EFORTT

WP 5:

Conference

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INTRODUCTION

The International Conference of the EFORTT Project (WP5), “Ageing with technologies: a participative conference on care in Europe”, took place on the 13th & 14th of September 2010 in La Casa de la Convalescència, in Barcelona.

The objective was to provide an opportunity for practitioners, users, carers, policymakers and scholars involved with or working on care and technology to meet and talk about their work and experience. Over two days, we exchanged experiences debated the actual and possible consequences of telecare developments, for all European stakeholders.

ORGANISATION & PROGRAM

In the preceding months, the organising team from the Autonomous University of Barcelona (UAB) worked to disseminate publicity for the conference among scholars, users and carers' organisations, policymakers and also commercial companies and practitioners. The conference was funded by the FP7 Science in Society (EFORTT) project, with the help of 'Agència de Pomoció d'Activitats i de Congressos', from the UAB, and the economic support of the Spanish Ministerio of Education for additional conference expenses. To develop and manage all these activities and to inform the general public and other interested people, we built an EFORTT Conference website with a public mail address. It was the point of reference for all information, communications and formalities about the conference. http://psicologiasocial.uab.es/efortt_conference

Combining the format of plenary sessions with workgroup discussions, the EFORTT Conference programme was organised through three main topics:

1. What counts as care?
2. Forms of participation: whose voices matter in system design?
3. Changing spaces of care

Each plenary session started with a brief presentation from the EFORTT Project, by members of the research Consortium, to help frame the theme and introduce the guest-speakers. These plenary sessions concluded with a general debate about the presentations and selected topic. Workgroup discussions followed in which participants could exchange more detailed experiences and ideas. At the end of each day a summary was presented with the help of rapporteurs. A concluding session synthesised the different proposals and priorities for future action on telecare in Europe that had emerged during the conference.

GUEST SPEAKERS & PARTICIPANTS

As can be seen on the website, guest-speakers at the conference combined international and heterogeneous experiences and work spaces around telecare. From scholars to technology companies, and from organisations for older people to service providers, all were professionals in the relevant fields of elderly people, care and technologies.

Guest-speakers:

- **Lino Paula** (European Commission FP7 Science in Society EFORTT Project Officer)
- **Mercè Pérez Salanova** (Researcher, psychologist gerontologist. Institute for Ageing, Universitat Autònoma de Barcelona, Spain)
- **Annemarie van Hout** (Project coordinator for AVEANT, Home Care Organisation, Netherlands)
- **Mercè Mas** (Social worker. Member of “Consell de la Gent Gran de Barcelona”, “Consell de la Gent Gran de Catalunya”, and 'OLDER WOMENS' NETWORK Europe, Spain)
- **Helena Cecilia Blackstad** (Philosopher and senior researcher, Dept of Industrial Economics & Technology Management, Norwegian University of Science & Technology, Dept of Safety,SINTEF Technology & Society, Trondheim, Norway)

- **Marjo Rauhala** (Researcher, Institute of Integrated Study, Vienna University of Technology, Austria)
- **Jelle van der Weijde** (Sales Director, Tunstall Group; Governance board at WDTM: Dwelling, services and technology for people; Governance board at STG/ Health Management Forum. Netherlands)
- **Isabel Dyck** (Social and feminist geographer. Researcher and member of Health, Place and Society Research Theme, Dept of Geography. Queen Mary University, London. UK)
- **Birgitte Holmene** (Project leader of Security.NET Norway)
- **Martí Matinez** (Responsible for the Program of telecare and new technologies addressed to older people. Catalan Red Cross)

Three guest-rapporteurs took notes from the debates and gave daily summaries.

- **Maureen McNeill:** Professor of Women's Studies and Cultural Studies, Sociology Department, Lancaster University, UK.
- **Elham Kashefi:** PhD, EFORTT Researcher, and Engagement Office Lancashire Local Involvement Network (LINK) UK
- **Louis Neven:** PhD student in Science and Technology Studies at the STePS group of the University of Twente. His work focuses on the ways in which engineers, designers and other professionals involved in the design of technologies devise representations of elder users.

118 participants attended from all over the world, but particularly Europe, including Belgium, Italy, Netherlands, Norway, Denmark, Austria, United Kingdom and Spain.

Some of those attending belonged to different bodies, organisations and institutions from the field of care and technology, e.g. University of Oslo (Noruega), Telecom Italia (Italia), The University of Auckland (New Zealand), Tameside MBC (UK), Technology & Utility Services (India), IT University of Copenhagen (Dinamarca), Research Executive Agency (Belgium), Red Cross (Spain), Fundació Ticsalut (Spain), Consell de la Gent Gran de Barcelona (Spain), Institute for Ageing (UAB, Spain), Citilab (Spain), Universitat Complutense de Madrid (Spain), Universitat Oberta de Catalunya (Spain), Fundacion TECSOS (Spain) or Associació de Treballadors Familiars de Catalunya (Spain).

