Dementia

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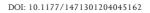What is This?

Ethical considerations in the ENABLE project

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Abstract This article describes the ethical considerations and the framework that formed the basis for the design of the research methods, as well as the basis for choosing the devices to be tried out, in the ENABLE project. The principles of autonomy, beneficence and justice are defined and applied to an analysis of researchers' experience. Some of the ethical difficulties arising from conducting an intervention study of this type with persons with dementia are outlined. The article needs to be read in conjunction with the other ENABLE articles published in this issue of *Dementia*.

Keywords carers; dementia; ethics; research; technology

Introduction

The objective of ENABLE is to investigate if assistive technology can support people with mild to moderate dementia and their families in daily life. The products were developed and tried out in the project aim to support memory, assist communication and provide entertainment. The context of user trials in ENABLE is set in five countries: Ireland, England, Finland,

Lithuania and Norway. The products were chosen after identifying the needs of the potential individual users. Each user was offered one product over a period of up to one year. Products were installed in the users' own homes and in day care centres. This article describes the ethical considerations and the framework that formed the basis for the design of the research methods, as well as the basis for choosing the devices to be tried out. A range of ethical considerations concerning research with people with dementia is discussed. Some of the experiences with ethical considerations in the project are exemplified and discussed.

Involving people with dementia in research projects is in itself a controversial issue (Downs, 1997). Trying out assistive technology where the aim is to investigate what impact devices may have on the quality of life of a user and her/his family raises many ethical questions. These questions have been addressed by Bjørneby, Topo and Holthe (1999), Magnusson and Barbosa da Silva (1999), and Topo, Jylhä and Laine (2002). In each country, there are laws, regulations and procedures that need to be dealt with in order to make it acceptable to carry out the research.

When planning the project and in the early phases, the research team found few similar studies. However, useful discussions were identified in work by Topo et al. (2002), Holthe, Hagen and Bjørneby (1999), Nygård and Johansson (2001), the Action project by Magnusson and Barbosa da Silva (1999) and the TED (Technology, Ethics and Dementia) and ASTRID (A Social and Technological Response to the needs of Individuals with Dementia and their Carers) guidebooks by Bjørneby et al. (1999) and Marshall (2000), respectively. The project team was therefore compelled to have in-depth discussions about issues relating to ethical considerations before starting the assessment study. The aim of this article is to summarize the previous work done on ethical issues and use of technology and to describe ethical considerations raised in ENABLE.

Justification for doing the research

Justification for doing the research lay in the challenge of finding ways to improve the quality of life of the increasing number of people with dementia living at home, as well as the need to address the burden this poses on care services and on family members. More and more people with dementia are now cared for at home by family caregivers. These same people have been largely ignored in terms of socio-technical research since most research effort is in relation to clinical/medical/pharmacological investigation. Therefore, the ENABLE project sought to narrow this gap in the literature by investigating how technology might have an impact on the daily lives of people with dementia at home.

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Seeing dementia only as a medical condition suggests that it is largely untreatable and that only medication can help those who suffer from it. Goldsmith, Kitwood and others have made attempts at approaching dementia from a different perspective, the perspective of personhood (Downs, 1997; Goldsmith, 2002; Kitwood & Bredin, 1992). This perspective does not deny the presence of a dementing illness, but sets it within a context that is social rather than medical. Within this context it is possible to see dementia as a disability where there are potential benefits to be achieved through supporting every day functions, adapting surroundings, products and activities for the affected person's interests and needs. This underlying principle in the ENABLE project calls for innovative, user-oriented devices, as well as ensuring that it is mainly the voice of the person with dementia that reports experience with the devices. Studies based on information gathered directly from people with dementia have provided important perspectives and vital information (for example, Proctor, 2001).

Type and function of technology

Several members of the project team had prior experience with EU research projects, namely TED, Biomedicine and Health Programme II, 1999 (Bjørneby et al., 1999) and ASTRID, EU Telematics Programme, 2000 (Marshall, 2000). It is important to note that work in the ENABLE project builds on the results and recommendations of these other projects. For this reason a brief description is given below of the contributions of each of these projects. Both TED and ASTRID resulted in the design of guidebooks for practitioners in the dementia field where ethical issues were addressed and discussed. An underlying principle in the TED and the ASTRID projects was that technology aimed at helping people with dementia should always be seen in a social context and as part of a care plan. If this is taken seriously, many ethical considerations may not be so controversial. A Forget-me-not calendar (Hagen et al., 2001) and a Picture Gramophone were tried out in the TED project but it was felt that further work needed to be done on their application and evaluation.

