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## Older people, telematics and care

Josephine Tetley, Elizabeth Hanson and Amanda Clarke

### Technological innovation and the caring services

As the number of health and social care professionals working in the care services reduces across Europe and the United States, interest in the use of innovations such as telemedicine and telecare has increased (Shortliffe 1998; Strode, Gustke and Allen 1999; Wootton *et al.* 1998). Whilst the use of technology within society and health care is increasing, the notion of providing support and advice using technology in place of, or even in conjunction with, ‘hands on’ contact remains controversial, with concerns being expressed that that the quality-of-care delivered may be reduced. At the same time, the increased use of personal computers in the home and at work has improved the lay person’s access to health care information which, in turn, has led to concerns that technology may increase people’s expectations to a level that care providers are unable to meet. This chapter therefore explores to what extent new technology can be used to improve the quality of life and everyday experiences of frail older people and their family carers taking into account the following issues:

- the pressures for technological development within care

- the role of patients and clients in the development of new technology
- user acceptance of new technology
- the extent to which technology affects the quality of life
- the role of technology in improving access to services and information
- access to new technology and the cost of equipment

Over the last twenty years health care has seen the rapid adoption of new technologies not only in biomedical applications but also in computerised information systems for care planning and records, routine data-collection, and the transmission of laboratory test results to practitioners. There can be little doubt that scientists and practitioners have driven much of this development. Whilst there may be benefits for patients, the development of expensive technology for diagnoses and treatment, rather than for prevention and management, is arguably not always the best solution for improving the health of individuals or society (Le Fanu 1999). Moreover, there are concerns that new developments such as telemedicine and telecare will also be developed more by professionals to drive forward biomedical boundaries, rather than to inform, educate and support individuals (Shortliffe 1998). The last few years have, however, seen increased calls for new and familiar technology to be used to improve public access to education, information and support, not least to avert hospital admissions and reduce the use of other high cost medical interventions (Department of Health 1998; 1999, Hanson, Tetley and Clarke

1999; Rogers, Flowers and Pencheon 1999; Rogers, Entwistle and Pencheon 1998).

### **The *ACTION* project**

Considering the value and limitations of technology in everyday caring contexts, this chapter draws on examples from a multi-centre European gerontechnology project, 'Assisting carers using telematics interventions to meet older persons' needs', known for short as *ACTION*. This is a 36 month project funded by the European Union programme *Telematics for the Integration of Disabled and Elderly People (TIDE)*, is the largest nurse-led project to have received funding from the European Union, and involves partners from England, Northern Ireland, The Republic of Ireland, Sweden and Portugal. It should be noted that the primary aim of the project was to explore to what extent the autonomy, independence and quality-of-life of frail older and disabled people and their family carers could be maintained or enhanced with the combined use of new and familiar technology (Magnusson *et al.* 1998). The *ACTION* project examined responses to a particular combination of devices: a video-phone, a television and remote control connected to a video conferencing system and a networked computer. The video-phone enabled the carers and frail older people who took part in the project to have face-to-face contact with other family carers and older people and with health and social care workers. The system also provided access to various multi-media programmes that were created by the project partners. The chapter

draws mainly from the authors' own research conducted in Sheffield but where appropriate draws on data generated by our European partners.

A clear preliminary finding from phase one of the *ACTION* project was the need for improved access to information. Family carers said that they often received information from other family carers, but that this was not always up-to-date and that its availability and receipt was uncertain. It was often only 'in an emergency' that carers found out about useful services such as respite care, and that 'some carers [were] unknown to professionals until a crisis occur[ed]'. In response to such vagaries, the British government has recognised the role of telephone help-lines by introducing *NHS Direct* and is promoting the use of the Internet. Moreover, the National Health Service *Information for Health Strategy* argues that a well-informed public, by having increased autonomy and control over their lives and more choice, will make more appropriate and selective use of services and that this will lead to a reduction in the burden of inappropriate calls on the service (Burns 1998, p.81). The strategy further proclaims that:

the latest information technology presents huge opportunities to improve the quality and accessibility of health services to patients. The government is determined that new information strategies should be a vehicle for improving the way NHS services are delivered, making them more responsive to patients'

needs. Improving the quality and range of information available to patients and the public about health and health services will be equally important. (Burns 1998, p.79).

