

Can Elderly and Frail People benefit from Health Telematics/Home TeleCare?

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1 Objectives

The objectives of this short paper are to

- contribute to a conceptually based, forward-looking discussion of the topics under consideration
- identify important trends
- briefly report on some ongoing projects/studies undertaken by empirica
- identify perspectives on developments needed in the care for older people

To reach this goal, first we will briefly touch upon some important trends - both challenges and opportunities - which need to be taken into account when considering the contributions telehealth and telecare can make towards a better care for older and frail people. Opportunities will include considerations with respect to techno-economic progress, medical progress and the advantages of expanding home care. This will be supported by briefly looking at some recent research on home care. To complement this view, ongoing research and expected results from some path-setting projects being undertaken by empirica will be reported upon. Finally, the views of some sceptics of tele-homecare and of older people who indeed have experienced a new, forward-looking service will be juxtaposed, and some development needs sketched.

2 Challenges and opportunities

2.1 Challenges

On the one hand, there are several challenges social and health care systems, care providers, financing institutions, the citizens, politicians etc. will be faced with:

- Life expectancy increases / the result is an "ageing" population
- Better informed citizens/patients will lead to an increasing demand for new, more advanced medical treatment and care
- Prevalence of costly, chronic diseases accelerates
- Health is the number one priority for older people, 85% regard „health“ as very important for themselves, even higher than „family bonds“

- The danger of a „Medical Divide“ is imminent, i.e. a two-tier care services system - both globally and locally - benefiting those who are better off, and fending off those who are less educated and poor.
- There is a growing danger of young people opting out of social security systems („silent revolution“ of the 21st century), thus undermining the financial basis of health and social care for older people.

2.2 Opportunities

On the other hand, a wide variety of developments suggests that there exist great opportunities to cope with these challenges and to further improve the quality of life for our older people and, at the same time, allow society to benefit from these developments. As was pointed out by Gro Brundtland of the WHO: an investment in health is an investment in the economic, social and political development of any country, and improvements of living conditions will allow our older population to become old in a healthy, socially integrating fashion.

2.2.1 Technical and economic progress

Technical research, innovations (i.e. the transfer of inventions into new business) and their diffusion are a prime mover of new developments, and progress is accelerating:

- Diffusion of innovations: It took 39 years, till 25% of US households got a telephone, but only 18 years for a PC, 13 years for a mobile phone, and 7 (seven!) for Internet access. Particularly information technologies are diffusing at an ever faster rate.
- As a result of this and the speedy falling of prices, productivity gains have been accelerating for about 10 years, leading to an unprecedented period of stable economic growth (the „new“ economy).
- An hitherto unknown venture capital boom has extended to the funding for high-tech companies with no assets - a totally new development also supporting new businesses in the telemedicine and e-health fields. Innovations do not only become available but also affordable at a faster rate than ever before. At the same time, the level of competition in open markets is rising.
- This has led to new job opportunities and a healthy labour market in those countries which have taken the most advantage of these developments.

2.2.2 Medical Progress

In parallel with these developments also medical progress is accelerating:

- Genomics is about to decode the entire set of around 100,000 human genes. Most of these genes serve as blueprints for the production of proteins, the „workhorses of living cells“.

- As a consequence, proteomics - the decoding of the complete set of human proteins - is fast becoming „biotech's next holy grail“. It is estimated that the genes in the human genome can generate up to a million different proteins - a tremendous task which can only be approached by applying modern IT-based methods.
- This, in turn, will lead to better, more objective means of diagnosis. Subjective symptoms can be related to real biological change, and protein markers are already known to indicate pre-malignant cancer cells.
- Therapeutics will also benefit: new drugs are already under development, and it is expected that proteomics will shorten the usual time span of 10 to 15 years from the laboratory to the general market to perhaps only a few years by helping researchers to identify safer, more effective candidate medicines earlier in this process.
- At the same time, already available new drugs and therapies like those based on low-molecular-weight heparins (LMWH) are revolutionising treatment and lead to vastly improved opportunities for home care - and cost savings for health systems.