Ethical issues raised in the TED and ASTRID projects

The description of technology in the TED guidebook (Bjørneby et al., 1999, pp. 56–57) demonstrated that technology can be used for:

- reminding people;
- providing people with something to do;
- pointing out or responding to dangers;

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- watching people (surveillance);
- restricting access;
- keeping in touch/maintaining social network.

Some of this technology clearly aims to provide safety and security through alerting carers or restricting activity, even if the person with dementia is not aware of a potential danger. If this type of technology is used, ethical considerations are serious and quite complex. Regarding ethical principles we can talk about a dilemma between beneficence and autonomy. The TED (Bjørneby et al., 1999) and ASTRID (Marshall, 2000) guidebooks discuss these considerations and make recommendations supporting practitioners in the decision-making process. Marshall (2000) reminds us that ethical practice is not 'recipe knowledge' by which simple, definite answers can be provided to complex issues and problems. She points out that ethical considerations and issues arise in dementia care, regardless of whether technology is being considered. Marshall claims that it is also possible that technology draws attention to ethical problems that have always been there, but have not been dealt with as such.

The ASTRID project showed that there was a lack of awareness amongst care professionals, family caregivers and suppliers of technology about the potential of assistive technologies to assist people with dementia (Marshall, 2000). Technology used in an ethically acceptable way may be the best way to meet some of the challenges outlined below, and, if not, care plans may not be ethically acceptable. The challenges outlined in the project of how technology might be of use included:

- How can memory, orientation and other cognitive capacities that are central to everyday life be facilitated?
- How can the safety and security of the person with dementia be ensured without infringing on their human rights?
- How can attractive and meaningful occupation be offered to people with dementia during the day?
- How can support be provided for family carers, including respite from caring responsibilities?

The emergence of the ENABLE project: Choosing the appropriate technology

The issues highlighted in the TED and the ASTRID projects formed a basis for designing the ENABLE project. In addition it was felt that, unlike the other two studies, in ENABLE the technical products would be tried and assessed over a longer period of time. The products would be tested with consumers themselves – people with dementia and their carers – in order

to validate their usability, usefulness and acceptance criteria. Through the trials, the potential benefits for the users would be evaluated.

Choosing the appropriate technology for people with dementia was one of the first concerns facing the researchers. In designing the ENABLE project, the aim was not to include technology that represents surveillance and monitoring of a person's functions and activities. ENABLE was designed to empower the person with dementia through supporting his or her memory, communication and entertainment. The need for products addressing these areas formed the basis for designing and choosing the devices. Accordingly, only products believed to comply with these specific aims were chosen for trial in each of the five partner countries.

The devices that were chosen in the project were therefore aimed at:

- Stimulation and enjoyment by listening to and singing along to familiar music and songs, using interactive multimedia technology. This product is the Do-it-yourself Picture Gramophone, operated by the user choosing songs on a touch screen.
- Facilitation of time orientation and the difference between day and night. This product is the Night and Day Calendar, which shows automatically day, date and whether it is morning, day, evening or night.
- Help to find lost objects. The product is the Locator, where the user can touch the picture of something that they cannot find, for example a purse, and a beeper on the purse will remain ringing until the purse is picked up.
- Improved safety/reduced risk when using a gas cooker. The Gas Cooker Monitor will turn off the gas if there is overheating by a pot cooking dry, or a plate left on for too long.
- Facilitation of communication by supporting the ability to make a phone call. The Picture Phone enables the user to make phone calls by touching the photo of a person on the telephone, without having to remember the number.
- Providing automatic lighting at night when a person leaves the bed. The Automatic Nightlight switches on dimmed when a person gets out of bed, and switches off when he or she is back in bed, in order to prevent falls in the dark.
- Memory support for taking medication. The Careousel is a medicine dispenser that runs on a battery and opens a slot and beeps when it is time to take medicine. It beeps until the pills are emptied out.

Underlying ethical issues

Even though the devices in ENABLE have a clear enabling focus, most are new and unfamiliar to the users, and this in itself can produce stress that has consequences for how beneficial the research is for the users and for the outcome of the research. As far as we know, trials of new technology where assessments in several countries are compared have not been previously reported in the literature. The project team found no standard framework for making an ethics protocol for the research, even if previous studies with some similarities have addressed this issue, for example, Topo et al. (2002) and Magnusson and Barbosa da Silva (1999). However difficult, it is necessary to do research with people with dementia in order to accumulate evidence-based knowledge that may lead to improvements in care provision (see also Vass, Minardi, Ward, Aggarval, Garfield, & Cybyk, 2003, p. 23).

