Care Is Coming Home. Towards a New Architecture of Health Service in Europe

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Introduction

We will start with some basics:

- The demographic change leads to an accumulation of diseases in the total population as well as to a growing need to meet the needs of elderly and chronically ill people at home.

- For the elderly living at home is the first choice: The vast majority wants to stay in their own homes as long as possible.

- Among other social and economic strategies, the use of Information and Communication Technologies (ICT) can help giving the elderly more chances to stay at home, even when restrictions due to age or illness occur.

- The household is already (and was in the past) an important health location and its importance will grow, but the socio-economic changes tend to undermine the help and health resources of families and households.

- The deployment of ICT for care in Europe is low and slow. Therefore, a new interdisciplinary dialogue is needed to speed up the design and implementation of adequate and sustainable socio-technical solutions. Additionally ICT has to be seen as only one component in a set of tools. The improvement of the care at home needs new means of support to enable elderly, families, friends, neighborhood and (medical and nursing) professionals to contribute to a better prevention, treatment and care.

A Brief Look at History

Long before Central Europe had a medical system consisting of surgeries and hospitals as we are used to have nowadays, the household in its various manifestations (manor house, castle, farm, town house) was the most important location, where coping with diseases and maintaining health took place (Murken 1988, Unschuld 2006). Back in 1896 in the German Empire 96% of all children were born at home, today only 2% of the children in the German Federal Republic see the light of day outside of hospitals
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(Major 2009). A similar tendency may be observed with death: In former times people died at home, nowadays they die primarily in hospitals and hospices.

“An interesting aspect as regards the function of hospitals teaches us the history of the Berlin Charité, which can celebrate its 300th birthday this year: “The Charité was a mere hospital for the poor until well into the 19th century. Wealthy citizens of Berlin kept away and got their medical treatment at home. The typical clientele of the Charité consisted of soldiers, destitutes, unmarried pregnant women and prostitutes. They were hospitalized by the Poor Board and usually medicated for free. Possibly, however, they had to work for their cure. Not until the end of the 18th century self-pay patients have been registered more often.”

The Household - Already a strong player in health care

Even though a large amount of the disease- and health related activities has been transferred to hospitals and surgeries in the last hundred years, many of these activities may still be found in the households these days.

“First of all, it serves as a reservoir for the little illnesses of everyday life – ranging from minor injuries over common colds to serious influenzas. Moreover it is cooperation partner and helper of professionalized medical care. Many therapies – from drug administration for bedridden patients over motion exercises with the chronically ill to changing bandages and braces – could hardly be carried out without the help of relatives, other household members or neighbors.

In excess of these quasi “normal” health activities of households, two additional health-related, from the view of health care politics and economically very important fields of activity of households have been established, which both benefit from a close cooperation with professional health providers: The domestic care of primarily elder people as well as the field of homecare where medical treatment of particularly chronic diseases is carried out permanently at home.” (Heinze et al. 2009)

In the year 2007 in Germany 2.25 Mill. people were in need of care and recipients of benefits from the nursing care insurance, this is why their number is known. 32 % lived

19 http://www.bmm.charite.de/aktuelles/dauerausstellung/BMM_Hintergrundinfos_Charitegeschichte.pdf
in nursing homes. The majority (68%) was cared for at home, mainly by wives and daughters. 66% were cared for by their kin only, the rest by ambulant nursing services (Statistisches Bundesamt et al. 2008).

In the year 2005 about 1 Mill. people suffered in Germany from dementia. About 200,000 people will develop dementia every year. Most of them are cared for at home (Weyerer 2005).

The socio-economic change tends to undermine the health and help resources of families and households

The structure of households has changed considerably in the last hundred years, especially as regards the number of household members. In addition, there has been a reduction in the period of time that partnerships last on average. Marriages end more often in divorce by the Family Court than by death. Moreover, other forms of cohabitation of men and women have established themselves apart from marriage.

