

# The Moral Framework of Confidentiality & the Electronic Panopticon

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## 1. INTRODUCTION

Patients' faith that what is said in the consulting room stays in the consulting room is utterly necessary for effective psychotherapy. Unless a patient has complete confidence in the confidentiality of the process, s/he won't be candid about matters that are embarrassing or shameful and certainly not about matters that may involve moral turpitude or illegality. Although few would disagree about the importance of confidentiality in psychotherapy, there is considerable controversy about its limits, that is to say, about the circumstances under which it may justifiably be breached. So far, this debate is mainly structured around two lines of argument. One line, the main reference point of which is the *Tarasoff v. Regents* (1976) case, debates the limits of confidentiality vis-à-vis the so-called "duty to warn", i.e, duty to prevent harm. The second line, exemplified by *Jaffee v. Redmond* (1996) and in Canada by *R. v. Mills* (1999), debates the limits of confidentiality vis-à-vis the need for probative evidence in the administration of justice.

However, a new context in which limits of confidentiality are asserted is emerging. We believe that it deserves a *lot* more attention than it is receiving. It is related to monumental changes in the health system generally. Two related trends are particularly relevant to confidentiality in psychotherapy.

The first is the trend to computerization. In digital form, information can be more readily and inexpensively searched, reproduced, indexed, collated, aggregated, and shared. This considerably enhances its usefulness or value for a variety of purposes, including financial and social policy purposes. Second, as information becomes easier to use, new policy contexts are creating bottomless demands for ever more health information. The new watchwords are "accountability", "audit", "quality assurance", "research", "efficiency", "evidence-based" and "cost effectiveness". All these objectives are information hungry.

These trends have resulted in arguments that breaches of confidentiality are justified that have nothing to do with the old considerations of prevention of harm and the administration of justice. The old context focussed on prevention of individual harms. The new context focuses on broad social objectives and the benefits that informed social policy can confer. Indeed, the very concept of confidentiality may be shifting. This new context, in our view, has not received the attention it

deserves.

Throughout the western world, psychotherapy has been less integrated into the general changes that health system is undergoing than most other areas of health care practice. Experience in places where that is beginning to change, for example in the United States with the introduction of managed care, suggests that where psychotherapy does become more integrated, it immediately begins to feel the same confidentiality-threatening pressures (see, for example, Kremer and Gesten, 1998; Tuckfelt et al, 1997). In this new context, not only payers and insurers but also auditors, researchers, licensing bodies, governments, and other members of the health care "team" seek access to information for reasons and under circumstances that have little or nothing to do with traditional claims about "third party harm" or "administration of justice". Psychotherapy everywhere is bound to be drawn increasingly into this new context.

In this paper, we want to map the territory of this change, elucidating certain foundational issues and delineating the dimensions of the shift. We begin by laying out a framework of ethical concepts for thinking about confidentiality and justifications for breaching it. Then, using this framework, we show what the traditional way of thinking about confidentiality was like and just how different the concepts that animate the new context are. These differences matter because policy issues concerning health information appear very differently depending on which conceptualization one adopts and one will be inclined to very different resolutions of issues concerning confidentiality. Next we sketch some aspects of the digital revolution in health information management that have led to the development of these new concepts and lay out some of the financial and policy developments behind the ever-increasing demands for health information. First we examine the digital revolution as it is affecting health care generally, then we turn to the threats and promises of information technology for psychotherapy specifically.

Matters of great importance are at stake as "the information age" becomes a major factor in health care. The final judgement about whether changes underway today will prove to be for good or ill will turn on choices that we will soon have to make, indeed in some cases are already making. The values we affirm or negate in making — or even in not making — these choices are not just about technology but about what counts as ethical treatment of people, therapeutic relationships and what the rights and responsibilities of everyone involved are. Ultimately, they are about the kind of society we are and wish to become. As we said, surprisingly little attention has been paid so far to the ethical, legal, and social issues to which the increasing use of information technology in health care

give rise.

## 2. TWO MORAL FOUNDATIONS FOR CONFIDENTIALITY

There is clearly a tension between the demands of confidentiality in psychotherapy and a variety of worthwhile social objectives concerning the health system: research, disease tracking, better health care, more efficient health care, control of irresponsible or abusive health care professionals, and so on. Where one comes down on the spectrum of possible resolutions of these tensions will be profoundly affected by how one understands confidentiality and what gives it its value.

Confidentiality is closely related to privacy and the value of confidentiality is linked to the value of privacy. Here is how we understand the two:

**Privacy** concerns the subject of information and his or her rights or interests with respect to whether others come into possession of that information and if so, who and under what circumstances.

**Confidentiality** concerns anyone who has come into possession of such information and his or her duties in connection with respect to sharing or not sharing that information with third parties.

To say that information is private is to say something primarily in relation to the subject of the information; to say that information is confidential is to say something primarily in relation to someone other than the subject to whom the information has been revealed.

Of these two issues, the important one for psychotherapy has always been confidentiality but let us say just a word or two about privacy. Privacy is a notoriously elusive concept, and different definitions highlight different aspects of the phenomenon. Commentators typically begin with Chief Justices Warren and Brandeis' (1890) famous "right of the individual to be let alone". Confidentiality would then be the right to expect that those to whom one discloses information will not allow it to be used so as to interfere with one's right to be let alone. In psychotherapy, confidentiality protects the patient's right to be let alone to explore personally important issues with another person without anyone else knowing about it. Privacy and confidentiality here are as much about freedom to reveal as freedom to conceal. The key thing is to be able to prevent or control access by third parties.

Confidentiality and privacy are closely linked. Confidentiality is important because privacy, i.e.,

being able to do or say certain things without others coming to know about them, is important. Nonetheless, confidentiality is the central issue with respect to psychotherapy and it is the one on which we will concentrate from now on.

### **2.1. *Two Bases for the Value of Confidentiality in Psychotherapy***

When may confidentiality justifiably be breached? This is where the two contexts that we sketched earlier enter. Let us call them the *traditional view* and the *emerging view*.

