

Supporting frail older people and their family carers at home using information and communication technology: cost analysis

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Aim. This paper describes a cost analysis of a home-based support service for frail older people and their family carers in two municipalities in West Sweden and using information and communication technology.

Background. A key challenge facing nurse managers across Europe is an increasingly aged population, combined with reduced numbers of young adults of working age. New solutions are needed to provide quality, cost-effective community care services to frail older people and their family carers.

Methods. A case study methodology involving five families was used, and included a detailed cost description of the technology-based service compared with usual services. Cost data were collected in June 2002. This work formed part of a larger project exploring the impact of a technology-based service known as, Assisting Carers using Telematics Interventions to meet Older Persons' Needs (ACTION). In addition to cost data, information was gathered on the quality of life of frail older people and their family carers, and the job satisfaction and work methods of nurses and other practitioners based in the community. The cost analysis comprised a description of the family and their caring situation, the perceived benefits of the telematic based support service and an assessment of its impact on the use of other care services. These analyses were carried out with the help of needs assessors who were known to the families, and nurses working in the ACTION call centre. All results were validated by the five participating families.

Results. Cost savings were achieved in all cases, and the benefits to older people and their carers were also considerable. As a result of the cost analysis and overall evaluation data, ACTION has been implemented as a mainstream service in the municipalities involved.

Conclusion. Researchers, nurses, other practitioners and community care managers can work together with frail older people and their family carers to develop quality, cost-effective support services that reduce demands on staff whilst providing benefits to users.

Keywords: community nursing, costs, family carers, frail older people, information and communication technology, quality of life

Introduction

Support for older people and their family carers in Sweden

With an increasingly ageing population and reduced numbers of young adults available to work in health and social care, community care managers face serious challenges in recruiting and retaining competent nurses and other professional carers to run existing care services for older people (Donnelly 2002). In Sweden over the last 10 years, as in other northern and western countries in Europe, community care policy has advocated the principle of 'ageing in place', arguing that the majority of older people wish to remain in their own homes. Thus, the numbers of nursing home beds have been greatly reduced and the majority of frail older people in Sweden who require help and support with activities of daily living tend to remain in their own homes with the help of their family and friends, as well as home care services (Johansson *et al.* 2003).

Over the last decade, government policy in Sweden has increasingly mirrored countries such as the United Kingdom (UK) and North America, so that community care in reality means family care, with the 'lion's share' of caring now carried out by relatives (Board of Health and Welfare Sweden 2004a). Thus, support for family carers is a policy priority in Sweden (Board of Health and Welfare Sweden 2002). However, as with other countries providing family carer support services, it is recognized that there is room for improvement in the quality and range of services available (Board of Health and Welfare Sweden 2004b).

Also, despite the voluminous literature in the field of family caregiving, there is a dearth of evidence about the effectiveness of current approaches (Nolan *et al.* 2003). Thus, there is an urgent need to find new and more effective ways of supporting older people, their family carers, and practitioners more effectively (Schulz 2001). The potential role of technology in enhancing the independence of older people living at home is increasingly being recognized in both the UK (Audit Commission 2004) and in Sweden (Board of Health and Welfare Sweden 2004b). Many such initiatives are currently being tested in the United States of America, where a range of nurse-led telehealth and telecare services has been designed to maintain older people at home for as long as possible, whilst also supporting their family carers (Magnusson *et al.* 2004). However, such initiatives have often been professionally-driven and developed largely without involvement of user groups, which increases the risk, already apparent

with traditional services, of support not being attuned to the needs and preferences of older people and their family carers, resulting in services being under-used or rejected by service users (Magnusson *et al.* 2004).

This paper considers an information and technology-based (ICT) project (Assisting Carers using Telematics Interventions to meet Older Persons' Needs, ACTION) that was user-driven from the outset. It places particular focus on the cost benefits of such a service and considers its transition from a pilot project to a mainstream service.

Background

The ACTION concept

The ACTION concept is an ICT-based support service for older people and their family carers and arose from the EU project ACTION, which developed and tested the service in Sweden, England, Northern Ireland, the Republic of Ireland and Portugal (1997–2000). Following the initial project, funding was secured from the Ministry of Health and Social Affairs to further develop and test the ACTION services in Sweden (2000–2002). A participatory research design was adopted in the EU ACTION study (Hanson *et al.* 1999a, 2000, Tetley & Hanson 2000) and further refined in the Swedish ACTION project (Magnusson *et al.* 2002a). A summary of the ACTION research methods is presented in Figure 1.

ACTION was designed to enable family carers to access education, information and support in relation to their current caring situation and over the course of their caring trajectory (Nolan *et al.* 1996, Hanson *et al.* 1999b). It was intended to empower families to be informed about the choices available to them and to engage in informed decision-making about their caring situation so as to avoid the

- User working groups
 - Individual interviews
 - Focus group interviews
 - User trials
 - Questionnaires
 - Log diaries
 - Field Notes
 - Field testing in people's homes and community care settings
- (Based on Magnusson *et al.* 2002a, Hanson *et al.* 1999a, 2000)

Figure 1 Summary of the research methods used in the Assisting Carers using Telematics Interventions to meet Older persons' Needs (ACTION) projects.

disempowering effects of crisis-oriented care, which tended to predominate practice (Hanson & Clarke 2000, Qureshi *et al.* 2000).