The Data Report 2004, published by the Federal Statistical Office (Statistisches Bundesamt 2004), gives an overview of the forms of households and life forms in Germany. In 2003 there were more than 38.9 million households in Germany. As regards the peculiarities and characteristics of this household landscape they become especially clear, when changes are viewed in the profile of this landscape. Then, the following trends especially attract attention:

- The extended family - with five or more people - belongs to the distant past. At the beginning of the previous century, it was with a share of 44% of the total number of households still largely the dominant family type. Now it has virtually become a marginal phenomenon with hardly more than 4%.

- In general, the trend is strongly towards smaller households. In 1950, 55.3% of all people still lived in a household with three or more heads, in 2003 this proportion had already almost halved, with 29.3%. The average household size in 2003 was only 2.13 persons, but at the turn of the century it had 4.49 persons (ibid. 41). Nearly 13.2 million people lived in two-person households.

- The growing importance of single households is especially noticeable. At the beginning of the previous century living alone was a marginal appearance,
1950 20% of all households were single person households, by 2003 the number again increased to 37%. "Overall, some 17% of the population lived and kept house alone in May 2003, in 1991 the figure was 14%," (ibid. 45). 13.8 million people were living alone counted by the number of heads. Living alone is particularly pronounced in big cities, while this trend has not become established on such a large scale in rural areas."(ibid. 45)

- The world of single households, living alone, is strongly influenced by older people. "Overall, just two fifths of the approximately 13.8 million living alone in May 2003 (38%) were in old age (65 years), while over a fifth (22%) actually belonged to the age of 75 years and more." (ibid. 45) However, this does not at all mean that an interest in living alone increases in old age, quite the reverse: the proportion of older people living alone has been declining since 1991, with 38 % for the senior citizens in May 2003 it was five percentage points lower than the proportion in 1991.

The households in Germany have become not only smaller and older; it is much evident that over the years they have become significantly more unstable. An important indicator in this context is the divorce rate. In 2003, 383 000 marriages were contracted in Germany, but also 214 000 were divorced. In 1960 the ratio was 1.0 divorce per 10,000 inhabitants, this ratio increased over the years more and more to 2.0 in 1990 and to 2.6 in 2003. "Considering the length of divorced marriages and the continuation of the current divorce rate, one could expect that about 42% of marriages are divorced in the course of time." (Statistisches Bundesamt 2004: 46)

Although the erosion of the traditional family is obvious, this does not mean that there are no bonds between the generations anymore. The intergenerational relations cover both the receipt of assistance for the elderly by younger family members as well as aid and cash transfers from the older generations towards the younger family generations. “Today, the multilocal cross-generational family is predominant. The vast majority of adult family members do not live within the same four walls and under the same roof. But nevertheless they are physically not far apart. The intergenerational relationships are characterized by a close emotional bond, by frequent contacts and by diverse and comprehensive support services.” (Bundesministerium für Familie, Senioren, Frauen und Jugend 2007: 153)
The Data Report 2008 (Statistisches Bundesamt et al. 2008: 49) refers upon the development of alternative forms of life: "Despite significant transformation processes of the family in Germany, the married couples with children are still the most widely used forms of life. In addition to traditional family forms alternative ways of life have established in East and West Germany. Solid partnerships outside of marriage are found in both common and separate households."

In addition, continued close relations between the generations can be observed: Adult children, who leave the parental home, are not necessarily difficult to reach or to be contacted. Even adult children live primarily in close proximity to the parents. Additionally, support services and communication within the family are strong. The vast majority of young women and men wish to have children for their own. For the German population the family has not only a high priority, people are very content with the family life as well.” (ibid.)

Besides the social changes of the households the economic changes should not be forgotten. The income and the asset of the elderly increased in the last years. But the distance between poor and rich elderly increased too. For the future one can expect that due to discontinuous employment and occupational careers the income of a lot of elderly will decrease (Enste 2009).

