Multimedia Software to Help Caregivers Cope

Mary G. Chambers, DPht, CEd, RN, DN, RNT, Samantha L. Connor, MSc, Mary McGonigle, MEd CEd, RGN, RM, Mike G. Diver, BSc

Abstract
Objective: This report describes the design and evaluation of a software application to help caregivers cope when faced with caring problems and emergencies.

Design: The design process involved users at each stage to ensure the content of the software application was appropriate, and the research team carefully considered the requirements of disabled and elderly users.

Measurements: Focus group discussions and individual interviews were conducted in five European countries to ascertain the needs of caregivers in this area. The findings were used to design a three-part multimedia software application to help family caregivers prepare to cope with sudden, unexpected, and difficult situations that may arise during their time as a caregiver. This prototype then was evaluated via user trials and usability questionnaires to consider the usability and acceptance of the application and any changes that may be required.

Results: User acceptance of the software application was high, and the key features of usability such as content, appearance, and navigation were highly rated. In general, comments were positive and enthusiastic regarding the content of the software application and relevance to the caring situation.

Conclusion: The software application has the potential to offer information and support to those who are caring for the elderly and disabled at home and to help them prepare for a crisis.


Background
Meeting the needs of the aging population and providing adequate care and support are challenges that our society must address.1 When caregiving is needed, family members provide most of the support, yet frequently find that they are unprepared for their new roles.2 Despite the significant contribution of caregivers to society, there is a wealth of evidence to suggest that their needs remain largely ignored.3,4 The knowledge and skills that family caregivers need to fulfill their role are learned “on the job” by a process of trial and error.5 As they wrestle with the realities of their role on a day-to-day basis, they develop competence and will ultimately become experts at what they do.6 Nolan et al.7 point out that many caregivers do not make contact with formal services until they are well established in their caregiving role. In light of this knowledge, it is not surprising that caregivers have come to rely on the process of trial and error to cope with caregiving.

Previous Home-based Telehealth Projects
With the growth in the use of information and communications technology and the pressure to provide low-cost, high-quality health care, researchers are seeking new ways to provide information and support for consumers. The literature revealed a number of projects that have utilized information and communications technology in home care. An early project, the ComputerLink project,12 provided computer-based information, communication, and decision support for people with acquired immunodeficiency syndrome (AIDS) and caregivers of Alzheimer patients. In a randomized field experiment involving 102 caregivers of Alzheimer patients, 47 caregivers had access to ComputerLink for 12 months. Behavioral indicators of use demonstrated that ComputerLink promoted collaboration by

Affiliation of the authors: School of Nursing, University of Ulster at Coleraine, Northern Ireland.

This work was supported by the European Commission Fourth Framework DGXII Telematics Application Programme, Disabled and Elderly sector. The authors thank the families, professional carers, and researchers who participated in the development of this software application.

Correspondence and reprints: Professor Mary Chambers, Room B035, School of Nursing, University of Ulster at Coleraine, Cromore Road, County Londonderry, Northern Ireland, BT52 1SA; e-mail: <mga.chambers@ulster.ac.uk>.

Received for publication: 09/28/01; accepted for publication: 05/04/03.
communication among caregivers and facilitated access to information. The results of pre- and postintervention interviews showed that ComputerLink appeared to be an effective tool for reducing strain for some caregivers.

The Comprehensive Health Enhancement Support System (CHESS) was used to provide HIV-positive patients with information, decision support, and connections to experts and other patients. A randomized controlled trial was conducted with 94 subjects receiving the CHESS intervention and 89 subjects in the control group. Subjects were surveyed pre- and posttest using measures of quality of life and health behaviors. The implementation of CHESS improved quality of life across a range of measures. Similar results also were found with patients with breast cancer and Alzheimer's disease.

