MAKING THE INVISIBLE VISIBLE IN HEALTH CARE: PROBLEMS, POSSIBLE SOLUTIONS AND THE ROLE OF INFORMATION TECHNOLOGY

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ABSTRACT

Health care today is characterized by increasing efforts to make it transparent to inside and outside observers. This paper presents the difficulties that typically arise when health care quality is to be visualized, and it suggests possible ways of handling them. Particular attention is given to the role of information technology. Drawing on recent empirical studies of transparency effort in health care, notably in Sweden, the problems are conceptualized as pertaining to the collection, representation, and interpretation of information on quality. Finally, the question is raised whether information technology could work as a knowledge technology, fostering the development not just of abstract information, but also of expressions and translations of embodied expert knowledge.
INTRODUCTION

Health care today is characterized by increasing efforts to make it transparent to inside and outside observers, efforts such as Evidence Based Medicine, public performance indicators, rankings of hospitals or whole national health care systems, medical auditing, computerized medical records, etc. As the cited examples suggest, this development implies soft regulation and different types of accounting as well as auditing. In fact, the pursuit of transparency appears to be a new type of governance logic in health care (Sahlin-Andersson, 2006), complementary to the logics of professionalism, politics, and managerialism, which have hitherto, in different periods, been dominant in health care (Scott, 2000). In this development, information technology plays an important role in enabling more and more advanced and increasingly accessible means of collecting, handling, and representing data on central health care processes.

The purpose of this paper is to present and conceptualize difficulties that typically arise in connection with efforts to make the invisible visible in health care, and to suggest possible ways of handling the difficulties. Particular attention is given to the actual and potential role of information technology. The paper is meant to contribute both to the knowledge of transparency efforts in health care and to the understanding of potential problems and opportunities of information technology applications in knowledge-intensive activities.

TOWARDS A TRANSPARENT SOCIETY?

A transparent society, where the dealings of power are clear and visible to all, is a central democratic ideal at least since the Enlightenment. Today, this ideal finally seems possible to realize, thanks to modern technologies for retrieving, processing, and circulating information, including camcorders, satellites, databases, and the rapid spread of world news (Vattimo, 1992; Livingston, 2000).

Transparency in public affairs is widely considered an indicator, contributing factor, and expression of democratic society (Grigorescu, 2003; Heald, 2003). ‘Regulation by revelation’ is used as a tool to fight a wide array of social ailments, from street crimes to corruption and environmental pollution (Florini, 1998). As for organizations, we can see the contours of a rising ‘audit society’, where organizations are increasingly occupied with internal and external inspection
Some global organizations coordinate complex work internationally with ‘transparency regimes’ that systematically visualize central processes to managers and co-workers (Knorr Cetina & Bruegger, 2001).

However, there are problematic aspects of this pursuit of transparency. According to Vattimo (1992, pp. 4, 23), the modern social sciences and mass media have not just created more openness and visibility to all; they have also revealed the plurality of perspectives and cultures, thus exposing the very ideal of a society that is transparent to itself as one of domination, rather than emancipation. Furthermore, controlling through seeing is a troublesome power technique. As argued by Foucault (1991) in his analysis of the centrally supervised Panopticon, it can be more invasive and insidious than cruder controls, since the subjects of power know they are observed and internalize the disciplining gaze of the central overseer. In the case of organizations recurrently submitted to different types of audits, there is a risk that increasing financial and intellectual resources are being devoted to the systems of inspection instead of to that which is being inspected, e.g. the product quality or the benefit of medical services to the patient, all while the audits and inspections themselves remain opaque and difficult to evaluate (Power, 1997; 2005).

Even researchers with optimistic views on the prospects of increased transparency discuss the problems of its ‘potential drawbacks’, e.g. that some secrets are legitimately worth being protected, that information is easily misinterpreted, and that knowledge of being observed is not always enough to make culprits change their behavior (Florini, 1998, pp. 60-61). Heald (2003, pp. 739-746) points at ‘trade-offs between values’ and the problems involved in government transparency, such as league-tables demoralizing low-performing public agencies, and the risk of falsification of records if everyone is expected to perform above average.

**TRANSPARENCY PURSUITS IN HEALTH CARE**

Health care is no exception to this general picture. On the one hand, there are strong forces pushing in the direction of increased transparency. There are increased demands for openness and accountability, linked to ideals of democracy, informed citizenship and patient rights (Finkelstein, 2000; Blomgren, 2006a). Due
to widespread New Public Management reforms, including internal markets and purchaser/provider splits, there is also a demand for externally accessible measures of quality and performance (Hood, 1995; Sahlin-Andersson, 2001; Kirkpatrick, Ackroyd & Walker, 2004). Thanks to information technological advances, there are new possibilities to process and transmit complex information at relatively low costs. On the other hand, there are problems when it comes to actually realizing the aspirations associated with transparency – problems that are all the more accentuated in the case of health care, given the type of knowledge it employs.