ACTION consists of a range of multimedia caring programmes that families access via their TV sets (in the EU project) and subsequently via their personal computers (PCs) (in the Swedish project). The programmes were based on carers' needs identified from the empirical caregiving literature and from extensive user consultation in the project, namely, caring skills in daily life, planning ahead, respite care services, financial and economic support and coping strategies (Magnusson *et al.* 1998). Videophone facilities were also provided, which enabled families to have visual and oral contact with professional carers and other families involved in the project. This was achieved via a small camera on top of the PC, the installation of videoconferencing hardware on the computer and ISDN2b lines in families' homes. Finally, families also had access to Internet and e-mail facilities.

At the request of the families, Swedish ACTION services were extended to include more multimedia educational caring programmes. Videophone access to professionals was improved by establishing two call centres run by nurses, who

provided dedicated advice and support to families. The Swedish ACTION services operated via a computer connected to ISDN 2b lines and the Internet (Magnusson *et al.* 2002b).

A typical user initially accessed the multimedia programmes to increase their knowledge and caring skills, and referred to them again as their caring situation changed. They had frequent contact via the videophone with other families to exchange news and to support each another. They also had regular contact with the call centre nurses to share how they were feeling and to ask for advice on an 'as needed' basis. During spare moments, they surfed the Internet and emailed their children/grandchildren, who lived some distance away (Magnusson *et al.* 2002a).

Overall the Swedish study demonstrated the positive impact of ACTION for those family carers who wished to care for their older relatives at home. A summary of the key findings is presented in Figure 2.

The study, together with a review of the literature in the field, identified a range of factors that appear critical to the success of such initiatives, as well as caveats to their use.

Frail older people and their family carers

- Family carers increased their competence, satisfaction and sense of security in their caregiving role as a result of using ACTION (Magnusson *et al.* 2005).
- Frail older people and their family carers became less isolated as a result of developing informal support networks with other ACTION families (Magnusson *et al.* 2002a).
- ACTION has the potential to empower older people and their carers and to enrich the caring relationship (Hanson *et al.* 2002).
- ACTION helps to increase the social inclusion of frail older people and their carers who are traditionally excluded from the benefits of information and communication technology (ICT) (Magnusson *et al.* 1999).
- Optimal benefit from ACTION occurs when the support service is introduced as early as possible within the caring process (Hanson & Clarke 2000).
- It is more likely that ACTION is accepted by older people if it is introduced as a tool to help families access education, information and support in their own home, rather than emphasizing technology *per se* (Magnusson & Hanson 2003).
- Frail older people and their family carers are happy to use ICT provided that it is easy to use, easy to learn, easy to understand and of direct benefit to them (Magnusson *et al.* 1999).

Nurses

- ACTION call centre nurses reported increased job satisfaction and client satisfaction as a result of working in partnership with families (Magnusson *et al.* 2005).
- Some professionals working in traditional care settings for older people fear that new technology will replace them and value direct human contact (Magnusson *et al.* 2005).

Research methods and theory building

- Direct involvement of frail older people and their family carers during the research and development process leads to high levels of user acceptance (Hanson *et al.* 2000, Andersson *et al.* 2002, Magnusson & Hanson 2004).
- In-depth user consultation with family carers can lead to the development of meaningful theory which then acts as a useful framework for multi-media education programmes for carers (Hanson *et al.* 1999b).

Figure 2 Summary of the key findings from the Assisting Carers using Telematics Interventions to meet Older persons' Needs (ACTION) projects.

Critical success factors identified from the empirical literature

Probably the most important factor of all is that older people and their carers are actively involved in the design of the ICT, enhancing the possibility of the content being seen as relevant to their needs.

Older people's attitudes towards new technology are also a crucial factor. Work carried out in ACTION strongly indicates that, contrary to public stereotypes, older people are not inherently negative about technology. Indeed, if they and their carers can see the benefits of technology, and are assisted and supported to learn basic skills, then they are likely to adopt it enthusiastically (Magnusson *et al.* 1999).

Conversely, for those who are sceptical about potential benefits, and/or for those carers who are possibly reluctant to care for an older relative at home, then ACTION and similar initiatives may not be appropriate (Magnusson *et al.* 2005). This points to the need for careful assessment and regular monitoring of the best way to meet the needs of older people and their family carers (Board of Health and Welfare Sweden 2004b).

A key drawback to the mainstream implementation of ICT in health and social care for older people is the lack of a technical infrastructure and a business model (Cowan & Turner Smith 1999, Curry *et al.* 2003, Audit Commission 2004). There is also an additional barrier to the transferability of existing services, as the majority of ICT-based projects are locally-based pilot studies (Darkins & Cary 2000). As a result there is often lack of co-ordination between projects, which leads to duplication of effort and incompatibility of equipment. There are also cost considerations in relation to the cultural adoption of ICT-based interventions, given that the majority of current initiatives are predominantly US-based (Magnusson *et al.* 2004).