In addition to the use of technology in health and social care, it is increasingly used for everyday tasks such as paying bills, banking transactions and food shopping (Ballabio and Moran 1998; Czaja and Sharit 1998). It can therefore be argued that the use of the new information technologies is becoming essential, and that the non-inclusion of older people, whether at the design stage, in training or product promotions will limit their ability to be fully participative citizens. Cowan and Turner-Smith (1999) stress the importance of consultation and partnership and argue that if health sector technology is to address quality-of-life issues, it must take on board much more than health care applications. The *ACTION* project therefore consulted with carers and older people about their perceived needs for support and services, and it involved them in the development of the *ACTION* system and its multi-media programmes.

### **Development of new technology**

During the first phase of the study, in the five participating European countries focus group discussions were conducted with: family carers (most of whom were aged over 65 years): professional carers from various health and social

care services: and individuals who work with the users of private and voluntary organisation services. The aim of the focus groups was to identify the key issues that affected the carers of frail older people. After the focus groups, questionnaires were distributed to the family carers, and local user groups were established to continue the consultation process as well as to research and develop the technological applications. Throughout the project, carers and older people were consulted. The family carers, older people and user representatives were recruited in Sheffield through the *Alzheimer's Disease Society*, the local carers' centre, two sitting services for family carers, an NHS hospital trust, a family doctors' practice and social service providers. We endeavoured to recruit recently engaged and long established carers, and carers from minority ethnic communities. The professional carers included nurses, doctors, physiotherapists, social workers and welfare rights officers. We acknowledge that in this initial stage we did not identify 'hidden' carers unknown to service providers.

During the development and evaluation of the technology and multi-media programmes, the consultation process followed a user-centred iterative approach which requires the designers of technology to recognise that:

- product specification is not an abstract exercise and that many requirements emerge out of the direct experience of using prototypes,

- in many cases developers may have to enter iterative cycles of development and evaluation before a satisfactory solution is achieved,
- it is important to obtain good feedback about product performance in actual use (Poulson, Ashby and Richardson 1996).

The aspiration of this user-centred approach was for enhanced access to education, information and support in a format that could be easily used by family carers and older people in diverse community and institutional settings (Berthold 1997, Clarke *et al.* 1999, Tetley and Bradshaw 1998). To test this premise, the *ACTION* system was installed in several locations in Sheffield. Site 1 was a social services neighbourhood centre that provides day-care and support for carers and older people. Site 2 was a hospital-based unit for older people, most being physically and cognitively frail and waiting transfer to a continuing care placement such as a nursing or residential home. The third site was a medical centre. At all three the intention was that family carers and older people and family carers could 'drop-in'. In addition, three family carers who were registered at the medical centre agreed to have the *ACTION* system in their home. Using high-speed telephone lines it was possible for family and professional carers to link to any of the sites through the video-phone.

### **User acceptance of new technology in care**

At the start of the project, we were aware of a widespread presumption that older people would not use a system of the kind proposed simply because it



was new technology. Our early findings did indeed show that family carers across Europe were worried about the use of modern technology, and that many had no previous experience of using a personal computer (Tetley *et al.* 1997). On the other hand, most carers were familiar with other electronic innovations such as compact-disk players and microwaves and most had used television remote controls. To enable older people and carers with limited experience of the new information technologies to have the confidence to learn the required new skills, using the television (the most familiar technology) as the information interface was seen as the best way of easing the transition between established and new technology. During the development of the *ACTION* system, usability was tested at the university by carers and older people (Clarke *et al.* 1999). Feedback from the user trials indicated that there were ways in which the system and the information content could be improved. Some users felt that the remote control handset was too small; while others wanted more information about the financial benefits or costs of services. Some also felt that a few of the terms needed to be simplified or explained, e.g. palliative care and reminiscence therapy. Although the usability trials indicated areas for improvement, we were encouraged to find that that our informants could easily use the equipment and operate the programmes.