HeartCare was an Internet-based information and support system providing individually tailored information and support for patient home recovery after coronary artery bypass surgery. The information contained in HeartCare was developed through a critical evaluation of over 1,000 existing Internet health information sites, with the development team adding information to fill the content gaps. A key strength of the system is that the health information is individually tailored to patient needs, and patients are able to access peer and professional support via e-mail.

The ACTION Project
This report describes the development of a multimedia software application to provide family caregivers with information and education to assist them in preparation for caring problems and emergencies. The software application was developed as a part of the ACTION (Assisting Carers using Telematics Interventions to meet Older Persons Needs) project. This was a European project in which technology acted as an important tool for family caregivers, providing information and education, as well as being a medium for increased communication and support. The project involved partners from Northern Ireland, the Republic of Ireland, England, Portugal, and Sweden and was originally funded by the European Union through the Fourth Framework Telematics Programme (1997–2000). The primary aim of the project was to maintain or enhance the autonomy, independence, and quality of life of frail, older, and disabled people and their family caregivers by the application of technology. Family caregivers were able to communicate directly with professional carers and other family caregivers as well as access educational and support material.

Previous findings suggest that family caregivers are in need of information and support in their roles. The ACTION project combined the strengths of earlier research by the provision of information validated by both professionals and family caregivers. The application described in this report differed from previous studies because it used a more generic rather than disease-specific approach to caring and had the caregiver as the focus. Other home telemedicine projects are reported in the literature; however, professionals drove the design. The ACTION project used a user- rather than professional-driven approach to both development and evaluation and addressed the previous absence of user-centered design in home telemedicine projects. Although this iterative design process is challenging and time-consuming, these challenges are worthwhile to have an end product that is relevant to users, meeting their needs and requirements.

Exploratory Needs Assessment
Fifteen focus group discussions were conducted across the five partner countries, three in each country, involving 42 family caregivers and 57 professional carers. Family caregivers were asked about their needs in daily life, their experience of technology, their need for relief, respite care and long-term planning, their coping skills, and requirements for financial information and economic support. Professional caregivers were asked their views about family caregiver needs in the above areas.

Themes and key issues identified from the focus group data were used to develop a questionnaire in conjunction with reviewed literature and personal experience. This questionnaire was designed to explore caregiver needs in five key areas—needs in daily caregiving, respite care and long-term planning, coping skills and emergency interventions, financial information and economic support, and the use of supportive telematics interventions. Four hundred fifty-one questionnaires were returned, results were put into the SPSS statistical package, and descriptive statistics were obtained. The findings of the focus groups and questionnaires corroborated the findings of previous literature: family caregivers felt their needs were not being met, and they required more information about many aspects of caring. To address these needs, six software packages were developed specifically for family caregivers. These were caring in daily life, with particular focus on moving and lifting, incontinence, and feeding; respite care and long-term planning; an instrument to determine caregivers' coping capacity; strategies to deal with emergency situations; a database of financial information; and using technology. These packages then were validated by each of the countries involved, and the results of this evaluation were fed back to the development teams, which resulted in a further prototype of the ACTION system.

This report presents the usability evaluation for one part of the ACTION system, a software program designed to provide family caregivers with information and education to assist them in preparation for caring problems and emergencies. The key stages of the development and evaluation process are described: the identification of key content through focus groups and semistructured interviews; design of the program; preliminary user testing of the prototype; and widescale evaluation.

Design and Development of the Software Application
Ethical Considerations
Each partner country received approval from its ethical committee or equivalent. To ensure anonymity in the focus group discussions, individual interviews, and user trials, codes known only to the researcher were assigned to participants for use in transcript material. Furthermore, an assurance was given that the tape recordings would be destroyed once they had been transcribed and only those involved at the analysis stage would have access to the raw data. Participants were suitably informed about all aspects of the research. The scope of participation, the scope and goals
of the research, and background information on the project were all provided in detail. The right to withdraw from the research for whatever reason at any time was stressed. The rationale was that family caregivers would view the program during quiet moments to prepare for caring problems and emergencies. At no time should the program be consulted during a crisis, and this was made clear to the users in the text of the program.