Recent reviews of the 'state of the art' in relation to ICT point to the relatively weak evidence base to support telemedicine interventions, particularly with regard to cost (Håkansson & Gavelin 2000, Mair *et al.* 2000, Wootton 2001, Hailey *et al.* 2002, Whitten *et al.* 2002, Jennett *et al.* 2003). Mair *et al.* (2000) and Whitten *et al.* (2002) identified key weaknesses in the published literature and posed 10 fundamental questions that should be taken into consideration when designing cost effectiveness studies in telemedicine. These are presented in Figure 3.

Against this background, in this paper we present the results of a cost analysis carried out within the Swedish ACTION project. The study findings will be discussed using the above criteria as a framework.

- Is there a clear hypothesis?
- Is there a clear statement regarding the perspective from which cost effectiveness is assessed?
- Is the methodology of high quality and appropriate?
- Is the comparator appropriate?
- Is the quality of the medical evidence adequate?
- Are appropriate costs and benefits considered?
- Has an adjustment of costs and benefits been made for differential timing?
- Is a marginal analysis undertaken?
- Is a sensitivity analysis performed?
- Is the analysis appropriate to the local environment?

Figure 3 Key questions to consider when designing cost-effectiveness studies in telemedicine (based on Mair *et al.* 2000, Whitten *et al.* 2002).

The study

Aim

The primary aims of ACTION are to increase the autonomy, independence and quality of life of frail older people and their family carers by providing information, education and support via the use of ICT in their own homes. The question addressed here is whether the use of ACTION by participating families will reduce their potential use/costs of other services whilst maintaining or enhancing their quality of life.

Methodology

The cost analysis work was conducted in Autumn 2002, was a sub-study within the overall Swedish ACTION project, and was in essence a cost description. Øvretveit (1998) defines a cost description as 'a measurement of the costs of one thing, or of more than one, in a way which allows an explicit or implicit comparison of costs' (Øvretveit 1998, p. 168). A cost description is often the first step in a full economic evaluation and is appropriate when developing and testing a new service, such as ACTION. A full economic evaluation, including cost-effectiveness, cost-utility and cost-benefit analyses is considered more appropriate when a service has been refined and is ready for testing in the form of a full randomized controlled trial (Flatley Brennan *et al.* 1995). A case study design was employed for the cost description analysis, which means that each selected family represented a case and the descriptive data concerning care service costs and the ACTION intervention costs was analysed with regard to the family's perceived benefits of ACTION, resulting in a hypothetical cost assessment of usual service costs. In this way, the

methods of the instrumental case study was employed, as the main area of interest was to gain a comprehensive description of the costs of ACTION compared with usual care services for older people and their family carers. Cases were chosen that helped to advance understanding of the potential of ACTION in relation to cost savings. However, although we simultaneously studied five cases, each case study was an in-depth inquiry into a single case. As Stake (2000) acknowledged, 'The case is still looked at in depth, its contexts scrutinized, its ordinary activities detailed, but all because this helps the researcher to pursue the external interest' (p. 237).

Participants

The sample for the cost description study was purposive and the ACTION call centre nurses were asked to select five participating families for whom they considered ACTION had a major impact in preventing increased care costs. The five families were selected from a total of 34 who participated in the ACTION project. The costs for these five families were used to calculate the final average hypothetical cost saving calculations for the total sample. Families were recruited from two municipalities in West Sweden. One municipality was an urban area with 100,000 inhabitants, with one district of 10,500 inhabitants participating in the project. The second was a mixed urban and rural area with 33,000 inhabitants. In both areas, 13% of the inhabitants were 65–79 years of age and 6% were 80 years of age and older.

Data collection

Following approval from the five families, the needs assessors (who knew the families involved), together with the ACTION call centre nurses, undertook a preliminary cost analysis for each of the five case families focusing on the following three areas:

- A description of the family and their caring situation.
- A description of the families' perceived benefits from ACTION.
- An assessment of the impact on ACTION on care service costs.

A description of the family and their caring situation was collated with the families' consent from existing general background demographic project data. The description of the families' perceived benefits from ACTION was gained from project interview data with the families. The needs assessors were then asked to make careful assessments of how many care services the five case families would have needed if they

had not had the ACTION service. The descriptions, together with the care assessment, were collected by the first author and validated by each family. The validation was carried out at a joint meeting in the family's own home between the family, the needs assessor, the first author and an ACTION call centre nurse.

Based on the results of these hypothetical cost assessments, an estimate of the average cost saving per family based on the total sample of 34 ACTION families was made. This calculation was based on the main study data, which demonstrated a moderate impact from ACTION for the majority of families and little or no impact for a minority (Magnusson *et al.* 2005).