**The importance of the household as a health location will increase**

With a decreasing trend in productivity – mainly due to an increasing number of single households – the demands on the household as a health location will rise. The following basic conditions play a central role:

- The motto „outpatient before inpatient“ in care and therapy leads to the fact that people stay longer in their homes.
- Shortening the length of hospital stays in the emergency and rehabilitation hospital, brings people faster, but not necessarily healthier back to their homes.
- The aging of society will also lead to more people in need of help and care, due to physical illness and / or disability but also because of demental disease.
- Although the medical, technical and scientific progress allows to remedy or at least mitigate age- and disease-related physical and cognitive deficits, it can also
cause the need for further support: By implantation of an artificial aortic valve, in most cases the quality of life may be improved considerably. Also, the patient must take anticoagulants for the rest of his life, which entails a permanent monitoring of blood coagulation and an adjustment of drug doses.

**ICT for Ageing and Health at home: An overview of history, devices and services**

**Social Alarm Systems**

ICT for housing designed for older people is not an invention of the 21st century. Early beginnings of ICT for housing in Germany can be traced back to the early 1970’s. Phone chains were organized by elderly people themselves or were initiated by professionals. A phone chain uses the standard telephone equipment. A group of persons forms the social component of the phone chain. Whenever one member of the chain does not react to incoming calls the caller initiates a predefined action (e.g. informing the doctor or the kin). This ancient form of ICT for housing is in use to this day and is even a promoted by professionals (Görgen et al. 2002, p. 35).

The next step in ICT for housing were social alarm systems. This development came along with the reorganization of ambulant nursing services. Until the 1970’s ambulant nursing in Germany was carried out mainly by district nurses. They were organized and financed by the Protestant and Catholic church. As fewer and fewer young women were willing to be a district nurse and the number of active nurses was steadily reduced by retirement, ambulant nursing in Germany had to be reorganized\(^20\).

The result of the reorganization was the “Sozialstation” (social welfare centre). In 1970 the first German welfare centre was founded in the city of Worms (Weber 2005). In the old days of ambulant nursing one district nurse alone took care of a rather large number of patients. In the new social welfare centre, the district nurse became a member of a team of professionals. Such stations are (partly) funded by the state and health insurances.

\(^{20}\) [http://www.diakoniestation.de/default/geschichte/geschichte.htm](http://www.diakoniestation.de/default/geschichte/geschichte.htm)
In the following years the new model of ambulant nursing spread out all over Germany. In 1974 the St. Willehad-Hospital in the city of Wilhelmshaven opened a social welfare centre. It was the first hospital in Germany, which opened such an organizational unit. Along with the new organization of ambulant nursing a new approach was developed to improve the ambulant patients’ situation by the use of ICT.

The hospital’s administrative director Wilhelm Hormann experimented with ICT in ambulant nursing and today can be looked upon as the “father” of the social alarm system in Germany (Hormann 1980). During the second half of the 1970’s experimental versions of the system were developed. One of the first prototypes was a wireless system (Paul 1976). Its development stopped, because the “Deutsche Bundespost” (the former federal agency for mail and telecommunication) did not provide the required frequencies. Furthermore the reliability of the wireless equipment was not sufficient at that time.

The following prototypes used the telephone net. In 1981 the time of experiments was finished and the HTS831 was presented (Marx 2006, p. 60). The system had been developed by the firm AEG. AEG also developed the technical equipment for the social call service centre. Later the AEG lab, which had developed HTS831, became a part of “BOSCH SICHERHEITSSYTEMES” (Seibt 2005). HTS831 was a box, which was connected to the telephone line. Frequently the customer’s telephone was placed on top of HTS831. The telephone and the box could be used without any modification of the telephone line. HTS831 had a red and green button. In case of emergency the user pushed the red button and was contacted by the emergency centre. If the user was unable to reach HTS831, he or she could initiate an emergency call via the “Funkfinger”, a wireless transmitter, which the user wears like a necklace. The green button had to be pushed at least once a day. If the user did not send this signal, he or she was contacted via HTS831. If she or he did not react, the centre initiated a predefined action.

