

The impact of information and communication technology on family carers of older people and professionals in Sweden

LENNART MAGNUSSON*, ELIZABETH HANSON*
and MIKE NOLAN†

ABSTRACT

Government policy in Sweden, as in other developed countries, pays increasing attention as to how best to support the family carers of older people. New and innovative means of support, such as information and communication technology, are emerging. This paper explores the perceived benefits of, and barriers to, information technology as a means of supporting family carers of older people. Following a brief overview of the care-giving literature, with particular reference to the Swedish context, interview and questionnaire data collected from 34 families who took part in the Swedish *ACTION* project are used to explore the role of user-friendly information and communication technology to inform and enable family carers of older people to exercise choice, to care more effectively and to work in partnership with professionals. Interview data from two groups of professionals that utilised *ACTION* are also examined to throw light on its potential benefits for both carers and professionals. Consideration is given to the barriers to using information technology, and to identifying those carers most likely to benefit. Areas for further development are the need for practitioners' education and a wider range of programmes to address carers' diverse needs. Clearly, lessons learned from the Swedish project have wider relevance, given that new forms of support are being developed in most technically advanced countries.

KEY WORDS – family carers, practitioners, partnership, information and communication technology, community care.

Introduction

Sweden has one of the oldest populations in Europe but the existence of a strong welfare system has meant that until recently there has been little expectation that the family will provide support for frail older people

* Department of Health Sciences and ÄldreVäst Sjuhärads Research Centre, University College of Borås, Sweden.

† School of Nursing and Midwifery, University of Sheffield, UK.

(Johansson *et al.* 2003). This stands in marked contrast to many other countries, particularly the UK and in north America, where reliance on family carers has underpinned policy for some time (Pearlin *et al.* 2001; Moriarty and Webb 2000). However, the economic recession of the 1990s in Sweden, coupled with increasing longevity, has led to a 'rediscovery' of the family as a principal provider of support, and to a complementary reduction in state provision (Board of Health and Welfare Sweden (BHWS) 2004*a*; Johansson 2001). Not surprisingly, therefore, the ways in which formal services can best support family caregivers has received increasing government attention in Sweden, with developing support systems for carers being integral to the national plan for the care of older people (BHWS 2002*a*). Between 1999 and 2001, under the *Family Carer 300 Initiative*, the Swedish government allocated 300 million crowns (£23.5 million) for distribution amongst the municipalities that provide services such as respite care for family carers (BHWS 2002*b*).

A recent evaluation of this initiative concluded that family carers had gained formal recognition of their need for support but acknowledged that much needed to be done to improve the overall range and quality of available services (BHWS 2003). Some carers rejected the help offered because the service was seen to be of insufficient quality, too expensive or was not geared to their routines and preferences. This highlights the need for routine monitoring of the effectiveness of family care support services (BHWS 2004*b*), and raises important questions about the rationale for supporting family carers.

Why support family carers?

The relationships between family carers and service systems and professionals is complex and sometimes conflicting, with carers perceived as occupying several potential roles including co-worker and co-client (Twigg and Atkin 1994). The main reason for helping carers is however instrumental and reflects the still prevalent view of carers as a resource. Most interventions designed to support carers are based on a stress-coping model (Schulz and Williamson 1997; Schofield, Bloch and Herman 1998; Montgomery and Williams 2001). As a result, reducing carer burden remains a key influence in gerontological policy and practice (Clyburn *et al.* 2000; Pearlin *et al.* 2001). There is now, however, growing acceptance that support for family carers should also improve the quality of life of both the carer and the cared-for person (Qureshi *et al.* 2000), by helping both to gain satisfaction and enrichment from their lives (Cartwright *et al.* 1994;

Nolan, Grant and Keady 1996; Qureshi *et al.* 2000). Furthermore, Bernard and Phillips's (2000) concepts of empowerment and partnership are increasingly applied to work with older people and carers, with both groups being viewed as 'experts' who possess important knowledge to which formal carers should pay greater attention (Nolan *et al.* 2003; Post 2001). This requires different ways of working with family carers and challenges the customary view of the professional as the 'expert' (Qureshi *et al.* 2000).

A wider definition of 'carer support' is emerging, namely any intervention that assists a carer decide whether or not to take up, or to continue or give up the care-giving role (Askham 1998). A refinement recognises that interventions should reflect the particular stage in the caring career (Aneshensel *et al.* 1995; Qualls 2000; Zarit and Leitsch 2001), to help carers 'do caring well', and to be better prepared and equipped for their role (Archbold *et al.* 1995; Schumacher *et al.* 1998). In addition, assisting carers who do not want to care to say 'no', or enabling carers to give up care if they wish to do so are legitimate aims (Nolan 1998). Such an orientation raises difficult questions, such as who legitimately defines the outcomes of interventions and determines whether or not support has been successful (Schulz 2001).

How to measure the 'success' of carer support

Methodologically, the 'success' or otherwise of interventions has been largely determined using experimental or quasi-experimental models which rely on quantifiable measures of outcome, such as a reduction in burden, stress or general psychological morbidity, and an improved quality of life. Most such studies have failed to demonstrate the effectiveness of current interventions (Cooke *et al.* 2001). Consequently there have been calls for clearer conceptual links between the support provided and the measures used to 'indicate' its success (Zarit, Gaugler and Jarrott 1999), with outcomes being meaningful to family carers (Thompson and Briggs 2000; Beck 2001; Magnusson *et al.* 2001), and reflecting what is reasonable and modifiable within a given care-giving context (Zarit and Leitsch 2001).

Schulz (2001) argued that there was also a need to address several important questions including *who* is the primary beneficiary of the intervention (care-giver or older person), *what* is the target or goal (*e.g.* care-giver skills or knowledge), *how* is the intervention to be delivered (*e.g.* individually or in groups, face-to-face or distant), and *when* is it most effectively delivered (at what stage of the caring career)? Such questions

need to be considered when developing new approaches to carer support, such as the use of information technology.