#### **Traditional View**

On the traditional view, confidentiality is vital to the therapeutic process. It has a close connection to the right to keep information about oneself private if one so chooses. On this way of thinking, information about a patient can be disclosed only under very special conditions (usually including rigorous protection of identity) and/or only for very powerful countervailing reasons, e.g., to prevent serious harm or a serious miscarriage of justice, the reasons introduced at the beginning of the paper. The question of who has the right to release or consent to release information is fundamental. In traditional liberal theory, consent on the part of the person whom information is about is at least a necessary condition for justified disclosure in contexts like the current one. Since, as we will see, consent is itself a vexed notion in psychotherapy where transference, primitive regressions, and so on may be taking place, in practice the therapist takes the patient's place and makes the decision as to when, if ever, circumstances are sufficiently severe to warrant a breach of confidentiality.<sup>1</sup> This role is not unlike schools acting *in loco parentis*.

#### **Emerging View**

On the view that is emerging in the context of the new technologies and new demands for health information, confidentiality is viewed as a matter of protecting or prompting patients' *interests*, not a matter of rights of the patient or duties of the therapist. On this new view, the question of under what conditions a patient's interests are protected (by deleting identity, aggregation, and so on) is not necessarily a matter for the patient or even the therapist to decide. This question can legitimately be decided by third parties, for example, insurance companies, policy planners, legislators, or the courts.

Clearly, the traditional view is the view of most psychotherapists and the emerging view is advanced

by policy planners, insurance companies, legislatures, and the courts and on the basis of general social benefits that may result, not (or not just) the rights and duties of the individuals involved in the therapeutic relationship.

## **2.2. *The Foundations of the Traditional View***

The traditional view, as we will see, has two main foundations. One is rooted in the dignity and autonomy of the individual. The other is rooted in the value of psychotherapy and therefore the value of the conditions for doing it successfully.

The traditional view is not without its stresses and strains. Liberalism with its emphasis on the value of liberty and the human individual is the underlying political philosophy of the democratic world. It might be thought that the traditional view of the values and limits of confidentiality flow out of liberalism in a fairly direct way. Interestingly, that is at most only partly true. Let us start with what a strict foundation in liberal theory for the value and justifiable limits of confidentiality might be like, then look at how the foundation in liberal theory gets modified or supplemented in actual debates about confidentiality within the traditional view.

### **Pure Liberal Basis for Protecting Confidentiality**

On a pure liberal justification for the traditional view, individuals have a right to privacy and confidentiality, a right that flows from the value of autonomy and dignity. To be autonomous, to have dignity, with respect to something it is at least necessary that you control it, that what happens with respect to that thing is solely up to you. Either your decision or your consent is required for anything to happen justifiably with respect to that thing. Put differently, with regard to a domain over which one has a right to autonomy, one has a right to exclude others.

On this account, confidentiality protects autonomy and dignity. Usually the best way to ensure protection of autonomy is to guarantee that those affected have control over matters of concern to them. When these are matters of information, to have such control entails that information can be released only with the consent, in fact the informed consent, of the person concerned. Informed consent is therefore central. Defending confidentiality (and privacy) on the basis of preservation of autonomy and dignity goes with arguing for tight limits on the right of the state or other third parties to intervene in the lives of individuals.

That is a strict liberal defence of what the right to confidentiality might look like. The key point is that confidentiality is viewed as necessary for protection of autonomy. In practice, psychotherapy has always modified pure liberalism in two significant ways, even prior to the new context sketched earlier. The first flows from the problem about informed consent that we have already introduced.

### **Consent and the Psychotherapeutic Dyad**

Because of transference (the rekindling of ancient, powerful feelings in a patient, now directed at the therapist), regression, and so on, consent in psychotherapy, as we said, is more complicated than pure liberalism would suggest, in at least two ways. First, patients are often highly dependent on the therapist emotionally for a period of time, to such an extent that even their capacity to judge situations in the therapy accurately may be affected. Second, some therapists tend to believe that they know what is in the best interests of their patients, sometimes even better than the patient him- or herself. For both these reasons, in psychotherapy, therapists tend to act as their patient's agent in the matter of deciding what information gets released, to whom, and in what form (usually without the patient consenting to the therapist assuming this role). That is, the therapist makes decisions for the whole patient/therapist dyad.

When this happens, it is clearly paternalistic and contrary to liberal principles, as many therapists realize, but they believe that they are better able to exercise the function of giving or withholding consent on behalf of both parties than the patient is. From a liberal standpoint, this practice could certainly be questioned, consent being what determines whether information can be disclosed or not for liberals. One of the few places where there is anything close to a consensus that patient consent is not definitive in therapeutic relationships is with respect to sexual relationships with therapists. Even if a patient consents to a sexual relationship, that consent, it is now generally accepted, does not absolve the therapist from blame for entering the relationship. However, this situation is different from the situation with respect to release of information. In the sexual relationship situation, consent is not sufficient but lack of consent would make the violation even more egregious. In the situation with respect to information, consent is not even necessary – whatever the patient's view, it is the therapist who makes the decision about release or non-release of information.

As we said, therapists assuming the right to make decisions on behalf of patients with respect to disclosure or nondisclosure of information could be questioned from a liberal point of view. Nonetheless, it is a standard feature of much psychotherapeutic practice.

## **The Harm Principle in Psychotherapy**

The second place where at least some psychotherapists depart from pure liberalism concerns what is often called the *harm principle*. Indeed, people holding the traditional view often experience some real conflict over the harm principle.

Most liberal theorists subscribe to the view that the autonomy rights of one person can be infringed or restricted when it is necessary to do so to prevent harm: certainly harm to another, perhaps even harm to self. A well-known example of this harm principle is Mill's example of shouting "Fire" in a crowded theatre: if acting as you wish here will create significant risks for, or cause significant harm to, others, your right to act as you wish can justifiably be abridged.

In psychotherapy, the harm principle gets invoked in at least four contexts:

1. where the patient reveals that he or she intends to or is harming another or others,
2. where the patient reveals that he or she has harmed others, and,
3. where the patient reveals that he or she intends harm to self.
4. where the information is needed in order for the courts to treat someone else justly.

The first is the land of *Tarasoff* — the patient in this case revealed that he intended to harm his estranged girlfriend. The second is the realm of boundary violations and abuse to children and the reporting laws that go with these things in many jurisdictions — if you reveal to your therapist that you have abused a patient or a child, she is legally obliged to report you. Notice that the exception in this case is quite different from the case of shouting "Fire!" in a cinema. In this case but not in the standard case in liberal theory, the issue is not risk of causing harm, it is harm already caused. The third is the domain of suicidal patients — if you reveal that you intend to harm or kill yourself, that is sufficient in many jurisdictions to allow your confidentiality to be breached in any way necessary to have you committed to an inpatient psychiatric care facility involuntarily. The fourth consideration comes up most frequently where someone has been accused of sexual or other abuse and either the accuser or the complainant, being in therapy, may have said something to his or her therapist relevant

to determining the truthfulness of the accusation.