Contemporary health care is an expert system that largely relies on the judgement of highly trained professionals. As emphasized by Tsoukas (1997), following Giddens (1991, p. 18), the expertise involved in such system is not just neutral, formal and easily transferable information, but more importantly embodied and context-specific knowledge that cannot be presented to non-experts without serious risks of misinterpretations. Public exposure of the inner workings of this kind of systems promises something that cannot really be delivered, i.e. understanding of processes that must in fact be experienced, through personal practice, in order to be wholly understood. What more is, detailed public information on the work of an expert system invites rivaling interpretations, since outside observers must put the out-of-context information into a new and different context in order to make any sense of it. These different interpretations may damage the trust necessary for the system to function well.

So, the more information outsiders seek to get about the system, the less likely it is that they will trust the system and reap the full benefits of it. To illustrate this paradox, Tsoukas (1997, pp. 835-836) takes the authentic example of a suggestion to allow close-circuits cameras in operating theatres, as way to supervise surgeons and record any mistakes. However, a camera cannot record what is actually going on during a surgical procedure, since it leaves out all that is tacit and taken for granted, which may nonetheless play a crucial role in the medical procedures. Some habits that can be normal and even helpful to surgeons in their daily life world, e.g. swearing or listening to heavy rock music, may appear careless if revealed to the patients concerned and undermined the confidence needed to bridge the different perspectives doctors and patients. In the same line, Strathern
(2000) warns that the visibility created by audits and quality assessments of an expert organization may conceal as much as it conveys, since what really makes the organization work, e.g. the pattern of social interaction, is difficult to capture in formal performance measures. So, ‘there is nothing innocent about making the invisible visible’ (p. 1).

VISUALIZING TECHNIQUES IN HEALTH CARE

Public performance indicators and rankings are important instances of the general ambitions to make health care more open and observable. However, there are also other manifestations, including techniques to visualize health care to provider organizations and professionals themselves (Levay, 2006b). Following Sahlin-Andersson (2006), three major expressions of transparency efforts in health care can be discerned: auditing, accounting, and regulation, each comprising a number of specific techniques. By inspiration from Power (1997), auditing is understood in a wide sense, including not just financial and medical auditing, but also assessments and appraisals carried out by different outside actors, such as league tables, evaluations or quality prizes. In addition to financial accounting, health care organizations deploy special types of accounting, such as medical records and quality reports. Finally, regulation includes formal law as well as guidelines, classifications, and ‘soft regulations’, e.g. clinical guidelines, Evidence Based Medicine, Diagnosis Related Groups, and priority lists.

From the examples mentioned, it is clear that most of these techniques imply the use of information technology, to a smaller or larger extent, and that this very use may lead to increased visibility. For instance, when medical records are computerized, there is at least a potential for a wider exchange of the information, such as when record information is automatically and recurrently downloaded into medical quality registries (Levay, 2006b).

The three expressions of transparency are interrelated in that they tend to nourish and promote one another (Sahlin-Andersson, 2006). Regulation often requests accounting and auditing, in order to make certain that rules are followed. Audits often reveal ambiguities, deficiencies and lack of openness, which generates demands for new rules and better accounting. However, audits can also become a supplement to or even a substitute for formal rules. Instead of being told exactly
what and how to do in advance, service providers are informed that accounting
will be demanded and auditing will be take place later on, which is a form a form
control through transparency.

Taken as whole, these expressions and techniques form a new kind of governing
logic which may even supplant the logic of managerialism that has been so
dominant in health care the past few decades. If the key words on the New Public
Management era have been markets, efficiency, cost control, and financial
accounting, the key word of the dawning era of transparency efforts in health care
are evidence, patient rights, and scientific knowledge (Sahlin-Andersson, 2006).

PROBLEMS IN VISUALIZING HEALTH CARE QUALITY

Quality of care is a key issue in virtually all transparency efforts in health care, as
a central object of measurement, comparison, and – at least that is the intention –
enhancement. However, as suggested by the reasoning of Tsoukas (1997) related
above, it is far from evident how to represent health care quality in a way that is
both correct and meaningful to a wider audience. This section develops and
categorizes the main problems involved, categorizing them into three major
types of problems related to collecting, representing and interpreting information
respectively.

