Chronically Ill Citizens and Home Monitoring: "Nothing to talk about"!

RN, MSN, PhD Jane Clemensen¹, MA Mette Atipei Craggs², RN Jan Petersen²,

MA Casper Dahl Marcussen², Prof. Dr. Helmut Prior³

¹University of Southern Denmark, Research Unit of Nursing, Institute of Clinical Research, Odense, Denmark

²MedCom, Odense, Denmark

³Goethe-Universität, Institut für Psychologie, Frankfurt, Germany

jclemensen@health.sdu.dk, mac@medcom.dk, jap@medcom.dk, cma@medcom.dk, prior@psych.uni-

frankfurt.de

Abstract— This paper presents local results from a large EU research study conducted from 2008-2012 (DREAMING). The aim of the study was to evaluate the effects of an ambient assisted living protocol, which may extend the independent life of chronically ill elderly people. Methods: The local findings are based on 10 semi-structured interviews with the involved citizens combined with local results of HADS and SF36. Results: Three main themes have been identified to have a positive influence on quality of life; feeling of safety, empowerment, and acceptance. Conclusions: all the citizens felt a positive influence on at least one of the mentioned themes and thethe technology was well integrated into their daily life.

Keywords: patient empowerment; health IT; telemedicine; home monitoring, quality of life

I. INTRODUCTION

The current global health care system is under pressure for multiple reasons including aging populations, increased prevalence of chronic diseases, shortage of clinical personnel and increasing expectations from the patients.

To live up to new patient expectations, the health care system must undergo a perceptual change towards increased centralization around the individual citizen – not patient. Hence, there is a need for a different approach in the way we – as a society – think of health care in order to accommodate this new role of the citizen. This new notion will require a change in culture both from staff in the health care sector and from society in general.

This new culture needs to be established upon a set of appropriate values, including respect, solidarity, and involvement towards the individual citizen. Doing so will allow for high standards as regards both professional and organizational quality as well as experienced quality by the individual citizen. We must thereby facilitate a paradigm change from present paternalistic disease management to a more holistic and empathic approach [1].

To enable this change, development of technology can be an important tool, in particular if the technology is created in close cooperation with the users. Experiences show that userinvolvement in technological development processes is an effective leverage for organizational and cultural change [2][3]. Part of the challenge associated with the new paradigm can be ascribed to the current fragmented nature of the health care system. There has been a tendency for individual health care providers to focus on isolated optimization of their own work flow (cf. the split into primary and secondary providers). The challenge becomes how to create a better continuity for the citizen in the navigation between the separate providers without sacrificing efficiency and experience for the individual provider [4].

Such a vision involves a change of mindset for all stakeholders in health care, which makes it a rather allencompassing subject. In some aspects, however, local and regional concrete initiatives can make individual contributions to the greater, global cause relatively independently from each other. In these cases, the question is how to incentivize and facilitate such initiatives within an overall frame while keeping the main goal in sight.

The European Union has a vision about creating a new health care model to help accommodating such needed changes. The path towards this new model involves collaboration between countries, so that countries can work for the same goals by cooperating and sharing knowledge. For most countries there is a need for a collective change of mind-set in creating the new health care model. As a consequence of this, the CIP-ICT-PSP program funded the EU project DREAMING (elDeRly-friEndly Alarm handling and MonitorING) under its objective 2.2 ICT for ageing well [5][6].

II. BACKGROUND

DREAMING was a research project under the auspices of the EU testing a range of welfare technology services in real life pilots in cooperation with public authorities under a randomized control trial. The project tested elderly-friendly alarm and monitoring technology in the homes of chronically ill citizens. The technology applied in DREAMING consisted of medical measuring equipment, environmental monitors, and video conferencing.

With the technology installed in their home, the citizens were able to take their own measurements, e.g. blood pressure or blood sugar, with the dedicated measuring instruments (see Fig. 1). Via Bluetooth, the instruments transmitted the measured value to a hub forwarding it to an internet based portal accessible to the district nurses. For each citizen, individual thresholds were set for the different values of relevance. If the measurements differed greatly from this threshold, the nurses received an alarm via SMS or email, depending on the severity of the deviation.

Also connected to the alarm system were the environmental monitors, e.g. fire alarm or gas leak sensor. If the monitors detected some kind of danger or incident out of the ordinary, an alarm was sent to the nurses, who could then take the appropriate action. Finally, a videoconferencing system was installed on the personal TV set of the citizen. This system enabled the citizen to talk to healthcare providers, friends, or family face to face on their own TV. Fig. 1 shows a model illustrating the technologies applied in DREAMING.