When Wilhelm Hormann started the development of social alarm systems in the 1970’s, similar projects were initiated in other European countries (e.g. France, Great Britain, Sweden, Switzerland) as well (Hormann 1980). Still, it took until 1981 when the German Red Cross installed its first Social Alarm System in Berlin.
From the beginnings in the 1970’s with a small number of subscribers the German social alarm system expanded to a nation-wide one with more than 350,000 subscribers in the beginning of the 21st century. In September 2006 the German Red Cross, the largest German provider of social alarm systems announced its 100,000th subscriber (Marx 2006, p. 56). Other important German providers are Arbeiter-Samariter-Bund, Arbeiterwohlfahrt, Johanniter- Unfall-Hilfe, Malteser Hilfsdienst and Volkssolidarität. While the technology of the home emergency call systems developed itself moderately over the years, the offered services have changed from “emergency call” to “service call” (Marx 2006, p. 35). The system is not only used to call for help in emergency, but also for the organization of help for housekeeping, shopping, ordering meals on wheels etc.

Since 2006 the German Red Cross offers a mobile emergency call service via mobile telephones. For the location of persons the Global Positioning System (GPS) is used. If the mobile telephone cannot receive the GPS-signal, the person can be located by using the signals of the Global System for Mobile Communication (GSM). In metropolitan areas the location via GSM is very exact. In rural areas the location can be somewhat imprecise (Walter 2006).

*TeleServices: Entertainment, activation and interaction with others*

In the early 1990’s again a new type of system emerged in the area of ICT for housing: In contrast to the older systems not only audio- information but also video-information was transmitted. In 1991 the "Haus-Tele-Dienst" (Home-Tele-Service) was established. “This has been world-wide the first fully inter active broadband video Communications project implemented in a real setting and operating over an extended period of time.”(Stroetmann und Erkert 1999).

In the middle of the 1990’s the Institute for Work and Technology (IAT) invented the “virtual home for the elderly”, a new concept for living at home in age. The technical basis of this virtual residence was a video conference system. In the "virtual residence", in reality the well familiar home, the range of services offered should not differ from that offered in real (good) residences for the elderly (Hilbert et al. 1999). IAT’s theoretical approach was tested in a pilot project called TESS inkontakt (Teleservices für Senioren - Teleservices for Seniors). TESS was carried out by Evangelisches
Johanneswerk, one of the largest providers of health care of the Diakonie, the German social welfare organisation of the Protestant church.\(^\text{21}\)

The technical infrastructure was provided by Deutsche Telekom, the successor of Deutsche Bundespost. The technical core of the "virtual residence for the elderly" was a communication and coordination centre, which was connected to the elderly’s apartments. The data were transferred via ISDN. In the participants’ apartments video telephones respectively TV sets with set-top-boxes were installed. One important additional feature was the video conferencing with up to eight participants. The centre offered the following services:

- responses to emergency calls
- responses to calls for “small talk”
- organization of different services: medical, nursing, entertainment, nutrition, household services etc.

The project’s results were rather ambivalent: The participating elderly appreciated TESS, especially the video conferences. Hence, while at the beginning of the project they had to pay no fees, only a few of them resigned when they were asked to pay for the TESS-services. The elderly had no problems with the handling of the visual telephones and modified televisions. However massive problems occurred on the providers’ side. The providers of technical, social and nursing services did not succeed in establishing a convincing and sustainable business concept. Such a concept was required to offer the innovative service on a continuous basis. The reasons for these problems were manifold. On the one hand in the beginning of the pilot project it was not clear, when the required technical equipment would be available at acceptable prices. On the other hand both firms involved – the social service provider and the telecommunication provider – had quite some difficulties to agree on whether TESS would make sense for them or not. Both firms were deeply involved in ongoing processes of business reengineering at that time and did not really care for details. At the end of the day, however, TESS inkontakt could be labeled a successful barrel burst.

\(^{21}\) http://www.johanneswerk.de/index.php? id=371
As a concept it was a ground braking innovation, which was probably the reason why it was accepted in pilot projects, but did not find its way to the mass market.

