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55 – Confidentiality Issues in Family Practice and Primary Care

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Introduction

Confidentiality of individual health data corresponds to the right to privacy as a basic human right, as declared in 1948 (1). For a long time, to share this knowledge with the individual has been a privilege of the physician as chosen by the patient, and legislation supported this (in the Western world). Sanctions were put on physicians for violating the law and this code of ethics. Exemptions were restricted to defined epidemic diseases (public health) and criminals. Due to the rising importance of cost-effectiveness in health care to society, social insurance systems and governmental health authorities require increasingly more information on individual health data.

Data per se are neutral facts that can be stored, retrieved and processed.
Data processing embraces impact of describing, specifying, categorizing and selecting data.
The ethical life includes the good fortune of not having to have a will.
The will as a subject enforces a decision. It introduces good and evil into a world of neutral facts, into a world of a timeless presence. (2)
Connecting data with a question, an intention, a hidden aim in algorithms, these soft components of a search machine produce an enormous surplus of information – uncontrollable by any individual concerned.

This applies even more so when links interlinking data bases are used.

Due to technical IT innovation, the 1995 EU Data Protection Directive (Directive 95/46/EC) (3) needed a reform.

In paper Com (2010) 609 (3), the European Commission presented “A comprehensive approach on personal data protection in the European Union”, suggesting the EU to have a single legal instrument for regulating data protection, in line with the EU Charter of Fundamental Rights (3). This Reform Paper was published on May 4th, 2016, the Directive entered into force on May 5th, 2016, the Regulations on May 24th, 2016, to be transposed into national law by May 2018.

Personal data includes all information relating to an identified or identifiable person (3). Data controllers and data processors are obliged to take account of all the means (4) likely to identify a natural person.

Health data as such are not sensitive data, as long as they do not relate to an identifiable natural person. The danger starts with data processing, and legislation should aim at that.

Why do we need confidentiality?

In this era where sharing intimate stories on Facebook is common, some might think that confidentiality of medical information is outdated.

But confidentiality is one of the core duties of medical practice.

If personal information of the patient were not protected, trust in the physician gets lost, patient relationship will be diminished and patients will be less likely to share sensitive information, which will negatively impact their care (5).

Cross linking of sensitive data relating to a natural person may harm our patients as individuals, e.g.:

- If you are HIV positive, you may be denied a bank credit.
- If you are suspected to develop dementia, you may be denied access to your bank account and control of your property.
- If you survived cancer, it is more difficult to get a life insurance or a medical insurance.
- And, least you forget the Godwin law, every discussion ends with Hitler and what his regime did with "affected people".

Exceptions from protecting sensitive personal data are defined by men made laws, by politicians elected by majorities ("Five C's") (6).

- Who protects the minorities?
- Who decides if religious / political convictions are criminal?

Timothy Garton Ash in his book "Free Speech" (2016) (4) speaks about Big Cats and Big Dogs and Mice (small people), where information is concerned.

Big Cats are Google, Amazon, Facebook or Apple (GAFA).

Big Dogs are the USA, China or Europe.

And small people … you and me.

The Big Cats know a lot about us, the Big Dogs hold the power to make laws about what can be shared as confidential information, and we, small people, can vote for Big Dogs but not for Big Cats (4).

Mariana Mazzucato (7) enlightens the interactive structure of the empowered virtual hybrid "DoCa".

Technical development, *the big business*, comes from scientists that are in first line innovative and in second line money-motivated. If you dig deeper the public money comes from the dogs, and the steering members of the dogs are motivated by the cats' money – as a kick back.

The state, or, in any case, the administration we have elected are shareholders and contractors of the companies, which develop the tools to destroy individualism and freedom.

Big Cats, Big Dogs (4)

Research of huge piles of meta data are now big business. The world is always in turmoil, at least according to the press, but that has a paradox effect:

There is more fear, and yet more people share more data … and leave it open to big corporations to deal with confidential information.

Google is the biggest, followed by Facebook, to know about your health. Every single byte you look up or share is noted, processed and followed by an anonym algorithm.

Follow the cash route and you can diagnose pregnancy, depression, intention to migrate.

Cross links and background storage of defined interpretation of content make that possible.

Future Issues

Now coming back to family practice and primary care and sensitive health data – how should we practitioners position ourselves?

- Do we act according to legislation?
- Do we keep secrets in the best interest of our individual patients?
- How do we handle arising conflicts of interest between public and economic matters and private individual benefit or welfare?

The contract is between the patient as "customer" and the practitioner as the "health provider" following certain safety rules – one of the most important issues is confidentiality.

The integrity of the contract partner is a fundamental cornerstone of trust and has to be protected against being violated by interests of other spheres like religious, political, ethnic and economic influences.

We all are members of the global society after a humanistic revolution in the middle of the 19th century. Despite the fact that many of us still do not realize this history of mankind yet, we are now all caught in a dense compressed face of this evolution.