The trouble is this. Whereas within liberal theory, the harm principle is widely accepted, in psychotherapy it is controversial. There is simply no agreement among psychotherapists about when, or even if, a patient's right to confidentiality can legitimately be abridged in any of (1) to (4). As *Tarasoff v. Regents* shows, there is no agreement over whether a patient's right to confidentiality or the therapist's duty of confidentiality can legitimately be overridden and third parties informed *even when* the patient has expressed a clear and credible intention to harm or kill someone else. There is a similar controversy over whether a breach of confidentiality can be justified even when the patient has expressed (clear and plausible) plans to commit suicide, or has confessed to abusing a child or a patient. In our judgment, there is not likely to be any general agreement here. Two values fundamental even within liberal theory, namely, preserving the confidentiality of the patient and protecting others or punishing a perpetrator are at war and there is no easy way within an autonomy-based approach to confidentiality to reconcile them.

On the issue of consent and the issue of harm, then, many psychotherapists part company with a traditional liberal analysis of the value to confidentiality and the conditions under which it can be abridged. However, psychotherapists within the traditional approach do not just modify liberalism when they set out to justify confidentiality. Many of them add an entirely different kind of justification, one based on *social good*.

### **A Social Good Basis for Protecting Confidentiality**

When psychotherapists and others switch to an argument based on social good for confidentiality, the social good to which they usually point is the social good of psychotherapy itself. Effective psychotherapy, the argument runs, is a good thing to have available in a society and if therapists are allowed, even worse if they are required, to breach confidentiality at certain points, for those patients in those circumstances, psychotherapy will be impossible. And we see this already. In jurisdictions with reporting requirements, there is no longer any effective psychotherapy available for abusers of children and patients. The position is well stated in *Jaffee v. Redmond*:

Effective psychotherapy...depends upon an atmosphere of confidence and trust in which the patient is willing to make a frank and complete disclosure of facts, emotions, memories, and fears. Because of the sensitive nature of the problems for which individuals consult

psychotherapists, disclosure of confidential communications made during counselling sessions may cause embarrassment...For this reason, the mere possibility of disclosure may impede development of the confidential relationship necessary for successful treatment... The psychotherapist privilege serves the public interest by facilitating the provision of appropriate treatment for individuals suffering the effects of a mental or emotional problem. (*Jaffee v. Redmond*, 1996)

The point is also well made by the Surgeon General of the U.S. (*US. Department of Health and Social Services*, 1999), who further argues for the importance of therapeutic relationships to the goal of promoting the mental health of the population.

Whatever we may think of this kind of argument, notice that the ground has shifted dramatically. Whereas on the liberal view, the starting point was protecting the autonomy and dignity of the patient, from the social good view one starts from the *social* value of psychotherapy and the need for uninhibited speech if one is to do psychotherapy. The basis for protecting confidentiality has shifted from the autonomy rights of the patients to the social good of psychotherapy. Both views require that breaches of confidentiality be few and far between but they do so on entirely different bases. On the social good account, confidentiality is merely an instrumental good, a means to an end. If good psychotherapy could be achieved without confidentiality, confidentiality would no longer have a special value. That would never be the case on the autonomy account.

So far we have focussed on the differences between the individual rights-based and the social good justifications for protecting confidentiality. Note that there are also some important similarities, similarities that mark them both off from the emerging view. First, both flow from liberalism. Second, they both focus entirely on the patient and the therapeutic setting. Third, although they assign importance to the protection of information in the therapeutic relationship for different reasons, they agree that protection of this information is of fundamental importance and any exceptions need a deep-running justification. The new, emerging context for thinking about confidentiality does not focus on the individual and argues that massive breaches of confidentiality are justified, so long as they are done in the right way.

### **2.3 *The Foundation of the Emerging View***

The new way of thinking about confidentiality, one becoming increasingly prevalent in debates about

health information, frames the right to confidentiality in terms of interests: patients' interests, therapists' interests and "society's" interests, that is to say (more aptly), the achievement of social goods. The traditional view is based on rights and duties, especially the duty to preserve confidentiality. The emerging view is based on achievement of social objectives and the interests of various parties.

Concerning confidentiality, the key question for the emerging view is: What interest does a patient or therapist have in keeping something confidential? It is those interests that we should be protecting, not autonomy or the ability to choose as such. The interests on which theorists of the emerging view tend to focus are harms to patients and they look to protective measures such as deidentification of data, strict security rules, confidentiality contracts, prohibitions on using information to discriminate against people, and assurances that information will not be used for administrative decisions against a person. Whether the individual has consented to use of the information is not important. On this view, when there is an important social objective and access to the information in question would not adversely affect the person the information is about, no confidentiality right is infringed, whether or not the patient or therapist has given consent.

As we just argued, those who argue for this conception of confidentiality tend to be concerned about the subject of the information only to the extent of protecting that individual from harm, where harm is fairly narrowly construed. Thus, they seldom pay much attention to more abstract and subtle things such as autonomy and dignity and the harm that can be done to them. Their main interest is in facilitating the movement of information for purposes unrelated to individual treatment aims (purposes such as financial control, accountability, and health policy).<sup>2</sup>

#### **2.4 *Comparing the Two Views***

The two views of confidentiality that we have been considering run partly in parallel with a deep-running distinction in ethics generally, the distinction between deontological and utilitarian justifications of ethical propositions. On the deontological view, what we are justified in doing flows from the rights and duties of the parties concerned. On the utilitarian view, it flows from what will maximize social goods, including the good of protecting the interests of those involved. To be sure, the parallel is not complete. As we saw, even within the traditional view, there is often a resort to a "social good" argument, namely, the social value of psychotherapy, to defend confidentiality. Nonetheless, even this "utilitarian" move by the traditional view yields a rights-based conclusion: the

social value of psychotherapy argues for granting patients a right to, and therapists a duty to defend, confidentiality, a right or duty that can be abridged, except when harm is at issue, only with the concurrence of the therapist, the patient, or both. Thus the parallel is broad and important. Let us from now on call the traditional view that reaches deontological conclusions the *autonomy* view. And let us call the emerging view based entirely on utilitarianism arguments the *social objectives* view.