The citizens included were at least 65 years old and suffered from diabetes, heart failure, or COPD (Chronic Obstructive Pulmonary Disease). The project was trialed at pilot sites in six European countries: Denmark, Sweden, Germany, Estonia, Italy, and Spain. A total of 284 citizens participated in the trial. Of these 139 were allocated to the intervention group (IG) and 145 were allocated to the control group (CG). In Denmark, the total number was 51, with 26 in the IG and 25 in the CG. Due to drop-outs, the number of participating citizens had been reduced to 11 in the IG and 12 in the CG at the end of the project. The Danish trial site was the island Langeland characterized by its rapidly aging population, remoteness and distances to large hospitals.



Figure 1. Equipment applied in the DREAMING project.

The Danish pilot trial faced a number of technological challenges, see Fig. 2, which were initially handled by the Danish project manager. However, it became clear that a local person from the island with technical knowledge who could establish a close cooperation with the citizens and the district nurses participating in the project would be needed. A retired farmer from the island was hired for this task and both his status as a local and as a senior citizen made it easy for the citizens to relate to him. The fact that he was always available for help and guidance resulted in a smoother trial run and helped both citizens and nurses feel safer about the technology.

The pilot trial ran from the beginning of May 2008, to the end of March 2012. For the purpose of studying health related quality of life (QoL) of the citizens, the validated and internationally accepted questionnaire SF-36 was used. The SF-36 is a multipurpose, short-form health survey consisting of 36 questions. It gives an average of the mental health and physical health components. The citizens in both the IG and the CG filled out the questionnaires at baseline, midpoint, and end of the pilot trial. The SF-36 score ranges from 1 to 100; QoL is deemed higher with increasing score [7]. As a supplement to the SF-36 questionnaire survey, the citizens were screened for anxiety and depression by means of the Hospital Anxiety and Depression Scale (HADS). As this questionnaire has been designed to provide a simple yet reliable tool for use in medical practice, it was deemed appropriate for this study [8]. It was important that the questionnaires were easy to fill out for the citizens and that the result was relatively easy to analyse. The citizens filled out the HADS questionnaires at the same time as the SF-36.

A. Litterature review:

To uncover the existing body of knowledge within the theme of acceptance and QoL in relation to chronically ill citizens and home monitoring, a literature study was carried out. A search on PubMed using the search terms "chronically ill", "citizen", "empowerment", "acceptance", "home monitoring", "technology", and "quality of life/QoL" in different combinations of two – four resulted in 13 relevant articles. Despite their relevance, however, none of the found articles turned out to give accounts of the citizens' personal experience of living with the technology for a relatively long period of time. In the following, the main trends uncovered by the study will be described and supported by examples.

Several of the articles focused on quantitative results such as cost-effectiveness [9], clinical outcomes [10][11], or both [7]. Others focused on the reliability of the data produced by applying home monitoring in the care for

- Internet access in the homes
- Compatibility Pairing issues between measuring equipment and hub
- Lack of integration to electronic patient records
- Organisational changes (workflow)
- Battery change

Figure 2. Technological challenges.

chronically ill citizens [12]. Many discussed how to involve and empower patients by employing self-care education [13][14] or interactive online environments [15], e.g. for self-management and self-monitoring [16][17]. In addition, some regarded empowerment as a solution to the problem of noncompliance/non-adherence [18]. It was found that even though telemedicine interventions can increase the feeling of self-efficacy, the citizen's healthcare providers and others related to the intervention play a critical role in engaging them in a new intervention, e.g. involving home monitoring [19]. In most articles touching upon the notion of QoL, this is measured by questionnaire surveys [20].

Many of these studies present hypotheses about the citizens' perception of the technology, but do not directly include the citizens in the study to determine what they really think.

B. Definitions:

Home monitoring can be defined as the use of information and communication technology in exchange of information between the patients' home and health professionals. This allows for the clinical staff to respond immediately to alarms from the citizen's home. Home monitoring also empowers citizens to learn and apply expert knowledge and thereby become more responsible for their own health situation [3][21][22].

C. Aim:

The aim of this paper is to present local results regarding acceptance and qualitative of life of the involved citizens from the Danish pilot site: Langeland. The overall question is "how was it to live and cope with the home monitoring in daily life?". The interviews were conducted in addition to the overall design of the project (HADS and SF36) to explore how the citizens' daily life was influenced by the technology.

III. METHODS

Data collection: The interviews were conducted in person in the homes of ten citizens who took part in the DREAMING project. These interviews were conducted as semi-structured research interviews [23]. According to this approach, a research interview can be regarded as a professional version of an everyday conversation where the interaction between the interviewer and interviewee contributes to the construction of knowledge. The purpose of qualitative research interviews of this kind is to understand phenomena from the perspective of the interviewee. In cases where a relative was present, this person took part in the interview. Data were recorded and transcribed, and then content were categorized and analyzed.