Communication among participants was facilitated by a simultaneous translation service through individual wireless receivers.

CONFERENCE SUMMARIES

Summaries from each of the three themes of the Conference.

THEME 1: WHAT COUNTS AS CARE?

Daniel López (EFORTT project researcher, Universitat Oberta de Catalunya, Spain) reminded the audience that care involves different practices and meanings and that, very often, they are presented in a fragmented way. He posed the question of what is considered "good care" in a context of fragmentation of care provision, and also noted that the values related to care may change. Regarding this, he noted that efficiency may be the focus (more than other criteria of "good" care) with emphasis on protocols for providing health and social care through technological systems, as quantitative and measurable aspects of care are more easily manageable than other aspects. However, he suggested that care may emerge in new ways, among other activities, thus indicating that the idea of care is very broad and constantly changing. In this sense, he warned that telecare should not be considered a substitute for other forms of home care. For instance, he pointed out that women often continue to assume the main responsibilities of care, although these responsibilities may have been reshaped and redistributed. He said that in recent global models, this has meant an increasing role for migrant women as providers of care in Western societies.

Mercè Pérez Salanova (research psychologist and gerontologist at the Institute of Ageing, Universitat Autònoma de Barcelona, Spain) addressed the understanding of care as a moral duty or as a work, and appealed to the feminist tradition for exploring the work of care and how it is gendered. She discussed some ways in which care involves building links and relationships. In addition, she reflected on recent changes in families and demographics, as well as diversity between families in Europe, which is significant when thinking about care in a contemporary context. This linked with the different conditions in which different generations have taken care of their elders. She noted that care should not be considered as a burden and reminded us that in some circumstances, it may offer the possibility for older people to reinvent themselves. Thus, creating opportunities for autonomy and independence could be part of good care.

Annemarie van Hout (Project coordinator for the AVEANT organisation in the Netherlands) introduced the audience to a project in which she had been involved that used communication technologies in the provision of nursing care for the chronically ill. With reference to this telecare project and to some of the material she showed, she suggested that relationships could change in such contexts. She asked us to reflect about whether there might be some unexpected developments when such technologies are introduced.

Mercè Mas (social worker and member of the Consell de la Gent Gran de Barcelona, EUROLINK AGE and the ‘OLD WOMEN’S Network’ Europe in Spain) emphasised the importance of experts speaking directly to older people. She contended that, with increasing life expectancy in Europe (and elsewhere), there would be increased need for care. However, she also cautioned that many older people had great capacity for independence, and that they generally wished to be actively involved in making decisions about their living arrangements, and in caring for themselves. Mercè foregrounded the importance of equal opportunities strategies which would address the situation of many women who were becoming ‘care managers’. She insisted that good care added value to many social situations.

Celia Roberts (EFORTT and Sociology Department, Lancaster University, UK) chaired the discussion. The discussion included calls for reflections about the relationship between social and technological changes. The question of the agency of particular groups was brought to the fore as requiring careful consideration so that issues pertaining to social justice remained in view in all discussions of technology and care. Attention to diversity was highlighted as crucial in thinking about care needs and care provision. The conference was also reminded that much of Europe was in the throes of economic cuts and that this would be the context for discussions of care and of technological innovation associated with it.

During the discussion, it was said that good care involves personalised care, so we must recognise differences and consider them as an ethical issue. It should be a principle promoted by EU and governments, not only as a principle at user's level but also at national specificities' level. The EU can promote these values and ethics in research and care work by allowing each country to implement telecare services in their own way, considering their own specificities and care's cultures. It was stressed that telecare should be considered as something that reconfigures care rather than replacing traditional care. It is widely thought that telecare technology can save funds, but there is ambiguity about this, and little evidence that telecare effectively save costs. In this sense, it is necessary to think about the quality of care and its forms, in order to integrate all the available forms of care.

GROUP DISCUSSIONS

The discussions in the workshops were guided by 4 questions:

1. Are we witnessing a fragmentation of care?
2. What are the positives and negatives in this process?
3. What counts as good care in this context?
4. What are the implications of this fragmentation in terms of well-being, gender and social justice?

1. Are we witnessing a fragmentation of care?

The group heard that fragmentation of care is a fact that has been occurring over at least 10 or 15 years. The use of computers (automatic processing and technology delegation) enables dividing care work into smaller pieces. However, communication technologies and information also act as a bridge: people in different locations can communicate through a webcam, for example. ICTs are also an opportunity. Technological devices interfere with care and replace the responsibilities of doctors, nurses and other carers towards ICTs, a new actor in care provision.