Both the autonomy and the social objectives views accept sharp limits on the disclosure of information to third parties. The grounds for limiting disclosure are quite different, however. Because of the supreme value of individual autonomy and dignity on the first view, one must have the concurrence of the therapist, the patient, or both, or demonstrate that the information is necessary in order to prevent or correct or punish a serious and imminent harm. (Even these limited grounds, as we saw, are controversial with many psychotherapists.) On the second account, access or disclosure is justified so long as the interests of the subject of the information are protected.

An example may help. Suppose that you are in a therapy session and unbeknownst either to you or your therapist, you are being observed, let us say by a researcher. Suppose further that this person does not know or recognize you, does not care about who you are, and that protections are in place that will ensure that nothing you say or do could possibly rebound on you.

On the viewpoint of protection of autonomy, your rights have nonetheless been violated. Someone has come to know things about you that you would not want them to know and the person had no remotely adequate reason (that is a reason having to do with preventing or correcting or punishing a serious harm) to gain access to this information. Whether or not you have been harmed, you have been wronged. However, your interests have not been adversely affected so, on the kind of rights that the interest-based account focuses on, your rights have not been violated.

This example may seem fanciful but in the digital age, closely analogous situations could arise on a regular basis. Information about a person, once digitalized, may be accessible to any number of third parties without the person's knowledge and against the person's wishes. Those who argue for confidentiality on the basis of autonomy deny that third parties should have access to information about us without our consent or the proxy consent of our therapist (except for the harm-based exceptions we have considered and we saw that even they are controversial). Those who argue for only as much confidentiality as is needed to protect the interests of patients tend to focus on how to ensure that third parties are constrained so as to protect these interests. Once such interests are

protected, disclosure to the third parties is no longer an issue.

The circumstances under which it is permissible for information to be disclosed without the concurrence of the patient and/or the therapist is the heart of the matter. This question is the crux of current debates about health information and legislation governing health information. Generally speaking, governments and various third parties who seek access to health information disclosed in the therapeutic relationship tend to favour broad exceptions enabling, or even mandating, the disclosure of information whatever the patient and/or therapist may think about it. Requiring concurrence or consent on the part of either party is viewed as a significant impediment to the achievement of important social goals. Indeed, in the absence of any requirement of concurrence or consent, the threshold of the test for whether information should be disclosed is often sufficiently low as to actually *favour* disclosure.

The confrontation between the two approaches is going on even as we write. As Timothy Caulfield has put it,

in the past few years ... governments have enacted or initiated the development of new health information legislation [that] has the potential to dramatically impact the legal framework within which health information is collected, stored and shared. ... The emerging conflicts between existing common law [which is based on the liberal conception of autonomy rights]... and new health information legislation illustrates the profound policy dilemmas created by the rapid advances that are occurring in the biomedical field. (Caulfield, in progress)

An example. A huge debate is currently taking place in the United States about whether the requirement that patients sign consent forms before information can be disclosed should be done away with, to be replaced by supposedly failsafe controls on how information is collected, aggregated, and used. Here is Donna Shalala of the US Department of Health:

We recommend that the traditional control on use and disclosure of information, the patient's written authorization, be replaced by comprehensive statutory controls on all who get health information for health care and payment purposes. The reality of the present authorization process is that the patient has little actual control of information. The approach we recommend would replace the often ritualistic authorization with direct statutory controls and a realistic and effective opportunity for patient intervention in instances where the patient

finds it truly necessary. (Secretary of Health and Human Services (Shalala), 1997)

This statement applies to all health care. As we argued earlier, psychotherapy is special because consent is itself a vexed issue. However, statutes mandating disclosure with or without consent would undercut the mechanisms at work to protect information in psychotherapy, too, including therapists' strong sense of obligation to protect the confidentiality of their patients and their conviction that, in addition to or even sometimes instead of the patient, only the therapist has the knowledge and sensitivity to determine what disclosures — if any! — are compatible with protecting the autonomy and dignity of the patient. Professional and patient groups argue for extremely sharp restrictions on disclosure without the agreement of the therapist and/or the patient. As we saw, therapists often resist even the standard liberal reasons for disclosure without consent, namely risk or fact of harm to self or other. Many patient groups agree with them on this. Such convictions would be completely negated by legislation such as Shalala proposes.

The tension between the traditional and the emerging views is reflected in a current controversy about codes of ethics and the law. The codes of ethics of many health care professions require that members obey the law. Such a provision is in the spirit of the emerging view because, as everyone involved knows, the laws in question include disclosure laws such as laws requiring the reporting of misconduct, laws requiring the disclosure of information to the courts, and laws requiring the disclosure of information for financial or health policy reasons. Since these laws usually require disclosure whether or not the therapist and/or patient has given consent, any requirement that members obey them is sharply contrary to the traditional view. For this and other reasons, the requirement that members obey the law has become controversial in many professional associations and a number of associations have removed such provisions from their codes of ethics. Once such provisions are removed, if a member decides to break the law in order to protect patient confidentiality, even if he or she goes to jail rather than breach confidentiality, that becomes merely a matter between the therapist and the state. It would no longer count as professional misconduct and would not affect the therapist's standing in his or her profession.

### **3. Factors Obscuring the Shift**

Our claim, then, is that a major shift is taking place from an individual, largely rights-based view of the value of confidentiality to a view in which confidentiality becomes just one social good among others, free to be sacrificed so long as no one's interests are harmed. So far, we have focussed on

psychotherapy but the same shift has been happening in health care generally. If such a major shift is taking place, why is there not more discussion of it? We see at least three reasons.

First, obfuscation and ambiguity concerning key terms is getting in the way of seeing the size of the shift. From the traditional perspective, things are very clear. Disclosures without patient and/or therapist concurrence are breaches of confidentiality. They may be justified by some other consideration but they are breaches. Indeed, some proponents of the traditional view hold that even disclosure *with* concurrence breaches *confidentiality*, whatever other values may be at stake and however well protected the identity of the patient. On this strict reading, even presentation of case materials for purposes of advancing science, supervision, and teaching are violations of confidentiality. The emerging view obscures the issues here. Is an *authorized* or *legally mandated* disclosure a breach? If it is authorized and thereby not reprehensible, how can it be a *breach* of anything? If a government can legislate away a patient's right to confidentiality and a therapist's duty to protect confidentiality, then what duty of confidentiality remains? The new conceptualization of confidentiality at the heart of the emerging view starts with broad social goods and tries to tease some anaemic notion of rights out of this starting point. Nothing but obfuscation can result from talking about a right to *confidentiality* in this new context. For present purposes, however, the important point is that when social and financial agents continue to do so, this talk obscures the magnitude of the shift taking place at the moment.