The costs for different kinds of usual care services were obtained from the financial departments in the two participating municipalities (N.B. the amount that the families would have had to contribute to the different kinds of caring services were not included in the case studies or in the final results). The ACTION service costs were therefore based on real actual costs for equipment, communication, technical support and the ACTION call centre. The use and cost for telecommunication and Internet were based on information from the telecom company's invoices for the period July 20001 to June 2002. The costs for development and maintenance of the ACTION programmes were based on estimations from previous experience within the ACTION project.

Validity and reliability

The case study cost analyses were validated by the five participating families. This was carried out by presenting a preliminary cost analysis to each family prior to the joint meeting. At the joint meeting, the draft analysis was presented and family members were asked if they were in agreement with the assessment and if they were satisfied with the way in which their caring situation and benefits from ACTION had been documented. All families agreed with the descriptions of their caring situation and the benefits of ACTION, with only minor adjustments. Four families agreed to their cost assessment. However, one family did not agree with the amount of services the needs assessor had suggested, and the calculation was adjusted to accommodate this difference.

The case cost analyses can be said to be reliable as they included the most recent figures for care services available from the municipality and the analyses were carried out by the first author in collaboration with independent, experienced needs assessors who knew the families situation, thereby minimizing potential errors.

Ethical considerations

Ethical approval for the Swedish ACTION study was obtained from the ethical review committee at the Faculty of Medicine, University of Gothenburg. For the cost analysis, the ACTION call centre nurses carefully explained this sub-study to the five selected families, reassuring them that their names would not appear on any reports or articles arising from the study and that wherever possible their identity would be protected. It was also explained that they would receive a draft of their cost analysis which they could accept, modify or reject as appropriate. Also, they would have an opportunity to discuss openly their views about the cost analysis during a home visit with the needs assessor and call centre nurse. It was emphasized that they could decline to take part or could withdraw at any time without any repercussions on the care they received or with regard to the overall ACTION study.

Results

The results consist initially of an itemization of the operational costs for statutory care services for older people and their family carers, followed by an itemization of operational costs for the ACTION service. A summary of the five cost case studies is presented (N.B. pseudonyms have been used to protect the identity of the families). Finally, a hypothetical calculation to explore the average cost savings per family (out of the total sample of 34 families) of using ACTION is presented.

The costings are presented in Swedish Crowns (SEK) and the exchange rate on 28 June 2002 was 9.08 SEK for one Euro (EURO), 14.01 SEK for one British pound (GBP) and 9.16 SEK for one US dollar (USD) (The Swedish Riksbank).

Usual care service costs

The costs for usual care services for older people and their family carers are based on figures for 2001 obtained from the financial departments in the participating municipalities. These constituted the most current figures available at the time the cost analysis was carried out. See Table 1.

Costs for the ACTION service

The costs of offering a family ACTION were 25,800 Swedish Crowns (SEK) per year (2150 SEK per month) (see Table 2).

The costs for a computer, videophone hardware, camera and appropriate software and antivirus programmes were approximately 25,000 SEK based on 'off the shelf' prices in

Table 1 Usual Care Service Costs year 2001 for the participating municipalities

	Municipalities	
	Municipality 1	Municipality 2
Attendance allowance	1176 SEK/month	1210 SEK/month
Home help	280 SEK/hour	301 SEK/hour
Day care – dementia		660 SEK/day
Day care – physically frail and rehabilitation	650 SEK/day	320 SEK/day
Respite care	1250 SEK/day	1250 SEK/day
Nursing home	900 SEK/day	1099 SEK/day

SEK, Swedish Crowns.

Exchange rate 28.6.2002: 1 EUR = 9.08 SEK, 1 GBP = 14.01 SEK, 1 USD = 9.16 SEK (The Swedish Riksbank).

This figures comprises all costs, including general administration for all services except attendance allowance.

Table 2 Cost for the ACTION service per family per year

	Cost
Equipment incl. software (based on writing of within 36 months)	8400
Technical support	1000
Telecommunication and Internet*	6000
ACTION program (based on 500 users)	2400
Local call centre (based on 50 users)	8000
Total	25,800

In Swedish Crowns (SEK).

Exchange rate 28.6.2002: 1 EUR = 9.08 SEK, 1 GBP = 14.01 SEK, 1 USD = 9.16 SEK (The Swedish Riksbank).

*An installation cost per user with 5000 SEK has to be added.

Sweden in March 2001. Installation of ISDN 2b was carried out by the Swedish Telecom Company Telia at an average cost of 5000 SEK, and the equipment was installed by the ACTION call centre nurses. Nevertheless, occasionally technical problems occurred which required the skills of a technician. This was estimated as a technical support consultation once or twice a year, with a yearly cost of 1000 SEK per family.

The actual average costs for Internet and video communication were 458 SEK per month, based on figures for July 2001–June 2002, which in the following calculations have been rounded to 500 SEK per month (6000 SEK per year). Table 3 presents the Internet and video communication costs for the 34 users.