Stage 1—Focus Group Discussions
Focus group discussions were conducted in the first stage to ascertain the perceived needs of family caregivers regarding their caregiving role. A convenience sample of 35 family caregivers participated in the discussions, which lasted between one and three hours each. One focus group discussion took place in each of the five participating countries; questions and formats were identical in all the countries. The interview schedule consisted of a series of open-ended questions. This was intended to encourage the group to explore issues of importance and relevance and trigger other issues as a result of natural discussion. Topics for discussion were situations that the caregivers felt were crises for them, how they dealt with them, what thoughts and feelings went through their minds, whether anyone helped them in these situations, what other resources would help them to cope more effectively, and what first aid information would be useful. Careful thought was given to the sequencing of the questions. Questions requiring factual information were asked at the start of the discussion, whereas those questions requiring greater thought and effort were asked toward the end.

Data from these discussions were transcribed verbatim, and the focus group transcripts from Portugal and Sweden were translated into the common language of English. Data were analyzed using content analysis\textsuperscript{19,20} with the purpose of discovering recurring themes and shared knowledge or experiences.\textsuperscript{21} To further organize the information, the themes were then used to create broad categories.\textsuperscript{22} The results of the content analysis revealed six key areas in which family caregivers in the sample would like to have more information and preparation. These were falling, choking, management of catheters and feeding tubes, bleeding, pressure sores, and eating problems.

Stage 2—Semistructured Interviews
The key concepts from the focus groups were used to construct questions for individual interviews to obtain in-depth qualitative data regarding the process adopted by family caregivers when responding to particular crises. A modification of critical incident technique\textsuperscript{23} was used to focus attention on the six critical incidents identified from the focus group data. A convenience sample of 14 family caregivers, all considered key informers,\textsuperscript{24} participated in semistructured interviews, lasting approximately one and a half hours each. Six of these family caregivers were from Northern Ireland, two were from the Republic of Ireland, two were from Portugal, two were from Sweden, and two were from England. The interviews invariably took place in the homes of the family caregivers.

Family caregivers were asked how they would react if the person they cared for had a fall, a blocked catheter or feeding tube, sudden or heavy bleeding, or a pressure sore; or if they choked or experienced eating problems. The main purpose was to encourage the family caregivers to describe what they had done in response to these events. Several open-ended questions were asked under five main headings—thoughts and feelings at the time of the crisis, appraisal of the situation, particular actions that were taken, resolution of the crisis, and how they coped. Family caregivers described their decision-making process, how they responded to a crisis, how they approached solving ongoing problems, and what information would be helpful.

The Content of the Software Program
The findings from the focus group discussions and interviews were used to design a three-part multimedia software application to prepare family caregivers to cope with caring problems and emergencies that may arise during their time as a caregiver. Despite having different cultural, educational, work, and social backgrounds, the family caregiver experiences and functioning were very similar within the sample. The caregivers interviewed indicated that many factors came into play when they began the process of what to do when faced with an emergency. The replies showed that the family caregivers made an initial assessment of the situation to help them work out how to proceed. They determined the requirements of the task, the adequacy of their existing resources, the accessibility of existing resources, and the urgency of the situation. The family caregivers felt that knowledge of the care recipient, experience as a family caregiver, and the underlying medical conditions of the cared-for person were very important when dealing with a caring problem or emergency. Such responses were used to design the first section of the software application that considered how family caregivers dealt with caring problems and emergencies. Information was given on how to anticipate difficult situations and plan ahead for them, how to cope, and what to do after the problem has been solved or emergency has passed. It was acknowledged that family caregivers needed to “wind down” after experiencing a range of emotions.