The second thing obscuring the magnitude of the shift is closely related. Policy-makers have also continued to use rights talk when they speak of confidentiality. Sometimes this talk is appropriate, for example, in the recognition of strong privilege in *Jaffee v. Redmond*. This case and the subsequent incorporation of that privilege in federal law in the U.S. are clearly in the liberal tradition of rights-based moral analysis and are significant steps forward. In other contexts, however, a lot of rights talk is confused. Although people on all sides of these issues speak of confidentiality as a right, when one probes the rhetoric the underlying defence of confidentiality is very frequently not based on rights at all. It is based on interests of the parties and broad social objectives. The use of the term "rights" is therefore simply misleading here. Whatever the rhetoric, broad social goods are the centre of focus, not the rights of individuals. Policy development, development of statutory law, and the demands of insurers and funding agencies are now often moving in directions quite opposite to those embedded in the liberal tradition of individual rights.

The third reason obscuring the magnitude of the shift is that many of those most concerned have

often not seen it happening yet. In the psychotherapy literature, debate concerning confidentiality is still centred on the harm principle: is it justified to disclose information without consent to prevent or punish harm (physical or emotional harm or the harm of wrongful conviction). These issues are extremely important, of course. But the bar is moving and the therapeutic community has yet responded. More and more, the issue concerning statutory disclosure of information is the desirability of achieving broad social objectives, not harm or anything else having to do with individuals in a therapeutic relationship. The managed care controversy in the United States has sensitized psychotherapists to certain dimensions of the issue but the emerging threats to confidentiality extend far beyond managed care. To be sure, achieving social objectives is a worthy pursuit and any adequate policy or legislation will probably take into account social objectives, not just individual autonomy rights. However, a shift to ever-greater attention to social objectives is occurring and the magnitude of the shift is not receiving the attention it deserves.

This completes our sketch of a framework for thinking about confidentiality. We have attempted to lay out how both autonomy rights and social good figure in traditional thought about confidentiality in psychotherapy and how this traditional view is being supplanted or at least supplemented by a new way of thinking about confidentiality based entirely on social objectives and the interests (rather than the rights) of those concerned. Let us turn to some recent developments in information technology (IT). IT is playing a rapidly growing role in health care. The information demands generated by this technology are creating some unique threats to patient confidentiality, threats that theorists have hardly begun to address. We will first consider the threats to confidentiality in health care as a whole, then turn to the specific threats the new IT poses for confidentiality in psychotherapy.

#### **4. THE EXPANDING ROLE OF INFORMATION TECHNOLOGY IN HEALTH CARE**

As we said at the beginning of the paper, new technology is making it ever easier to process vast amounts of information, and new policy initiatives are developing to take advantage of this information-processing capacity. First the new technology.

##### ***4.1. The Technological Context: Proliferation of Information Technology***

Although the health care sector has been less quick to capitalize on the potential of computerized health information than other sectors of the economy, it has been crucial to some of the most dramatic changes in the health system in recent years. Examples include:

- plans in most countries for (as it is called in Canada) a “Health Information Highway”;
- the development of health information systems and networks with the capacity to link information from a variety of institutions and systems;
- the growth of the internet and its use for the transmission of personal health information for consumers and providers alike seeking health information;
- the emergence of a robust e-health industry delivering various products and services over the internet;
- initiatives concerning the development of the electronic health record;
- the use of telehealth for a variety of applications, including remote consultation, diagnostics, and patient care;
- the proliferation of databases and registries;
- the deployment of IT in comprehensive health and disease surveillance systems.

Market trends and a commitment by governments to investment in health infrastructure make it extremely likely that technological developments along these lines will accelerate.

Computerization can enhance the value and usefulness of health information. For example, once patient information has been entered into a computer, subsequent retrieval and processing of that information for various purposes becomes much easier than when the information is recorded in paper form. Enhanced capabilities include:

- the ability to produce electronic copies of all or parts of the information relatively quickly, effortlessly, and economically;
- the automated ability to search, process, aggregate, and reformat the information into new files or databases and to gather information from different records under select headings, whether for the same patient or for different patients;
- the ability to link information from a variety of sources in a common database that may be instantly accessible by any number of users;
- the ability to automate a variety of administrative tasks.

#### **4.2. *Health Policy and Ideological Context***

Now the policy context. As computerization puts patient information in a form that is much more

readily accessible to a variety of users than ever before, changes in health policy and health policy ideology are intensifying or even creating "needs" or any rate demands for health information for a variety of purposes and by a variety of users. Here are some of the activities and policy objectives calling on ever-increasing amounts of information and ever-increasing power and sophistication in IT:

- **Efficiency and Cost Containment:** For some decades, the health care system was perceived to be growing constantly as a percentage of GNP (gross national product). There is some debate about the actual factors but the perception was enough by itself to give rise to intense scrutiny of the health system from the point of view of cost containment and even reduction. The computerization of health information has the potential to facilitate this. For example, the centralization of patient information and the possibility of linking databases from diverse sources could promote the detection of fraud or inappropriate use of the health system, could identify less expensive ways of trying to deliver a given kind of health care (one of the main motives behind Health Management Organizations in the US), and could assist system planners in deciding how best to allocate resources to achieve the greatest value per unit of money spent.
- **Accountability:** Cost consciousness has prompted increased scrutiny of the accountability by various players in the health system, trying to determine if the results they achieve warrant the resources they use. This has led to the development of devices very alien to the context of health care such as outcome measures, performance indicators, and report cards. Whatever one may think of such initiatives, it is clear that they could not work without intensive use of information and sophisticated IT. Since many forms of psychotherapy are time- and therefore resource-intensive and since these new measures make extensive information demands and therefore threaten confidentiality, they are of particular concern to many parts of the psychotherapy community.
- **Evidence-Based Decision-Making:** The imperative to base medical decision-making on evidence requires extensive therapeutic information.
- **Quality Assurance:** Activities such as utilization review and audit may be expedited and enhanced by greater access to, and use of, patient information. While commendable on the face of it, the move to evidence-based decision-making and quality-assurance measures are often invoked in the name of increased accountability.
- **Health Surveillance:** Information systems make possible health and disease tracking, and also tracking of such problems as practitioner abuse of or irresponsibility toward patients, parental

abuse of children, and so on, to a much greater degree than any previously-existing technology. However, health and disease tracking requires mandatory reporting, which gives rise to all sorts of questions about the autonomy rights of patients and the need for confidentiality, especially where illegal or unethical conduct may be at issue.