The outcome of the project will depend on how the ethical principles of autonomy, beneficence and justice are respected (see, for example, Downs, 1997). However, ethics principles are not absolute. They may have to yield to other principles in concrete situations, depending on the relevant facts or the context of the ethical problem. For example, it may be desirable to maintain a person's autonomy, but the person may not be able to know the implications of using or not using a product, and therefore not be able to give informed consent until the product is tried. The value of the ENABLE research is that it allowed the team to apply ethical principles and to test them out in real life situations. The next section provides a brief overview of the key ethical issues that were addressed by the ENABLE researchers.

Dealing with ethical considerations

How can we make certain that the above-mentioned ethical principles are taken into account in research with people with dementia? The paper by Vass et al. (2003) calls for a clear consensus and an agreed framework to be established in relation to research with people with dementia. The same paper gives a useful starting point for these issues to be brought forward into developing an ethics protocol in all such research.

Based on discussions in the project group, and national legal constraints, both ethical and consent procedures were carried out in all five countries prior to implementing technology into the homes of people with dementia. Therefore, in addition to considering the three ethical principles in each case, it was acknowledged that unfamiliar and newly invented products in themselves might lead to negative reactions and distress. Moreover, compliance with several inclusion criteria was needed as stated

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earlier in order to avoid undesirable effects on the persons with dementia and their carers. These included:

- the users should have a family carer close by;
- the users are diagnosed with mild to moderate dementia;
- the device was chosen after a thorough, individual user needs analysis;
- any sign of stress or unwillingness to participate should always lead to termination of trial and removal of the device;
- each user should have only one device;
- each user could withdraw from the project at any point during the follow up period.

How ethical principles are dealt with also depends on how various factors affect the usability, usefulness and acceptance that the users express in relation to the devices, factors related to:

- the user;
- the carer;
- the environment;
- the product;
- the researcher.

Effects are a result of a combination of these factors. The ethical dilemmas are mostly related to attitudes, actions and responses of the researchers and of the family or professional carers that are involved in the individual situations of the research participants with dementia. Problems with devices also raise ethical dilemmas, as shown in the next section, which discusses the experience of the researchers in the project.

Some experiences from carrying out the research

Table 1 gives a brief summary of comments made by the researchers during the trials. It provides a preliminary view of their experiences.

Discussion of ethical issues in the project

Several ethical dilemmas arose during the assessment studies. Some were anticipated in advance and hence when confronted, were solved before the trials started, whilst others were discussed and addressed during the course of the study through project meetings, teleconferences and in email discussions.

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Table 1 **Summary of researcher comments**

Country	Ethical approval
Ireland	It was complicated adhering to the requirements of a Formal Research Ethics Committee originally set up for medical rather than social science research.
UK	This involved a timely and complex process with four different local ethical committees.
Finland	It was necessary to apply to local social or health authorities if participants were recruited via social or health care services.
Lithuania	Lithuanian Bioethics Committee gave approval because the trial is multicentral and international.
Norway	Approval of research protocol was obtained from Regional Committee for Medical Research, South Norway.
All five	All the countries followed the Helsinki Declaration and received approval from respective authorities.

Country	Informed consent
	The project is for people with mild to moderate dementia, so there were no major problems achieving informed consent. All participants in the trials had given their consent.
Ireland	In Ireland some people with dementia are not told their diagnosis, this raised ethical issues about their involvement, even if they were informed and gave consent.
UK	This was complicated, due to the different procedures for ethical approval.
Finland	Informed consent was achieved separately from the person with dementia and from the family carer. The Alzheimer's associations did the recruitment. Sometimes a family carer tried hard to motivate the user.
Lithuania	The researchers sometimes found it difficult to motivate and get informed consent from elderly persons who were afraid of technology.
Norway	The recruitment was through memory clinics and dementia health service, and both patient and family carer signed consent. Important that those recruited into the study felt under no duress or pressure to participate.

	Needs assessment
	Sometimes the user needs assessment was carried out by the researchers, sometimes by those who referred the patients. It is related to the principle of beneficence, 'who benefits?'
	Sometimes the referrals were not consistent with the inclusion criteria in the project.

	Research questionnaires
Finland	The questionnaires were quite long, and sometimes caused fatigue in patients. More frequent contact and fewer questions would have helped.
Norway	Many questions about opinions of the product and quality of life were difficult to answer. Researchers therefore found it necessary to take stock of non-verbal responses and attempts by the user to terminate the trials.

Table 1 **Continued**

	Use of Quality of Life assessment forms
Finland	At the end of the questionnaires, some participants were too tired to continue answering questions asked.
Norway	Non-verbal responses were considered equally important as verbal responses.