Empirically, this analysis draws on a number of previously presented studies of
the pursuit of transparency in health care in Sweden (Levay & Waks, 2006a) and
in other countries. Several inputs and examples are taken from the case of the
Swedish national quality registries, which are clinical data banks containing
information on diagnoses, treatments and outcomes for a number of condition groups.
(Levay, 2006a; 2006b). The creation of the registries and the subsequent
introduction of new usages have occurred in close connection with information
technological developments. The registries were first started in the 1970s by
medical researchers employing new mass data processing technology for purposes
of scientific research and development of surgical methods. Later on, the registries
have also been used for local quality improvement, facilitated by new techniques
for online registration and flexible data retrieval, e.g. quickly and easily accessible
performance reports tailored to the individual hospital department. Recently, there
have been increasing pressures to publicize registry information on the quality of
individual health care providers. However, it is doubtful to what extent present registries can actually provide information suitable for a wider audience.

Several other studies are referred to or have otherwise inspired the conceptualization presented here. They describe and analyze aspects of accreditation (Robelet, 2001; Waks, 2006), Evidence Based Medicine (Hult, 2006), clinical guidelines (Castel & Merle, 2002), the cost of transparency (Forssell & Ivarsson Westerberg, 2006), public performance indicators (Marshall, Shekelle, Leatherman & Brook, 2000; Snelling, 2004), the response of professionals to transparency efforts (Levay & Waks, 2005; 2006b), transparency from the patient’s perspective (Winblad Spångberg, 2006), and the field of transparency pursuits in Swedish health care (Blomgren, 2006b).

Problems related to collecting information

Intangible aspects
Some things in health care are easy to measure, e.g. the number of relapses after a surgical operation to cure a well-defined and well-researched ailment, while other are more difficult to quantify and compare in a sensible way, e.g. the quality of human care of elderly and perhaps demented patients, or the treatment of patients with multiple diseases. When quality is to be made visible, there is a risk that such ‘intangible’ aspects of quality are systematically neglected and that patient groups with less easily monitored illnesses are underserved. In the case of the Swedish national quality registries, the early and/or the most developed registries deal with knee arthroplasty, hip arthroplasty, and cardiac intensive care, while struggling or failed registries concern areas such as psychiatric diseases and geriatric care (Levay, 2006b).

Differing organizational conditions
Some types of medical care are more suitable grounds for collecting information than other. While it is relatively easy to collect high quality data in specialized care units, it is more difficult in primary care units, since they treat much larger numbers of patient and illness groups. Again, important aspects of quality of care may be overlooked. And again, this is reflected in the varying success of different national quality registries (Levay, 2006b). The Swedish National Diabetes Registry is a relatively elaborated registry. It provides support in the patient-
professional encounter by generating patient profiles with basic medical data at each session. The printouts can be used as voluntary agreements of care, helping patient to monitor their health and their own part of vital treatments. Despite this added value, and despite the involvement of a particularly active and vocal patient organization, the diabetes registry struggles with limited coverage and insufficient reporting to the registry, since much of the diabetes care takes place at primary care centers, where many other conditions are also treated. As for psychiatry and geriatrics, they are doubly disadvantaged, since they are largely practiced within primary care, in addition to containing several quality aspects that are difficult to measure.

**Increased administration**

Collecting information is time-consuming and largely done by highly qualified health professionals. At least in Swedish health care, there are signs that doctors and nurses already devote more and more time to administrative duties (Forssell & Ivarsson Westerberg, 2006). In addition to eroding professionals’ work satisfaction (Levay & Waks 2005; 2006b), transparency efforts may turn out to be unexpectedly costly. In an approximation of the time devoted to transparency efforts in Swedish health care, Forssell and Ivarsson Westerberg (2006) estimate that it takes up 25 per cent of nurses’ and doctors’ working time, and that around half of that is used to create external transparency and legitimacy among outside audiences. Forssell and Ivarsson Westerberg particularly warn health care services of being overly compliant with outside demands for detailed documentation and of letting patient documentation expand at the expense of patient care. Instead, they encourage organizations to set their own, carefully considered priorities regarding what is to be documented, thereby protecting the core health care activities.

**Problems related to representing information**

**Case-mix and other complexities**

The best surgeons, or the best the best surgery departments, may have the highest mortality figures, since they take on the most difficult cases. This is usually called ‘case-mix’, and it can be handled by classifying cases and adjusting the quality figures accordingly. However, this creates new problems of deciding which
categories to use and how to classify unclear cases. It also makes calculations more complex and hence less transparent to patients and other non-professionals.

The same goes for a number of other factors that make it hard to represent quality without risking misleading non-experts. This is not just a question of medical complexities, but also of problems with communicating the meaning of statistical computations in general. For instance, statistical margins of error are easily ignored in newspaper reports on the performance of different health care providers. This happened in at least one major tabloid coverage when, for the first time, the mortality rate of heart attack patients at different Swedish hospitals were made public (Levay, 2006b). Just as when the problem of case-mix is concerned, these difficulties can be handled with adjustments in the presentation, or with suppression of any uncertain pieces of information. But again, the more sophisticated the modes of representation become, the more opaque they are to a lay audience.