New approaches to supporting family carers: the potential of technology

New and innovative approaches to supporting carers of older people, such as technology, are now emerging (Sorensen 1997). Indeed, the UK *Audit Commission* (2004) recently argued that 'new assistive technology can play a vital role in supporting the ways in which millions of older or disabled people can maintain or regain their independence ... it can support the aspirations of many older people by providing them with greater choice' (2004; 3). The report acknowledged the specific role of information and communication technology (ICT): 'ICT comes under the umbrella of assistive technologies that can help older or disabled people to live independently and safely at home' (2004; 10). Likewise, in Sweden, the *National Board of Health and Welfare* has recognised the potential for modern technology to make life easier for family carers of older people (BHWS 2004*b*).

Technological initiatives, however, are often developed primarily for economic reasons rather than to promote the social inclusion of older people and their family carers, particularly in the USA, where various tele-health and telecare services that support 'ageing in place' have emerged (Magnusson, Hanson and Borg 2004). Tele-health focuses specifically on home monitoring, *viz.* procedures that make it possible for a clinical process to be conducted remotely. By contrast, the more diverse telecare services include virtual visiting, reminder systems, home security and social alarm systems, all of which have the overall aim of avoiding hospitalisation or an admission to long-term care (Audit Commission 2004).

Several *European Union* funded research and development projects have explored the potential of 'smart home' technology products and services to increase the everyday independence of people with dementia (Woolham and Frisby 2002; Marshall 2000; Engedal 2004). Numerous studies, mainly from the United States, have focused on virtual home visits and remote monitoring for older people with advanced chronic illness who live at home (Arnaert and Delesie 2001; Bowles and Dansky 2002; Cherry, Colliflower and Tsiperfal 2000; Chetney 2003). Overall, elder participants and their carers respond positively to such initiatives. In contrast, participating nurses express concerns that technology may replace direct human contact and obviate the need for professional staff

(Whitten *et al.* 2003). Such attitudes may change as professionals become more accustomed to using technology in the workplace (Danskey and Bowles 2002).

Regarding family-carer support with ICT, the majority of studies to date have been of US telephone-based models (Magnusson, Hanson and Borg 2004). The interventions are usually managed by professional carers who provide counselling and support, mainly to dementia or stroke family care-givers, to reduce their stress and to promote optimal coping. Of particular interest is the PREP model of nursing interventions that aims to increase the knowledge and skills of family carers by raising their Preparedness (PR) for, Enrichment (E) from, and the Predictability (P) of their personal caring situation. This is achieved by providing individualised advice and support, initially through home visits, and subsequently by telephone (Archbold *et al.* 1995).

There are proliferating Internet-based information and support systems for family care-givers (Pierce, Steiner and Govoni 2002; White and Dorman 2000), many targeted at dementia care-givers, such as the 'Computer Link' program (Flatley Brennan *et al.* 1995). Participating carers are able to discuss issues with each other using a public bulletin-board, have ready access to an electronic encyclopaedia of information, and receive individual advice and support through private emails from a nurse facilitator. The benefits include access to informal advice and support from fellow carers, increased self-confidence in decision-making, and in some cases reduced care-giver strain (Bass *et al.* 1998). User-friendly websites for family carers have proliferated, United States examples being the National Institute on Ageing's *Computers for Caregiving* project (Irvine 2003), the National Institute for Health *Senior Health* website project (www.nihseniorhealth.gov), and the *Alzheimer's Caregiver Support Network* (Loomis 2003). In the UK, the Alzheimer's Society's *Learning to Live with Dementia* project has created a user-friendly website with the active involvement of people with early dementia and their family carers (see www.alzheimers.org.uk).

Despite such developments and whilst being optimistic about the potential benefits of ICT, the UK Audit Commission cited evidence that few carers actually made use of websites, and concluded that enhancing awareness and accessibility remained a critical issue (Audit Commission 2004). The Board of Health and Welfare in Sweden (2004 *b*) also recognises the potential role of ICT in supporting family carers, but stresses the need for a greater focus on their views when developing IT products and services. Against this backdrop, this paper will consider the effectiveness of the Swedish *ACTION* scheme that actively worked with family carers of older people in two municipalities in the west of Sweden; it developed

an ICT-based service that provided them with information and support in their caring role.

The ACTION concept: a brief overview

The concept arose from an EU-funded *ACTION* project, *Assisting Family Carers Using Telematics Interventions to meet Older Persons' Needs*. Its aim was to enhance the independence, autonomy and quality of life of frail older people and their family carers by providing information, education and support through ICT.¹ *ACTION* was developed and evaluated in close cooperation with family carers in the partner countries of England, Northern Ireland, the Republic of Ireland, Portugal and Sweden (Magnusson *et al.* 1999). Following the EU project, additional funding was secured from the Swedish Ministry of Social Affairs to develop and evaluate the concept in two municipalities in the west of Sweden.

The *ACTION* concept builds upon Nolan, Grant and Keady's (1996) temporal model of family caring and stresses the importance of providing appropriate support at key transitions in the caring trajectory, whilst recognising family carers as 'experts' about their particular caring situation. In the Swedish study, *ACTION* incorporated elements of the PREP model of interventions to enhance carers' level of preparedness, to enrich their care-giving relations, and to help carers the better to predict future demands (Magnusson, Hanson and Nolan 2002).

The initial *ACTION* services were several multi-media caring programmes that participating families could access using a television remote-control. The TV set was connected to a personal computer that stored the information programmes. Families also had access to videophone facilities through the television, which enabled them to have direct verbal and visual contact with professional carers and other families involved in the project. This was achieved by placing a small camera on top of the TV set, with video-conferencing hardware in the computer, and installing ISDN2b lines² to the families' homes. Internet access was also available for interested professionals and families. In Sweden, several families preferred to use a personal computer rather than their television to connect to the Internet (Magnusson *et al.* 1999).