	Technology and its reliability
Ireland	When devices did not work, the researcher was put in an invidious position, having from the commencement of the study highlighted the potential help the devices might offer.
UK	Faulty devices also made subject recruitment more difficult. Frustrations were experienced when products no longer worked.
Finland	Failure of products caused stress for families and resulted in drop-outs. This matter needed to have been discussed earlier in the project.
Lithuania	Researchers often felt responsible for the well-being of the user. Disappointments led to low motivation and inconveniences. This caused problems.

Questions about autonomy

Respecting the decisions, dignity, integrity and preferences of persons with dementia relates to the principle of autonomy. Obtaining informed consent from people with dementia is an essential part of the principle of autonomy. Informed consent needs to be voluntary, competent and inclusive of sufficient information. Kane (1998) reports that informed consent is a complicated issue in dementia care, because of cognitive impairment. It poses problems for everyone doing research into the quality of life of people with dementia. This is especially true in the ENABLE project because the project tries out new and unfamiliar technology in the private surroundings of people with dementia.

Vass et al. (2003) discuss the principle of informed consent and that of somebody acting in the best interest of a person with dementia. Whilst, no doubt, it is challenging to act on behalf of another, the question of who has the authority to decide what constitutes another person's best interests needs to be raised. Indeed, in the same context, one might ask: whose interests are being served?

In the ENABLE project, the main principle of autonomy, that of informed consent, was dealt with by each of the partner countries in accordance with the Helsinki Declaration. The procedures in each country required that the respondents who agreed to participate sign the informed consent form. Nevertheless, ethical dilemmas were still confronted by some. In Ireland, for example, the diagnosis of dementia was not always disclosed to the person participating in the research. This meant that on at least one occasion the researcher was compromised when asked by the

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family caregiver not to mention the word 'dementia' and not to disclose to the cognitively impaired person the fact that she worked for a Dementia Services Centre. Whilst informed consent was always provided, certain areas covered during in-depth interviews with people with dementia and, in particular, in relation to quality of life issues, caused a very small minority of participants in the research some distress. The ethics of continuing an interview when a reaction like this arises needs further consideration. In the ENABLE project, each case was dealt with on an individual basis.

Questions about beneficence

The principle of beneficence is the basis for western medical ethics. However, this principle can be understood and used wrongly by carers and family members, because their opinion of what is best for the person with dementia may differ from the opinion of the person with dementia. There may also be a lack of awareness of whose needs are being met. The result can be paternalism ('father knows best'), a position usually considered undesirable. Therefore, researchers need to be aware of their own values and also those of the carers in order to question the beneficence of implementing the products. In Finland it was felt that in some instances undue pressure may have been exerted on the individual with dementia by the family caregivers to agree to participate in the project, since the product may have been potentially of more benefit to the family caregiver than to the person with dementia.

ENABLE products were in themselves not expected to harm anyone. But the research had the potential to pose challenging situations that may have been perceived by the user or caregiver to be harmful as, for example, when malfunctioning devices proved irritating and generated distress. The researchers tried to avoid such a situation from worsening by quickly removing faulty devices from peoples' homes and ensuring their repair or replacement.

In each of the five countries, ethical dilemmas were experienced by researchers when products failed to work. Some of the products were prototypes, and even though much effort had been put into perfecting their correct functioning, it sometimes happened that they were faulty or unreliable. This caused problems in the recruiting phase and during the trials, because the researchers felt an obligation towards the well-being of the user, and they found that faulty products caused frustration and stress for the users. The researchers had assured families that the research would not bring any harm. The product developers in the project worked very closely with the researchers during the user trials, and took this challenge very seriously indeed. The intervention of the engineers was quick and efficient, and products were removed if considered potentially harmful. But the

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international cooperation and long distances between partners caused some delay in the work. Such problems were not discussed enough in depth at the beginning of the project. In discussing the results of the project, these types of dilemmas need to be discussed in the context of numbers of drop-outs and as factors affecting the outcome of the assessments.

In some cases, the researchers discovered that the family carers wanted the product very much, while the user was not interested. This can of course create a dilemma, because there is a conflict between the user's expressed wishes and those of the proxy decision makers. In the ENABLE project, the family member was combining his/her own interest with the interest of the person with dementia. If the user definitely rejected the product, the trial was terminated. But if the carer seemed happy to use the device and felt it was a support, and the user was not negative to it, the trial would continue, because the principle of beneficence was still being respected. In one case the carer did not find the product beneficial, but because the user wanted to continue using it, the trial was not terminated. However, it is important to remember that deciding what is in the best interest of a person with dementia does not involve simple decisions.