The estimated cost for programme development and maintenance was 1,200,000 SEK per year, which gave rise to a cost of 2400 SEK per family per year based on 500 users. These figures were based on the premise (from our research and development work experience over the last 7 years) that

Table 3 Costs for using telecommunication and Internet per family per month, during the period July 2001–June 2002

	Internet		Telecommunication			Total
	Time (hour:minute)	Cost (SKR)	Calls (number)	Time (hour:minute)	Cost (SKR)	
Mean	18:33	247	10	01:04	211	458
Lowest	00:17	102	1	00:01	200	303
Highest	101:10	854	44	06:29	281	1135

In Swedish Crowns (SEK).

Exchange rate 28.6.2002: 1 EUR = 9.08 SEK, 1 GBP = 14.01 SEK, 1 USD = 9.16 SEK (The Swedish Riksbank).

Table 4 Total cost for the local call centre per year

	Cost
Salary, including social insurance and vacations	340,000
Housing costs	15,000
ACTION-equipment (based on writing of within 36 months)	8400
Telecommunication and Internet	7200
Additional: travel, education and social activities with the families	29,400
Total	400,000

In Swedish Crowns (SEK).

Exchange rate 28.6.2002: 1 EUR = 9.08 SEK, 1 GBP = 14.01 SEK, 1 USD = 9.16 SEK (The Swedish Riksbank).

there was one nurse and one IT-worker working full-time on programme development and maintenance in order to guarantee 'state of the art' work. Costs for equipment, office and administration were also included in the yearly figures.

The total cost for a call centre was 400,000 SEK per year for providing a service for 50 families. This was based on estimations from the empirical literature and from experience in the ACTION call centre that one nurse working full-time could support approximately 50 families; this was a sum of 8000 SEK per year per family. The costs for the call centre are specified in Table 4.

Summary results of the cost case studies

A summary of the cost case study data is presented in Table 5; this gives an overview of each case study family in relation to their individual caring situation, followed by their perceived benefits from ACTION and, finally, a condensed cost assessment.

Results of the hypothetical cost calculations

The majority of the 34 family carers taking part in the overall project considered that their quality of life had increased through using the ACTION service (Magnusson *et al.* 2005). From the case study data, it was clear that the five families

benefited considerably from ACTION. The estimated cost description data revealed that, for these five families, the average net cost savings for the municipalities were 217,700 SEK per family per year (see Table 6).

However, amongst the total project sample of 34 family carers there were five families who had very little or no use of ACTION (Magnusson *et al.* 2005) and as a result there were no cost savings at all. For these families, ACTION resulted in a cost of 25,800 SEK per year. Our estimation is that, for the remaining 24 families, the cost savings were in the region between the average highest and lowest cost savings.

Thus, we calculated the average cost savings for all 34 families involved in the project by taking the average cost saving between the five families where there was a high cost saving of 217,700 SEK per year and those where there was no cost saving – 25,800 SEK per year. The average cost saving was then calculated as 96,000 SEK per family per year.

Discussion

The methodology and results of our cost description study will now be discussed using the criteria for evaluating cost effectiveness studies in telemedicine suggested by Mair *et al.* (2000) and Whitten *et al.* (2002) in their systematic literature review of empirical research in the field (see Figure 3).

The first question to consider is whether the methodology was appropriate and of high quality. It needs to be acknowledged that the study had a number of limitations, the main one being the small number of cases involved. Therefore it can best be seen as a feasibility study. A further weakness in the cost study design was that the costs for the families themselves were not taken into account. Another limitation was the lack of a control group with which the actual costs could be compared. As an alternative, a comparison was made between the costs for the actual service for the families, including ACTION, and the cost for the estimated services the families would have needed if they had not had ACTION. Clearly, this is a difficult calculation and there is a risk that

Table 5 Swedish ACTION Cost Case study families (all names are pseudonyms)