Combined with the interviews, the findings include results from two questionnaires: HADS and SF36. The questionnaire survey was conducted in all six European countries. It was analysed for the overall sample, but also for each of the sites separately. In this paper we focus on the Danish results.

Materials: 10 out of eleven citizens (six women and four men) from the rural area in Denmark called Langeland who have lived with the technology for more two years. These

citizens represent all the remaining participants in the IG, the CG was not involved in the semi-structures interviews. However, one of the citizens in the IG was not capable for an interview. The age was between 66-82 years at the beginning of the project period. Seven subjects lived alone in their homes and three lived with a relative. Nine lived in their own homes and one lived in sheltered housing.

IV. RESULTS

A. Qualitative interviews:

The interviews revealed three main themes: feeling of safety, empowerment, and acceptance. In the following, the themes will be defined and supported by concrete findings from the study.

Feeling of safety: This can be defined as a feeling of trust and confidence.

A general perception amongst the citizens was that the monitoring equipment increased their feeling of safety. The fact that professionals had an eye in the home and reacted to alarms from the system had a great impact regarding this feeling. As one expressed it: *"The best thing is that someone is keeping an eye on me. It makes me feel safe"*. Another subject put it this way: *"It's reassuring, because they call me if the measurements are too high"*. Only one citizen didn't feel safer: *"It doesn't make me feel safer, I'm safe enough"*. She was one of the participants who had experienced some problems with the equipment. Therefore she did not have a lot of trust in it. In one case, there was a positive effect on the spouse. The wife of the participant said: *"I feel safer now, because he doesn't tell me if his measurements are good or bad. But if the phone rings, then I know"*.

Empowerment: In its most general sense, empowerment refers to the ability of people to gain understanding and control over personal, social, economic, and political forces in order to take action to improve their life situations [24].

For nine out of ten, the technology empowered the citizens to different degrees. In general it gave most of them a sense of freedom, because they were less dependent on visits from nurses or visits to GPs. Or freedom because they, to a further extend, could take the measurements themselves.

The technology increased their awareness toward issues related to the disease: "I'm experiencing that I think more about what I'm doing" or as another said: "I'm more aware of when I take my measurements and when I should take the insulin".

The technology was no longer only "a tool to better manage my disease", but for two of the participants they found a way of using it for rehabilitation. The video conference system was thereby used to link the community physiotherapist and the citizen and as one expressed it with a smile: "I have started using videoconference for physiotherapy – I wouldn't get it done, if I had to go somewhere else". Both staff and citizens have great expectations towards this new way of using it for rehabilitation. The same two citizens and a third also played with the possibility of using the videoconference for communicating with relatives living away: "I want to use videoconference for talking to my children who live in *different parts of Denmark"*. Furthermore one of the two frequently used Skype for this type of communication; a development that was clearly connected to participating in the DREAMING project.

Acceptance: No sufficient definition of acceptance has been found to be available. We define acceptance as integrating something new, in this case technology and a new way of receiving healthcare services, in your daily life and letting it have a positive influence on it without requiring too much attention.

It was obvious that the technology had become a naturally integrated part of the citizen's daily lives: "In the beginning we talked about it, now it is just there", or as another expressed it: "It has become a habit" – a habit they did not wish to live without: "I wouldn't mind keeping it after the project, because it helps me getting around to taking my measurements. As seen from the quotes in Fig. 3: the citizens had fully accepted the technology and found it better than ordinary care.

Observations from the researchers: having the opportunity to enter the home of ten citizens, who had lived with the technology for a relatively long period of time, we were curious about the physical appearance of the technology. Most had it out in the open on places of convenience for using it, but one had it hidden away – not because of the expression of the technology, but to keep it safe from the grandchildren.

- "There is nothing bad about it"
- "It has become a daily routine"
- "Would recommend it to others"
- "No problem using the technology"
- "I prefer technology over ordinary care"
- "It is nothing out of the ordinary"
- "It has been easy to use"
- "Wants to keep it!
- "It has become a habit"
- "It's a piece of cake"
- "I would miss it"
- "I don't think it is difficult to handle"
- "I like having it"
- "It doesn't make me nervous or anything"
- "It is nothing to talk about"