In some cases the researchers believed that care professionals were negative to the use of technology in dementia care. It was felt that these attitudes may have prevented the user from actually getting a device that he or she was interested in. This was the case in some day care centres where a device for entertainment was tried out. The staff and the users were interested, but implementation problems occurred because the Heads of the Department did not think it was in the best interest of the users. Attitudes changed when positive user reactions were found.

Questions about justice

Treating the persons with dementia fairly and respecting their rights relates to the ethical principle of justice. Rauhala Hayes (1997) argues that the principle of justice is about what members of a community are entitled to. Also the principle of justice attempts to answer how burdens and benefits ought to be distributed amongst the members of a given society. The right of persons with dementia to have products that can give them a feeling of enablement and entertainment is basic to the project; these we consider to be a basic human right. But sometimes professionals do not consider it necessary for people with dementia to have such products as assistive technology. One reason for this may be that dementia is not always considered a disability, and, because of this, people with dementia may not have the same legal rights to receive assistive technologies as is common for other categories of disabled, as is the case in many, especially Nordic, countries. Another reason is the attitude that technology is not 'good for them', and

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that it might cause confusion. This assumption is related to how the principles of autonomy and beneficence are dealt with.

'Technophobia', as reflected in the attitudes of some care managers and staff, can actually discriminate against people with dementia, since potential users do not gain access to technology because of the attitudes of care staff. Marshall (2002) points out that if we were all seriously concerned about justice and community care, we would be working hard to ensure that people with dementia have their share of passive alarms in community alarm services.

There are very few products designed for people with dementia and there is a lack of awareness of the need for or the existence of such products and how to include them into care plans (Marshall, 2003). The cost–benefit aspect of the ENABLE study will make a valuable contribution to the literature if the disability model of dementia is used in health-economic analysis. If dementia is considered a disability, then the individual diagnosed is entitled to the same rights to assistive technology as other persons with disabilities, provided that they and their carers can benefit from this.

Preliminary conclusions

In ENABLE and in the context of the principle of autonomy, complications about getting informed consent were mainly related to different procedures used within the five countries for acquiring ethical approvals to conduct the research. There were varying degrees of detailed procedures and formalities, which sometimes caused delays in launching the trials. However, all the countries followed the Helsinki Declaration and acquired informed consent from those users and carers who wanted to participate in the study.

As regards beneficence, at the commencement of the research, the issue of researchers being obligated to closely monitor the trials so that products would be removed in the event of undesired effects emerging, was discussed at length. The experience of the researchers demonstrated that one reason for drop-outs was product prototype errors. Reasons for dropping out of the project are the subject of a separate analysis in the project, and it is expected that this analysis will shed light on several of the ethical confrontations and experienced dilemmas. Discussing the reasons for project drop-outs will give some indication of product usability, usefulness and acceptance, but will also form a basis for understanding the factors that affect research situations like this.

The design engineers' responsibilities for the safe, easy and error-free operation of the devices has been challenged in the ENABLE project. However, and indeed paradoxically, this is why the project ENABLE was first undertaken: to attempt to trial prototype products in order to achieve real

user experience as part of product development. Hence findings about faulty products are useful for future product refinement and development. Naturally, however, since in ENABLE the users were people with dementia, the situation was more complex and difficult.

Our experience shows that having a multi-disciplinary approach to dementia care was a very valuable and positive aspect of the ENABLE project and the inclusion of a broad range of disciplines allowed for cross-fertilization of ideas and new insights. Discussions of ethical issues are not an everyday part of the normal engineering and design work and likewise an understanding of engineering and design problems is not common in social science research and care work. The collaborative nature of the ENABLE project which has involved the participation of occupational therapists, engineers, doctors, sociologists, social workers, engineers and other formal and informal care staff has resulted in a much broader, more holistic understanding of the area being investigated.

Finally, the principle of justice has not been seriously challenged in the project, because all users were presented with the opportunity to try out a device, and if they found the experience positive, to keep it free of charge after the end of the trials. At this stage there is insufficient material available from the trials to draw any substantial conclusions about how the ethical principles are adhered to, but it is possible to see some trends emerging.

Preliminary results suggest that the technologies tested in the project may be useable, useful and acceptable for people with dementia and their carers if their individual needs are carefully assessed first. If this is the conclusion of the project, there are challenges ahead, relating to making technology user-friendly, accessible and available for people with dementia.

As a conclusion we can state that the success of this type of project depends on thorough and in-depth discussions and considerations about the ethical issues that apply. However, further research on these issues is necessary in order to achieve better quality of life for people with dementia.

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