Family	Care history	Benefits from ACTION	Cost assessment*
Family 1: Elsa (80) cares for her husband Göte (82) who is largely wheelchair bound since his stroke in the Summer 1999	<p>Following a period of rehabilitation at the hospital, Göte came home to a new purpose-built flat. Initially, they did not want any help from the municipality. After 2 months, Elsa requested home care once a week and 2 hours of respite care. They also received Attendance Allowance.</p> <p>Elsa wanted to be able to care for Göte and they did not want other people coming into their home. After a year Göte was granted an extended day once a week at the local rehabilitation day centre. ACTION was installed in their home in August 2001.</p>	<ul style="list-style-type: none"> • They both enjoyed the ACTION training and relaxation programmes • Elsa used the ACTION stroke, transfer and technical aids programmes to help her care for her husband • Elsa learned to use email which helped them to keep in regular contact with their children/grandchildren. She also enjoyed surfing the Internet and playing computer games • Regular contact with the ACTION call centre nurses enabled Elsa to feel more secure in her caring role • Regular contact with other ACTION family carers enabled Elsa to make new friends 	<p>The Needs Assessor, Elsa and Göte are convinced that they would not have managed at home without ACTION. Göte would probably have entered a nursing home (alt. 1), or he would have needed regular periods of respite care at a nursing home and some home help (alt. 2). ACTION, together with day care once a week, enabled them to manage their situation in a way that suited them.</p> <p>The cost saving using ACTION for alt. 1 is 240,200 SEK per year and for alt. 2 is 146,500 SEK per year. For the hypothetical calculation the second alternative has been chosen as this enabled Göte to stay at home in accordance with both their wishes.</p>
Family 2: Britt (74) cares for her husband Yngve (75) who has been disabled since 1980 with a rare form of neurological disorder causing difficulties with many ADLs	<p>Yngve is prone to frequent falls. As a result Britt does not like to leave Yngve alone for any length of time. They had help from the municipality with adapting their house. They also had meals on wheels when Britt was sick.</p> <p>Yngve has two weeks of respite care four times a year. They receive Attendance Allowance. ACTION was installed in their home in June 2000.</p>	<ul style="list-style-type: none"> • The ACTION programmes about being a family carer, falls and information about choking were of direct benefit to Britt in her caring situation • The ACTION exercise/relaxation programmes helped Britt to feel less anxious • Regular contact with other family carers in ACTION and e-mail contact with her children and grandchildren helped Britt to feel less lonely and isolated • Weekly contact with the ACTION call centre nurses helped Britt to feel valued as a carer • Britt enjoys using the computer and has enrolled on an advanced computer course with four other ACTION carers 	<p>Without ACTION, Britt acknowledges that she would be more anxious. The Needs Assessor also considered there was a risk that she could become depressed and then would no longer be able to manage her caring situation, resulting in Yngve being cared for in a nursing home (alt. 1) or requiring two weeks of respite care in a nursing home every month (alt. 2).</p> <p>The cost saving using ACTION for alt. 1 is 218,600 SEK per year and 117,600 SEK per year for alt. 2. For the hypothetical calculation the second alternative has been used as Yngve can stay at home in accordance with both their wishes.</p>
Family 3: Tore (82) cares for his wife Inga (83) who has had a stroke	<p>Inga returned home to their first floor flat following an initial period in hospital followed by respite care in the municipality. For the first month they had some home help. After this, they managed on their own. Inga attended a day centre one day a week in order for Tore to get a break. They also received Attendance Allowance. Prior to her stroke, Inga managed all household chores. They became involved in the Swedish ACTION project in September 2000. Inga moved into a nursing home in the Summer 2002 as Tore became seriously ill with cardiac insufficiency and prostate cancer.</p>	<ul style="list-style-type: none"> • Tore gained practical help and support with food preparation from the ACTION Eating and Drinking programme • He also learnt via the Transfer programme how to transfer Inga safely which made Inga feel more secure • Contact with other ACTION family carers helped Tore in his role as a novice carer • Access to the ACTION call centre nurses enabled Tore to feel more secure in his caring situation • Tore was able to spend more quality time with Inga as he was able to carry out his banking over the Internet • ACTION enabled Tore and Inga to understand each other better and come closer to each other 	<p>The Needs Assessor, Tore and Inga agreed that without ACTION they would have needed at the very least more home help (alt. 1), or Inga would more realistically have needed to move into a nursing home much earlier (alt. 2).</p> <p>The actual costs using ACTION give a cost saving of 382,500 SEK per year for alt. 1 and 344,000 SEK per year for alt. 2. Alt. 1 was chosen by Inga, Tore and the Needs Assessor. This would have been more expensive for the municipality. However, it is in accordance with the municipality's principle of 'ageing in place' and, more importantly, it is in accordance with Inga and Tore's wishes.</p>

Table 5 (Continued)

