Digital Patients: A Typology of Emerging Patient Roles

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Abstract. Applying four analytic lenses (consumption, communication, community, and responsibility) and three forms of agency (objectivation, activation, and engagement) this paper develops a conceptual platform for the analysis of the impact of health-care ICTs. It is argued that a closer study of applications within tele-medicine, health informatics, and e-health needs to take into account (changes in) patient roles to tie innovation to the *act of health-care delivery.* The typological multi-faceted concept of *digital patient* is suggested as an inspiration towards a continued and strengthened multi-disciplinary approach to research on and development of information systems within health-care.

1 Introduction

Public health systems in the developed world have put greater emphasis on the role of information technologies, for increased quality, distribution and cost-effectiveness of services. Although various changes occur in the delivery of health services, changes in information technology is not delivering that ever more effective provision, which often is hypothesised. Such 'missing successes' in the health informatics area may be explained by diverging political and professional awareness among actors involved [1]. On the other hand, we have witnessed a contrasting strong diffusion of health-related use of the Internet [2]. Tele-health policies and research have documented a significant lay (patient) interest in new opportunities of communicating about health and illness, and novel technologies for improved clinical outcome, empowerment and stronger involvement [3-7]. Accordingly, a more nuanced approach to social forces and mechanisms behind changed application of information technologies in health care needs to include patient roles and changes in patient roles. Hence, this paper suggests a typology of emerging patient roles, to comprehend the complexity of current changes and non-changes, with the introduction and diffusion of health service ICTs.

With large natural resources, a well-educated population, and significant level of trust among people towards policy, public services, as well as technology, Norway is something of an extreme case of a supposedly well-functioning public welfare system. Norwegian state initiatives have framed the development and integration of ICTs as a key priority for better coordinated and integrated healthcare, for instance by establishing a secure national health-care network to support the technological integration of systems across the various health-care institutions. In addition to this,

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there is great belief that the Internet (used by patients as well as professionals) will offer opportunities for better coordination of (integrated) care, for instance through care plans across health care levels, and including patients (and sometimes next-of-kins) as active participants.

The aim of this paper is to reframe (potential) patient-provider relations that are relevant for reflecting on an ever larger impact of ICTs in the health services, with emphasis on the patient (citizen) role. Through a typology of emerging patient roles, I suggest here a generic framework for a non-normative consideration of the future patient. The term *digital patients* is introduced as a concept encompassing the nuances and variations within these roles, in which patients are both subjects and objects. While ‘digital patients’ points towards future roles, the concept has been developed through a series of iterations since 2004, from *various types* of digital patients [8, 9], through the notion of changing agencies (objectivation, activation, and engagement) in collaboration with Anne Grete Sandaunet [10] and later by introducing four analytic lenses (consumption, communication, community, and responsibility) [11] and a stronger concern about *the patient of the future* [12]. In this paper, a twelve-cell typology of the digital patient is suggested, as basis for a nuanced viewpoint of changing roles (and agencies) of patients/citizens, and by which further reflections on the impact of health-ICTs may be developed. Before I introduce these, I will briefly outline the three applications that have inspired the construction of concept of 'digital patients'.

2 Three ICT Applications

Despite a complex field of health-related information technologies, three distinct applications may be identified; *telemedicine* (i.e. transfer of various types of digitalised patient information between clinicians), *health informatics* (i.e. electronic patient record systems, etc), and *e-health* (here, health-related use of the Internet, while this term is increasingly also used as a common term encompassing all three applications). Most importantly, diffusion of these applications seems to be driven by different actors. Since the early 1990's, the diffusion of telemedicine has been extremely slow. Although the development of these technologies has been given a priority within research and development in Norwegian health care over 20 years, only a limited number of applications have been established in routine operation. In fact, the tele-health field seems to be characterised by a ’plague of pilots’,[13] in which a vast number of very limited projects have been established as non-permanent test-projects and only occasionally maintained in routine practice. In the health informatics field, on the other hand, Norway has been one of the first countries with a 100% diffusion of electronic patient records among GPs (already in the 1990's) and with a more recent total diffusion in the hospital sector. During a number of hospital ethnographies the recent years we have however noticed very little impact of these systems on the use of paper, work procedures, and efficiency[1].

3 Agencies

The term *digital patient* includes a typology of various agencies; 'objectivation', 'activation', and 'engagement'. Objectivation is the construction of objective patient data, mainly as numbers and images. Activation is the technologically mediated delegation of responsibility and action from providers to users, but by which health service providers are still managing the systems and ‘rules’ of communication. Engagement is users'/patients' initiation of health-related action by applying various information services, mainly on the Internet. While both activation and engagement describe health service users' action, there are different sources of the motivation of the initiatives and actions. The three processes happen in parallel although they may represent opposite (or contradictory) processes.

