

SELF-CARE, TELEMONITORING AND MULTI-DIMENSIONALITY IN PERSON-TO-PERSON INTERFACING: A NEW ANGLE ON SELF-MANAGEMENT IN CHRONIC DISEASE

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Abstract

I raise the question how a tool permitting us to follow our own endeavours, habits and thoughts in an electronic journal (across the cerebral hemispheres: analogue -in pictograms- and digital -in words) can be fitted to medical needs,

I stress the pragmatic value such an illustrated diary could have, providing long-term empirical data flows in diagnostic, therapeutic and self regulatory processes, not least in providing telemetric data from relevant physiological parameters, as enabled by the growth in the area of physiological sensors and transmitters.

I further stress ways in which our thinking about interfacing the most trusted helper should be differentiated into

A) the sedimenting textual chat, where exchange is relatively undemanding for both parties and

B) the privileged virtual face-to-face & virtual room-to-room conversations, and their multidimensionality.

Here the shareable journal, and the shareable mapping of the client’s scenography play a central role in the interfacing, and so does the client’s mapping of relevant cyberspace, and the health-educational aspects of such mapping, also shareable with the doctor.

Expected constraints on such developments are exemplified, but expected enablers from the educational system,, the correctional system, the energy-saving system, the consumer-protection system and the exporting-democracy systems are noted.

Free and shareable tools for self-documentation must be the ultimate in ascendant innovations, because they proceed upward and onwards from the ground level of users’ exploration and parsing, seeking to improve what they can do with already-existing technologies and services

Keywords:

Self-management, Shared care, Shared journal, Diary, Compliance, Chronic Disease, Health care, Health costs, Open source, Freeware, Multimedia Interfacing, Tele-monitoring

1 TELEMEDICAL PERSON-TO-PERSON COMMUNICATION

How can we improve telemedical person-to-person communication and educate patients in their IT handling of their handicaps by ways of IT-self-monitoring?

Efforts like www.newhealthpartnerships.org, www.improvingchroniccare.org, www.patienteducation.stanford.edu and www.expertpatients.nhs.uk are introducing concepts of ”self-monitoring”, ”shared electronic journals” and ”patient education”.

Target groups include Diabetes-2, Asthma, Heart diseases, Hypertension, Anticoagulants treatment, Depression, Cigarette smoking, Alcoholism; but also - more generally- “shared care” and “self-management” approaches for people with chronic conditions.

It is time to consider the shared interests between all such approaches, be they as different as they are, across the specialised medical fields.

For each of these target groups, proprietary projects are developed, with demands and offers to patient-interfaces, including for each their specific tests and monitoring tools.

They all aim to relate to the individual citizens via their personal computers, establishing exclusive, health-focussed interfaces for shared electronic journaling.

But in doing this, they may be overlooking the obvious: the basic new conditions for self-presentation and close communication afforded to the citizen by the computer and access to the Internet

2 THE MEDICAL INTERFACING AS AN EXTENSION OF THE PERSON'S INTERFACING HER- OR HIMSELF.

The entire possible set of *options for electronic interfacing self* around the clock, available to the laptop user is one thing

The wide range of options for *electronic interfacing others*, extending from telephone, SMS and e-mail to long, hands-free, face-to-face, but also (even through head mounted camera) room-to-room and (yet unusual and expensive) desktop sharing is another thing

It is time to consider the shared interests between all such approaches, not only across the medical disciplines but also across language and cultural barriers.

We must see “the electronic journal, in a medical sense” as just one dimension of “a person’s laptop diary”.

And we must see “the electronic client-helper interfaces” as very special narrowed-down versions of optimal “electronic close interfacing with trusted others”.

3 THE BODY IN THE DIARY

My own research has focussed on means permitting us to follow our own endeavours, habits and thoughts in an electronic journal (across the cerebral hemispheres: analogue -in pictograms- and digital -in words) understood as illustrated diary. (Bjerg 2008, 2009)

Here one’s body constitutes a necessary frame of reference, even for the healthy person.

So, before focussing on any specific target group, we might cooperate to find general formats for personal body referring over time, in a diary. 2-D and 3-D maps of one’s body, permitting one to bookmark and comment spots and areas anywhere in one’s body.

General formats can also be created for visualizing in the diary relevant physiologic parameters over time. Beginning with the most obvious: curves of sleep length, number of pills, and for some: numbers of colas or drinks or cigarettes, --or injections, - maybe as basis for occasional reflections. If daily blood pressure monitoring, daily bloodsugar-selftest, daily bodyweight etc. were enabled, this would just enrich the picture.

Many such data could a priori be accepted for sharing with one or more helpers.

As regards the text of a private personal diary, sharing should of course be limited to dated quotes from it, concerning symptoms, advices and prescriptions received and relative compliance.

The point I wish to convey is, that in all of this we can see the medical interfacing as an extension of the persons interfacing her- or him self.

4 INTERFACING THE MOST TRUSTED HELPER

Seeing client-helper as a special case of future close multimedial interfacing with trusted others, points to important improvements in the long distance person-to person communicative space.

To the extent our now-and-here, within-sight and within-reach info-environments (including desktop) now electronically can be made shareable, participants can point in real time to spots and areas both in

own and others' body, paraphernalia, instruments, surroundings, practical situations, sequences of typical events.

Interfacing the chronic patient might well empower the patient to display and refer not only to his body but also to his room, even showing, in a conversation, by pointing and looking at things. (Bjerg, 2000, 2001)

Citizens will increasingly depend upon, and anchor themselves through information in and out from their computers. Their acquired orientation, personal inputs and outputs, trails and landmarks across Internet sites and neighbourhoods will increasingly reflect and condition their thinking and problem solving.