Family	Care history	Benefits from ACTION	Cost assessment*
Family 4: Maja (82) cares for her husband Gösta (83) who has had a stroke and has Parkinson's disease, in addition to memory loss	<p>Their caring situation became more difficult when Maja felt that she could no longer leave her husband alone at home. They also began to feel more isolated as they had less contact with their friends. They received no care services from the municipality apart from Attendance allowance. The Needs Assessor previously advised them that it would be beneficial for both of them if Gösta attended the local dementia day centre. Neither Maja or Gösta wanted this. However, they visited the day centre on several occasions. ACTION was installed in their home in Spring 2002. They also receive advice and support from staff in the dementia day centre.</p>	<p>Maja learnt more about dementia and how to care for and support her husband via the ACTION Dementia programme</p> <ul style="list-style-type: none"> Regular contact with the ACTION call centre nurses and the dementia day centre helped Maja feel more secure as she knew that help was close at hand Regular social contact with other ACTION family carers prevented Maja from becoming isolated 	<p>Maja recognized, along with the Needs Assessor, that if she did not receive help and support to get a regular break from caring (alt. 1) she would be at increased risk of developing health problems herself and Gösta would then probably need to move into a nursing home (alt. 2). The Needs Assessor considered that contact with the ACTION call centre nurses and the dementia day centre staff could help them to consider the support options available.</p> <p>The preferable alternative according to the Needs Assessor and Maja gives a cost saving of 326,400 SEK per year. This is the alternative that is used in the hypothetical cost calculation.</p>
Family 5: Ingrid (72) cares for her husband Kurt (75) who had a stroke in July 1999	<p>Following an initial period of hospitalization, Kurt moved to a respite care unit in the municipality whilst their house was being adapted so that he could live at home. At home, they had home help twice a week initially and then on an occasional basis depending on Ingrid's health. Kurt attended a rehabilitation day centre twice a week. They received Attendance Allowance and Kurt was eligible for a transportation service. ACTION was installed in September 2000.</p>	<ul style="list-style-type: none"> They both learnt more about stroke & Ingrid learnt how to care for Kurt, in particular, transferring & about the technical aids available The ACTION call centre enabled them to access ongoing professional support as well as advice on an 'as needed' basis Regular social contact with other ACTION families helped them to reduce their feelings of isolation and loneliness ACTION helped Ingrid to be aware of her own strengths and skills as a carer 	<p>Ingrid and Kurt agreed with the Needs Assessor that they would not have managed without the support they received from ACTION. The alternatives would have been more home help or a nursing home. The Needs Assessor considered Inga needed help on a daily basis (alt. 1). However, Ingrid felt it would have been sufficient to have home care services twice a week (alt. 2).</p> <p>The hypothetical calculation is based on an average cost saving between alt. 1 and 2 with a cost saving of 115,350 SEK per year. The decision is based on the fact that Ingrid was resolute in her wish to take care of her husband at home with as little help as possible. This also reflected Kurt's wishes. However, the Needs Assessor considered it was necessary for them to have more help, otherwise Ingrid would no longer be able to sustain her caring role because of her own health status.</p>

*See also Table 6.

Table 6 Actual care costs and hypothetical cost savings using ACTION per family per year in Swedish Crowns*

	Care services	Actual cost using ACTION [†]	Estimated costs not using ACTION [†]		Cost saving using ACTION [†]
			Alt. 1	Alt. 2	
Family 1	Day care once a week	33,800			
	Attendance Allowance	14,112			
	ACTION	25,800			
	Home help, once a week	14,560			
	Home help, twice a month				7,280
	Respite care				227,500
	Nursing home			328,500	
	Total cost [‡]	88,300	328,500	234,800	146,500
Family 2	Attendance allowance	14,112			
	ACTION	25,800			
	Respite care, four times a year	70,000			
	Respite care, 2 weeks per month				227,500
	Nursing home			328,500	
	Total cost [‡]	109,900	328,500	227,500	117,600
Family 3	Day care one day per week	16,640			
	Attendance allowance	14,520			
	ACTION	25,800			
	Home help, 2 people 2 times/day			439,460	
	Nursing home				401,000
	Total cost [‡]	57,000	439,500	401,000	382,500
Family 4	Attendance allowance	14,520	14,520		
	ACTION	25,800	25,800		
	Day care 1 day per week		34,320		
	Nursing home				401,000
		Total cost [‡]	40,300	74,600	401,000
Family 5	Day care twice a week	33,280	33,280	33,280	
	Attendance allowance	14,520	14,520	14,520	
	ACTION	25,800			
	Home help, 2 people 2 times/week			62,600	
	Home help, 2 people 2 times/day				219,730
		Total cost [‡]	73,600	110,400	267,500
Average [‡]		73,800	256,300	306,360	217,700

*Exchange rate 28.6.2002: 1 EUR = 9.08 SEK, 1 GBP = 14.01 SEK, 1 USD = 9.16 SEK (The Swedish Riksbank).

[†]See also Table 5.

[‡]Rounded to closest 100 Crowns.

the estimations are not entirely accurate. To make the estimations as credible and objective as possible, need assessors with extensive experience of assessing older people's needs and who were also familiar with the families' situations were closely involved.

As to the question of whether the comparator was appropriate, we consider that ACTION does not really have an appropriate comparator because it is a new service that empowers older people and their carers by enabling them to make informed decisions about their caring situation. Thus, there are associated difficulties of developing appropriate outcomes that are sufficiently sensitive to measure the effect

of ACTION, given that services such as this are often preventive in nature and the majority of older people and their carers have chronic progressive health conditions (Magnusson *et al.* 2004).

The question of whether the quality of the medical evidence is adequate links to the previous issue about the comparator. Mair *et al.* (2000) and Whitten *et al.* (2002) argue that it is usually assumed that the benefits of the traditional service and the ICT-based service are equal, which rarely is the case. As previously explained, it is difficult to compare the benefits of ACTION with those of nursing home or more help at home, given the different aims of the services.

As there is not any appropriate comparator available, the cost description analysis was carried out in relation to the total care cost savings for the five families.