We also noted a gap between health and social care. The latter is more oriented towards relief from loneliness whereas the former is just addressed to monitor health problems. Both types of care receive differing amounts of funding and are governed by different standards and different regulatory bodies. Are there differences between countries? Are there integrated projects? The Dutch project presented by Annemarie van Hout combines different things: health with social care. In the case of England, health care is more likely to be state funded than social care, although telecare services go towards a more comprehensive assessment of social-care health. In Spain, the provision of care services is fragmented between public social services, health system and private providers.

As care work increases, the trend is also towards an increasing fragmentation. It is desirable that there should be no such fragmentation, but an integration of the plurality. However, the caregiver still has a central role, acting as the manager of the care process, although not (always) the executor. There will always be the need for someone to assume the central role - a person in the family, a caregiver - as good care depends on the coordination of efforts and coordinated work. If there are no well-defined roles it will be hard to create synergies. If the work is multidisciplinary, then we're not necessarily talking about fragmentation, but about the need to coordinate and to support the main caregiver. Fragmentation is not always inevitable.

Fragmentation of care involves:

- **Professionalisation.** It was said that would create many jobs, but people have not always been appropriately trained.
- **Specialisation.** Users require specialised caregivers, but there is little professional training (for elderly careers).
- **Coordination.** We should think about a "program" to deal with ageing, although there is doubt about "recipes" for elderly care.
- Supporting the main **caregiver** to avoid the sense of abandonment when they have to cope with difficult situations. This requires trained people as an integral way to resolve complex problems or pay attention to different needs.
- **Empowerment.** The older person should be able to "manage this care" (select, plan, etc.). This is usually done by the family.

Fragmentation of care means:

- **Heterogeneity** (several agents and care settings)
- **Breaking-off care relationships**
- **“Merchandising”**(paying for care) **and saving money.**
- **Existence of economic problems:** The impossibility of paying for a ‘live-in’ (integral) caregiver.

What challenges do we face due to the fragmentation of care?:

- People are not familiar with telecare and thus many older people are resistant to it. Telecare only becomes known and active when an accident happens. It's necessary to have information campaigns.
- Encouraging an attitude of "citizenship" in older people to enable them to assume a more active role in "managing care", without waiting for the state to respond to their needs. In the first instance, there is the person cared for, as opposed to the term that refers to the "last instance". The person who needs care should always be the first consideration when deciding on forms of care. This person should have the right to decide about his/her autonomy and the right to negotiate directly with all the actors involved in his/her own care process.

2. What are the positives and negatives in this process?

Fragmentation of care is neither a positive nor a negative, but a change of trend.

Positive	**Negative**
- Wellness for caregivers and family. - Provides expert care. - Responds to the diverse needs of the individual. - It can give a role of "manager" to the family or the user. - It's cheaper to have one only carer "qualified."	- (Possible) user discomfort. Confused elders. - No training / Missing "vocations." - It disrupts the coordination of care. It diminishes the role of the family. - Coordination of the different agents of care is expensive. - It can facilitate abuse and mistreatment. (neglect)

In the case of telecare and other remote systems of care, it includes the following aspects...

POSITIVE

- From some people's point of view, it is against fragmentation and facilitates integration
- Allows monitoring and prevention, for example, by measuring blood pressure, activating the alert when the results are negative.
- Increases sense of security and control.
- Fast emergency response.
- New relationships (sometimes also positive) between the family and the elderly. Relatives commented that telecare helps them to take care of their older relatives, increasing their commitment.

NEGATIVE

- New forms of relationship (sometimes also negative) between the family and the older person. For example, in cases where older people feel abandoned by their families when telecare has been installed. The family calls less, doesn't visit for so long, because they may feel less obligation to look after their older relative. Negligence.
- Telecare does not save money. The patented technologies are expensive. One solution might be to access open source technologies
- Contact and face to face relations are lost.
- When something is not easy to explain, some technologies reduce the "grey areas", the nuances of responses, (for example, in the project explained by Annemarie van Hout, the only options that appear on the screen for answers are 'yes' or 'no'.
- Users are afraid of damaging the telecare unit or the pendant, so they keep it in the drawer and don't wear it. What happens then? The care provided does not work.

- The provision of telecare generates a lot of information about users, but nobody knows where it goes or what is done with it. How should this data be managed or interpreted?
- How can telecare be used by generations of older people who have not been socialized into the digital culture? What happens when you do not know how to handle the technology? Will there always be new exclusions as technology develops further? Telecare is impossible to handle when cognitive impairments become more severe.