To the extent the option of showing/sharing what can be seen on one's laptop is an evidently relevant feature in future close communication between laptop users, it enables to share evolving personal patterns of subjective relevance on the Internet in detail and over time, - an important aspect of health-education

Citizens' dealing privately with all this – not to speak of private dealing with IT-tool use – will, also more generally, profit from being enabled to share this in distance-conversations with close friends and trusted helpers.

“Patient literacy” and “patient education” explicitly refer to the know ledges distributed and distributable on websites and WIKI's. If patient education is an aspect of the shared health-management it should support telecoaching within the frames of the patients further orientation on the Internet.

Such added features in interfacing the lonely handicapped and chronic patients would at least compensate somewhat for the missing expensive corporeal visits of the helper.

The possibilities of shared interfaces in the future are a tremendous Pandora's box.

5 ENABLERS AND CONSTRAINTS

What is available already - available to whom - depends on e-literacy. E-literacy concerning the use of proprietary software among the deciding specialists must be enormous. But the problems here to be discussed are those of attaining a most basic e-literacy for the clients.

The point I am making is, that a turn of attention shall be made to a discussion of conditions for basic e-literacy as defined by client-need and not as defined by doctors' need.

If such a base can be constructed the further needs of relating to the health-system will be defined from the ground up.

Free and shareable tools for self-documentation (call it journaling, logging or diary-keeping) must be the ultimate in ascendant innovations, because they proceed upward and onwards from the ground level of user's exploration and parsing, seeking to improve what they can do with already-existing technologies and services. (Von Hippel, 2001, 2005, Cardon 2005)

The social appropriation of digital technology must take individual everyday life experiences as the starting point.

On equal footing: The everyday life experiences of the maybe clients, and the everyday life experiences of the doctor.

Equals play best.

Expected constraints come primarily from the competitive market-games among developers of new proprietary electronic software tools for this and that target group of patients, which implies increasing

and unnecessary expenses from public and private healthcare budgets and may slow down more widespread adoption of the health cost reducing self-management turn.

So we must discuss the alternative: networked cross-disciplinary cooperation in development of open-source and cross-platform electronic diary freeware tools (translatable across languages and adjustable to the different demands of cultures and of target-groups)

I have in my paper; “Personal electronic Journaling” at this conference (Bjerg 2009) described the proceeding development of freeware, cross-platform, software, facilitating the user’s private and personal logging of subjectively relevant phenomena.

In the healthcare context this applies not least to the time-indexed registration of symptoms and of palliative measures taken.

6 DELINEATING A STRATEGY

* The prototype personal electronic journaling software shall be improved to structurally reflect the user’s body in 3 dimensions, in ways, which will permit users to point to, refer to, annotate to, colorize, daily or lasting, any selected area of own body. (A virtual body)

* A corresponding enterprise is that the software shall be improved to structurally reflect the user’s home in 3 dimensions, in ways, which will permit users to point to, refer to, annotate to, colorize, daily or lasting, any selected area and furniture of the home, and especially from the basic bodily positions: at desk, in bed, in wheelchair, in kitchen etc etc (A virtual home)

* The software shall be improved to facilitate recording of physiological data and convenient mechanisms to inspect such recordings as coloured curves

* A radical expansion of the glyph-fonts to symbolize medical symptoms shall enable patients with a click to record whenever one or a number of symptoms appear/persist.

*Models for citizens’ wireless close encounters with trusted helpers,

- referring to own symptoms as empirically validated,
- displaying curves of drug intakes and physiological self-monitoring data, and
- sharing the clients mapping of (at least) health relevant Internet Sites

comes next.

7 PRAGMATIC APPROACH TO THE PATIENT-DOCTOR INTERFACING

There is a problem in the fact that the potential caretaker or doctor normally will wish for the shortest possible interfacing, while the client/patient from the beginning will need long interfacing.

Therefore a pragmatic approach will be to integrate a sedimenting time stamping chat format with the diary.

It is necessary to consider close face-to-face audiovisual interfacing, supplemented with optional desktop sharing (e.g. concerning relevant internet sites or relevant body areas) as beforehand agreed upon episodes (in continuing doctor-patient text-chat) as time set and time-limited “scenes” or “episodes”. (Consultations)

8 CONDITIONS FOR DIFFUSION

I am talking of the future, but it is a future, which (on the client side) could be brought into reach of all (English or Danish reading) laptop-owners with an Internet connection within a year.

The simplification of it, to make it useful for the most seriously handicapped and the translation of the user interface to cross language barriers may mean another year.

But as the health-target is not the only relevant for these projects there should of course be made coordination with:

- a) *The educational system*: the pupil and students personal electronic journal, and interfacing to teachers.
- b) *The energy-system*: The citizen's personal electronic monitoring the variable, domestically distributed, electrical consumptions and their economic consequences
- c) *The correctional system*: The prisoner's personal and confidential laptop-diary, (going – toward release – to include more or less screened access to local and public sites, at least the official Citizen Site, and the establishment of personal digital signature and a bank-account.) The interfacing between prisoners and possibly trusted helpers in the prison might be designed in analogy with those between patient and most trusted health-professionals.
- d) *The consumer-protection system* is also a relevant player in this scenario. Especially in regard to the information economy there lies a strong consumer-protective interest in empowering consumers to document over time (on daily, weekly, and monthly basis) consumption of proprietary services and deliveries. This applies not least to the mail, SMS and telephone promises and demands, waiting times, contact routines and errors encountered from the citizen-side.
- e) *The exporting democracy system* Across all these aspects an important meta-aspect must be kept in mind: We are dealing with cooperative development of non-proprietary cross platform software of a particularly democratic nature. This means, that it may be translated to use by laptop-owners in any country.

In a time of recession and inescapable reductions in healthcare and educational budgets the rationality of such approaches should be obvious.

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