- **Patient Participation:** Many patients are assuming a more active role in their own health care. The growth of the internet has made health information much more accessible to patients and has spawned an industry providing health information to consumers.
- **Health Research:** In many jurisdictions, the amount of public and private money being devoted to health research is ramping up very fast. Plans regarding IT and such things as the development of registries and databases are part of this expansion, as are new demands for accountability and hopes for improving efficiency.
- **Health System Reform:** Many of the trends currently driving health care reform, trends for example toward integrated health care systems and managed care, mandate increased and more ready access to patient information.
- **Population Health:** The goal of improving and safeguarding population health by addressing the broader determinants of health is aided by patient information, especially aggregated in computerized form. Moreover, because the population health framework extends to other sectors besides health care, including social services, there is a demand that databases and information linkages extend well beyond the health system into virtually all other areas of social and economic service and policy.
- **The Commodification of Health Information:** Health information, in a variety of forms, has become increasingly valuable as a commodity. The growth of markets in health information — and private sector involvement as buyer, trader, or seller — increases as health information becomes increasingly valuable.
- **Private/Public Partnerships:** The involvement of the private sector in health care is increasing, especially in the area of health information. The mixture of public good purposes and the for-profit incentive in partnerships being formed for information infrastructure development, research and other initiatives gives rise to a variety of ethical tensions and issues concerning such matters as conflict of interest.

These trends are "information hungry". In particular, many of them are generating huge increases in the demand for patient information. In many cases, the purposes for which the information is being demanded are not the purpose for which health information used to be collected — for the immediate benefit of the patient from, or about, whom the information is being collected. The purposes now

often have to do more with broad social objectives.

## 5. SOME OF THE NEW ISSUES TO WHICH COMPUTERIZED HEALTH INFORMATION HAS GIVEN RISE

The issue of primary concern raised by the ever-expanding role of IT in the health care system and the new policy initiatives that have been developed to exploit this new capacity is the threat to confidentiality. We will first sketch this issue and related issues as they arise for health care in all its forms, then in Section 7 turn to confidentiality and related issues in the specific context of psychotherapy. Note how the conflict between the traditional and the emerging view of confidentiality arises in issue after issue. Some of the issues overlap.

- **Ownership and Sale of Health Information:** Health information is becoming increasingly commercially valuable, particularly as amassed in large databases. Who owns health information? Where health information includes a significant component contributed by the clinician, does this make the information in question the clinician's intellectual property? What rights do patients have concerning revenues that might be generated from health information? Is it appropriate for health care providers or data custodians to sell health information, with or without patient consent?
- **Genetic Information:** Advances in genetics are occurring in step, and converging with, health information initiatives, as recent events concerning the Icelandic database demonstrate. Iceland has had a stable population for a long time, so its genetic record is particularly valuable. When the Icelandic government began to market it, questions arose almost immediately. What standards should apply to genetic information? Who owns the information? What provisions should be in place to protect patients from powerful commercial interests? What protocols for consent are appropriate when information collected from one person also reveals something private about the genetic make-up of another? What protections should be in place to ensure adequate protection from inappropriate discrimination based on genetic information?
- **Provider Information:** Health information includes information about health professionals as well as about patients. The demand for health provider information is growing in the name of such things as cost containment and accountability. What rules should govern the collection, use, and disclosure of information about providers? What rights do providers have in their information? Under what circumstances should it be collected, used or disclosed without their

consent?

- **Registries and Databases:** Registries and databases are proliferating in health care. The focus on the potential benefits to be accrued often occurs at the expense of due attention to privacy and other ethical concerns. What rules should govern registries and databases? Should inclusion be premised on consent? Should there be limits on what data can be matched with other data? Should there be common privacy and security standards for databases?
- **Telehealth:** Telehealth involves the translation of information — text, images, sound, what is felt, etc. — into digital form and the transmission of this information between locations that are typically quite distant. Are the general standards that obtain in health care adequate for telehealth or does telehealth introduce complexities requiring additional standards? Should the standards applied be those pertaining to the patient or the provider? What constitutes appropriate consent in the telehealth context?
- **E-health:** The internet is spawning a variety of health-related initiatives, including web-based electronic records. Most of these are in the private sector and sustained on a commercial, for-profit basis. Several codes and ethics statements have been advanced to address the many issues that arise concerning privacy and confidentiality, advertising, accuracy of information, conflict of interest, sale of information, and so forth, but such codes are themselves contentious. How should e-health be regulated? What standards should govern e-health initiatives? Who should set the standards? How might e-health impact on patient rights and on quality of care and how might it enhance or disrupt the patient-physician relationship?
- **Electronic Health Record:** The electronic health record is becoming a subject of increased debate. Who should have control of the record? Who should fund it? What rights of access do patients have to their own record? Who should be able to provide input into it? What information should it contain, and what linkages should it facilitate? Under what circumstances, if any, would it be appropriate for access to occur without patient knowledge or consent? Should patients be able to opt out of having their information in an e-record or an electronic database? What security protocols are appropriate?
- **Data Flows:** The data flows in the health system are becoming increasingly complex. Whose responsibility is it to describe and track information flows? What controls should there be on these flows? What do patients and the public need to know about information flows in order for their confidentiality to be protected and their participation in the health system to be autonomous?
- **Private, For-profit Enterprises:** Insurers and other private-enterprise bodies require information for a variety of purposes, including to rate risk, determine eligibility, and verify

claims. How much information are they entitled to require? Should they be limited in their ability to require information when doing so might impede patients from seeking tests for fear the information generated might disadvantage them or create legal, social or personal risks for them? How should patients and health professionals respond in the face of broad "consent" forms for insurance purposes? Should there be standards to govern such forms and limit the information they can require?