3. What counts as good care in this context?

Fragmentation is not a term that helps us to think of good care. Plurality and heterogeneous agents or types of care is not bad, but it shouldn't necessarily mean fragmentation. These terms shouldn't be confused. It is better to speak of:

- Shared care, which falls on the heterogeneity.
- Specialized care, which involves expertise.

'Good care' would be guided by a set of general principles:

- Respond to (or even anticipate) the needs and characteristics of older people.
- Be sensitive to the risks and threats faced by older people (abuse).
- See the person as a "whole", especially to recognise the affective components (i.e.: depression in the elderly, the ability to "listen" of caregivers).
- Promote ageing at home with the support of specialised institutions and well-trained and coordinated caregivers. In general, nursing homes and day centres are not perceived by older people as 'good care'. People prefer to age at home. We ask: do older people not like day care centres because of the lack of information about them or because they are not designed to be attractive?
- Good care is what I would want for myself. It refers to what is a good life for the person. Care that responds to individual needs. (The type of old age which we can access is different for poor than for the rich. There are noticeable differences in the possible choices of care depending on the purchasing power of the elderly).

The values that govern this 'good care' would be:

- The person, the individual as the centre.
- Dignity.
- Autonomy.
- Quality of life / welfare.

4. What are the implications of this fragmentation in terms of well-being, gender and social justice?

- In the case of telemedicine, the tasks and workload moves from the doctors (mainly male) to nurses (mainly female).
- In relation to diversity, ‘Could we talk about 'ethnic gap'? Ethnic minority people complain about language barriers when call centre workers in UK answer calls in English. By policy, there should always be translators, but is it impossible to answer these demands?
- The technologies do not solve the problem of differential power relations unless there is participatory design.
- Who gives care? Women migrants. Women are still responsible for the care.

THEME 2: FORMS OF PARTICIPATION: WHOSE VOICES MATTER IN SYSTEM DESIGN?

Hilde Tygessen (EFORTT project researcher at the University Diakonhjemmet Oslo, Norway) introduced the session by stressing the importance of understanding how people interact with telecare technologies in their everyday contexts in order to develop guidelines for the use of technology care. To do so she provided examples of field work under EFORTT research about how people use, adapt, or misuse technology in their homes.

As illustrative of the above experience, the first speaker, **Helene Cecillia Blakstad,** recounted her experience as a caregiver for her husband, (who suffers from dementia), and offered interesting examples of how a GPS device was used and continuously adapted so that her husband could be tracked safely during his walking trips. She highlighted the fact that far from being a simple solution to their problems, the GPS technology caused stress, additional problems and doubts. In fact, she questioned whether the technology was actually an answer to everything her family needed.

Marjo Rauhala, (Vienna University of Technology) spoke about three projects she has been involved with. These projects led her to question the validity of the processes that engage users, viewed as quite active and interested older people, rather than the fragile and vulnerable older people who need help from technology. Interestingly the technologies used by older people affect the way they are perceived by the rest of the population, in addition to contributing to the social construction of self identities of older people. There are huge ethical implications in relation to this when it comes to consideration of what technologies should be developed and who should be involved in such processes. Ultimately, we should ask, what image of older people we want to offer? Other questions were: Who are the users, how powerful are their voices and why they are not listened to? The involvement of older people has been seen as a way to contribute to the acceptance of devices by users, and identify their needs and problems. There are different and competing claims by the primary users of the service, by users' organisations as well as by those who finance care. In practice, it happens that there are always voices more powerful than others. Bad experiences with prototypes and pilot studies, affect the willingness of older people to try new versions of a device. The involvement of users at last minute, in the final stages, is disastrous and investment in design is extremely expensive and costly at the time. In practice, the selection of trials and tests should be within the limits of user skills. It should evaluate the device and not the user, and the tools to gather research data also influence what can be collected (e.g. a highly structured questionnaire may simply reflect the agenda of the developer, whereas qualitative data can provide rich data about users). Also, how are participants selected? Do they really represent those who need the care devices and should be consulted? Understandably, this selection of participants does not include the frailest people, as this could be risky.