**Long-term effects**

Some central indicators actually indicate the quality of health care providers several years ago, such as cancer survival rates 5 years after diagnosis, or reoperation rates 10 years after hip-replacement surgery. This is a specific kind of complexity that may easily be overlooked when the information is transmitted further, for example in public quality rankings. There is no real way of overcoming it – even if there may be appropriate proxy quality indicators, some important outcomes are inevitably available only ex post, and that simply cannot be adjusted away, no matter the level of sophistication in the design of presentations.

**Balancing diverse factors**

In order to indicate and compare the quality of different health care providers, several indicators and aspects must be weighed together, e.g. medical outcomes, accessibility of services, and patient satisfaction. However, there is no given way of weighing them, and the question arises if aggregated figures or ratings actually convey any meaningful information. This problem appeared in connection with the contested ‘star rating’ system which was used until recently to appraise UK hospitals. The way different hospitals turned out in the ratings largely depended
on the methodology, which varied from year to year (Snelling, 2003). One criticism of the system concerned the weight accorded to seemingly trivial indicators. In the debate, examples were mentioned of trusts that lost a star simply because a single patient had to wait too long, or because budget targets were missed by a minor amount (National Board of Health and Welfare, 2003, p.15).

A related question is at which organizational level the factors should be aggregated – at the hospital, department, or ward level, or perhaps at the regional or national level, as in some international comparisons. In order to make any sense, the type of unit chosen must be considered reasonably homogeneous – if not, how could the overall quality data say anything about the quality of the subunits? For instance, how else could the overall rating of an entire hospital indicate the quality of services at, say, the department of orthopedic surgery? However, this assumption of homogeneity is highly questionable, since resources, routines and competencies may vary from one unit to another within the same department, hospital, or region.

Problems related to interpreting information

**Complexity of information**

From the perspective of the patient, the problems of presentation come out as problems of interpretation. If it is not evident for health professionals how to present comparisons between different providers, or for journalists how to report on ratings and quality assessments, it is not easier for patients to decipher them. Normally, patients also need to apply the general information to their specific situation and to the real choice options at their disposal.

**Apparent lack of patient interest**

According to previous research, patients tend not to seek out, understand, or use public performance data as a basis for choice; they actually seem to put more trust in anecdotal information from the press or from friends and family (Marshall et al., 2000). Considering the complexities involved, this is perhaps not surprising. Furthermore, in the case of Swedish health care, it is not primarily patient organizations that have been pushing for more public health care quality information, but investigative reporters, individual opinion-makers, and a variety of public and private organizations (Blomgren, 2006b; Levay, 2006b).
This apparent lack of interest could depend on a lack of presentations that are both meaningful and accessible to patients. However, it should be remembered that more information does not automatically mean better understanding; instead, more information can generate rivaling interpretations and less trust in health care providers.

SOLUTIONS AND THE ROLE OF INFORMATION TECHNOLOGY

When it comes to handling the potential pitfalls and unintended consequences of transparency efforts, there are no obvious or tested solutions, at least not to the knowledge of this author. However, in view of the problems in question, one can conceive of a number of possible approaches:

- **Active health care professions** that not only decry unjustified rankings and evaluations, but take an active part in developing meaningful quality criteria and modes of collecting and processing data. In fact, there are several signs that even if professionals initially may resist public exposure, they can also get actively involved in developing transparency techniques later on (Waks & Levay, 2005; 2006b; cf. Robelet, 2001; Castel & Merle, 2002).

- **Translation efforts.** There appears to be a need for careful and conscious translation of complex medical information in several instances along the chain of communication. First, in the editing of quality rankings and reports directed to a lay audience; next, when information brokers such as auditors or media reporters are to make sense of the material; and finally, when the individual patient, politician, or manager is to apply the general evaluations to his or her particular situation.

- **A critical – and transparent! – discussion** that involves patient groups, media outlets, public and private health care organizations, as well as standardizing bodies and professional associations. It appears pointless to attempt to isolate everlastingly correct measures or modes of representation. In contrast, a continuous discussion about the terms of transparency might arouse a wider consciousness of patients’ actual needs for information and the inevitable limits of any representation of health care quality.
Information technology has played a crucial role in enabling ever-intensifying collection and dissemination of more or less meaningful quality data, and has thus played a part in ‘letting the ghost out of the bottle’. One may raise the question if information technology could also help coping with the new visibility in health care, so that it can lead to real, meaningful knowledge. Instead of an answer, this paper ends with an evocative question, reconnecting to Tsoukas’ (1997) discussion on the futility of trying to convert embodied, experienced expert knowledge into neutral, decontextualized information open to all. Is it possible to imagine a new type of ‘knowledge technology’, which could be used not only to gather and compute health care quality data, but also to foster new ways of presentation and interpretation, through continuous and critical dialogue?
REFERENCES


