CareCamera: Tensions between User Needs and Ethical Issues

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Overview

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THE EUROPEAN HEALTH SYSTEM DEPENDS ON THE INVOLVEMENT OF INFORMAL CAREGIVERS TO ENSURE CARE PROVISION TO ALL WHO NEEDS IT.

Taking care = Highly responsible demanding task

BURDEN AND SOCIAL EXCLUSION BECAME ONE OF THE MOST DIFFICULT CHALLENGES IN OUR SOCIETY.

Research Context

- Use of monitoring systems for informal care (Koch 2006; Milligan et al. 2011)
  - Examples: telecare, telehealth, electronic surveillance, wandering technologies, tagging, tracking
  → to increase the independence of both carers and care receivers (Niemeijer et al. 2010)
Research Context

- **Ethical considerations** about their use (Zwijsen et al. 2011; Niemeijer et al. 2010)
- No ethical consensus has yet been found so far → not enough attention, often treated superficially or not a priority
The Online Platform for Informal Caregivers

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OUR GOAL
is to understand informal caregivers’ needs and design ICT solutions to support them in their daily needs
Our Approach

• **User-centred design** with qualitative inquiry of user context and requirements
  – End-user involvement from the elicitation of the system requirements, through the system design, to its evaluation
  – Ethnographically informed study, based on different data collection instruments – e.g. shadowing observations, in-depth interviews, diaries

• Video surveillance technologies could reduce some of the burdens of informal carers, especially for carers who need to be absent for some time from their care receivers

  → **CareCamera** as a video surveillance solution for informal caregivers
Example 1 – Mr. Sorgsam

- 65 years old
- Care for his 68-years-old spouse (> 2 years)
- 2 sons and 1 grandchild (no regularly contact)
- Not living in the same household (30-45 min distance)
- Anxious and concerned every time he cannot reach his partner
- His solution = install a camera in her partners’ house and monitor her now and then
Example – Ms. Netzwerk

- 59 years old
- Care for her 80-years-old mother
- Not living in the same household (50 km distance)
- Visiting her once a week for 2-3 days including overnight stay
- Calling her mother every day at 5pm
- Mother tells about her day and Ms. Netzwerk can only listen

- Concerned because her mother might hurt herself, in the garden …
- Her solution = monitor her to make sure that she is ok
Example – Ms. Netzwerk

- Our first user decided to have a CareCamera installed in her mother's home
- CareCamera was placed in her mother's living room
- Ms. Netzwerk can see the whole living room including the dinner table and also part of the kitchen
Example – Ms. Netzwerk

• Her mother accepted it without a problem: the single fact that her daughter would be less concerned about her was a strong motivation to accept the installation of the camera

• Ms. Netzwerk
  – At the beginning: took a look in the camera several times a day
  – Then: this levelled off to three times a day - in the morning after waking up, at lunchtime and in the evening
  – Now: this works for her very well

• She is feeling more secure and reassured, but she is still concerned if her mother is not there
Example – Ms. Netzwerk
Our Solution: CareCamera

- **Low cost (only cameras!)**
- **Wireless technology with HTML5 representation**
- **Easy to install**
Our Challenges

• **Great resistance** within our project consortium because of …
  – Professionals being recorded when coming to the care receivers’ home
  – The extent to what such technology would reduce carers’ burden or increase it, given they could feel compelled to check upon the care receiver several times
  – Technological limitations, e.g. unidirectional video without audio, arose immediately after the consideration of adopting the technology → either a total surveillance system or nothing
  – Permission for the use of all stakeholders needed
  – Use of cameras in private rooms problematic (sleeping room, bath and toilet)
  – Risk of abuse

• **Which additional value**, compared to a traditional emergency system do we generate?

• Confronts the **user-centred design methodology** with ethics
Our Challenges – Our Questions

• Which types of policies do we need to regulate the use of surveillance technologies and what are the variables associated to their definition?
• Who should be in charge of deciding whether and how such technologies can be offered in particular settings?
• Is it ethical at all to decide for the users?
• Should the users not be autonomous in deciding what is good or bad for them?
• How is user-centred design approach supposed to work?
• How about when what they want affect other people?
• …
Lessons Learned so far

• Ethics discussions are very general and focus mainly on work environments. Caregiving is a different thing.