Jelle van der Weijden (Director of Tunstall Group sales), stressed the importance of these previous issues. There should be a change in emphasis, from a focus only on the component to a focus on the user. There should also be a change in the position of the users: from subordinate to autonomous. Finally, the medical system should be reoriented from a perspective focused on the medical to a patient-centred view. From this aspect, telecare and telecare technology can help people to manage their own health (e.g. using GPS) because in the future there will be a reduction in the number of health/medical workers and social support. In making the case for the continued need for telecare, Jelle painted a bleak picture of old age due to rapid deterioration in health (even reading a poem about how it may be better to be dead than old). He provided us with examples of technologies which have the ability to monitor the smallest of activities in the home (such as how many times the fridge door is opened, the kettle is boiled, the toilet is used, how long the TV is watched), which raise ethical questions in relation to the levels of surveillance we may find acceptable in the home. He also explained how Tunstall knows the needs of their 'customers' (i.e. health authorities, health purchasers and the like) but are not so aware of the needs of telecare users, which is why they're interested in being involved in social research projects such as EFORTT. Many small projects can fail because, though good, they are not able to achieve a widespread use. The most successful telecare system worldwide is the pendant alarm because of its simplicity.

These points prompted the delegates to ask: at what point does social research such as the EFORTT project become an exercise in intelligence-gathering to help companies such as Tunstall increase their share of the market, rather than provide ethnographic data in order to develop *ethical* frameworks for the use of technology developed by such companies? What is our response as researchers to corporate use of our work?

GROUP DISCUSSIONS

These were guided by two questions:

> 1. What would telecare look like if you (users) had been there at the beginning of the design process? What do we need and how could we design technologies to meet those needs?
>
> 2. What practical strategies can we suggest to ensure older people's views have an impact on policy, practice and design?

1. What would telecare look like if you had been there at the beginning of the design process? What do we need and how could we design technologies to meet those needs?

A technology's design where people had been involved from the start...

- Should not lead to substantial changes in the user's life: the devices should be simple and should have a supportive response to the difficulties that may be associated with its use. Non-invasive devices.
- Should be "warm", "helping people living alone". Telecare appears like a "cold state" but human beings need something more: attention from professional caregivers. It's perceived there may be a danger of "replacing people" with telecare. There was a hope that the technology will be simply another "resource" to enable professionals to work better, but this must be accompanied by good training. It must be recognised that people need not only medical care but also communicational support, i.e. a response to loneliness, not just clinical needs.
- It should not convert the home into an extension of the hospital/institution.
- Should "open the home to the world", as for example with video-calling and PAL4 systems.
- Must be flexible, able to be easily modified. Not only in its surface characteristics, but also and above all in its background conception: in the very idea that gives rise to the design.
- "It incorporates the user in the design process", which means, in fact, the incorporation of different users and relationships. Since there are different situations and needs for design, we need to ask whose needs we are meeting - whether for families or older people. Are we not perhaps talking about the need for control and safety for the caregiver rather than user's needs? Devices and installations should avoid the big differences that sometimes exist between "pilot" users and the "real" users.
- Users' participation also means understanding what, for them, constitutes a feeling of wellbeing, a relationship defined by a greater control and security, by the relationship between risk/safety, etc : "The technology should help me to be myself, to live the life I want to live, individually, socially, emotionally ". It means, it should respond to individual needs, although this aspect is in line with social individualisation. That is, users would need to respond to the question " how I would like to be supported?"
- The priorities of potential users should aim to prevent technology dominating their lives.
- It is preferable to use common and already familiar technologies than experimental designs: for example, it's preferable to use an existing GPS than a specific development in progress.
- Should be based on the following principles:
    - Simplicity
    - Aesthetics
    - Reliability
    - Security
    - Adaptability to specific problems
    - Improvement of self-control
    - Autonomy on the degree of integration of technology in their own lives
    - Affordability
    - Flexibility, specific designs for many specific conditions, for different purposes.

The ethical dilemmas associated with telecare and remote care are proportional and correlated with low social participation in the process of being cared-for, which also includes the process of technology design. The participation should be included not only in the design phase, but also in the implementation procedure, strengthening the idea of process. Thus, the later we include users in the design process more difficult the possibilities of change and correction become. The technological design process is often uncertain, unpredictable, and it cannot be known in advance what the final design or the final use will be. It is impossible to know all the problems that arise with the introduction of new technologies until we use them and look closely at what difficulties people are facing when they have to handle them. The participation of users in the design process should also be a dialogue with developers, because it is also necessary for them (the users) to know what it is possible and what it is not.

2. What practical strategies can we suggest to ensure older people’s views have an impact on policy, practice and design?