The content of the latter sections was based on specific situations in which family caregivers requested help. Again, the needs and experiences of caregivers were very similar across the partner countries. The second section provided information on four common caring problems that the sample of family caregivers in the focus groups felt were most pertinent to them—eating problems, pressure sores, problems with feeding tubes, and urinary catheters. This information was supplemented by graphics where appropriate. The third section introduced the main principles of first aid and detailed how to compile a first aid kit at home. Information was also given on five emergency situations that may confront someone who is a caregiver. These were putting someone into the recovery position; mouth-to-mouth resuscitation and heart massage; and how to cope with falls, bleeding, and choking. A short video clip illustrating the techniques described followed each of these emergency situations. The rationale behind the software is that family caregivers would view the contents during quiet moments to prepare for possible emergencies. This information and education aimed to increase the preparedness of family caregivers and have a positive influence on their self-efficacy and confidence.
The experiences of the caregivers from the focus group and interview data were used together with previous research and clinical practice knowledge in content development. Experienced health care professionals developed the software in consultation with skilled family caregivers and experts in the field and in accordance with appropriate European Union (EU) legislation. A user advisory board made up of representatives from user and health care organizations across Europe validated the content of the system and examined it for accurateness and presentation of facts. A user advisory group of caregivers and user representatives in each country provided the user perspective and help with the development of the system.

**Design Implications Relating to Aging and Disability**

Issues relating to the physical and cognitive characteristics of the end user are imperative in the design of software for the elderly and disabled. Accessibility is a key feature for user acceptance of technology. There are several relevant cognitive, perceptual, and motor changes that occur with increased age. Older adults generally take more time to perform most motor and cognitive tasks. In screen design, this means that fast-moving objects should be avoided. Memory function declines somewhat with normal aging and older adults have difficulty processing complex or confusing information. Taking this into consideration, the amount of information displayed per screen was limited and, as far as possible, images were used to compliment text instructions. Age-related changes to the visual system mean that greater degrees of illumination and greater contrast between objects and their backgrounds often are required. Large writing on the screen was used for those with poor eyesight, and yellow writing on a blue background was chosen because it has high contrast. It was thought that older people may find a computer in their home rather daunting, so familiar technology was used wherever possible. A television set replaced the monitor, and a remote control operates the software instead of a mouse. There also is reduced motor control with increasing age, so it is better to ensure that fine motor control is not needed to operate equipment and that buttons can be used with a minimum of force. The remote control aided ease of use for those with frail hands, because it required less dexterity.

**Supporting Hardware and Software**

The main aim was to make the technology user-friendly and appropriate for the older user. The hardware consisted of a multimedia Windows 95 or 98 PC with ISDN capability connected into the TV of the patient’s family, all operated by a hand-held remote control. The ISDN card allowed video conferencing with professional staff and other caregivers using complementary equipment. A small video camera and microphone completed the video conferencing arrangement.

All information systems and presentations (incorporating pictures, diagrams, sound clips, and video clips) were built using HTML. Shockwave Player was used to present some of the custom-built presentations that were then available via a Web browser. Javascript programming language was used to improve overall control and presentation and assist user input. The system was menu-driven. A switching program written in C++ programming language allowed the user to switch back and forth between the Web browser and the video conferencing system. A technical description of the project can be found in the article by Kraner et al.

**USERfit Methodology**

USERfit methodology was used in the design and evaluation of the software application. This design philosophy is perhaps best captured by the term user-centered. USERfit takes as its basic premise the view that product development should be driven by user requirements as opposed to technological capabilities. USERfit is concerned with ensuring that products have real value for end users, are matched to user capabilities, and are fit for the purpose for which they were designed. The concept of usability is central to USERfit because it is important for developers to consider the characteristics of users, what they want to do, and where and when they want to do it. Usability in design concerns the creation of products and systems that are effective, efficient, safe, and comfortable for the user. The methodology considers definition of the problem (context of use and user analysis) and uses the findings to build and test the product via usability evaluation tools. In-depth details of the variety of tools available can be found in Poulson et al. This manual was used to guide the choice of tools for the research. The authors place emphasis on iterative design, recognizing that developers may have to enter cycles of development and evaluation a number of times before a satisfactory solution is reached. USERfit emphasizes the importance of gaining feedback about how the product performs in actual use during the design process, a common weakness of many design activities. For these reasons, it was decided to evaluate the first prototype of the software application using user trial methodology.