• Don't generalise the use of monitoring devices for caregivers in ambient environments.
  – Otherwise you focus only on negative aspects.

• Define the special use context/setting for the deployment of such systems.

• Use – Place – People – Time – Technology

• General use → Special use
Lessons Learned so far

• Inform the users → Improve their awareness of the use aspects to avoid anxiety / mistrust / resistance

• Empower the users, e.g. by enabling switch on/off the system
  – They decide when to use it, not the technology and not other 3rd parties.
  – Give the user as much control as possible but only if it makes sense, e.g. control the position of the camera, etc.
  – Regarding on/off: It is a must but one has to keep in mind that it might be the case that the user forgets about turning the system on again.
  – Be careful with certain care receivers, consider their health condition, inform them, get their consent, facilitate an agreement between caregivers and care receivers on the use of monitoring systems.

• Make sure and communicate explicitly that professional caregivers or other service providers in ambient environment are not monitored.
Einverständniserklärung für die Verwendung der Care Camera

1) Ich erkläre mich bereit, im Rahmen des Forschungsprojektes „TOPIC – Computerunterstützte Plattform für pflegende Angehörige“ an der Erprobung der Care Camera bzw. an der damit verbundenen Nutzungs- und Evaluationsstudie teilzunehmen.

2) Ich bin damit einverstanden, dass drei Care Cameras in meinem Haushalt installiert werden und meine Tochter auf diese Care Cameras mittels Smartphone und vom Projekt zur Verfügung gestellter Software zugreifen kann.

3) Ich wurde über die Care Camera und dessen Ziele, sowie die Modalitäten einer Teilnahme an der Erprobung und Evaluationsstudie und über den Ablauf der Teilnahme bekannt, alle meine Fragen zu meiner Zufriedenheit beantwortet und für mich klar und verständlich formuliert.

4) Ich weiß, dass ich bei Fragen oder anderen Anliegen jederzeit an die für die Benutzereinbindung zuständige Kontaktperson wenden kann. Anschrift und Telefonnummer habe ich vorab erhalten.

5) Ich nehme freiwillig an der Testung der Care Camera teil und weiß, dass ich meine Zustimmung zur Teilnahme jederzeit, ohne besondere Gründe zu nennen, zurückziehen kann. Darüber hinaus ist mir bewusst, dass ein Abbruch der Evaluierung meinerseits keinerlei Folgen hat.

6) Ich wurde darüber informiert und bin damit einverstanden, dass ich für die Testung der Care Camera keine finanzielle Entschädigung erhalte.

7) Die Testung der Care Camera ist für mich mit keinerlei Kosten verbunden.

________________________  _______________________
Ort, Datum Name

________________________  _______________________
Unterschrift
Lessons Learned so far

• Help to reduce the complexity of the maintenance of the CareCamera by caregivers, reduce cause for getting confused
  – too many components that can be causing the problem
  – support by providing user guidance and direct contact (on the phone or on site) for clarification
  – support by helping in case of system problems
  – provide an explicit service around the care camera like for installation and support
Conclusions

• Older people tend to accept such technological solutions, so they can continue living in their homes whilst caregivers can still provide them some support (Zwijsen et al. 2011)

• Listen to your users, involve them. Don't decide for them, decide with them.
  – But first inform them properly and carefully about positive and negative aspects of the use of monitoring systems
  – User-centred (iterative) approach
  – Co-creation of solutions together with users
Conclusions

- Suggestion how to develop and deploy better, acceptable, ethical monitoring systems on site
  - Inquiry, study and understand the use context
  - Define the stakeholders that are in direct contact with monitoring devices
  - Explore technology and organisational solutions to deal with the challenge
  - Create real use scenarios
  - Evaluate them in cooperation with stakeholders
  - Adapt them as needed
  - Run, study and evaluate in pilots by being critical especially from ethical point of view
  - Adapt, improve and deploy the revised system, be ethically sensible while doing this
  - Assess regularly the use setting and adapt the system if needed
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Thanks for listening!