- The design process should be user-centred: each device has many types of users and each of them has different perspectives, characteristics, needs, values and conditions relating to the use of technology. So we should take into account this diversity of relationships, habits and technological conditions (geographical location, community in which they are embedded) to find the minimum commonalities. Older and disabled people especially have many agencies trying to speak on their behalf. It's about breaking the trend of designers dealing with users as a homogeneous stereotypical group. In discussions about technological devices, the following questions should be answered: Who is the user? What are the voices that count as users’?, What happens if these voices are incompatible?
- Giving voice to older people in policy could be done by creating a political party for older people or pressure groups within parties. This means giving older people proper access to parliaments, local councils, and the courts.
- Participation is not just an issue of "political" institutions and governments, but it also involves the technology development companies. A proposal of participation would be to create independent working groups with different agents involved in telecare to identify relevant actors, their positions (perspectives, values, needs, etc) and work on it. These independent groups should be able to transfer these discussions to areas of policy decisions.
- Given the difficulty that politicians may have in listening to users and older people, there should be activism from local communities as a starting point. Part of the political question concerning the participation has to do with our power as citizens. This is not about the users and older people's involvement in design but the broader right to participate and be heard. Older people are becoming more active and more articulate.
- It is also worth mentioning that there are already other forms of autonomous participation, efficient and grass-roots, generated by users, independent of technological development.
- Scheduled health policies should include telecare and follow a "bottom-up" management and planning and not the opposite.

THEME 3: CHANGING SPACES OF CARE

Christine Milligan (EFORTT researcher Lancaster University, UK) explained that the focus on the provision of care has shifted from institutions to "ageing at home", so that telecare has been seen as a way to respond to the "care crisis." Telecare can be free from geographic constraints (taking care at a distance) but how does it affect home care and the sense of "feeling" at home? Who participates in the care?

‘Low-level’ technologies (such as guardrails or hoists) have been around for a long time and when people start to feel vulnerable, the layout of the house can begin to change and these changes are visible. Despite designers trying to market devices looking more "homely", they continue to affect how people perceive their home. Even without big video surveillance devices, the sense of security or of being watched can change. In this sense, there are basically two forms of telecare, taking into account the perspective of users: one that gives them the feeling of being more independent and be more confident (e.g. pendant) and other that gives them a sense of vulnerability to surveillance (e.g. sensors and cameras at home). A common feeling among users of telecare is social isolation and lack of human contact (visual, physical, etc). Sometimes monitoring centres are situated in a different area of the country/region of the world: does this make a difference? Is local knowledge important?

Over time, tele-operators can turn into care workers, caregivers at distance, and emotional support providers, although originally their role was seen as ‘technical’. They have also dilemmas and experience a sense of uselessness when, as in some cases, the problem is not serious enough to call the emergency services and they can not do anything for the caller except talk and try to cheer them. Care interactions also change within the home and change the meaning of ‘care’ itself. In short, the distance reshapes care relationships, those who are involved in it and the places where it happens.

Isabel Dyck (social researcher, feminist geographer, Queen Mary, University of London, UK), began her presentation talking about the meaning of home: the emotional dimension of care, the porosity of the boundaries of the household, and other issues such as autonomy and identity of the persons represented in the tension between independence and security.

In summary, the main concepts to define home are:

a) a space for long-term care

b) a complex material, social and symbolic place where meanings are fluid

c) a physical and spatial imagery

d) a place with porous boundaries

e) gendered, that is, where gender roles and tasks are reconfigured and reproduced

With the introduction of new telecare technologies in the home, the materiality and significance of the latter are restructured. Even the perception of self can be altered by the physical presence of handrails and other assistive devices. The existing social and symbolic configurations about care and home are threatened and the limits of public and private sectors in the home are blurred. Even the entry into the home of a whole new network of caregivers, expands the notion of home and the horizons of those who live there, and provides people with opportunities to share their memories.

Despite these changes, we cannot neglect the affective dimension that is in the fact of caring and being cared for. One must ask about what interests are being represented by all these transformations. In this case, taking an overview of the technology according to the theories of Social Construction (SCOT Program) is very relevant for interpretive flexibility of the devices and systems, because they question these meanings and interpretations of the technology and what new realities they bring or reshape.

Birgitte Holmene (project leader of Security.NET, Norway) showed the audience an online communication program that is basically a discussion forum (using a webcam), aimed at families, caregivers and cared-for people. The different roles that family-carers adopt in this forum are: to be strong, to experience the pain of others, as listeners, as providers of comfort and of having obligations relating to the tasks of care.

After showing an online communication in action, the speaker posed the question of whether Security.NET could reduce hospital admissions. This project, initially, provided support to families of patients. It provides relief for them and, above all, a guiding tool for all participants engaged in care. The main objective is preventing "burn out" and assisting caregivers in their caring role by providing a space for social communication and support. Security.NET is also being used as an organizing tool for social events or other issues that emerge over time.