3.1 Engagement

To start with the last one, engagement, it is reasonable to exemplify this with the use of Internet for health purposes. Interaction in (lay) discussion forums on the net is characterised by links to 'biomedical web pages' as well as acknowledging lay users’ advice. There is significant trust between lay and professional actors, but with traditional power relations, i.e. in which professional actors maintain a monopoly of information sources assessment, as well as regulating access to public health care resources. Physicians may also hesitate to establish electronic communication with their patients [14], or regard online support groups as a threat to their expert status and control over decision-making processes.[3, 4] With the introduction of Web 2.0 and increased opportunity for users themselves to apply web services and form content more independently, through blogs, Twitter, videos on YouTube, Facebook, Second Life and specialised applications such as PatientsLikeMe, and 23andMe, the engagement becomes patient-initiated and independent. Users of such services may develop large health-related communities without any participation from the professional sphere.

3.2 Activation

Many web-based services are however clinically moderated, such as medical information services and clinically managed support systems, by which users (or patients) are led and motivated to take care of themselves through customised programmes. Often such services may be part of follow-up programmes after treatment. The term 'activation' draws attention to how users/patients are activated by professionals. In discussions related to empowerment, activation is a particularly interesting process, as the role of the user is not clear-cut. On one hand, it represents a 'de-medicalised' situation, in which medical (or medically framed) knowledge becomes well distributed among lay people.[15] On the other hand, lay access to medical information is suggested as ‘a growing penetration of the clinical gaze into everyday lives of citizens',[16] or even worse, 'when the language in which people could experience their bodies is turned into bureaucratic gobbledegook'[17]. Successful support-programs have demonstrated however, that patient/next-of-kin empowerment can be facilitated (activated) through the use of Internet forums[18].

3.3 Objectivation

Objectivation is the process of transforming patient characteristics into objective patient data, mainly as numerical data-sets and images. Both in telemedicine and health informatics, i.e. when we are dealing with information systems within and across organisational borders, the detailed digital representation of the patient is a prerequisite for more efficient and precise medical decision-making. Representations of patients for instance in hospitals change the role of the patient in numerous ways. Electronic patient record (EPR) systems have, on one hand the potential for more open patient engagement through bedside terminals and personal health records. On the other hand, EPR and digital representations open up for distributed clinical work (tele-medicine), by which the patient is to larger degree represented as data (images, sensor data, etc.) than as an active subject. Electronic records may therefore both be used to involve patients as active communicators and/or to represent them as transferrable clinical data.

4 Four Analytic Lenses

To discuss the three agencies (objectivation, activation, engagement) I apply four different analytic lenses; consumption, communication, community, and responsibility. Within the social sciences, a vast array of such lenses (or perspectives) may be applied for analyses of almost any theme. These specific four lenses are chosen, as they very explicitly draw our attention to relevant aspects to the provider-citizen (or clinician-patient) interaction.

Within a consumption lens we establish relations as markets, by which actors act as sellers and buyers of products and services. With a growing number of private providers of products and services, and many Western welfare state establishing internal markets within a New Public Management model, the consumption lens is relevant both for individuals and institutions.

Within the communication lens we emphasise interaction between actors, exchanging information, negotiating terms and conditions for health-care, and so on. It is well established that patient-provider encounters matter [19], that negotiation is in the core of service provision [20], and that ICTs influences these processes [21, 22].

The community lens directs our observation towards various forms of community and communal processes. We find different clinical communities in hospitals that form basis for medical work and research, and also keeping the department together as an unique entity [23]. The use of ICTs affords distributed (tele-medical) work that extends such clinical communities beyond physical location, potentially towards smooth collaboration despite distance [24]. The community lens is not at least relevant for the development of patient-driven web services and discussion (support) groups. We have for instance shown that adolescents with mentally ill parents are able to normalise an otherwise extraordinary everyday life, through participating in web forum with peers in a similar situation [25]. Experiencing empowerment is communally produced through communication.

At last, the responsibility perspective builds on observation of current Western societies in which individualised handling of risk [26-28] is becoming integral parts of everyday life. In our ‘liberal-democratic’ societies, vast areas of individual choice is hypothesised [28], through which the individual is supposed to navigate. A decreasing scope of state-funded welfare services, which we find for example in the British NHS, leaves greater responsibilities on individuals and families.

The four lenses are useful because they place health-related uses of ICTs in a larger context, which are both cultural/structural basis for technological systems and health-care delivery, but are also being influenced by changes in technology and health-care services.