2.2.3 Expanding home care

Expanding home care has - in most settings - various advantages when compared to (long-term) residential or hospital care:

- most citizens prefer to be cared for at home
- it relates to a higher quality of life
- life expectancy increases with home care
- lower health care costs (per case!)
- the average number of hospital (re)admissions and the length of stay in hospitals decrease

To support this assessment, let us briefly present some selected research results on home care:

a) In Israel, a research project showed that intensive home-care surveillance prevented hospitalisation and improved morbidity rates among elderly patients with severe congestive heart failure (CHF). Cost savings amounted to about 50%. Their 42 patients (mean age 78) received at least weekly home visits by an internist or paramedical team over 1 year. „Compared to the preceding year, total hospitalisation episodes per patient decreased on average from 3.2 to 1.2 and admission days from 26 to 6... [P]utting aside the clinical and moral benefits for the patient from such a program, the estimated service cost per patient (after including other staff costs) equals the cost of 10 hospitalisation days per year. A 10-day cost vs. a 20-day saving.“

b) By focusing on preventive and pre-emptive home care for patients suffering from quadriplegia, Aids and mental retardation, an American HMO in New England could realise savings of about 50% Community Medical Alliance (CMA) in Boston deals with

a relatively few 800 patients suffering quadriplegia, Aids and mental retardation, traditionally difficult and expensive conditions. CMA focuses on preventive and pre-emptive care, largely provided by home visits by nurse practitioners. "When CMA adopted managed care principles in 1991, Massachusetts Medicaid paid it \$2,228 per patient a month. ... But last year [1997], using capitation, CMA's monthly patient costs were running at about half that, \$1,199 a month." (That is about \$1,100 a month lower than the costs for similar Massachusetts Medicaid patients still in fee-for-service programs.) Almost the entire savings - \$1,016 - comes from keeping people out of hospitals.

c) A European survey suggests that home care for dialysis patients improves their length and quality of life, and that cost savings can be considerable. Mignon and colleagues puzzled over the European variations in usage of (largely home-delivered) peritoneal dialysis (PD) versus (largely institution-delivered) haemodialysis (HD). Rates for PD are 45% in the UK, for example, but only 10% in Austria and Germany. E.g. in France, nurse visits for PD support at home are reimbursable, "and this clearly influences the choices made by both doctors and elderly and handicapped patients."

3 Experience and perspectives: research projects by empirica

This section will briefly report on some path-setting projects being undertaken by empirica in fields related to health telematics for older people.

3.1 HausTeleDienst: the world-wide first interactive (CATV-based) HomeTeleService

The objective of this pilot project was

- to prove the ability of older and mobility-impaired people to live independently
- to demonstrate new strategies to reduce the load on social and home care service resources
- to gain experience in new technologies
- to experiment with a new service organisation

Work on this pilot started already in 1988. It became operational in early 1990. Its location is Frankfurt/Main, Germany, and there in Westhausen, a residential area the development of which dates back to the early 1920ies. From the start on 17 older persons (aged 70 to over 90) in 15 households were connected who, in most cases, had been living there for 40 years and more. They were self-selected; on average they were more isolated and less mobile than other people of the same age living in the same area. Service provider is "Frankfurter Verband für Alten- und Behindertenhilfe e.V. (FV)".

Service components included remote care; information and assistance; emergency, counseling, training and exercise services.

Within a relatively short time period, a kind of general service usage pattern developed: Almost 2/3 of all households called the service centre daily. A sizeable minority of calls (39%) lasted less than five minutes, 16% lasted between 5 and 10 minutes and 22% between 15 and 30 minutes. In 9% of all cases, contact was established for longer than half an hour, some of them reaching up to 75 minutes. In general, the clients' need for communication was high, particularly during times of physical or emotional stress. Not unexpectedly, it was higher during the winter than during the summer.

Issues of acceptability of a video camera in the home were much less important than involved researchers, and especially the service provider organisation, had expected. The camera was placed inside a set-top box on a regular TV and could be closed and opened by sliding a simple, relatively large shutter back and forth. Because even very old ladies were able to handle it without any problems, it immediately gave them security and a feeling of being in power of the technology. In addition, the very personal and close relationship to the staff - which was supported, not inhibited by the video communication - was a major factor in the positive acceptance of the service.

In the context of the European ATTRACT [Applications in Telemedicine Taking Rapid Advantage of Cable TV networks] project, presently the cable network is transformed towards digital technology, and a new home care service and tenant oriented services will be implemented again. Further developments include the TESS project in Bielefeld/Germany and its commercialisation efforts („HausTeleDienst II“) supported by the European TEN-CARE project.

