

ASI Presentation 2

Where to from here? Ethics, Technology and Care for People with Dementia.

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As we have seen from the results of the telecare project, ethical considerations are central, but not necessarily straightforward, in telecare. The ability of people with dementia to give full and informed consent is necessarily tied to the severity of their dementia. While those with mild dementia can understand the telecare system, these people may not wish to have such technology in their home, either because they do not want to feel dependent on it for getting on with their lives, or because they have not yet come to terms with their diagnosis. Obtaining informed consent is a difficult and complex concept in the case of people with dementia, and in many cases it is the informal carers of people with moderate to severe dementia who give consent.

In this project, both the care co-ordinators and the carers who took part felt that it was the carers who benefited most. The carers were also the main users of the technology. This gives rise to a number of ethical considerations that deserve our attention.

1. How do we balance the need to intervene earlier in the course of a person's dementia with making sure that people do not feel coerced into accepting interventions that they do not want and may not need?
2. Relying on an informal carer to give consent is sometimes the only way to proceed in situations where the person with dementia does not have the capacity to do so, however, in the absence of an ethical framework that is accessible to carers and service providers, they may be asked to do so in a vacuum, with little or no guidance to support them. Whoever makes the ultimate decision must be conscious of the responsibility and the ethical dilemmas involved.
3. Finally, the project has highlighted the thorny issue of who benefits from a specific intervention, and how we should negotiate between the respective needs and rights of people with dementia, and those of informal carers.

This all points to the need to develop a strong ethical framework for the use of technology in health and social care, especially with regard to vulnerable groups such as people with dementia. Any such framework must attempt to capture the different aspects of telecare, and, crucially, the overall social and care context of the people with dementia, their informal carers and their formal carers. It does not make sense to discuss ethics and technology independently of the overall ethical and social care context (Downs, 1997).

Recent research at European level (ICT and Ageing, 2009) has begun the process of developing a framework to help identify and examine the various layers of ethical issues that arise in this domain. They have found that, perhaps unsurprisingly, the boundaries between 'research ethics' and 'service delivery', and between 'medical' and 'social' care, are often quite blurred. In addition, decisions as to what activities are or should be subject to ethical scrutiny and governance as research or as practice can be very arbitrary. Care for older people is a multidisciplinary process

and includes both social and medical care, and existing traditions in medical ethics may not be well-suited to the key issues that arise in this area.

In terms of specifically technology-related ethical issues, a number of defining features of telecare and Telehealth highlight the accompanying ethical issues particularly well:

Remote care

The ethics of remote telemonitoring have received less attention than video-consultation. There are a number of ethical issues that need to be addressed in this context, such as the difficulties that may be faced by nurses, both because of the distance from the client and the requirement of the response protocols that they must adhere to. The issue of handling of medical calls or data by non-medical personnel is also of increasing importance, as are the more general ethics of interaction with and response to clients by social alarm services and staff.

Monitoring and surveillance

Key ethical issues here include transparency and informed consent, proportionality and purposefulness, privacy and dignity, and location monitoring.

The principle of informed consent states that people should know what they are signing up for. This is closely linked to transparency. A particular challenge in relation to informed consent and transparency arises in situations where the capacity to engage is reduced, as we have highlighted earlier. The implications for families also need to be clearly explained.

The principle of proportionality requires that the level of intervention should be restricted to what is really necessary for the situation. This is very much related to the ethics of trade-offs between risk and safety and security, which is a common dilemma in the use of ICT-based services for older people, and is especially to the fore in relation to the monitoring of the activities and whereabouts of people with dementia. Allowing people to make their own risk versus security trade-offs as much as possible should be a core ethical principle, as should making an effort to understand and facilitate the needs and desires of those who cannot easily articulate them themselves.

The principle of purposefulness states that information should not be gathered unless it has a clearly specified purpose that is related to the needs being addressed.

There are also key ethical concerns about issues of privacy, and personal and family dignity. Monitoring of activity or lifestyle raises privacy and dignity concerns, with the key issues being what data are collected, what types of processing, interpretation and presentation are permitted, and who should have access.

A particular form of monitoring and surveillance is location monitoring. This has come to the fore in the case of people with dementia because of the tendency to wander, to become disoriented and lost, and generally to be at risk in this way. Key issues concern under what circumstances it becomes acceptable or necessary, and what types of monitoring should be allowed (continuous or periodic, for example).

Impact on families

It is very important to bear in mind that family care arrangements and relationships can often be very precarious and finely-balanced, and that any intervention poses the risk of disruption. The stability of the environment and regularity are very important for people with dementia.

Given all these inter-related ethical considerations, across Europe there is a rather dispersed and patchy frame of reference for ethical guidance of the various actors in the ICT and Ageing field, ranging from generic principles such as respect for

personal dignity to concrete regulatory requirements such as protection of personal data privacy. At EU level, while there is no dedicated legislation or policy addressing the ethics of ICTs in care for older people, there are a number of relevant policies, including the European Charter of Fundamental Rights and the Data Protection Directive of 1995.

However, much work needs to be done to strengthen ethical guidance in the field. There is a need to consolidate and use effectively the developing evidence base arising from the actual impacts and outcomes of RTD, trials and implementation of technology. In addition, targeted efforts in areas where gaps in the evidence base exist should be explicitly encouraged. In addition, informed dialogue should be actively encouraged especially with regard to:

- Presentation and dissemination of information and evidence
- General opinion gauging
- Focused consultation with specific stakeholders

Regulation, guidance and promotion

At least some of the ethical issues raised here have such importance that they warrant attention through legislation and regulation. A key challenge here is the transformation of ethical issues into an operationally useful form that can guide policy and practice. This is not a simple task as ethical issues tend to present as dilemmas, where there is no obvious right or wrong. Given this complexity, it is not surprising that there is no one, simple ethical rulebook available to guide research and practice in this field. However, there are a variety of guidelines, codes of practice and so on that have been developed, and it would be very useful to collate and analyse relevant existing guidance materials and approaches, examine the possibilities and limits to developing an ethical framework, and identify priorities that could be addressed by relevant stakeholders.

A number of projects have been recently initiated that aim to do this. For example, the Senior Project is a two-year support action funded under the 7th FwP of the European Commission that aims to provide a systematic assessment, using dialogue as the key instrument to evaluate the social, ethical and privacy issues involved in ICT and Ageing. The project website is:

<http://seniorproject.eu/index.php>

The EFORTT project aims to deepen the understanding of ethical issues raised by these developments and ultimately to develop a grounded evaluative and ethical framework for Telecare Technologies for older people. The project website is:

www.lancs.ac.uk/efortt/index.html

References

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