Family carers worked in local groups across the partner countries to develop the scope, content and layout of the multi-media educational programmes (Tetley and Hanson 2000), with a focus on practical care-giving skills, available social security benefits and services, and ways of coping. The programmes were thoroughly reviewed by the families and quality was assured by several professionals (Hanson, Tetley and Clarke

1999). Finally, the *ACTION* services were field-tested in the homes of frail older people and their family carers in all the partner countries (Magnusson, Hanson and Nolan 2002). In the Swedish project, to enable the *ACTION* families to access more readily professional advice and support, a call-centre was established in each participating municipality. One was run by two experienced assistant nurses and the other by a district nurse. Additional multi-media programmes covering stroke, dementia, pressure-sores and end-of-life care were also developed and tested with several carers (Magnusson 2002).

Evaluating the Swedish *ACTION* project: methods and procedure

A multi-method pluralistic evaluation model was used, which captured the views of all key stakeholder groups (Bond 2000). This paper focuses on the carer questionnaire and the data from the carer and professional interviews. A modified version of the PREP evaluation questionnaire was used with family carers. It comprises 40 statements that explore the PREP domains of preparedness for, predictability of, and rewards and satisfaction with caring. Family carers evaluated each item on a five-point Likert scale: not at all ('1'), a little ('2'), some ('3'), quite a bit ('4') and a great deal ('5'). Finally, a global item asked about the utility of the intervention as a whole, using an 11-point Likert scale, from 'not at all useful' ('0') to 'extremely useful' ('10').

The families were interviewed after the field tests about their experience and evaluation of the *ACTION* services. Similar interviews were conducted with the call-centre staff on the benefits of the project for the participating families and its impact on their ways of working. Three focus group interviews were also carried out with staff from the participating care settings about their experiences of using *ACTION* with older people, family carers and other care staff. With the participants' permission, interviews were tape-recorded and transcribed *verbatim*. The interview data were content analysed to identify the key themes, wherever possible using the participants' own words to ensure that their experiences and views were given priority (as recommended by Bernard and Meade 1993). Glaser and Strauss's (1967) constant comparative technique was used to identify the diverse positive and negative experiences of *ACTION* among both family and professional carers.

Research settings

The participating families were recruited from two municipalities in the west of Sweden, one a district with 10,500 inhabitants in an urban area

TABLE I. *Characteristics of the samples*

Family carers	Cared-for persons
Age: Average: 70 years Range: 47–88 years	Age: Average: 77 years Range: 60–100 years
Gender: 21 females and 13 males	Gender: 16 females and 18 males
Relationship to cared-for persons: 27 spouses, 4 daughters, 2 sons and 1 daughter-in-law	Diagnoses: 16 stroke, 5 dementia, 5 diabetes, with urinary problems, lung diseases, Parkinson's disease, rheumatism, fibromyalgia, multiple sclerosis, cerebral palsy, cancer and physical frailty
Living arrangements: 28 living together, 6 living apart	Statutory services: 9 had home-help (from once a week to twice a day), 3 had day-care once a week, 1 in sheltered accommodation, 2 had a week of respite care at least once a year.
Time as carer: Average: 6 years Range: 0.5–22 years	
Number of subjects: 34	Number of subjects: 34

of 100,000 inhabitants, and the other a mixed urban/rural area of 33,000 inhabitants. In both settings, 13 per cent of the inhabitants were aged 65 to 79 years, and six per cent were aged 80 or more years. The community care settings included long-term care homes, day centres and senior centres. The *ACTION* call-centre in each municipality was located in a central office that was regularly accessed by other members of the care team. The recruitment selected family members who were caring at home for a frail relative aged at least 60 years. People with acute psychiatric illness were excluded, as were carers deemed to be experiencing significant stress, since it was considered that participation in the project might add to their strain. A recruitment protocol was followed by staff in the municipalities to ensure that ethical considerations were upheld.³

Results

A total of 34 caring dyads tested the *ACTION* system and services in their homes for from approximately three months to a maximum of one year (see Table 1 for a profile of the participants). The following section presents their perceptions of the *ACTION* system, as well as those of the professionals involved in delivering various components of the service. It begins with a summary description of the quantitative data from the family carers.⁴ Given the low number of carers involved, no statistical

tests produced significant differences, and caution must be exercised in interpreting the results. Subsequently, illustrative quotes are presented from the post-intervention interviews with the participating families to explore the variations in their experience and the influential factors. Finally, data from both the interviews and focus groups with participating staff are presented to illustrate their experiences of working with the scheme.

The views of family carers

According to the PREP data, the overall usefulness of the *ACTION* service was rated as 6.4 on the one-item global scale (from '0' to '10'), and the mean PREP individual item score was 3.1 (on a scale from '1' to '5'). For the majority of participating families, therefore, *ACTION* had a moderately positive effect on the preparedness, rewards and satisfaction of caring. There was, however, considerable variability, and three groups of carers were discerned which, whilst not demonstrating statistically significant differences, nevertheless corroborated the interview data.

The seven carers in the 'It was definitely helpful' group scored '4' or more across virtually all of the questionnaire items on preparedness, satisfaction, reward and predictability domains, indicating a high positive impact. In marked contrast, the four carers in the 'It was definitely not helpful' group scored less than '2' on the majority of the preparedness, reward and predictability items, suggesting that the intervention had little or no impact. The most frequent summary assessment, given by 22 of the 34 carers, was that 'It was quite helpful': this group scored '3' or more on the preparedness and satisfaction items and '2.5' or more on the reward and predictability items. Evidently their rating was that *ACTION* had a moderately positive impact.