Martí Martínez (Head of telecare and new technologies for older people, Red Cross, Catalunya, Spain) explained the Red Cross' home telecare service and said that the service is useful for being in contact with people living alone or in physical or psycho-social danger. For people with cognitive deterioration like Alzheimer's, the Red Cross offers the use of GPS and mobile devices in a service called SIMAP. This technology serves to enhance people’s mobility for as long as possible. However, the tasks of care also can use other non-electronic and homely devices that make daily life easier and more autonomous for older people.

These presentations lead people to wonder about the resistance to or acceptance of certain monitoring devices by users. It also appeared that technology implementation itself is a form of politics. Each choice in relation to technology highlights different perspectives of different groups, so that the decisions made by politicians may not reflect the views of carers and people cared-for.

GROUP DISCUSSIONS

The discussions in the workshops were guided by three questions:

- How does telecare reshape care interactions within the home and what it means to feel at home?
- How does telecare reshape who is involved in the delivery of care and where it takes place?
- What forms of telecare in the home go beyond what can be seen as ethically acceptable for those involved in care process?

1. How does telecare reshape care interactions within the home and what it means to feel at home?

Feeling at home can mean different things: to stay at home when sick or disabled; to be able to do daily activities; for others the ability to go anywhere without anyone to watch over you; to embody your own story, to remember what you've been or have had, etc ... Many people would accept using telecare and telecare devices if it would allow them to remain at home and if they feel that what ‘home’ means is not going to change. Although not all people want to live in their homes and many prefer to live in protected places such as nursing homes or sheltered housing schemes.

Without doubt, telecare changes the meaning of home. Not only physically and spatially (some devices or specifically the ways in which they are installed, are rejected by users. That they are available does not mean that are accepted / acceptable), but telecare itself is an indication that you have changed and you have some care needs. Telecare has an ambiguous connotation: it means a “wound”, it indicates that you are vulnerable, but at the same time it gives peace and makes feel safe. That's why the widespread reason for accepting a telecare service is the aim to feel safe in case something goes wrong. To take control of your life, start to feel at home. And to do that, telecare can help to control your life and get by. In relation to this, most of the time, telecare is not installed at the request of users, but at the desire of the older person’s children who live far away. And ‘users’, in many cases, like to satisfy the wishes of their family.

For many older people, having a telemedicine unit at home is like having a piece of hospital at home, whereas before they had to visit the doctor. However, the fact that the home is the referent area of health care is not something new, as before the hospitalisation process, it was the privileged place for care (instead of hospitals). The difference between a home from "pre-hospitalisation" era and a home with telemedicine devices is their connectivity.

Privacy is also a highly valued aspect of home, being able to control your own space. In this sense, telecare is interesting because it implies that what is 'outside' can enter the home, at least symbolically. And on the other hand, telecare is used to maintain order at home. The difference with the phone or computers (devices that also allow input from the outside to home) is that telecare devices are linked to monitoring centres. In relation to privacy, there is a curious effect. And while researchers and scholars problematise and criticise the lack of privacy in the domestic space, users, when asked, have no problems about it. If they did not want to use the service, they would simply leave the device in a closet. One of the fears that appears is the privatisation of home, in the sense that it's shifting from being a intimate but publicly care space to a space increasingly privatised and commercialised with the entry of enterprises and companies in the world of care. It has also become an increasingly medicalised and technologised space.

Another point to note is that the home has variable meanings: the less you can get out from it, the more important the surrounding areas are, as well as the neighbourhood. The relationship established between the home and other areas and how the latter reach part of it is an interesting research question. In fact, it is considered that the home is not only the building, but also a set of practices that include the environment and the local area where it belongs.

Nor are there universal solutions: it is important not to take anything for granted, do not assume too much, because the home can also be a place of mistreatment and abuse. Many people do not want to stay in their homes but they can't move into a care home because there are no places available. Resources are limited. Each person is different and we need to analyse the differences and needs to evaluate each case carefully. In this sense, many people prefer to be in sheltered accommodation.

In this context it is important to consider what makes a space a desirable place to live. This may include friendly carers, maintaining established relationships, be part of a community or be close to your family. This implies that the home where people have lived for many years is not necessarily the preferred place to live as other areas may offer new or better opportunities. In the rhetoric of telecare however, the home is generally regarded as the only place where it is better to live. Thus, governments usually promote telecare technologies for all situations, and every problem seems to have a technical solution. Other solutions, however, should be equally possible, such as not staying home. In any case, those who choose to live at home should be able to choose which technologies they want to live with.

2.- How does telecare reshape who is involved in care work and where it takes place?