**Telehealth Monitoring**

Social alarm systems enable users to call helpers to their apartments in cases of emergency. Telehealth Monitoring Systems enable users to carry out diagnostic and monitoring actions by themselves in their apartments, which formerly had been carried out by medical professionals in hospitals or doctors’ practices. An example for telehealth monitoring in the area of cardiac diseases is AUTARK (Körtke et al. 2006). The acronym AUTARK stands for “ambulant and telemedically based follow-up rehabilitation after cardiac interventions”. The AUTARK-project was devised and conducted at the Institute for Applied Telemedicine (IFAT)\(^2\), founded in 2003 and attached to the “Heart and Diabetes Centre North-Rhine-Westphalia”, which in turn belongs to medical faculty of the Ruhr-University Bochum. Participants in AUTARK during their treatment in hospital were trained in the application of a mobile electrocardiograph (ECG), which is shaped more or less like a cell phone and which they took home when they left the hospital. In cases of cardiac problems the patients record an ECG and the result is immediately transmitted via an integrated telecommunication device to the respective hospital unit.

The advantage is that easily and without asking too much of the patient “Patient data, i.e. so-called vital parameters such as ECG, INR values, blood sugar levels, weight, blood pressure, heart sounds, as well as up-to-the-minute cardiovascular and metabolic data, can be sent directly by patients from their homes to our hospital for evaluation. This system is especially effective in detecting acute coronary syndrome, an imminent apoplectic fit, facilitating prompt and appropriate diagnosis and therapy. Telemedical controls (or telemedical consultations) are also especially well suited to all other cardiac and diabetic diseases.” resumes IFAT’ s director Heinrich Körtke\(^3\).


Meanwhile similar services to those delivered by IFAT are offered by a growing number of further providers. One example for such a firm is the “Personal Health Care Telemedicine Services GmbH”\textsuperscript{24}.

An overview of the current situation of telehealth at home in Germany can be derived from this project: E-Health@Home identifies, evaluates, designs, and implements telemedicine services for the elderly. The project contributes to the solution to problems resulting from an aging society. The objective is the development of alternatives for those who have been living in residential nursing homes due to health impairment\textsuperscript{25}.

In spite of several encouraging developments, telehealth monitoring as an application of ICT for housing is far away from being a standard procedure in medical treatment.

\textit{Ambient Assisted Living, or: Barrier-free, healthy and smart homes relieve living with disabilities!}

Video-based home emergency call systems are being prepared for rollout since 15 years - but rollout is still being waited for. Nevertheless the next innovation of ICT for housing has arrived: Ambient Assisted Living (AAL) and Ambient Intelligence (AmI).

“In a short way Ambient Assisted Living may be defined as the use of AmI in everyday life. Assisted means assistance by technical devices as well as by technical or human services”. (Giesecke et al. 2005, p. 44). The most important technical devices of AAL are small computers, most of them invisible for users. These computers are frequently wireless networked and have numbers of sensors to collect information about their environment. Additionally they have actors to manipulate their environment. The concept of AAL and AmI is based on considerations of Mark Weiser on “Ubiquitous computing” (Weiser 1991). The systems of ICT for housing described in the previous chapters needed no or only little additional dedicated hardware. ICT for Housing with the label Ambient Assisted Living, however, implies the use of much additional hardware and networking.

\textsuperscript{24} http://www.phts.de/

\textsuperscript{25} http://www.iat.eu/ehealth/
The promotors of AAL for housing intend to construct a flat or a house that cares for its inhabitants, monitors and shelters them. Main components of AAL-centred ICT for housing are sensors, actors, (body area, local area, wide area) networking, and (invisible) computers. Monitored by sensors are kitchenware, windows and doors (open/close), temperature, heating etc. The actors can manipulate the monitored devices. The kitchen stove is switched off automatically, if the cook forgot to do it. The heating is switched off as well, if a window is opened in winter. Additionally vital parameters are monitored of the inhabitants of the “intelligent” house. Either the monitoring of the vital parameters is done the way described in the chapter above, or it is done by a wearable.

A wearable is a garment that contains sensors, which continuously monitor vital parameters of its bearer. The wearable’s sensor is part of a Body Area Network (BAN). The BAN transmits the data collected to the Local Area Network (LAN) of the “Intelligent” House. The LAN transmits the data via a connection to Wide Area Networks to a remote medical centre.