The data revealed no significant differences by age, gender, relationship between the family carer and the cared-for person, living arrangement or duration of being a carer. Nonetheless, the interview data clearly indicated that other factors, such as a carer's willingness and desire to care for their relative at home, strongly influenced whether they benefited from *ACTION*. Other potentially important factors were whether or not carers considered that the technology and services increased their caring competence, and reduced their feelings of loneliness and social isolation.

A closer inspection of the PREP responses of the 'It was definitely helpful' group indicated that they felt better prepared to care for their relative, were able to keep going, and understood more about their relative's needs and about how to care more safely. *ACTION* also enabled

them to obtain appropriate information and support from statutory services and to discuss issues more openly. In addition, it boosted their confidence to continue caring for their relative and, more particularly, raised their ability to handle specific care-giving problems. Overall, *ACTION* helped this group to improve the predictability of their care-giving situation, and to enhance their perceived effectiveness. The interview data support the conclusion that the participants in this group experienced a rise in their perceived ability to care, both for their relative and for themselves. The effect is illustrated by the following quote from a recently retired woman who cared for her mother who was approaching 100 years of age:

I can recall when my mum became ill as a result of a stroke. When she came home and needed to be cared for ... I didn't know anything about turning a person in bed or how to help mum get up or with other practical things. I got very useful help from the *ACTION* programmes. I read a lot and it gave me a greater insight into how she was thinking, feeling and experiencing things. I also got very good advice about how to look after myself.

ACTION also had unanticipated benefits, and it was clear that active involvement in the development of the multi-media programmes helped some carers to validate and reinforce the importance of their role:

Many interesting discussions took place when we were part of the discussions about the different programmes' structure and content. I felt that I was seen and listened to and that I could share my views with others in the group. When the programme started to come together, with help from the *ACTION* team, you immediately saw the value and substance in each programme which you could directly use in your daily caring.

Other unanticipated benefits for carers included an increase in self-confidence from having mastered the computer. This sometimes stimulated a desire to learn more:

I looked forward to the group lessons. When I felt I could manage the programmes well, I wanted to go further on and know more. I enrolled on a computer course at KOMVUX (a local adult education centre). So, *ACTION* not only benefited the relative you were caring for. An extra bonus was that I studied further in an area I hadn't at all considered learning more about in old age.

The PREP responses indicate that the majority (22) of the participants, those in the 'It was quite helpful' group, perceived the main benefits to be enhancing their preparedness for caring and increasing its satisfactions. They particularly valued the help that they received in finding out about services, in understanding more about their relative, and in getting useful ideas that enabled them to carry on caring. *ACTION* also made them feel more comfortable in the things they were doing to help their relative,

and boosted their confidence about their caring situation. The interview data confirmed that the majority of carers wanted to care for their partner at home, but most participants in the 'It was quite helpful' group had a small social network from which to draw support, and most had little prior knowledge of caring. Therefore one distinct benefit of *ACTION* was the access it provided to a wider social network. One woman who was looking after her severely disabled husband expressed this well: 'It's helped to break my isolation. I felt very lonely and very inadequate a lot of the time. It helped when I got *ACTION* and could get in touch with others in a similar situation. I've got many new contacts that I get on well with. I've got several that I have regular videophone contact with'. Having the scheme at an early stage also helped carers throughout the entire caring process, as in maintaining contact with a relative after their placement in a nursing home:

It's great that I got *ACTION* in the beginning just when I started caring for my husband. There were some very good tips about what to do (in the programmes). Contact with other carers in the same situation was priceless. Using the videophone for the second care-planning meeting with all the professionals was also very good. Later on when I was ill at home and my husband was in the nursing home ... to see each other, using the videophone was fantastic.

The participants in the 'It was definitely not helpful' group, in contrast, identified little or no positive impact from *ACTION*. Although the project seemed to help them to see caring in a more positive light, it had little or no impact on their levels of preparedness or predictability. The interview data revealed that several participants had been caring for a partner with high needs for a long time and were unsure how much longer they could continue. Several stressed the difficult nature of their situation and hinted at problems in their caring relationship. One carer explained that the demands she faced made it difficult to have the time to use *ACTION* appropriately:

When I'd been sitting there for five minutes he said something, and I replied, 'You have to wait'. Then he was shouting at the top of his voice, 'I'm not going to wait'. So to sit down at the computer, you can forget it. It's impossible ... I have absolutely no use for it (*ACTION*). Not when I can't sit there. And he never did it. He didn't try to learn, even if he went to all the meetings. ... If anything happens, then I know to call his physician. I've kept on for so long with this with my husband.

One couple did not complete the PREP instrument as they considered the items were irrelevant, and they explained during the interview that they found *ACTION* redundant because they enjoyed an extensive support network, which included professional carers that they knew personally.

Moreover, they already had access to the Internet through their personal computer and were skilled in searching for health information. There were early problems with the technical reliability of the service, and these prevented several carers from being able to benefit fully from the scheme, even those who expressed interest. As one female carer in the 'It was quite helpful' group explained, 'I'd like to learn more, I'm very interested, but there's quite often something wrong with the computer. Sometimes it's impossible to switch it off and sometimes the picture disappears'. Such difficulties reduced substantially as the technology improved.

All three of the evaluation groups reported similar null effects, as for the levels of stress, peace of mind and the time available for themselves. Several participants reported that they needed flexible respite services to help them in their caring situation, and indeed to benefit from *ACTION*. As the following response from one participant makes clear, the experimental or indeed any ICT-based intervention cannot provide some valued forms of support service, such as 'getting a break':

Unfortunately I can't take part in your nice days with the *ACTION* programme (group educational sessions). Why? Yes, [it's about] who should be with my husband, who is 94 years of age, has bad eyesight, Parkinson's symptoms and so on? I miss having a pool of volunteers that can offer respite care here at home. If I could have that, it would be super.