In answer to the question whether appropriate costs and benefits were considered, it has to be acknowledged that future costs were not included. Future costs for equipment and communications will probably decrease because of increased supply and demand in ICT services by computer literate adults of working age (Ballabio & Moran 1998). However, the expectations and wishes for higher specifications and more sophisticated solutions among the next generation of older people is likely to increase (Cowan & Turner Smith 1999). Moreover, the issue of technology obsolescence was not taken into account in the cost description analysis. However, to minimize this possibility, ACTION worked with 'state of the art' technology in research and 'off the shelf' equipment and solutions (Kraner *et al.* 1999). No costs were included for further research and development work. The analysis only included costs for maintenance of the service. This is a weakness in the study that must be addressed in future cost effectiveness work, which would need to include a comprehensive sensitivity analysis to take into account such issues as well as the effect of marginal costs and short-term vs. long-time savings.

Another important question is whether an adjustment of costs and benefits should be made for differential timing. The case cost description analysis was carried out at one particular point in time, as opposed to using a longitudinal design. Thus, short-term cost savings with ACTION may be feasible as a result of more optimal use of home care services, respite services and delayed entry to institutional care. However, in the long-term, this could easily be off-set by an increased demand for home-based IT services, given the current high levels of unmet existing needs amongst older people and their carers in the community (Magnusson *et al.* 2004).

No marginal cost analysis was undertaken, which is another important issue raised by Mair *et al.* (2000) and Whitten *et al.* (2002). However, we consider that the marginal costs for a new user are largely the same as for existing users, because the main cost is equipment, communication and support. Additional services, such as virtual home visits by physicians, monitoring health status and alarm systems, can easily be added to the ACTION service at a reasonable cost as the ACTION families already have computer, videophone, broadband and Internet access.

Having acknowledged the main limitations of the ACTION case study cost analysis, it is important to consider the strengths of the study. In answer to the question whether there was a clear hypothesis, the study had a clear precise hypothesis that included the local context.

In response to the question of whether there was a clear statement about whose perspective was used to assess cost-effectiveness, our cost study was conducted from the users' perspective, namely the family carers and, wherever possible, the older person they cared for, but also from the professional providers' perspective. This is in contrast to the majority of cost studies, which only focus on professionals' views (Mair *et al.* 2000, Whitten *et al.* 2002). The case studies vividly highlight the benefits of ACTION for older family carers who are resolute in their desire to care for their aged partner at home, and wish to retain as much control as possible over their caring situation. In particular, there were increases in their perceived independence, autonomy, self-esteem and caring competence, and a major reduction in social isolation.

Finally, we need to consider whether the analysis was appropriate to the local environment. This can be seen to be the case, as all the key players were actively involved, including older people, families and practitioners in both the municipalities (Magnusson *et al.* 2005).

However, the main strength of the study lies in the events that followed the evaluation, as both municipalities decided that ACTION would become part of their family carer support services. In reaching this decision, local politicians considered the evidence available from the evaluation of the Swedish ACTION service, including the quality of life benefits for older people and their family carers, enhanced work satisfaction of nurses and other professionals directly involved in the project, and the cost study data (L. Magnusson, I. Eriksson, F. Edberg, P. Svensson & R. Lidskog unpublished data). We firmly believe that the politicians would not have decided to continue with ACTION without such multiple sources of evidence to support their decision.

Clearly, it is not possible to generalize from the results of this small cost study. However, it can be argued that it is possible to replicate the evaluation of ACTION in other municipalities across Sweden, as the evaluation work was conducted in municipalities with similar geographical and demographic circumstances to other municipalities in Sweden. However, it is important that future cost studies address the key limitations raised in our discussion.

It should also be possible to replicate the evaluation work in other European countries, as ACTION began as an EU-project in five partner countries. Quality of life and usability results were positive, and the developments to the Swedish ACTION service were based on the temporal model for family care support and user involvement methodology that informed the original study (Hanson *et al.* 1999a, Magnusson *et al.* 2002a). However, research and development work would also need to involve translation and cultural adaptation, which was not costed in the original EU project.

What is already known about this topic

- Nurses working in community care need to explore the potential of information and communication technology-based support services as an innovative and cost-effective way of working.
- The current evidence base on the cost-effectiveness of technology-based services for older people and their families is relatively weak and further research in this area is needed.

What this paper adds

- Technology-based support services have the potential to empower frail older people living at home and their family carers whilst yielding cost savings in community care services.
- Partnership is important when working with older people, their family carers, nurses and managers in order to transform an innovative project into a cost-effective mainstream service.

Conclusion

This paper has highlighted the complexity of evaluating the cost effectiveness of ICT-based support services. The next step is to take the lessons learned from the initial cost study and to conduct a full randomized controlled trial and a detailed sensitivity analysis.

However, the success of the study locally demonstrates what can be achieved. All too often innovative services are never adopted after the initial financial support has been withdrawn. This study has indicated that this need not be the case. In response to demographic challenges and rapid developments in our current information society, nurse managers might more actively explore the potential of innovative ICT-based support solutions for older people and their carers in their local communities by involving other decision-makers, practitioners and service users. Finally, nurse educators at all levels need to teach nurses about the current evidence base for the use of ICT in health and social care in the community.

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Author contributions

LM and EH were responsible for the study conception and design, drafting of the manuscript and obtained funding; LM performed the data collection and analysis; EH made critical revisions to the paper and supervised.

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