3.2 Development of European Home-Care Management Systems: The TEN-HMS project

The aim of this European Union TEN (Trans European Networks) project European Home-Care Management Systems (TEN-HMS) is to develop and implement a modular set of home telecare systems for chronically ill people, older/disabled citizens in need of long-term health care or patients who will benefit from constant vital data surveillance while at home. Due to its random design and an observation phase of 450 days, the five hundred patients involved, and the implementation in 3 countries and 12 hospitals together with local specialists and GPs, this telemedicine project is without precedence world wide. Its concrete objectives are to

- improve medical outcome for people suffering from congestive heart failure (CHF), but also from diabetes, end stage renal failure (ESRF), and hypertension, and increase the uptake of „Best Medical Therapy“

- enable citizens to take a more active role in the care of their personal health in out-of-hospital settings
- improve the quality of life of (chronically) ill and older people
- and to improve the efficiency (cost reduction) and continuity of healthcare processes.

The TEN-HMS systems interface devices monitoring vital data (like weight, pulse and rhythm, blood pressure) which can be easily used by a range of patients at home, with standards-based cordless communications suited to a domestic environment to further improve ease of use. Data captured are transmitted through secure networks to co-operating systems and a service centre, with interfaces to electronic health records, supporting the medical staff monitoring and making decisions real-time on treatment for the remote patients. TEN-HMS tele-care systems thus enable care to be delivered to patients at the point of need.

Due to extensive prior work, the requirements for home-monitoring for congestive heart failure - CHF - (due to left ventricular systolic dysfunction) patients at high-risk of readmission are well understood, and appropriate systems providing the basic functions are implemented rapidly. This enables the R&D project to include a large-scale medical research experiment (200 randomly selected patients supplied with home monitoring equipment; two random control groups of respectively 200 patients to be supported by a telephone service and 100 patients treated in a „conventional“ fashion) across three European Union Member States (Germany, Netherlands, United Kingdom) to provide detailed and statistically reliable information on clinical outcomes and total system cost-effectiveness for this key group. Leading cardiologists in 12 hospitals - who provide the telemonitoring service centres -, specialists and local GPs are involved. All data are collected and analysed by an independent research institute. In order to not influence the behaviour of any participant of this world-wide unique research project, results will be made available only after the end of this trial in late 2001.

Primary outcome measure is bed-days occupancy in acute medical beds. Secondary outcomes include a composite measure of patient well-being, Best Medical Therapy Score, costs of care and mortality.

In parallel with this work, investigations with specialists and of patients with other conditions will provide a harmonised set of requirements across all prevalent chronic conditions - including diabetes, hypertension, renal failure - whose sufferers can benefit from home monitoring. In each case, processes of care provision will be studied and optimised for remote delivery of care, and the system specification will incorporate features to meet requirements arising from the redesigned processes. This will enable the drafting of the architecture of the complete TEN-HMS system, defining the standards to be used to ensure open connection of third-party equipment, providing solutions for data protection and other specialist requirements and thus preparing the TEN-HMS system for acceptance in a global market.

3.3 Videophone-based home care for Peritoneal Dialysis (PD) patients

Worldwide, more than 800,000 patients suffering from end-stage renal failure (ESRF) are dependent on dialysis. Prevalence has almost doubled during the last decade. Research has shown that home dialysis relates both to considerably improved medical perspectives and to higher quality of life for patients. The aim of this pilot - in the context of the European ATTRACT project - is to explore the possibilities of extending home care to more dialysis patients (initially only for continuous ambulatory peritoneal dialysis - CAPD) through video-based support. Initially the short-term and longer-term benefits expected both from the medical (doctors, nurses) and the patients sides were elaborated, then an application scenario developed from these expectations, and an analysis of the organisation in the outpatient dialysis clinic performed. This was followed by the selection and testing process for low-cost ISDN video equipment and auxiliary devices (like additional camera), and the training and initial tests with doctors and nurses and later a simulated patient. Supporting material and forms - for both doctors/nurses and patients - were developed, and 5 patients received a standard video telephone connected to a basic ISDN line (2 B channels). In parallel, more advanced equipment, particularly various types of cameras connected to the video phone for better medical supervision, have been tested. Test site is an outpatient clinic of the German Kuratorium fuer Dialyse (KfHD) in Frankfurt; the KfH services more than 15,000 dialysis patients in 188 clinics. The extension of home dialysis is a high priority for it.