- **Impact Assessments with respect to Privacy and Confidentiality:** The idea of conducting privacy and confidentiality impact assessments prior to the introduction of new information systems is attracting a lot of attention. What kind of considerations should be looked at in such an assessment? Should standards be developed? What role should such assessments play in system planning?
- **Transparency and Accountability:** There is very little public information about current health information policies and practices and little public knowledge about how extensive and interrelated existing databases are. How can these practices and policies be made more transparent and subject to public scrutiny? What obligations do data custodians have to inform data subjects and the public about their practices?
- **The Role of the Public:** The issues that need to be resolved as rules for collecting, managing, and using health information are developed touch upon fundamental values and have far-reaching implications for society. They are not technical or expert issues but rather public issues, and the public should be involved in debating and resolving them. How should the public be educated about the issues? What methods and processes best facilitate meaningful democratic public involvement in debating and resolving issues? What role should public opinion play in forming the rules of the game?

The issues we have just outlined indicate how broad the range of issues posed by the computerization of health information is and sketch some of the potential benefits and risks. The issues are becoming increasingly complicated and legislative and policy initiatives concerning health information and IT are not only generating a lot of contention; they are falling ever farther behind the state of the art in the technology. It is unlikely that things will become more settled or more adequate in most information-intensive countries any time soon.

## 6. POTENTIAL BENEFITS OF COMPUTERIZED HEALTH INFORMATION

The situation with respect to the new information technology and health care is not unremittingly troubled and gloomy. Indeed, IT in health care holds the promise of much benefit, not just to society

(we sketched some of those benefits) but also to individuals.

By facilitating ready access to personal information when it is needed for purposes of care, computerization has the potential to enhance patient care by providing treating professionals with tremendous stores of information about their patients and about treatment. Indeed, with appropriate controls on access, IT could even do a lot to address concerns about confidentiality across the health care professions. It could improve patients' ability to control their health information, enable health professionals to guarantee virtually unbreachable confidentiality, and increase trust in the therapeutic relationship.

IT also has the potential to empower patients to become more involved in managing health and disease by facilitating ready access to generic health information. The internet in particular is a very powerful tool for patients to do research and become better informed about health matters of concern to them. However, the internet is evolving with a very strong marketplace orientation, and countervailing factors can undermine the potential for patient empowerment. In particular, the problem of unreliable or just plain false "information" on the internet is becoming very serious. The interests of information compilers and providers in generating revenue do not perfectly coincide with patients' interest in accurate, unbiased, and trustworthy information. Whether empowerment is achieved will depend on how the internet evolves to mitigate against misinformation, manipulation, and exploitation and on the existence of a robust primary care system with trusted health professionals available to help patients interpret information they have obtained from other sources.

The potentials described above are from the perspective of patients interested in enhancing the direct care they receive, becoming better informed about their health and possible diseases and in limiting third parties access to information they provide for the purpose of receiving care. These objectives are in some tension, of course, with the objectives of third parties seeking access to patient information for purposes such as system planning, research, fraud detection, accountability, and quality assurance. To be sure, the use of information for purposes other than direct patient care can also enhance patient care (although this is not something to be taken on faith). The research of today can produce better treatments for tomorrow; reduced costs can help to free up money for patient care; quality assurance can lead to improvements in the quality of care available. Whether, or to what extent, the benefits will be achieved and the risks avoided will depend in part on how well we anticipate and manage the issues that we have identified.

Except possibly for the devices to protect confidentiality, these benefits do not accrue to psychotherapy patients in the same way as they accrue to patients of other kinds. Neither the treating professional having access to information about the patient nor the patient having access to information about his or her condition connects to the treatment situation in such a way that direct benefits to the treatment clearly ensue. There are also costs and risks special to psychotherapy. For example, the way that threats to confidentiality from IT relate to psychotherapy is different from the way they relate to other kinds of health care.

## 7. CONFIDENTIALITY AND THE SPECIFIC SITUATION OF PSYCHOTHERAPY

Many of the initiatives designed to promote broad social objectives that use electronic health care information systems threaten confidentiality (and therefore trust in the therapeutic relationship) wherever they are found in the health care system.

- **Impact on Confidentiality.** The usual way to protect confidentiality in situations where information-gathering threatens it is to require patient consent. (Thus, any proposed information collection activities that do not require consent are suspect for that reason alone.) Even where consent is required, hard questions arise. Under what circumstances, if any, is it acceptable to use or disclose information without consent? In cases where consent is required, what form should the consent take? How much does a patient need to know for consent to be sufficiently informed? Are blanket consents ever appropriate? Under what circumstances, if any, can consent be implied? Are "opt out" regimes acceptable in some cases? Is consent ever an adequate gatekeeper for confidentiality and privacy? Are there some things to which people should not be permitted to consent? Should they be able to selectively block parts of their health information? Would it be justified to require people in countries with universal health coverage to forego the right to consent as a condition of enjoying the benefits of a publicly funded health system? In psychotherapy, however, other considerations arise, because, as we saw earlier, in psychotherapy consent is not the gold standard for protection of confidentiality.

In addition to the problem of how to think about protection of confidentiality in psychotherapy, the expanding role of IT in health care gives rise to some other issues peculiar to psychotherapy.

- **Impact on the Therapeutic Relationship:** In psychotherapy, mandatory reporting requirements affect the therapist/patient relationship directly by distorting the development of

affect, fantasy, and transference in the patient. An obvious example are requirements that psychotherapists report boundary-violating and other transgressive patients. Such a requirement makes psychotherapy with such people essentially impossible. If potential patients know or even fear that something they say about themselves could end up in a database cross referenced to data bases used by the police, potential employers, etc., they simply will not be candid in therapy. How should these potential consequences be weighed in the development of rules for health information?

- **Impact on Clinical Practice:** Closely related to the issue of impact on the therapeutic relationship is the potential of IT to change clinical practice. Should information practices of psychotherapists be standardized with respect to information about their own techniques and practices, so as to enhance communication with other practitioners and potential or actual patients? Should the needs of various secondary users of health information influence what information psychotherapists provide about themselves?

So protecting confidentiality, the therapeutic relationship, and clinical practice gives rise to special issues in psychotherapy. Consent is not a safe protection because, as we saw earlier, in the context of transferences, primitive regressions, and so on, the notion of informed consent is itself inherently vexed. Yet breaches of confidentiality can have much more profound effects in psychotherapy than in other areas of medicine. My oncologist revealing to someone that I have cancer might infuriate me and undermine my confidence in her but it is not likely to have much effect on how well the chemotherapy she has prescribed works. By contrast, if my psychotherapist reveals that I am in psychotherapy to someone, that could destroy the therapy. Likewise, because of the enormous individuality of clinical practice in psychotherapy, measures requiring standardization of clinical practice are likely to have far more profound effects on psychotherapy than on, for example, oncology. So how should we think of the threats to confidentiality in psychotherapy posed by the new demands for information?