**User Trials**

To test whether the prototype had good functionality and was accepted by the target group, user trials were conducted. These followed the format suggested by Poulson et al. in which real users test the user interface of a product in a relatively controlled or experimental setting. The result is a “problem list” that designers use to improve the usability of a product. The testing procedure originates from experimental psychology and may be performed in a very formal way using controlled experiments and statistical analysis techniques, but the approach described here is a simpler, more qualitative method.

Conducting a user trial requires careful planning to achieve the goal of design feedback. The first step involves planning the logistics, the schedule of the trials, and the number of subjects and compiling the procedure. Poulson et al. state that good results can be obtained from as few as six subjects, but that larger numbers are preferable. The second step involves preparing the test material such as instructions, tasks, scenarios, interview guide, and observation measures.

Groups and individuals were invited to use the software application, working alongside the researchers. Initially, each individual worked at a computer, one on one with a researcher. As the research progressed, groups of users participated in the trial at the same time with one or two researchers. There was no time limit set for completion of the
trials, and every effort was made to make the experience as informal as possible with users made to feel at ease in every way possible.

Users were verbally prompted to talk through what they were doing and express any difficulties verbally as well as their feelings about the process. Each participant read instructions and completed four task scenarios based on the content of the software application.

Task 1
Imagine you have a few minutes to spare as the person you look after is having a rest. You have the ACTION system installed in your house and decide you would like to read how other caregivers approach problems. Use the “Dealing with caring problems” program to learn how others approach caregiving problems.

Task 2
It has been a long time since you had any training, and one evening you decide to access some information using ACTION. Because the person you look after is unsteady on his or her feet and prone to falling, you think it would be good to get some advice on falling in case of an emergency. Use the “Dealing with caring problems” section to access information on falling.

Task 3
The person you care for has been extremely difficult all day, he or she has been uncooperative and, in fact, a little aggressive. He or she has been shouting at you and refusing food. You are tired and don’t know how to deal with these eating problems. Use the “Everyday problems” section of the program to get a few suggestions for how you could deal with this situation.

Task 4
The person you care for had fallen a few weeks ago and cut his or her head. At the time you panicked and now feel that you did not deal with the situation as well as you could have. Use ACTION to gain access to the “Dealing with caring problems” program and get some supportive information from other caregivers on how you could deal with a crisis. Now you decide to revise what you could have done at the time with the injury. Gain access to the bleeding and head injury sections of the program.

Detailed information of which menus to choose to access the relevant information for each task was given. After the participant had completed the four tasks, he or she then was asked a set of predetermined questions about content and usability. These questions explored their feelings during the task, if they found the information they wanted, if the information was appropriate, how they felt about the instructions, how the content could be improved, if the navigation was straightforward, how the presentation could be improved, and any other comments or suggestions.

The replies were recorded on tape. A researcher observed the users and recorded any problems they experienced during the trial, how they behaved in response, and any comments they made. This aimed to identify problems, for instance, any difficulty in using the controls, reading the words on screen, or interpreting the language used. Users were made aware that their feedback would be used to develop a system best suited to their needs and requirements.

Participants
A convenience sample of seven family caregivers and 19 professional caregivers participated in formal user trials of the software application. Twenty-two of these participants were women and four men, with ages ranging from 32 to 78. Family caregivers were selected through contact with local voluntary agencies. These family caregivers were chosen because each was considered to have the necessary insights into caring together with the appropriate social skills. Professional caregivers were selected because they possessed skills and relevant experience to the subject area, for example, first aid experts, nurses, and university lecturers who taught trauma skills.