Initial results have been ambivalent. Particularly the transmission quality of the video signals used for checking the catheter exist site in the peritoneum have not met the medical needs of the physicians, and further tests will be undertaken with more advanced equipment.

3.4 Support of mobile care personnel in the field - a TEN-CARE pilot

The European Union TEN (Trans European Networks) project Telecommunications-based Home-Care Services for European Citizens (TEN-CARE) offers the opportunity to develop and implement a whole set of service components designed to support mobile care personnel in the field. The overall service design includes IT components to support

- the management of non-professional home care personnel
- improved and faster communication between mobile staff members and professional experts in the service centre
- better information access and information flow.

The chosen technology consists of a mobile phone connected to both a mobile device (notebook/PDA) and a digital camera. This set is used by a team of mobile care personnel. The set is assigned to a car which is shared by one care unit of up to 5 staff members.

The overall approach is aiming to

- reduce direct and indirect health care provision costs by offering more efficient care
- improve the quality of care
- improve the quality of life for older and disabled patients

Mobile personnel in the field will always be able to contact a service centre staffed with high qualified personnel. The digital camera allows to make, send and discuss pictures - if necessary in real time. The expert in the service centre does not need to travel to the client as often as in the past. He/she will also be able to support his personnel more frequently.

Initial results indicate that handling and usage of the equipment does not cause more than the usual implementation problems. Based on the better support of less qualified personnel the given quality of care can be guaranteed. The improved possibilities for communication between the service centre and the mobile staff members have reduced unnecessary and costly duplication of efforts, and they have improved effective and efficient health care delivery. - Initial implementation site has been the Johanniter Unfallhilfe in Iserlohn and Lüdenscheid/Germany. It is a large service organisation operating across Germany and in various European countries, and a wider implementation of this successful, IT-supported organisational set-up is planned.

3.5 Global market research on IT-supported products and services for older people: the SeniorWatch Project

The European Union supported SeniorWatch project addresses the need to better understand and monitor market dynamics of Information Society Technology (IST) applications targeted towards older and disabled citizens. It will provide a unique global source of reliable empirical information on market potential. Information gathered through an innovative approach includes Europe-wide representative surveys (10,000 older citizens, 1,200 decision makers of the care sector), country reports (all Member States, USA, Japan, Norway), leading edge case studies and industry-lead technology analyses. Its syntheses will contribute to key industrial and social policies.

Insufficient market data, lack of awareness by industry and uninformed users and politicians hamper the rapid exploitation of market opportunities for design-for-all and assistive IST applications for older and disabled people. SeniorWatch supports industry, incl. SMEs, to address this rapidly growing, global market and challenge the competitive advantages of US industries; spreads market information thereby fostering RTD and employment; empowers older and disabled citizens, their associations, and care services to articulate their views, needs and priorities, informs them about IST applications and encourages them to demand IST products and services which meet their requirements; disseminates results to all key players to achieve maximum impact. Social objectives addressed include social and economic cohesion, quality of life and health.

A unique approach integrates in an innovative manner empirical methods to establish a globally recognised observatory and key benchmarking resource for industry, users and politics: It starts with the design and execution of representative surveys of older and disabled people and decision makers from care services. In parallel, an Industry Expert Technology Watch Group starts its work focusing on technology and industry trends and new opportunities emanating from emerging IS techniques. It provides key guidance for the project and functions as a sounding board for innovative ideas, performs quality control and, through its leader, becomes directly involved in the management of the project. Three workshops are held where the status-quo, expected developments and trends as well as industry perspectives for IST markets in this sector are examined and reported on, and generic case studies of leading edge IST applications are compiled. The work of the expert group, case and country studies are guided by the approach and instruments designed on the basis of the SeniorWatch framework. Survey data, technology studies, cases and country reports are analysed and integrated into a comprehensive portrait of situation and trends in and across Europe and vis-à-vis global markets. This provides input to a synthesis of policy implications, for recommendations and a final summary report.