The perceptions of the professionals

Data were collected from two groups of professionals to obtain their views on the impact of the scheme on both the carers and on their own ways of working. Individual in-depth interviews were held with the two assistant nurses and the district nurse who were most closely involved in the call-centres. Focus-group interviews were also conducted with various professionals who worked in several care settings where *ACTION* was installed. It became clear from the interviews with the call-centre staff that the scheme had several marked effects. It raised the awareness of the need for professional and family carers to work in partnership. The staff reported new insights into the situation of family carers, into the interdependencies in caring relationships, into the knowledge and expertise held by carers, and into their own potential to enhance these caring resources. As one professional said:

In home-care and nursing homes when the family carer tells you how to do things, you feel they're interfering and hard work. But really they're the one who knows how their relative wants it. They're the one who's the professional, not us.

But if they're always doing right, that's another matter. Perhaps they've always done things in one way, say transferring their relative from the bed to the chair and that's worked out, but it's maybe not so good for them because now they're starting to have back problems.

Those most closely involved in providing regular support to the families now saw their own role as primarily to empower the carers to take greater control of their own lives. They also believed that the availability of advice and support encouraged the carers in their interactions with others. As one assistant nurse said, 'They [the carers] dare more to push themselves forward in their contacts with other professionals because they know that there's someone who's giving them back up. They aren't alone'.

To get the most out of *ACTION*, the professionals needed to be alert to the sometimes subtle clues as to why a carer might be calling them: 'I think it takes a lot to listen. It's not that they call and say, "Now I need help". You have to be more knowing. It's often that they want help, but they don't say it straight out'.

During the course of the project, those operating the call-centres became increasingly skilled at judging the type of support, and the level of contact, that would most benefit carers at various points in their caring 'career': 'Early on it's more medical issues and questions about their own role. At the end, there are a lot of practical issues. Who can I contact? Where can I have that help and so on? Afterwards, it's more to follow them over time and see how they're coming back to life again.' The use of ICT is often seen as a threat by professionals, who feel it is taking over their role. *ACTION* appeared, however, to have the opposite effect, at least for the three professionals most closely involved, as the following quote suggests:

We've had such an enormous response from the families and that makes me proud. To have been able to do something that means a lot for other people. That's the reason I'm a nurse, but I've never felt it as strongly as I have done in this project.

The interviews revealed that the professionals saw *ACTION* providing many benefits for both family carers and themselves. The scheme stimulated carers to contact others in a similar situation, which not only provided mutual support and advice, but also enhanced carers' social lives. As one nurse said, 'After a while carers have said that they want to continue meeting each other and that's what they've done too! They play bowls and meet in the day centre when it's bad weather'.

Focus group interviews with staff at the care settings

Three focus-group interviews were held with 13 staff from the two municipalities, including nine assistant nurses, a physiotherapist, a registered nurse, a social worker (a needs-assessor), and a recreation leader. Their expressions identified several positive benefits of the service, although with more references to the gains to the professionals than to the carers. They also identified some barriers to the more widespread implementation of ITC interventions in everyday practice. First, as during the interviews with the call-centre staff, several professionals emphasised the positive part played by *ACTION* in developing the informal social support networks of the families. As a physiotherapist in a rehabilitation unit said, 'I've been involved in linking patients with each other who didn't know one another before. Through *ACTION* they've got in contact and been able to support each other'.

Many of their assessments referred to improved communication with colleagues working at different care settings in the municipality. An assistant nurse in a day-care centre for people with dementia said, 'We've had very good contact with the other care settings equipped with *ACTION*—contacts we probably wouldn't have had to the same extent if we hadn't had its computer. We've got to know them much better by being able to see each other on the screen. You get another sort of relationship ... it gets much more private, in a way'. The technology enabled staff to conduct care-planning meetings and educational sessions using the videophone, which saved travelling time, as was emphasised by several participants. Finally, a number of staff considered that the multimedia caring programmes were valuable and user-friendly sources of educational material for students. As a physiotherapist in a rehabilitation unit said, 'The education programmes are good—they're illustrative and easy to use. When we've had students, we've always tried to show them so that they can sit and go through it. In some ways it's much more stimulating than to read a book'.

The professionals also identified several significant drawbacks, many associated with the practical issues of introducing a new intervention and ensuring that it worked smoothly. First, there were issues to do with the location of the equipment (Magnusson, Hanson and Nolan 2002). For example, home-care workers in one municipality quickly realised that staff spent most of their time away from the central office where the *ACTION* equipment was installed. Further, the feasibility of sharing the equipment was raised by the needs-assessor, who required a quiet and private room for her confidential work with older people and carers: 'If I had my own computer in my room, it would be easier. Now I've to go across the way.

And then I maybe interfere there in the room where the computer is, so it's easier to use the telephone'.

An issue raised by the majority of staff was the perceived lack of time, compounded by insufficient knowledge of and training in computer use. For several staff, this prevented them from being able to make optimal use, or sometimes any use at all, of the equipment. Fear of computers, technophobic prejudices and a lack of interest were openly discussed by several staff during the focus group interviews. An assistant nurse who worked in respite care aptly summed it up: 'It's almost that the staff are more anti-computer than the older people'. An assistant nurse who had been actively involved with *ACTION* at a dementia day-care setting openly admitted that she felt that the target group were older people and their families, and that staff were relatively excluded:

For the families I think it's been very nice. Everything that's been around the *ACTION* computer, the meetings and such things. We've been very interested so we've got our voice heard. But those who're not so interested, they don't really know. Then they're not so positive.

The fear that technology might replace human contact was also raised in one focus group discussion as a potential unintended consequence of *ACTION*, as were ethical issues concerning the use of the videophone as a form of surveillance in the homes of frail older people. As one home-care nurse put it:

The danger, as I see it, is that when you compensate for human relationships and start with seeing into peoples' homes ... it replaces human beings with technology. ... We want the patient to feel safe so we could use the camera to show us directly what the problem is, and we also see the possibility to save one visit. But then you can overstep the mark. There are always two sides of the coin.