5 The Twelve Roles of the Digital Patient

Combining the three agencies and four analytic lenses results in the following 3-by-4 table, by which I aim to nuance the complexity of future patient roles.

Table 1: Twelve roles of the digital patient

		AGENCY		
		objectivation	**activation**	**engagement**
ANALYTIC LENS	**Consumption**	patient data as commodity	patients as buyers of commercial services	patients as demanding and/or empowered customers
	Communication	patient data as clinical communication platform (telemedicine)	patients as users of professional information services	patients as users of clinical research and communication
	Community	patient data as resource in the clinical community	patients as participants in clinically moderated support groups	patients as creators and users of health-related social media
	Responsibility	patient data as delegated clinical responsibility	patients as responsible (compliant) by delegation	patients as responsible for own by action/initiative (self-managing)

When we look on the process of objectivation (column 1), various forms of agency are made possible. The role of patient data may be analysed through the lens of consumption, as commodities, which can be transferred, and bought and sold through a clinical market, for instance between hospitals and commercial x-ray labs. Both images, and interpretation of images, may be sold through such markets. Objectification also provides a potential for communication, as demonstrated by telemedicine, in which responsibility is transferred or delegated. Patient representations, rather than the physical patient in flesh, also provide a resource for the collegial performance of medicine.[23] Consequently, objectivation has communal potential.

Through the process of activation (column 2), the four suggested lenses are still relevant, but with other potential. It has become evident that patients in many cases are regarded as consumers, as buyers of commercial health services. Other forms of communication are possible with access to other clinically supported services. Also, in the activation process, users of health services may participate in projects with various forms of communal potential, for example through web-supported life style change programs initiated by an obesity clinic [29]. Responsibility is often delegated from clinicians or programme managers to users or patients, by which they are expected to take an active role, take control, and be empowered: the aim is *empowerment by delegation* within continued paternalistic health-care services.

The last form of agency, engagement, is based on production and consumption of information during users' own development and application of web-based resources. In many such services we observe communities being developed between regular users. The increasing number of social media applications provides a vast range of opportunities for lay users (patients) to act independently with responsibility for their own presentations. Outside the control of health service providers or state regulations (web presentations are generated across borders and national juridical restrictions) promotion of ‘anti-healthy’ behaviours [30] demonstrate the independency.

6 Implications

This paper is mainly aiming at a more nuanced basis for reflection on the complexity of processes that both respond to and produce new patient roles in an information society. The roles and responsibilities of providers and users of health services are occasionally challenged, but often surprisingly well maintained. Potential conflicts may arise as patients and citizens spend more time and effort in accessing health-related information on the Internet, while access to services are rationed by clinical assessment and regulated through health-care policy.

Especially column 3, engagement, points to citizens/patients as resources that now tend to operate independent of (public or private) health-care providers. Innovative uses of web-based data access and entry, as well as smartphone apps, have the potential to make use of such resources. I expect for instance that personal health records, through which citizens are able to record and keep track of health-related data, will be introduced in the very near future. How such systems will influence consumption of health-care delivery however, depends on many factors, worthy a final sociological reflection.

The medicalization hypothesis is well rehearsed within medical sociology [31, 32], in which various forms of deviance get medical attention [33] and where medicine is given a strong position in society [34]. We should worry about a continued medicalization propelled by citizen-centred ICTs that demand professional responses [35]. In a ‘brave new world’ of personal health records and self-monitoring applications we must expect that a growing ‘worried-well’ group of patients will foster an increasing demand for services. This group is not so clear-cut however, as people will find themselves as dwellers in the ‘In-Between, taking place alongside hypochondriacs, the worried-well, the worried-and-maybe-not-well, and the not-worried-but-think-maybe-they-ought-to-be’ [36]. A further analysis and reflection of for instance the relation between technologies and markets for health-care delivery must be informed by the very plasticity of demand factors and how these are socially shaped (i.e. by social processes). While there are certain business interests in a new market in anxiety being opened up, with technologies for self-screening and DIY home-based diagnosis, public debate and policy need a sober attitude towards technological opportunities. The ‘fetishism of efficiency’ [37] (p96) in health service management today may turn out to increase the cost of health services tomorrow.

My aim with this paper has been to suggest a framework to better understand nuances of changes and non-changes when various ICT applications are made available for health-related tasks for lay and professional users. From the viewpoint of sociology, health ICTs are both shaped by, and shaping, societal aspects such as communication, community, responsibility, and market mechanisms. A focus on the patient role contributes to an emphasis on the act of health-care delivery, which should be at the centre of technological development. The digital patient typology points towards a continued and strengthened multi-disciplinary approach to research on, and development of, information systems within health-care.

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