What is special to psychotherapy is that disclosure of information to third parties is a violation of a patient's legitimate expectations and therefore autonomy and threatens the treatment *whether or not the patient consents*. Psychotherapy requires that certain kinds of information be kept private to the patient and therapist. (The teaching and research practices of psychotherapists pose a threat of their own to this requirement and we will come back to it.) If consent is not an adequate protection of confidentiality in psychotherapy, what would be?

We might look to the very technology that caused the problem. There are promising developments in the field of privacy- and confidentiality-enhancing technology, including such things as anonymization software. Can these technologies protect confidentiality in psychotherapy? Should, for example, anonymization provisions be mandated in all health care information systems? We might also look to securing databases where information about psychotherapeutic treatments is housed. Security includes both human and technological measures to protect information against unauthorized access, use, or disclosure. Here we would have to decide what level of security is appropriate for such information. Perhaps some of the developing security provisions such as secure internet sites could be used to begin to protect confidentiality. If information is going to be collected about psychotherapy, with or without patient consent, even if collected anonymously, everything that can be done should be done to enhance privacy and confidentiality, of course. We doubt, however, that provisions such as these are likely to ensure the level of confidentiality needed for effective psychotherapy any time soon, for the following reasons.

First, in psychotherapy the standard of confidentiality that must be met is very high. Patients of means have been known to insist that they pay the whole treatment themselves and that the treating professional not take notes. Here is how Herbert Sacks, a psychiatrist and former president of the American Psychiatric Association, describes the situation in that country:

[A] grave concern ... has to do with ... the demands of managed care organizations for full medical records. They claim they need them for accountability. That is not true. ... [Plus,] there are leaks all over the place. In my private practice dealing with ... patients who work in corporations, banks, and the media, perhaps half of them who have coverage will not use it. They pay out of pocket because of their concern about these breaches, because of what they observe in their own workplaces. (Sacks, 1996)

Such a concern can have many motives: clinical paranoia; holding down a highly sensitive job; risk that professional effectiveness would be diminished if it were known that the person had been in psychotherapy; or prior illegality or immorality or fear that earlier actions might have been illegal or immoral. *For purposes of psychotherapy*, these are *all* legitimate reasons for absolute confidentiality. Paranoia, for example, may or may not be justified but it is an entirely appropriate reason for seeking psychotherapy and the therapy won't work unless the patient can trust that nothing will violate the confidentiality of his or her information.

With the confidentiality bar set this high, not just the demands of health policy initiatives but also the standard liberal exceptions to do with harm to self or other begin to look like they should be resisted. Both because of the rights-grounding autonomy and dignity of the individual and because psychotherapy is a highly valuable social good, psychotherapy needs a near-unbreachable standard of confidentiality. For this reason, we doubt that the confidentiality needs of psychotherapy, on the one hand, and the legitimate demands of courts and child protection agencies and the agencies charged with developing health policy are reconcilable. In our own view, in all cases or nearly all cases of conflict, the value of effective psychotherapy to a society is greater than almost any value that could be achieved by violating confidentiality.

What is sauce for the goose, however, is sauce for the gander. Treating confidentiality as nearly unbreachable would cut against some common practices of psychotherapists, too, clinical case studies, for example, and use of cases, vignettes, quotations from sessions, and so on in teaching, supervision, and research. Probably private clinical conversations between therapists would not constitute a breach of confidentiality even under the stringent regime we are proposing but a lot of communications with groups of clinicians might turn out to be violations of confidentiality. Indeed, can information about individual patients, transcripts of what patients say, and the like be so much as *generated* without distorting the therapeutic process? And once the information has been generated, can it be used without threatening confidentiality? The standard protection is to remove identifying material. But (a) can one remove identifying material without distorting the rest of the material, and (b) can one ever disguise material so as to make it unrecognizable even to the patient concerned? (Patients read journals, too.) In general, is there any way to use information from psychotherapeutic sessions that is accurate enough to be scientifically useful and yet poses no threat to confidentiality?

## **8. CONCLUSION**

The goal of this chapter has been to contrast the traditional and the emerging frameworks for thinking about confidentiality and to lay out some of the risks to confidentiality in the information revolution currently going on in health care. The prospects for avoiding these risks are not good if we as a society continue to demand more and more information about highly sensitive, emotionally-wrought activities such as psychotherapy. We think that it is past time for the community to shift from its near-exclusive focus on the individual treatment context and how therapists should respond to the harm principle and to begin to think about the implications for psychotherapy of the new risks to

confidentiality deriving from every-increasing demands for information to help us achieve broad and for the most part admirable social objectives.

There should be much more debate in the therapeutic community, patient community, and the general public than there is. In the absence of debate, the agenda of users of health information with large resources and political clout are apt to prevail. Their point of view has been the dominant one in the design and regulation of health information systems so far. Serious things are at stake, such as the very possibility of effective psychotherapy. It is imperative that the providers and beneficiaries of health care identify the issues clearly and face them squarely. By delineating the very different value foundations at work in current thinking about confidentiality, we have tried to take a first step in this direction.

The choice with respect to confidentiality is to think about it on the basis of autonomy, modified perhaps by a qualification about harm to self or other, or to think about it in the context of social objectives or the needs of financial or other institutions. The first approach is built on respect for patients' autonomy but comes at some cost to third parties and the good of society generally. The second approach may achieve some important social objectives but at the cost of seriously damaging psychotherapy, itself a major social good, and, often, treating both patients and health care professionals paternalistically.

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<sup>1</sup> Note that in practice, the circumstances that leave therapists feeling justified in disclosing information about their patients in the traditional context are broader than harm to others and miscarriage of justice. So long as identities are disguised and anonymity is preserved, most therapists feel justified in disclosing information about their patients, in the form of clinical vignettes and case studies, in seminars, when supervising training therapists, in publications in professional journals, and so on. It is another question, of course, whether these breaches *are* justified, certainly in individual cases or even at all. We return to this issue briefly below.

<sup>2</sup> For further reflections on the emerging view, see Etzioni 1999.