Overall, therefore, while the focus group and interview data identified several potential benefits for carers and professional staff, they also suggested that interventions such as *ACTION* may not be suitable for all carers and that, to overcome the resistance of some professionals, they require careful introduction and specific training programmes.

Discussion

For this discussion of the impact of the *ACTION* scheme, it is useful to return to Schulz's (2001) key questions about the appropriateness and sensitivity of support services: *who* is the target of the intervention, *what* are its goals, *how* is the support best delivered, and *when* are the most appropriate times? How the scheme was delivered is most readily

addressed, for the *ACTION* services were provided through user-friendly ICT in the person's own home. It was therefore readily accessible and it facilitated videophone contact with informal and formal sources of support at a distance. Our findings reinforce the emerging recognition that, with appropriate education and support, older people can fully engage with ICT. Clearly, the *ACTION* services were flexible and responsive to individual need, and they facilitated group support and enhanced the social contacts of the participating families.

Turning to the primary target of the intervention, family carers, the findings suggest that the *ACTION* services were most appropriate for those who expressed a desire to care for an older relative at home, *i.e.* those in the 'It was definitely helpful' and 'It was quite helpful' groups. The scheme encouraged carers to continue in their role by enabling them to feel more prepared and confident. It is also evident, however, that user-friendly ICT services are not appropriate for all family carers of frail older people, particularly those who are already heavily burdened, are in a crisis situation, or are ambivalent about their caring role, *i.e.* those in the 'It was definitely not helpful' group. Such carers probably require different forms of support, including information about alternatives to home care. Thus, a critical consideration is whether installing ICT support in a carer's homes indirectly coerces her or him to continue caring for their older relative, and makes more difficult a conscious decision to relinquish the role (Askham 1998).

ACTION also influenced the practitioners who gave time to support family carers at the call-centres. It provided them with new insights into carers' needs, and promoted more inclusive and empowering ways of working. Thus far, however, the scheme has been less successful in changing the awareness and attitudes of the health and social care professionals who work in traditional care settings for older people. Consistent with the recent policy and empirical care-giving literature, our findings indicate that education and training for professional carers is of crucial importance if ICT-support initiatives are to be optimally effective. In particular, professionals need to respect the experience and knowledge of family carers, regard them as experts about their particular caring situation, and work actively with them as equals. Likewise, professionals need appropriate computer-skills training to enable them to feel confident to use ICT systems. Research on and the development of sensitive educational programmes for practitioners is a priority.

The *ACTION* services to date have focused largely on care-giving skills and knowledge (as reflected in the higher preparedness scores). In particular, the multi-media educational programmes concentrated on skills training and advice, as on moving and handling, the care of

a person with incontinence, and assistance with food preparation and nutrition. Despite this orientation, the findings of this study suggest that the scheme enriched the caring situation by facilitating the development and maintenance of informal support networks amongst the participating families. In some cases this reduced social isolation for cared-for persons and family carers (Cowan and Turner Smith 1999). There remains, however, scope for developing new programmes with a more explicit emphasis on enriching care-giving relationships (see Nolan *et al.* 2003 for a review).

In contrast, *ACTION* was less successful at targeting predictability and decision-making in the caring situation. The lower predictability scores might be explained in the Swedish study by the slight educational content on planning ahead and decision-making. While the scheme demonstrated several benefits, it was relatively ineffective in reducing the perceived stresses of the caring situation. This finding reinforces the importance of providing a range of support services, especially respite and other forms of relief. It is therefore concluded that ICT-support services do not replace existing statutory or formal services, but rather facilitate their optimal use and stimulate new forms of help. Finally, there is the crucial question of when is such support best provided? The findings make clear that the scheme was most effective when delivered at the earliest opportunity, for then it enables the carer early access to the information, education and support services. In the same vein, an additional benefit for a family carer of ICT-support at an early date is the opportunity to be actively involved in developing new services, something which many find empowering (Hanson, Tetley and Shewan 2000).

Acknowledgements

The Swedish *ACTION* project was funded by the Ministry of Social Affairs with additional support from the Borås and Mark municipalities, the West Sweden Health Region and the University College of Borås. We extend our sincere thanks to all the families and practitioners who were involved. We also thank Professor Inga Wernersson, University of Gothenburg, the anonymous external reviewers and the Editor for their constructive comments on an earlier version of this paper.

NOTES

- 1 *ACTION* was a 39-month project (September 1997-March 2000) funded by the Telematics Applications Programme, Disabled and Elderly sector of the Fourth Framework R&D Programme of the European Union.
- 2 Two telephone lines with a band width of 128 kbs.
- 3 Ethical approval for the study was granted from the Ethical Review Committee at the Faculty of Medicine, University of Gothenburg. The recruitment protocol approved

by the ethics committee was: ‘Assistant nurses and social workers from the municipalities explain the project and give out information sheets to those family carers and frail older people who could potentially benefit from having the *ACTION* system and services installed in their home. Staff carry out a second visit to the families that express an interest in participating, at which time the project is explained in more detail. Families could seek further clarification about the project as appropriate. Informed consent will be gained from all family carers and where possible from the persons they cared for. At this time, ethical considerations with regard to privacy, confidentiality and rights to withdraw will be emphasised’.

- 4 The final PREP aim of reducing hospital utilisation and costs is not part of the PREP evaluation instrument. A cost-effectiveness study of *ACTION* for the participating families has been carried out and is the subject of another paper (in press) by the first two authors.