Telecare reshapes the role of caregivers, the relationship established with older people and the interactions among caregivers. Telecare also modifies responsibilities, so that, for example, if caregivers press the alarm, they are co-responsible for the older person who while they are still fallen on the ground. Also tele-operators who act wrongly are responsible for what happens. When you delegate tasks to the machine, you're still (as user and family) responsible for the machine, but we must distinguish between civil responsibilities and filial and familiar obligations. There is a difference between feeling and being responsible. Nor should we forget that we are responsible for taking care of ourselves. In this sense, telecare fits neatly with the neo-liberal emphasis that each individual is responsible for themselves. Telecare would then be only an instrument that increases the possibility for contact or help.

Telecare can also change the behaviour of people asking for help. Before, when someone fell, she called her closest relative, but now has the possibility of pressing the pendant alarm. Family members and care provider organisations urge you to use the pendant. Thus, the person needing help has a dilemma: should I call my family or should I use the pendant?

3. What forms of telecare in the home go beyond what can be seen as ethically acceptable for those involved in care process?

Telecare is not ethically acceptable when it separates you from your environment, it moves you away from it and it restricts you.

Continuous monitoring of your daily life and activities generate ethical doubts (although many older people who have been asked about this are not worried about it): it threatens the sense of freedom at home. If you come to the point that, to live independently, you need so many devices, sensors and controls, perhaps you should no longer live at home. The installation of all these monitoring devices and sensors will force you to use them, for example, making you get out of your bed when the alarm sounds, or changing your habits, making you open the refrigerator too often.

Given this, it creates a doubt: are the suppliers of this technology finding that the devices are being used correctly? The current problem for suppliers in relation to monitoring habits and practices is that they do not know exactly what data is collected about each habit and practice and what happens to this data. They hope that one day all work and all informational systems be integrated. Then, participants ask: why do they sell things which generate information they do not know what to do with? People are concerned about privacy and transparency in the use of data from these devices and sensors: who will use these data?, why, where and for what?. What is the relationship between costs and efficiency generated with all these devices?

Telecare would be ethically unacceptable if it makes false promises about what it offers, what you can choose. Also, since the family often assumes the use of the service on the older person's behalf, there is some implicit coercion. Thus, although telecare should not be an obligation, it may be forced upon the user.

In the United Kingdom telecare is promoted by the government as a solution for demographic ageing. If every home is full of devices, sensors, might this end up becoming unethical? What matters ultimately is the willingness, acceptance or refusal, and choice of each person. If there are abuses of installations and of use of devices, users may reject them and not use them anymore. There should be a range of possibilities. And if those concerned cannot choose, others may make the selection. In some cases, telecare may not be the best option for them. And if those concerned cannot choose for themselves, and others have to make the choice for them, perhaps telecare is not a suitable option for them.

The debate on ethics in telecare is also related to the quality of services and the care and support provided. In this sense, it is more longitudinal and complex than a simple yes or no to the adoption of a device. We must also ask whether the telecare in question is a service free of charge and for whom, and what happens to those who cannot afford it. In this sense, there are other factors (ie the level of financial support) playing a role in the choice about using the telecare. Therefore, the ethical debate also relates to the relationship between dependence and independence.

The discussion turned to the notion of choice and, in particular, the choice to live independently at home. Participants asked which are the options in the context of telecare and whether the notion of choice is a good basis for the definition of an ethical framework for telecare. It appears that in the context of older (vulnerable) people the idea of choice is a complex concept. This should not be seen as a simple decision in certain situations, but as an ongoing process that takes place in a complex and changing context, an ambivalent context of dependence and independence.

What does dependence and independence mean? Often, independence - for example, in the sense of being able to live independently at home - is only possible thanks to dependence on somebody or something, for example, depending on children, neighbours, technologies, etc. Independence and dependence are closely linked. You can only choose to live independently if there is already a network of dependencies, ie, relationships on which to rely. In this sense, we are not dependent or independent, but we achieve independence only because we are dependent (have reliable support).

Therefore, being dependent is not necessarily negative, and having a single notion of living independently may be too simplistic. Ethical telecare technologies recognise that dependence and independence are not opposites but are intimately linked, and that decision-making takes place in this context. The debate concluded with the question of whether it would be better, therefore, to talk about desire or willingness rather than choice.

PHOTOGRAPHS from the EFORTT Conference:

Second theme speakers and chairs: H Thygesen H.C.Blackstad, J Van der Weijde, M Rauhala, J Pols

Third theme speakers and chairs: C. Milligan, I Dyck, B Holmene, M. Martinez, M. Domenech

General view of delegates listening to the third theme discussion

This report has been augmented thanks to the notes taken by the conference rapporteurs: Maureen McNeil, Elham Kashefi and Louis Neven; by Kristrun Gunnarsdottir and Josephine Baxter.