

Chapter 17

A Client Perspective on E-Health: Illustrated with an Example from The Netherlands

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ABSTRACT

After the Second World War democratization, information technology and globalization changed healthcare. Democratization made that clients from an object of treatment by professionals became active participants in taking care of health. Globalization brought the free market place closer to choices clients made for services. Information technology accelerated the way knowledge was accumulated and communicated by medical sciences, medical practitioners and clients. In research studies indications are found that healthcare facilitated by information technology (E-health) improved the care. However the evidence was not quite strong, also because the used research designs were not always suited for E-health. An overview of research designs leads to the conclusion that action-research is more suited for E-health, particularly when clients are taken serious as partners in healthcare. An example of action-research in mental healthcare in The Netherlands illustrates this. It also shows that a partnership between professionals and clients can be beneficial for both actors.

A HISTORICAL PRELUDE TO E-HEALTH

Healthcare in our modern Western European societies has been developed in a long social tradition. It took some time, for example in the Netherlands, before the foundation of the welfare state was

laid into solid laws as a product of the negotiation between a ruling class and the labor class. And it was only after the Second World War that the laws for social security were completed by a law (1947) that obliged everyone in the Dutch society to take a health insurance. Private insurance companies, at one hand created for the rich, on the other hand founded by trade unions for the poor, became state

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regulated. It was also after this Second World War that the flourishing economy made it possible for the state to go from a policy that took care of well-fare (a minimum income for example) to a policy that focused on well-being (for example taking care of leisure time).

This paradigm shift from welfare to well-being was supported by science. Earlier in history the medical sciences extended their skill and knowledge from physical healthcare to mental healthcare. Moreover later on psychiatry extended her medical domain to a social domain: social psychiatry was born. In the fifties of our late century social support activities had been regarded and reconstructed by American researchers (Lewin, 1948; Benne et al 1976) as 'social engineering' with the aid of knowledge from the social sciences. The practice of social support was reflected and guided in a scientific way. In Europe the scientific reflection of social support led to such disciplines as social medicine, community based psychiatry, social pedagogy, organizational psychology, adult education and disciplines for leisure time (studying cultural and touristic activities). The old mission of the labor class was taken seriously by some of those pioneers who focused their work on values such as emancipation and democratization.

This led in the seventies of the 20th century to a booming business of public activities for social support, by employees of: healthcare, social work, cultural work, community development and adult education.

With the prosperous economy society developed the luxury of democratization. Clients of the social services were invited to take part in this emancipation of citizens. The government for instance made laws in which institutions for social services were compelled to involve clients in their board. Such an atmosphere stimulated clients, for example in healthcare, to go public and openly ventilate, sometimes invited by media, their grievances. Research of the quality of healthcare revealed that there was still a lot to win. In mental healthcare, patients were still

without rights, isolated in isolation cells, unwillingly treated with old fashioned methods such as electro-shocks, complaining about side-effects of medicines. A confederation of clients of the mental healthcare has been founded in those times. Clients participated more and more in the decision making of institutions of social services and sometimes. They sometimes worked together with professionals that wanted to reform the status quo of the social services. In psychiatry, for example, an alliance of anti-psychiatry between professionals and clients was formed against the medicalization (Ilich, 1975) and isolation of abnormal behavior in psychiatric hospitals. Was that abnormal behavior also not caused by a dysfunctional social environment, and would it not be better to change that environment as well? From an object of treatment of professionals, patients became a participant in the process of recovery of themselves and the environment. Patients and their relatives, stimulated by the state, got involved in healthcare policy making.

Professionals as such were ambivalent about this situation. They welcomed the participation of clients, but were also afraid to get out of power. However soon they retained and by using technologies of informatization they strengthened their instruments of administration and control. At the end of the 20th century when the ideology of the free market became stronger (the state drawing back from economy) healthcare was left to the free market. That had the consequence that patients became weak actors in a complex free market system that operated businesslike and was mostly controlled by professionals and insurance companies. Also the globalization of this system made it more complex for patients. Patients in the Netherlands who were put on a waiting queue discovered that in neighboring countries they could get help immediately. That introduced in theory more possibilities and choices for patients. But it also turned out in practice slippery because of lack of adequate information and unknown financial interests of globalizing professionals.

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