One important player in the field of AAL is the Massachusetts Institute of Technology’s (MIT) Department of Architecture. It’s “house_n research” is focused on how the design of the home and its related technologies, products, and services should evolve to better meet the opportunities and challenges of the future. Massachusetts Institute of Technology researchers are investigating methods for merging new technologies with person-centred design. They are generating new ideas, technologies, and methodologies that support the creation of innovative products and services that satisfy the emerging and future needs of people as they live in their homes.

In Germany the counterpart to MIT is the Fraunhofer-Gesellschaft (FhG), “the largest organization for applied research in Europe.” The FhG has set up the "inHaus-Innovation-Centre", which consists of two components:

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26 http://www.wearable.ethz.ch
27 http://www.ban.fraunhofer.de/index_e.html
28 http://architecture.mit.edu/house_n/intro.html
29 http://www.fraunhofer.de/fhg/EN/company/index.jsp
30 http://www.inhaus-zentrum.de/site_en/
The goals of MIT’s house and the Fraunhofer’s Inhaus are very similar. Meanwhile the European Union has discovered its interest in Ambient Assisted Living, too. This interest ended up in the preparation of a new European technology and innovation funding programme: “The programme is intended to address the needs of the ageing population, to reduce innovation barriers of forthcoming promising markets, but also to lower future social security costs. AAL aims - by the use of intelligent products and the provision of remote services including care services - at extending the time older people can live in their home environment by increasing their autonomy and assisting them in carrying out activities of daily living.”

“Europe Is Facing a Demographic Challenge. Ambient Assisted Living Offers Solutions” is the title of a country report, which was compiled in preparation of the funding programme described above (Steg et al. 2006). This is a very optimistic view, when you take into consideration that AAL has still remained in the phase of research and development. Both German and international experiences in the field of video-based service systems for the home teach the lesson that the way from research and development to a working application and business model is, more often than not, much longer and stonier than anticipated.

The strengthening of the household as a health location by ICT is necessary, but also slow in Europe

Many research and development projects have demonstrated that ICT for housing offers opportunities to support living (comfortably) at home in age. Yet in spite of these results especially Germany has difficulties to use the potential of ICT for housing:

- social alarm call systems needed 25 years to find 350,000 subscribers,

video-conferencing-based systems have not left the state of pilot installations since 15 years on,

- telehealth monitoring is struggling for future prospects,

- ambient assisted living, for the time being, is only a topic for insiders in the research and development business.

To date there are no scientific studies which would explain the reasons why ICT for housing in Germany is so difficult to implement. One topic most beloved by politicians is an alleged "German technophobia"; however, in most cases this has proved to be rather nonsensical. More serious arguments worth to be followed up might be found along the following, though still speculative, assumptions:

- In Germany many social workers, gerontologists and caregivers perceive technical support and enabling systems as inhuman; instead they see face to face contact as essential. They believe the quality of help would suffer if it is technically supported or even substituted.

- Under the influence of the above argument social and health politicians are reluctant to provide financing of services discussed in this article or to put them on the list of accepted treatments of statutory insurances respectively. Hence, as long as politics, industry and insurances play the game of log-rolling any more encompassing concepts will be moving beyond reach.

- Many engineers have little understanding and little knowledge of the world of social work and care for the elderly and they have a certain reluctance towards "participative" strategies of development and design. Therefore they have difficulties to design systems which would fit real life conditions of larger numbers of elderly and working conditions and concepts of social workers.

- Many pilot projects can only be started with the aid of public funding. The public financiers expect "successful" developments. Under this constraint pilots are more promising than large scale applications which always involve risks – particularly in the intersections where technology and "traditional" social services meet.
- Though large numbers of pilot projects, working groups, professional circles and societies exist in the field, there is no systematic development of technical norms nor coordination and communication about results and outcomes, so that many projects necessarily end up in the archives.

**Concluding remarks**

As has been shown in this article the bottleneck for the implementation of ICT to support living at home in age is not technology – rather it is the "philosophy" of development strategies, design and fit with the circumstances of everyday life of the elderly and caregivers. Technology is no end in itself. It makes sense only when it really "supports" people to fully utilize their options. From this point of view the present patchwork of pilot projects, model applications and aims definitely need more streamlining, structure and direction, if investments, both past and future, are expected to return profits.
References