Data Analysis
Data from the trials were transcribed verbatim as a user trial report. The observational data recorded by the researchers also were incorporated into the report. The key purpose of user trials is to produce a list of problems for the designers/developers of a system for iterative design and the identification of any necessary further improvements. Three members of the research team analyzed the user trial reports by content analysis. The user trial reports were analyzed as a whole to establish an overview of the data. The data then were examined to identify key problems for action.

User Trial Results
User acceptance of the software application was high and the key features of usability such as content, appearance, and navigation were highly rated. In general, comments were positive and enthusiastic regarding the content of the software application and relevance to the caring situation. Some of the suggested changes to the content were subjective and very specific to a particular caring situation, for example, how to care for someone having an epileptic fit. There also were some useful suggestions for modification of the software application, to both content and appearance. A few minor amendments were suggested in the section on eating problems, and more information was requested in the section about falling. It was felt that some of the language and terminology used in the text was a little repetitive and, on occasion, patronizing for caregivers. Users commented that the pictures and cartoons looked good and helped the presentation; however, some felt that the clarity of the graphics could be improved somewhat. Users felt that the quality of the sound and video footage could be enhanced, with older actors in the video footage. The respondents generally liked the use of color and found the yellow writing on a blue background easy to read.

Some professional caregivers felt that it was important to state that the contents were for information only and were no substitute for seeking medical assistance. They also felt that it was important to emphasize that family caregivers should call their doctor immediately if they feel concerned about the health of the care recipient. Several respondents stressed the need for a disclaimer at the beginning of the information and an introduction to emphasize that if the caregiver was not competent in first aid, he or she should immediately call for medical assistance.
After the user trials, the following changes were made to the software:

- A disclaimer was added at the beginning to remove liability.
- More detailed information was added in particular sections, for instance, on falling in the home.
- Wording of certain parts was adapted to a more user-friendly language.
- General improvements were made to sentence structure to improve overall clarity.
- Larger and clearer photographs and pictures were added.
- Improvement was made in the navigation of the software application.

Usability Evaluation

The objective was to evaluate the usability of the modified software application. Family caregivers, care recipients, and professional caregivers were targeted in 25 health care sites including urban and rural nursing/residential homes, general practice offices/health centers, and rehabilitation centers. The software also was taken on a laptop to various educational sites and home settings of family caregivers in the five partner countries of England, Northern Ireland, the Republic of Ireland, Portugal, and Sweden. Participants were encouraged to use the software, complete an evaluation questionnaire, and place it in an envelope. The sealed envelopes were placed in boxes and collected by the researchers, and only a code number identified questionnaire s to ensure responses were anonymous.

Participants

A total of 234 casual users completed evaluation questionnaires. These were defined as individuals using the software application for the first time. Thirty of these were care recipients, 97 were family caregivers, and 107 were professional caregivers. The majority of respondents (76%) were women. A description of the sample is given in Tables 1–3.

Data Collection Instrument

The Website Analysis and MeasureMent Inventory (WAMMI) usability instrument version 2.5\textsuperscript{31} was used under license for evaluation purposes. The authors developed the five usability subscales of Attractiveness, Control, Efficiency, Helpfulness, and Learnability from analysis of large numbers of responses by subjects. The Attractiveness scale indicates if users find the software to be visually pleasant and of direct interest in both functionality and information. The Efficiency scale measures whether users can quickly locate what is of interest to them and if the software responds at a reasonable speed. The Learnability score shows whether users can use the software with the minimum of introduction and whether everything is easy to understand from the start. The Controllability scale measures how easily users navigate around. The scale of Helpfulness measures whether the software corresponds with user expectations about content and structure. Version 1 of the instrument achieved Cronbach’s alpha reliability coefficient measures of 0.7 for control, 0.83 for efficiency, 0.86 for learnability, 0.89 for helpfulness, and 0.90 for attractiveness, a combined reliability of 0.96. Version 2.5 used the 20 most reliable items from version 1 while retaining the five subscales. The WAMMI took approximately 15 minutes to complete, and some minor changes were made to the wording in consultation with the author.