We are elements of that - the evolution of information flow, of access to knowledge and the ability to communicate in real time round the globe – including abuse of these instruments.

The challenge is to humanize the evolution of knowledge within our social human society and to avoid that the evolution becomes a revolution eating up its advantages ("-children"(8)).

The way out might be (sOP versus sPP):

***Strict Open Transparency of the Dogs and Cats and strict Protected Privacy for the individuals*.**

A symbiosis of humanism and knowledge described as a dynamic process (Prof.Dr. W. Leinfellner, Editor of the journal Theory and Decision) needs time and space and the chance to realise self-organization.

Small minded political actors and misled public mainstream are not only obstacles in a dynamic interactive development – but also they can have dangerous impacts.

The future therefore lies in a physically separated data storage equipment, encrypted and under the strict control of the physical person who is the data's owner.

Take Home Message

- Every individual can be defined by a set of data. Harm arises from data processing, not from data as such or data storage.
- Data processing is driven by hidden interests in gaining economic and / or political power over individuals, societies, governments and the globe. Media are a tool of the "dogs"- Dogs are often paid and steered by the cats and the tax payers have to cover the holes in the budget (7) .
- Possession of data is the basis of power. Processing data rules the world. Who gets the benefit? Who asks the questions – and which are their (cats & dogs (4)) aims?
- A strong ethical impact is needed. Pure ethic is free of political and religious influences. Legislation to protect individuals must be based on ethical intentions – but consider: the way to hell is paved with good intentions.
- As Primary Care Physicians and Family Doctors, we must keep in mind the best interest and safety of our patients – and last but not least – of ourselves.

Original Abstract

http://www.woncaeurope.org/content/161-confidentiality-issues-primary-care-qualitative-study

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   "Das ethisch gute Leben entspricht dem Glück, dem „Nicht Wollen" zu müssen. Das wollende Subjekt erzwingt Entscheidung, es bringt das GUT und BÖSE - in die Welt einer neutralen Fakten Gegenwart." Zitat nach Wittgenstein (Tractatus Logicus Philosophicus – 6.43)
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7. Prof. Dra. Mariana Mazzucato, a leading Italian economist, describes the connections between the states as enterpreneurs and their role as discrete motivators in the background to keep a persisting war engine running. (The Enterpreneurial State, 2011; Das Kapital des Staates, 2014)
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Primary care is that care provided by physicians specifically trained for and skilled in comprehensive first contact and continuing care for persons with any undiagnosed sign, symptom, or health concern (the "undifferentiated" patient) not limited by problem origin (biological, behavioral, or social), organ system, or diagnosis. Primary care includes health promotion, disease prevention, health maintenance, counseling, patient education, diagnosis and treatment of acute and chronic illnesses in a variety of health care settings (e.g., office, inpatient, critical care, long-term care, The importance of maintaining confidentiality in the physician-patient relationship has been recognized since the 4th Century BC.Â do they promise confidentiality to the patient in an effort to build a therapeutic alliance and improve physician-patient communication, or do they breach confidentiality to inform others, usually the patientâ€™s parent(s), about the patientâ€™s medical condition? Although many older pediatric patients have the cognitive capacity to understand medical decisions,5 individuals eighteen years. Family based interventions which focus on improving communication within the family had some success in treating behavior problems. In family therapy, the primary goal is to change dysfunctional family systems, clarify family roles and promote honest and open communication among family members. Good quality day care can have positive psychosocial benefits, particularly in case of children from poor or disordered homes. References. 1. Bhargava S., Garg O.P., Singhi S., Singhi P., Lall K.B. Prevalence of behaviour problems in Ajmer school children. Indian J Pediatr. 1988;55:408-15. 2. Bhatia M.S à¡¯ sample practice confidentiality policies and staff confidentiality, agreements. à¡¯ guidelines on producing and displaying publicity informing young people about confidentiality, training suggestions and case studies a method of auditing standards of confidentiality in the practice.Â Primary Care Trusts appoint a Caldicott Guardian to look at and advise on the protection of patient confidentiality. GPs remain responsible for the confidentiality of individual patient information within the practiceâ€™s clinical governance framework.Â Child protection issues are not always clear cut. Health professionals often have concerns rather than evidence and these should be discussed with colleagues within the practice or with social care. The term primary care physician is synonymous with family practitioner, or general practitioner; meaning a medically qualified clinician who is the first point of access to health care, with general responsibilities which may but do not necessarily include child health or obstetrics and gynaecology. Other primary care clinicians; nurses, physiotherapists, midwives, and in some situations pharmacists may face similar issues, and some (confidentially, prioritisation of patients) may also involve administrative staff. In some healthcare systems primary care specialists may also encounter many of ...Â Papanikitas A, Ethicality and Confidentiality: Is There an Inverse-Care Issue in General Practice Ethics? Clinical Ethics 2011; 6 (4):186-190.