rule should apply also regarding health information of a deceased. The view of the US Court of Appeal in 1969, which has since been followed by other US Courts, was that “only the person about whom facts have been published without authorization may recover. Consequently, the right lapses with the death of the deceased and nobody can recover for this kind of invasion as being the infringement of the privacy of a relative, no matter how close the relationship”.31

Unless public health matters or criminal proceedings demand otherwise, any demand of disclosure of health details of the deceased is, in our opinion, sheer voyeurism. Kahn stated: “voyeurism is not a good enough reason to violate medical privacy”32. We believe this to be true even when the patient has died. The deceased’s heirs should have the right to decide what information could or should be revealed, if at all.

---