Data Analysis

Questionnaire data were checked, coded, and input into the Statistical Package for the Social Sciences for Windows (Version 9.0). As per the license agreement for the WAMMI questionnaire, the SPSS file for each country was sent to the author for analysis in the form of the standard WAMMI data report. The WAMMI data report included an overall usability score; a general rating; a more detailed usability profile in terms of attractiveness, controllability, efficiency, helpfulness, and learnability; and a detailed listing of aspects that are especially good or problematic. In the interpretation of usability for the questionnaire, a score of 50 is average; therefore, below 50 is lower than average and above 50 is above average.

Usability Questionnaire Findings

User ratings of the software application from the WAMMI questionnaire are detailed in Table 4. Usability analysis generated a Global Usability score well above average. The highest score was on the scale of Helpfulness; however, the software scored highly on all subscales.

More in-depth analysis of each of the 20 statements in the WAMMI questionnaire showed the amount of agreement or disagreement users expressed with each. These ratings were given on a scale of 1 to 5, with 1 representing strongly disagree and 5 representing strongly agree. This identified the strongest features of the software application and those that required any improvement. Statements such as “Everything is easy to understand,” “The program seems logical to me,” and “It helps me find what I am looking for,” received a very high level of agreement. Only a few areas received slightly weaker ratings—“Learning to find my way around is a problem” and “Remembering where I am is difficult.”

Table 1 ■ Countries of Origin of the Users of the Software

<table>
<thead>
<tr>
<th>Country</th>
<th>Number (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Ireland</td>
<td>59 (25%)</td>
</tr>
<tr>
<td>Sweden</td>
<td>54 (23%)</td>
</tr>
<tr>
<td>England</td>
<td>42 (18%)</td>
</tr>
<tr>
<td>Portugal</td>
<td>49 (21%)</td>
</tr>
<tr>
<td>Republic of Ireland</td>
<td>30 (13%)</td>
</tr>
</tbody>
</table>

Table 2 ■ Age Range of the Users of the Software

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Number (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;20 years</td>
<td>9 (4%)</td>
</tr>
<tr>
<td>20–29 years</td>
<td>54 (23%)</td>
</tr>
<tr>
<td>30–39 years</td>
<td>49 (21%)</td>
</tr>
<tr>
<td>40–49 years</td>
<td>63 (27%)</td>
</tr>
<tr>
<td>50–59 years</td>
<td>35 (15%)</td>
</tr>
<tr>
<td>60–69 years</td>
<td>12 (5%)</td>
</tr>
<tr>
<td>70–79 years</td>
<td>7 (3%)</td>
</tr>
<tr>
<td>&gt;80 years</td>
<td>5 (2%)</td>
</tr>
</tbody>
</table>

Table 3 ■ Length of Time Caring among the Users of the Software

<table>
<thead>
<tr>
<th>Time Range</th>
<th>Number (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;6 months</td>
<td>23 (10%)</td>
</tr>
<tr>
<td>6 months–3 years</td>
<td>79 (34%)</td>
</tr>
<tr>
<td>&gt;3 years</td>
<td>102 (46%)</td>
</tr>
</tbody>
</table>
The body of literature on family caregiving stresses that the needs of family caregivers are not adequately being met by current services. The Needs Assessment complemented the findings of this professional literature. One particular area in which caregivers requested help was coping with caring problems and emergency situations. Researchers have found that family caregivers often learn to cope with their role through trial and error, eventually becoming experts at what they do. This report has described the user-centered development of a software program, the content of which integrates the expert knowledge of both family caregivers and the clinical practice knowledge of professionals.