References

- Alzheimer’s Society Dementia Care and Research 2003. *Learning to Live with Dementia Project*. Alzheimer’s Association, London. Available online at www.alzheimers.org.uk/have/llwd.html [Accessed January 12, 2005].
- Aneshensel, C. S., Pearly, L. I., Mullan, J. T., Zarit, S. U. and Whitlach, C. J. 1995. *Profiles in Caregiving: The Unexpected Career*. Academic, San Diego, California.
- Archbold, P. G., Stewart, B. J. and Miller, L. L. 1995. The PREP system of nursing interventions: a pilot test with families caring for older members. *Research in Nursing and Health*, **18**, 1–16.
- Arnaert, A. and Delesie, L. 2001. Telenursing for the elderly: the case for care via video-telephony. *Journal of Telemedicine and Telecare*, **7**, 311–6.
- Askham, J. 1998. Supporting caregivers of older people: an overview of problems and priorities. *Australian Journal of Ageing*, **17**, 5–7.
- Audit Commission 2004. *Assistive Technology: Independence and Well-being 2*. Audit Commission Publications, Wetherby, West Yorkshire.
- Bass, D., McClendon, M., Flatley Brennan, P. and McCarthy, C. 1998. The buffering effect of a computer support network on caregiver strain. *Journal of Aging and Health*, **10**, 20–43.
- Beck, C. 2001. Identification and assessment of effective services and interventions: the nursing home perspective. *Ageing and Mental Health*, **5**, S99–111.
- Bernard, M. and Meade, K. 1993. *Women Come of Age*. Edward Arnold, London.
- Bernard, M. and Phillips, J. 2000. The challenge of ageing in tomorrow’s Britain. *Ageing & Society*, **20**, 33–54.
- Board of Health and Welfare Sweden (BHWS) 2002a. *Nationell handlingsplan för äldrepolitiken: Slut rapport [National Guidelines for Elderly Policy: Final Report]*. BHWS, Stockholm.
- BHWS 2002b. *Anhörig 300: Slut Rapport [Family Carer 300 Project: Final Report]*. BHWS, Stockholm.
- BHWS 2003. *Ett år efter Anhörig 300 [One Year Later: Family Carer 300 project]*. BHWS, Stockholm.
- BHWS 2004a. *Äldres levnadsförhållanden 1988–2002. Hälsa, funktionsförmåga och vård – och omsorgsmönster [Older People’s Living Circumstances 1988–2002: Health, Functional Capacity and Health and Social Care Patterns]*. BHWS, Stockholm.
- BHWS 2004b. *Framtidens anhöringsomsorg [Family Carer Support in the Future]*. BHWS, Stockholm.
- Bond, J. 2000. The impact of staff factors in nursing home residents. *Ageing and Mental Health*, **4**, 5–8.

- Bowles, K. H. and Dansky, K. H. 2002. Teaching self-management of diabetes. *Home-Healthcare-Nurse*, **20**, 36–42.
- Cartwright, J. C., Archbold, P. G., Stewart, B. J. and Limandri, B. 1994. Enrichment processes in family caregiving to frail elders. *Advances in Nursing Sciences*, **17**, 31–43.
- Cherry, J., Colliflower, S. and Tsiperfal, A. 2000. Meeting the challenges of case management with remote patient monitoring technology. *Lippincott's Case Management*, **5**, 191–8.
- Chetney, R. 2003. The Cardiac Connection program: home care that doesn't miss a beat. *Home-Healthcare-Nurse*, **21**, 680–9.
- Clyburn, L. D., Stones, M. J., Hadjistquropoulos, T. and Tuckko, H. 2000. Predicting caregiver burden and depression in Alzheimer's disease. *Journal of Gerontology, Social Sciences*, **55B**, S2–13.
- Cooke, D. D., McNally, L., Mulligan, K. T., Harrison, M. J. G. and Newman, S. P. 2001. Psychosocial interventions for caregivers of people with dementia: a systematic review. *Aging and Mental Health*, **5**, 120–35.
- Cowan, D. and Turner Smith, A. 1999. *The Role of Assistive Technology in Alternative Models of Health Care for Older People*. Appendix 8, Research volume 2, Appendix 2, Royal Commission on Long Term Care, *With Respect to Old Age: Long Term Care-Rights and Responsibilities*. Her Majesty's Stationery Office, London, 325.
- Dansky, K. and Bowles, K. 2002. Lessons learned from a telehomecare project. *Caring*, **21**, 18–22.
- Engedal, K. 2004. The ENABLE Project, Norway. Available online at www.enableproject.org [Accessed 22 November 2004].
- Flatley Brennan P., Moore, S. and Smyth, K. 1995. The effects of a special computer network on caregivers of persons with Alzheimer's disease. *Nursing Research*, **44**, 166–72.
- Glaser, B. G. and Strauss, A. L. 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine, Chicago.
- Hanson, E., Tetley, J. and Clarke, A. 1999. A multimedia intervention to support family caregivers. *The Gerontologist*, **39**, 736–41.
- Hanson, E., Tetley, J. and Shewan, J. 2000. Supporting family carers using interactive multimedia. *British Journal of Nursing*, **9**, 713–9.
- Irvine, B. 2003. Computers for Caregiving. Paper given at the *Setting Priorities for Retirement Years* (SPRY) Foundation National Conference, Computer-based technology and caregiving for older adults, October 2–3, Bethesda, Maryland.
- Johansson, L. 2001. Recent Developments in Caregiver Support in Sweden. Paper given at the 17th World Congress of the International Association of Gerontology, Vancouver, 3 July.
- Johansson, L., Sundström, G. and Hassing, L. B. 2003. State provision down, offspring's up: the reverse substitution of old-age care in Sweden. *Ageing & Society*, **23**, 269–80.
- Loomis, J. 2003. Florida Dementia Caregivers Home Telehealth Support Network. Paper presented at the *International Conference on Aging, Disability & Independence*, Washington DC, December. Available online at www.AlzOnline.net [Accessed October 21, 2004].
- Magnusson, L. 2002. The Swedish *ACTION* project 2000–2002. Unpublished final report to the Ministry of Social Affairs, Stockholm. [In Swedish. English summary available from the author].
- Magnusson, L., Berthold, H., Hanson, E., Chambers, M., Brito, L. and O'Reilly, A. 1999. Carers tap into the information highway. *Nursing Times*, **95**, 48–50.
- Magnusson, L., Hanson, E., Berthold, H. and Nolan, M. 2001. Working with older people: the Äldre Väst Sjuhäräd model. *Quality in Ageing*, **2**, 32–8.
- Magnusson, L., Hanson, E. and Nolan, M. 2002. Assisting carers using the *ACTION* model for working with family carers. *British Journal of Nursing*, **11**, 759–63.

