How Can Telehomecare Support Informal Care?

Examining What is Known and Exploring the Potential

Final Report

submitted to:

Home and Continuing Care Policy Unit
Health Canada

Submitted by:
John C. Hogenbirk, MSc
Linda Liboiron-Grenier, BA
Raymond W. Pong, PhD
Centre for Rural and Northern Health Research
Laurentian University
and
Nancy L. Young, PhD
Population Health Sciences
The Hospital for Sick Children

May 31, 2005

ISBN 1-896328-15-6

Executive Summary

Telehomecare and the broader field of telehealth continues to gain prominence and support as evidenced by the financial and political support from governments all over the world. Many health care commissions have advocated the wider use of telehealth, particularly in rural, northern and remote settings. The importance of expanding homecare and supporting informal caregivers and the potential role for telehealth, or more specifically telehomecare, has also been given strong support. This report examines the potential impact of telehomecare on informal caregivers (ICGs).

The literature review and synthesis focussed on studies of telehomecare and ICGs with direct relevance to Canada for documents published between 1990 and the first three months of 2005. We searched several on-line bibliographic databases including Ovid, EBSCOhost, Academic Search Premier, Telemedicine Information Exchange, ProQuest and Web of Science. These were augmented by searches on the world wide web, search of specific journals, consultations with experts and examination of the literature cited section of retrieved documents. Documents identified through keyword searches were screened to select those that dealt specifically with telehomecare and ICGs. The result was a summary (Appendix 1) of 48 telehomecare documents and 12 informal care documents. These documents were augmented in the report by other publications of particular relevance to the impact of telehomecare on ICGs.

We also searched on-line databases and the world wide web for telehomecare projects or programs, focussing on Canadian projects and selected international projects. Thirty Canadian projects and 71 selected international projects were identified and summarized in Appendix 2.

The report provides a brief summary of informal care in Canada, collected from various sources, to paint the background picture for this literature review. The report then reviews the available literature on telehomecare and ICGs by synthesizing the main finding in five main themes: *Access*, *Acceptability*, *Integration*, *Quality* and *Benefits & Costs*—all defined from the point-of-view of the ICG.

Access is defined as the availability of the right support services at the right time without undue burden. The main finding was that telehomecare improves access to care and support services for ICGs, though data are sparse.

Acceptability is the degree to which ICGs are satisfied with a service or are willing to use it. Data abound, but are largely anecdotal. The picture that emerges is that prior positive exposure to the use of information or telecommunications technology by the ICG leads to greater utilization and higher satisfaction. Perhaps one strategy to encourage acceptance and utilization of telehomecare is to start the service gradually, with training adapted to the individual and demonstrate its advantages before ICG burden becomes too high.

Integration is defined as the degree to which telehomecare services and other health care services work with one another to support the needs of the ICGs, reduce care burden or improve quality of life. Data are sparse and largely anecdotal, though there is an increasing number of examples of widespread use of telehomecare services in Canada and internationally. The issue of integration seems to be one that is resolved on an ad hoc basis by the individual programs, organizations and jurisdictions and, unfortunately, is not well documented.

Quality of Technical Service relates to the performance of telehomecare equipment and technical support services, plus measures of the match between home and equipment, with emphasis on the impact on the ICG. Evidence is sparse for measures of technical service quality in the databases that we searched. The information may be available in trade or technical journals. Or, once again, it may be an issue that is solved as required, shared informally and not well documented.

Quality of Interventions assesses the degree to which telehomecare service compares favourably to alternative support services provided to the ICG. The little evidence that is available suggests that ICGs find the telehomecare interventions to be as good as or better than the standard intervention.

Quality of Outcomes is the degree to which telehomecare service directly or indirectly reduces the care or cost burden or improves health outcomes of ICGs. A synopsis of the findings from randomized clinical trials (RCTs) suggest that caregiver depression is reduced by telephone support for ICGs of stroke survivors and may be reduced or unaffected by telephone-computer interventions for ICGs of Alzheimer's patients. Caregiver burden was not affected by telephone support for ICGs of stroke survivors or Alzheimer's patients. There was partial support for improvement in outcomes such as strain, bother, problem-solving, preparedness, social functioning, quality of life or anger. For ICG satisfaction, there was some evidence for improvement or less of a decrease relative to the control. The caveat is that the majority of the studies focussed on telephone/computer support of ICGs of Alzheimer's patients and to a lesser extent on ICGs of stroke survivors.