At one stage four family carers, aged from 45 to 85 years, took part in conference video-phone links with project partners in Barcelona. Their

successful participation supports the argument of Thurze, Nusberg and Prather (1995) that older people have witnessed and adapted to many new technologies throughout their lifetimes, and therefore no intrinsic incompatibility exists between advanced age and learning to use new devices. It must, however, be recognised that the *ACTION* project was not open-endedly exploring the use of technology by carers and older people but specifically its *application to care*. It could not be assumed that a generally positive attitude to technology would prevail in the caring situation. Indeed, during the first phase of testing, one carer requested that the equipment be removed from her home as it provided a constant reminder of the intimate caring tasks that she performed. She found the system an eyesore and its presence in her home distasteful (Hanson and Clarke In press). By contrast, another informant carer invited the neighbours in to admire the system, suggesting a positive attitude and possibly even pride as a pioneer innovator – analogous to being the first person in a neighbourhood to possess a car or a television set.

*The Royal Commission on Funding Long Term Care* recognised that, ‘users (and their carers) will most readily use technology that is desirable because it enhances their social status as well as enabling them to do things or making them feel better’ (Cowan and Turner Smith 1999, p. 335). In sum there are diverse influences upon and reactions to new technology. Whilst our primary research interest was in the response of older people and family carers,

we were aware of the need to explore the attitudes and experiences of professional care workers in using new technology and that, because professional carers act as 'gatekeepers' to services and resources, it is important to recognise that they must have a positive attitude to technology if they are to encourage older people to adopt the innovation (Barnes 1997; Barron 1996; Rogers and Elliot 1997).

As the project developed and the prototype multi-media programmes were tested there was considerable positive feedback. Some 347 professional carers from the five participating European countries completed usability questionnaires and filled in log-diaries. These enabled users to write down what they had found helpful or unhelpful about the programmes, the remote control and the video-phone. The professional carers generally felt that the videos were beneficial. One said, 'I think that having the videos and photos is excellent. They would be good for patients to watch when choosing nursing homes.' Another said that she liked the videos and felt that they were suitable for people who could not read well. The *ACTION* system comprises eight multi-media programmes and a video-phone. The professional carers suggested that a different coloured background for each of the programmes would make it easier for users to navigate through the system. Nevertheless, negative attitudes persisted and in the later phase of the study, some professional carers in Sheffield were still concerned that older people would not use the system because it was computer-operated. One commented that,

‘Older people ... tend to say, “Oh no! I’m not going to use it. I know you’ve simplified it, but it’s still difficult for us that haven’t used a computer before to take it on board”’.

This was not, however, borne out by our tests of the system. In the first phase of field-testing at the five centres, 217 evaluations were completed by family carers and older people. The ages of the older people using the system ranged from 56 to 101 years, while the carers and relatives were aged 19 to 88 years. The majority of the participants reported that using the system was easy. The two oldest users, aged 91 and 101 years, reported that using the system was difficult. Both were visually impaired and one had difficulty with fine motor skills. Although from a relatively small number of informants, these findings indicate that the prototype system could be developed to enhance its usability for frail older people. We are now looking for remote controls with larger buttons and are making ‘voice-overs’ of the text on each page.

The field-testing produced other evidence of the value of the system to the end users. In the hospital setting, neighbourhood centre and the medical centre the use of the system was casual. Older people involved in this way said that the programmes were ‘good for providing information’ – they found the information about the shopping service particularly useful. One family carer described the system as being ‘very user friendly.’ He said that it

‘certainly, save[d] time rather than endless visits and phone calls to agencies.

The actual in-depth information about the homes [was] very useful’.

**Technology, individual needs and quality of life: a case study.**

It is important to recognise that a good quality-of-life encompasses many things and not solely aspects of health. Thus any initiative that aims to address the quality-of-life should consider ways of exploring and meeting needs holistically (Cowan and Turner Smith 1999). The potential value of the *ACTION* system for enhancing the quality-of-life can be illustrated by the case of John and Olive, who had the system in their home for several months.

John, an older man with several physical health problems cared for his wife Olive who had dementia. He had thought about the possibility of arranging respite care for his wife before looking at the programmes on the system. John had tried to encourage Olive to view a video entitled *A Short Break in a Nursing Home*. Unfortunately Olive become angry and said, ‘I’m not going into one of those’. John reported in his log-diary that he had again encouraged his wife to look at the respite care videos. John was surprised to find that it then captured her interest and that afterwards she said that she would like to go into a nursing or residential home for respite. They then used the programme to find a nursing home that they both liked and was near to their home (Hanson and Clarke In press).