- Magnusson, L., Hanson, E., Chambers, M., Berthold, H., Brito, L. and Daly, T. 2002. Supporting family carers through the use of information technology — the EU project *ACTION*. *International Journal of Nursing Studies*, **39**, 369–81.
- Magnusson, L., Hanson, E. and Borg, M. 2004. A literature review study of Information and Communication Technology as a support for frail older people living at home and their family carers. *Technology and Disability*, **16**, 223–235.
- Marshall, M. 2000. *ASTRID: A Social and Technological Response to Meeting the Needs of Individuals with Dementia and Their Carers*. Hawker, London.
- Montgomery, R. J. V. and Williams, K. N. 2001. Implications of differential impacts of caregiving for future research on Alzheimer care. *Aging and Mental Health*, **5**, S23–34.
- Moriarty, J. and Webb, S. 2000. *Part of Their Lives: Community Care for Older People with Dementia*. Policy, Bristol, Avon.
- National Institutes of Health. 2003. *NIH Senior Health Initiative*. National Institutes of Health, Bethesda, Maryland. Available online at www.nihseniorhealth.gov [Accessed October 28, 2004].
- Nolan, M. 1998. Outcomes and effectiveness: beyond a professional perspective. *Clinical Effectiveness in Nursing*, **2**, 57–68.
- Nolan, M., Grant, G. and Keady, J. 1996. *Understanding Family Care*. Open University Press, Buckingham.
- Nolan, M., Grant, G., Keady, J. and Lundh, U. 2003. New directions for partnerships: relationship-centred care. In Nolan, M., Lundh, U., Grant, G. and Keady, J. (eds), *Partnerships in Family Care*. Open University Press, Maidenhead, 257–91.
- Pearlin, L. I., Harrington, C., Powell-Lawton, M., Montgomery, R. J. V. and Zarit, S. H. 2001. An overview of the social and behavioural consequences of Alzheimer's disease. *Aging and Mental Health*, **5**, S3–6.
- Pierce, L., Steiner, V. and Govoni, A. 2002. In-home online support for caregivers of survivors of stroke: a feasibility study. *Computers, Informatics, Nursing*, **20**, 157–64.
- Post, S. G. 2001. Comments on research in the social sciences pertaining to Alzheimer's disease: a more humble approach. *Aging and Mental Health*, **5**, S17–9.
- Qualls, S. H. 2000. Therapy with ageing families: rationale, opportunities and challenges. *Journal of Aging and Mental Health*, **4**, 191–9.
- Qureshi, H., Bamford, C., Nicholas, E., Patmore, C. and Harris, J. C. 2000. *Outcomes in Social Care Practice: Developing an Outcome Focus in Care Management and Use Surveys*. Social Policy Research Unit, University of York, York.
- Schofield, H., Bloch, S. and Herman, H. 1998. *Family Caregivers: Disability, Illness and Ageing*. Allen and Unwin for Victorian Health Promotion Foundation, Melbourne, Australia.
- Schulz, R. 2001. Some critical issues in caregiver intervention research. *Ageing and Mental Health*, **5** (supplement 1), S112–5.
- Schulz, R. and Williamson, G. M. 1997. The measurement of caregiver outcomes in AD research. *Alzheimer's Disease and Related Disorders*, **11**, 1–6.
- Schumacher, K. L., Stewart, B. J., Archbold, P. G., Dodd, M. J. and Dibble, S. L. 1998. Family caregiving skill: development of the concept. *Image: Journal of Nursing Scholarship*, **30**, 63–70.
- Sorensen, S. 1997. Preparation for Caregivers: Caregivers' and Potential Care Recipients' Perspectives. Paper presented at the 16th World Congress of the International Association of Gerontology, Adelaide, July.
- Tetley, J. and Hanson, E. 2000. Participatory research. *Nurse Researcher*, **8**, 69–88.
- Thompson, C. and Briggs, M. 2000. *Support for Carers of People with Alzheimer's Type Dementia*. *Cochrane Review*, Issue 4, The Cochrane Library, Update Software, Oxford.
- Twigg, J. and Atkin, K. 1994. *Carers Perceived: Policy and Practice in Informal Care*. Open University Press, Buckingham.

- White, M. and Dorman, S. 2000. Online support for caregivers: analysis of an internet Alzheimer mailgroup. *Computers in Nursing*, **18**, 168–76.
- Whitten, P., Doolittle, G., Mackert, M. and Rush, T. 2003. Telehospice: end-of-life care over the lines. *Nursing Management*, **34**, 36–9.
- Woolham, J. and Frisby, B. 2002. How technology can help people feel safe at home. *Journal of Dementia Care*, **10**, March/April, 27–9.
- Zarit, S. H. and Leitsch, S. A. 2001. Developing and evaluating community based intervention programmes for Alzheimer's patients and their caregivers. *Aging and Mental Health*, **5**, 84–98.
- Zarit, S. H., Gaugler, J. E. and Jarrott, S. E. 1999. Useful services for families: research findings and directions. *International Journal of Geriatric Psychiatry*, **14**, 165–77.

Accepted 18 January 2005

Address for correspondence:

Lennart Magnusson, Department of Health Sciences and
ÄldreVäst Sjuhärad Research Centre, University College of
Borås, Allégatan 1, S-50190, Borås, Sweden.

e-mail: lennart.magnusson@hb.se