The design process had three key stages:

- Needs Assessment—a preliminary focus group and survey identifying the concerns of family caregivers.
- Design Development—second focus groups and in-depth interviews.
- Usability Evaluation—user trials and WAMMI assessment.

This process took a year to complete, and although this is costly in terms of time, it is worthwhile to have an end product tailored to the requirements of the end user. The iterative nature of the design process meant that the software could be changed during design and development, rather than major changes being made as a result of the usability evaluation.

An identical design process was used in the development of all the programs comprising the ACTION system. In terms of compiling content, some issues arose due to the multicountry nature of the project. These issues were ensuring applicability of the information and that the techniques illustrated were acceptable across all partner countries and making sure that important elements of any procedure were clear and unambiguous in terms of both content and illustration. Because of differences in language and culture, some meaning may have been lost through translation of the question schedules and caregiver comments. Despite this risk, the findings represent a unique piece of cross-cultural caregiving research, raising important issues worthy of exploration.

USERfit methodology was found to be an excellent form of user-centered design, providing detailed data from the perspective of future users of the software. The design and development approach is generalizable with a little modification to any study requiring user-centered design. At the time of the study evaluation, there were few appropriate questionnaires available with which the software could be evaluated. The WAMMI was designed originally for evaluating the usability of Web sites and, as such, was not wholly appropriate for the study. In hindsight, a reliable and valid questionnaire specifically dedicated to this kind of technology would have been more useful and would be a recommendation for future evaluations of this type.

The main difficulty of using this type of methodology with this user group was time. By nature of being a family caregiver, it is difficult to find time to attend a focus group meeting, user trial, or questionnaire evaluation sessions, and, as a result, sample sizes were not as large as originally hoped. Family caregivers also were unable to leave the cared-for person in some circumstances. A recommendation for future application of user-centered methodology research with this user group would be for the researchers to provide paid care for the elder while the caregiver is participating in the research. Another recommendation would be for the researchers to conduct research in the homes of the family caregivers with the software loaded on a laptop.

The overall scales on the WAMMI scores were well above average, with the helpfulness, attractiveness, and efficiency of the software receiving the highest ratings. The navigation aspects received a slightly lower rating. These results were borne out when individual items were analyzed. These data show that the software application demonstrates the key aspects of usability of being easy to learn, efficient to use, easy to remember, and subjectively pleasing.

Conclusions

It is acknowledged that because of the size of the study, the results must be considered as tentative rather than definitive, but the findings nevertheless make an important contribution to existing knowledge about family caregivers and the context of caring. From the data, it would appear that the software application has the potential to offer information and support to those who are caring for the elderly and disabled at home and to help them prepare for caring problems and emergencies. The manner in which this is done, both in terms of software content and the practical application of technology, is in need of further refinement. This research shows the importance of considering carefully the design issues relating to the end user group when designing software, the importance of iterative design, and the value of involving users in the design process.

Current Status of the Action Project

Currently, the ACTION system is installed in a number of family homes and professional sites across the participating countries, and more content has been added to tailor the information to certain conditions such as multiple sclerosis and dementia.

References


Table 4: Numeric Summary of WAMMI Questionnaire Ratings

<table>
<thead>
<tr>
<th>WAMMI Scale</th>
<th>Score</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attractiveness</td>
<td>65</td>
<td>65.51</td>
<td>25.15</td>
</tr>
<tr>
<td>Controllability</td>
<td>60</td>
<td>59.87</td>
<td>29.49</td>
</tr>
<tr>
<td>Efficiency</td>
<td>65</td>
<td>67.40</td>
<td>23.93</td>
</tr>
<tr>
<td>Helpfulness</td>
<td>74</td>
<td>69.58</td>
<td>23.81</td>
</tr>
<tr>
<td>Learnability</td>
<td>63</td>
<td>61.20</td>
<td>28.83</td>
</tr>
<tr>
<td>Global usability</td>
<td>64</td>
<td>64.35</td>
<td>19.90</td>
</tr>
</tbody>
</table>