Figure 3. Citizens about technology



Data from the HADS evaluation are shown in Fig. 4. The bar graph shows data for all subjects who took part in any of the assessments. The line graph only depicts the scores for subjects who continuously contributed to all three evaluations. A within subject ANOVA (ANalysis Of VAriance) on these data with time as a repeated measure revealed a main effect of the intervention condition (F(1,15)=3.74; p<0.05, one-tailed). However, while there was no difference between controls and subjects in the intervention group at the start if all subjects are considered (see bar graph), subjects who continuously took part already differed in the beginning of the study with lower depression scores in the intervention group. This pattern is very similar to the overall result from six study sites. It indicates a higher dropout rate of subjects with high depression scores in the intervention group. In the SF36 there is no group difference (p > 0.8) in the physical component score (PCS) which is a measure for overall physical health (Fig. 4, bottom). Both groups show a similar development over time (F(2,15) =9.59, p< 0.001), with a slight decrease over the first year and a large increase over the second year. Consistent with this pattern, both the linear trend (F=4.92, p<0.05) and the quadratic trend (F=13.70, p<0.005) of the within subject factor time are significant.



In the mental component score (MCS) there is a significant development in the control group (F(2,14)=10.36, p<0.005) as well as in the intervention group (F(2,18)=4.04, p<0.05), but the group difference is not significant nor is the interaction intervention x time.

V. DISCUSSION

Before interviewing the citizens, we were prejudiced in relation to what we would find. Prejudices like that it was a big issue for the citizens to be involved and use the technology, that it was a challenge for them to handle the technology and that the citizens would discover being a part of a modern and cool group living with technology and that their surroundings would think the same. However, what we found was: "Nothing to talk about"

But it took some time. One big and maybe crucial advantage in the project was the time - all in all four years to prepare, test, and educate citizens including two years of pilot testing in the home of the citizens. To begin with both staff and citizen were hesitant toward this new way of working/new way of handling chronic diseases. A lot of effort was put into addressing the hesitancy by involving all stakeholders in the process. There was time for overcoming technically obstacles - for example getting internet connections to run in the homes of the citizens and the devices to be trustful and functioning. One really important issue related to the positive outcomes was hiring the old local farmer to support and help with small and big issues arising in the process. Speaking the language, being a person the citizens knew kicked in doors that might have been far more difficult to get access to.

In the DREAMING project, the citizens gained more freedom and empowerment, and the health services were provided far more on the terms of the citizens than on those of the system. Part of this was the contribution of the technology to the empowerment of the citizen indirectly in keeping them fit and thereby prevent side effects from the disease. Combined with the increased feeling of safety it can explain the high acceptance in receiving home monitoring. The results from the interviews are supported by the Danish results from the questionnaires (HADS and SF36). Citizens in the intervention group were less depressed than the control group and had a slightly higher quality of life. A review from 2012 [25] including studies from 2007-2012 – 68 studies in all, showed a clear trend towards better behavioral changes of the citizens leading to better empowerment and higher quality of life.

It takes time to turn around habits and start a whole new culture based on change of mindsets for both staff and citizen and maybe many projects do not have the needed time for obtaining positive results?

We are of the conviction that the success experienced in the DREAMING project was linked to the long period of time to run the pilot – it became a habit – a habit that now has turned into daily practice without the citizens' awareness. The involved citizens in DREAMING had a chance to develop along with the technology. It will be interesting to follow further implementation to the community's other chronically ill citizens where this kind of technology and organization is relevant. Will they have to start all over or will they be able to gain from the previous experiences?

It would seem that the elderly chronically ill citizens in general are not resistant towards technology, maybe because the technology has a meaning and a direct purpose (as in the DREAMING project). The future citizens will be more and more used to having technology as a part of their daily life (as using home banking, internet shopping, social media, etc.) and then become more familiar using home technology for handling and improving health issues.

In this case, the technology became leverage for this change and maybe we have started a small revolution in changing a shift in paradigm as addressed in the introduction.

VI. CONCLUSIONS

The overall conclusion is that, having lived with home monitoring technology for more than a year, they had fully accepted it. When interviewing the citizens they looked at us as if we asked how it would be to live with your hoover – good to have but nothing to talk about!

VII. LIMITATIONS

Research involving elderly citizens with a chronic disease can be a challenge in relation to keeping up the number of participants. In the DREAMING project, we began with including 51 citizens and ended up with 23 (control and intervention). The project lasted four years and the citizens were included from the beginning. In such a long period of time, this, often frail, group experiences acute worsening of their condition, are admitted to hospital – do not full recover and some die.

VIII. PERSPECTIVES

In Langeland the research has turned into daily practice and more communities are on the way of implementing the results. The staff, using the technology, finds new areas where same technology can be used – for instance for young people with diabetes and for rehabilitation. Regarding the citizens, three of the participants were already experimenting or using the technology for new purposes such as rehabilitation or communication with relatives or friends (Skype). Another expressed that he would like to use technology if he should get another kind of disease.

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