4 Home Telecare: Two contrasting views

In this section, we will briefly juxtapose the views on home telecare from two rather different perspectives, those of so-called (but uninvolved) experts and those of some old people who indeed have concrete, personal experience with a home teleservice over an extended time span.

4.1 Scepticism of uninvolved "experts"

In a letter to empirica, the leadership of the German Heart Foundation in Frankfurt/Main voiced its strong scepticism about teleservices for older people and patients. It regards them as merely serving the creation of new markets without real improvement in care. They underlined their position that personal care must be strengthened.

In a letter to the editor - in response to a report about the HausTeleDienst in a journal - a GP articulated his opinion that there does not exist any need for such a "sterile" teleservice. He believed that, on the contrary, robust help is needed when older and frail people are incontinent or vomit.

Substantial reservations against such a service were also articulated in an internal paper by the Deputy Minister of Finance of a German State - marked as his personal opinion. He, too, expressed his belief that teleservices will only substitute personal contacts. At the same time he stated that, as a politician, he would support such a cost saving service.

5 Future perspectives and development needs

Based on our experience so far we strongly believe that home telecare has a realistic potential to ensure and improve the self-assurance of older people, their ability to communicate and socially interact, their medical support and their safety. At the same time, it can be a means to alleviate the burden on professional people and home carers, to better and more efficiently organise their work, and to spend a higher amount of their time on caring in person for those older people who are in most urgent need of personal attention.

However, our experience also indicates that present technology needs further development. It must become easier to be implemented by "normal" technicians and service people, easier to be integrated in legacy systems, sometimes - particularly in a medical environment - a better performance is needed, and sometimes it needs to be better designed such that it can be handled more easily by both care service providers and older people.

Perhaps most urgently - to really prove a business case for such applications - large scale experiments and implementation projects are needed integrating the various aspects of such services into one holistic concept. Moving from a perspective focusing on functional disabilities of older people to a market-demand orientation integrating the various needs of older people will prove a key success factor. These may involve:

- video-telecommunication for everyday activities, social exchange and „chatting“
- telemetings focusing on specific interests and hobbies
- general information and assistance, arranging of appointments, delivery of products and services etc.
- domotic/intelligent home applications/security
- medical support
- telemonitoring and home care.

All of this will support the quality of life, health and security of older people, assist family members and friends caring for them, provide new business opportunities and jobs in public and private health and home care services. In this context, one should also integrate volunteer and paid jobs for older, still fit persons. Our own experience indicates that there exists a great interest with medical and social service providers, housing agencies etc. to proceed along these lines.

The HausTeleDienst as sketched above in Section 3.1 has been the topic of numerous TV programmes. Almost invariably such productions also involved contributions by similarly sceptical experts. All of them miss two decisive points:

- a) Such a service is not intended and cannot substitute for personal services, rather it will always complement them, allowing care givers more time in the home in those situations where personal help is most needed.
- b) They presumptuously disregard and negate the opinions of those older and frail people for whom these services have been developed.

4.2 Acceptance of home teleservices by older people

When considering the views, expectations and opinions of those older people who indeed have had long-term, real life experience of a home teleservice, the picture changes dramatically. The HausTeleDienst in Frankfurt/Main was rated very positively by most of its clients. Suggestions for improvements concerned additional personnel and longer service hours, if possible 24 hours a day. The most valuable service component from their point of view was the active care and information service, although the users did regard the various HausTeleDienst services as one general service consisting of different service elements. 10 of the users pointed out that the opportunity to get in contact with someone when they want it is most important for them. The second most important advantage of the service is the possibility for immediately getting direct, personal help if needed.

Almost all of the users emphasised their very personal and close relationship to the staff - which was not inhibited by video communications. The new service had quite an impact on their lives. Five of them believe that the service directly changed their lives. Statements range from „I don't feel lonely anymore“ to „I have more regular daily routines, I've regular meals again“ or „I have more joy in my life“. Much better than any other research results can these statements describe the real, lasting, positive impact of this video-based social support system on its clients' quality of life.

Another important aspect is that through this service some older people improved their communication skills, reduced TV consumption and established new, personal contacts which they actively pursued also outside of their home.

Health Telematics for the Elderly
German-Japanese Workshop
Dagstuhl, Germany
May 8th/9th, 2000

German-Japanese Cooperation Council
for Hightech and Environmental Technology

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