Pescosolido and Boyer (1996) make the point that use of a service is never a single ‘yes/no’ decision, rather one based on patterns and pathways. In

this instance the *ACTION* system enabled John and Olive to access the information on more than one occasion. They were able to re-consider the merits of a service as their caring situation changed. The flexible timing of the decision to access respite care was of particular advantage to John, Olive and their family because during the field testing John had to go into hospital for a minor operation. Olive used the respite care service whilst he was away. Her family doctor later told the research team that he had spoken to Olive and that she had thoroughly enjoyed her stay. This prevented a crisis in care for all concerned. The video-phone was also helpful to John and Olive. John used the video-phone to consult a welfare rights officer who was able to assess the home situation and answer John's questions regarding council tax benefit. When subsequently John had his rent book to hand, he was able to supply the officer with the information he sought. The welfare rights officer was also able to observe John and Olive helping one another, so confirming their mutual caring situation. Following the video-phone consultation, a home visit was arranged to process the paper work. The result was that the couple were £62 per week better off. The welfare rights officer was surprised to find that John and Olive were under-claiming to such an extent (and added that the circumstances were untypical of most welfare rights assessments).

Several aspects of this caring situation case suggest, however, that John and Olive represent many similar couples. Their case illustrates the strengths of technological innovations in supporting older carers and care recipients.

While many fear that technology will replace face-to-face contacts, in this case the welfare rights officer stated that the video-conference was more appropriate than a telephone consultation or an appointment at the welfare rights office because it enabled a better assessment of John and Olive's situation. For John, who was unable to leave Olive alone in the house, it was the only way in which he could access this information. Other factors may have contributed to John not having sought welfare rights advice earlier: their family doctor had previously advised the couple on welfare rights and thought that they were claiming the full range of benefits to which they were entitled. Parallels can be drawn with the work of Rogers, Hassell and Nicholass (1999), who found that primary health care staff often act as gatekeepers to secondary services. The assessing officer further acknowledged that John and Olive had 'fallen through the net', as they were unknown to social services. If John and Olive had ever sought help, part of the assessment would have included a welfare rights assessment.

The case study of John and Olive demonstrates how technology can contribute to the empowerment of older people as well as improve their quality of life. With the back-payment of the previously unclaimed benefits, they were able to go on holiday. We recognise that quality-of-life is a broad concept and that *ACTION* has largely focused on the health domains. Feedback from carers to date reveals that in order to enhance other aspect of the quality-of-life, we need to develop the system by including information

and guidance on housing, leisure, culture and transport, services and opportunities.

### **Information, technology and empowerment**

Reforms in the provision of community care services during the 1990s emphasised providing people with services that meet their individual needs (Barnes 1997, Tinker 1997). It has been argued, however, that many carers and older people are actually disempowered in the assessment process for they have little knowledge of the full range of available services, of the financial contribution they may have to make, or of the ways in which they can influence the services they receive (Department of Health 1998; Tinker 1997). Moreover, improving access to local services is not straightforward. During the development of the *ACTION* system, concerns were expressed by formal care providers that increased knowledge can cause difficulties as the demands for services and people's expectations may be raised to levels that they are unable to meet.

Barnes (1997) observes that those undertaking community care assessments are often caught between calls for the provision of needs-led services and their responsibilities 'as a gatekeeper to public resources'. Rogers and Elliot (1997) also suggest that many primary care professionals are concerned about growing work-loads and patients' rising expectations, and tend to see 'demand' and 'need' as dissociated. Whilst we are sensitive to



concerns voiced during the consultation process (particularly about raising expectations and user acceptance of new technology), we also recognise that a failure to improve access to information and services for carers and older people inhibits their abilities to judge for which services are most appropriate for their situation. This view is supported by Rogers *et al.* (1998) who argue that information has an important role in helping people consider how best to help themselves. Rogers and Elliot (1997) further propound the idea that the provision of information is essential if patients are to become both active participants in their care and able to make informed decisions.

The *ACTION* system has offered information about services using video, text and photographs with the intention of supplying a full picture of what is available. This does not necessarily lead to increased demand, but rather the aim is to provide a tool for carers and older people to think more clearly about their needs and how best to meet them. Thus, *ACTION* can begin to help people have more say about what they do and do not want in their caring situation. It is emphasised that the *ACTION* system provides information about the services offered by many statutory, voluntary and independent health and social care providers. The value of an integrated information system has been emphasised by Rogers, Flowers and Pencheon (1999), who found that it enables people to help themselves and manage their progress through health and social care systems without putting overwhelming strains on those services. For example, most carers and older people in the

hospital used the system to help them manage the transition between home, hospital and the entry into long-term care facilities such as nursing homes.

The programmes enhanced the hospital's discharge procedures by providing patients and their carers with photographs, videos and maps, as well as written descriptions of nursing homes. One family carer found a home on the programme that he thought would meet his aunt's needs and decided to make a visit. He had felt helpless since he did not know where to start, and said that the system helped him. A second family carer said that the system was 'useful', as she was able to look at all the potentially appropriate nursing homes for her mother. The carer was pleased that they had been able to choose homes in the area where her mother had lived for most of her life, and that she had been able to get information from the *ACTION* system at the right time. Professional carers also appreciated the value of 'having all the information together in one system'.

### **Access to equipment and meeting the cost of new technology**

The principal barrier to the use of new technology within health and social care is cost. As shown by the *ACTION* demonstration project, the main costs are:

- Equipment - computers, video phone, security locks and, for some clients, a new television that can connect to a computer.
- Installation, line rental and use of fast telephone lines.

- Making and reproduction of videos.
- Programming and updating the programmes.

It is difficult for local health and social care providers to invest in new technologies when there are already cost pressures in maintaining existing levels of service provision. The situation is compounded in community care resource allocation by the tension between support for carers and support for the clients in greatest need (Warren 1999). The cost of new technology is reducing all the time and there is the possibility that an information system such as *ACTION* could be offered through the use of digital television, making it more accessible to a greater number. As Evandrou (1998; p. 282) has argued, we must be concerned that the *connected* and the *not connected* will be the 'haves' and 'have nots' of the future. This danger is clearly reiterated in the *NHS Information for Health Strategy* where it is recognised that, 'The opportunities of the information age must be open to all', and that, 'strategies for providing public information on health and health services take account of the "information poor" in society' (Burns 1998 p. 82).

### **Conclusion**

Given that 60 per cent of carers do not receive care or services from mainstream health and social care services (Department of Health 1999), it is important that a system such as *ACTION* should be available without going through professional care agencies. However, carers who used the system in

their own home, and those who accessed the system easily or regularly, appeared more likely to benefit than those who accessed the system once only. If we are to progress beyond crisis-orientated care, it is therefore important that carers and older people are enabled to access education and information before or when they need support (Nolan, Grant and Keady 1996; Rogers, Flowers and Pencheon 1999; Burns 1998). We need to recognise both that the Internet and local digital television services will provide a radically improved guide to services that may prove unusually socially inclusive, and that there is an important continuing role for professional staff (Burns, 1998). As both our study and the literature shows, when others are positive it is more likely that older people will take up new technology, which underlines the importance in product development of user consultation, (Cowan and Turner-Smith 1999) stipulated that, for technology to be used by older and disabled people, they must be able to influence its design to ensure that it meets what they want and not what others assume they need.

This chapter has described the positive ways in which technology has enhanced the quality-of-life for some of the carers and older people with whom we worked, but also made clear that for some carers, new technology does not provide the answers to their care problems. We do not therefore advocate new technology as a panacea for all the problems facing carers and older people, but rather see electronic information systems as potentially useful in helping carers and older people make more informed decisions

(Cullen and Moran 1992). We have found that carers (family and professional) and older people have been cautious about using new technology but that, once they used the system, their confidence increased. These early findings from the *ACTION* project corroborate the view that older people, because of their lifelong experiences of change, are more willing to utilise new technology than is widely thought (Cullen and Moran 1992). The findings help to dispel the myth that older people and new technologies are incompatible.

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