Benefits and Costs include dollars, time, convenience, mental and physical health or well-being and so forth. Economic evaluations rarely, if ever, consider the impact on the ICG. It seems likely, however, that ICGs would save money and time if telehomecare can reduce the need for travel. ICGs have stated in several studies that they consider telehomecare a convenient and time-saving method of receiving health care services, advice, information and other support services. Another benefit is the reduction in family separation by allowing the patient back into the home. There is a downside, however, if the equipment, need for care, anxiety, etc., interfere with family functioning. ICGs welcomed virtual visits with providers and with care recipients who may be residing (temporarily) in a health care institute. ICGs and care recipients (CRs) were very reluctant to have virtual visits replace all face-to-face visits. Educational interventions may raise expectations of services available elsewhere that cannot be supplied in the current location, though it may increase ICG and CR advocacy for these services.

There are a few limitations worth noting. Very few telehomecare documents measured the impact on the ICG: most measured the impact on the CR or on the health care system. Studies that were the exception focussed on interventions to support the ICG. A few studies considered the impact on both the ICG and CR. Of the 48 documents summarized in Appendix 1, 42% used descriptive study designs and 27% used comparative designs. Those studies that did employ comparative designs had small sample sizes or strict screening criteria for ICG eligibility or examined specific telehomecare applications such that results were not readily generalizable. Limitations to our search strategy seem relatively minor: a literature review of information and communications technology in support of family caregivers published in 2004 found similar numbers of documents.

The following major findings, implications and recommendations are listed, with the above caveats noted.

- There is a large number of health and health-education services that could be offered via telehomecare, but telehomecare is not a one-size-fits-all solution;
- Telehomecare has improved access by ICGs to support services and has improved communication among CRs, ICGs and formal care providers;
- Most ICGs accept and are highly satisfied with support services;
- Telehomecare can be a success when:
    - The ICGs' technical skill level matches (or is trained to match) the level needed to use the telehomecare equipment;
    - ICG support of all types is built-in right from the start;
    - The ICG’s perspective and feedback is sought on a regular basis;
    - The impact on ICGs is measured on a regular basis and used to modify the program accordingly.
    - Technologies and programs are designed and adopted with the needs of CRs and ICGs in mind, rather than driven by the technology developer or vendor incentives.
    - Telehomecare becomes integrated with existing health care services, particularly with respect to continuity of care or care management.

Additional recommendations and challenges were identified from the knowledge and knowledge gaps:

- Policies, guidelines or standards may be needed to determine who has the responsibility for care and under which circumstances should it/can it be transferred to others;
- Policies, etc., may be needed to recognize the importance of proper assessment of the CR and ICG during the transition from formal care institution (e.g., hospital, nursing home) to home (with telehomecare services) and back again. In other words, telehomecare needs entry and exit policies;
- The quality of the intervention and quality of the outcome (with respect to the impact on the ICG) should be monitored and evaluated, using robust research designs that compare telehomecare to alternatives;
- Economic evaluations of telehomecare programs should explicitly consider the impact on the ICG (as well as other users and stakeholders);
- CRs who look after themselves are also the ICGs. This poses additional challenges to the success of telehomecare and would be the task of another study.

The need for homecare and thus the role of the informal caregiver is expected to increase as the population of Canada ages over the next few decades. The extent of this care need is unknown and so is the exact role for the informal caregiver, principally because of uncertainties in the future health status of seniors, success of interventions and effectiveness of service delivery. Telehomecare offers an opportunity to improve service delivery, thereby improving the availability of and access to health care and support services. Telehealth and, more specifically, telehomecare has the potential to change the very structure of the health care system. There are winners and losers with any change and it is incumbent on health service workers (including researchers, providers, administrators, decision- and policy-makers) to ensure that care recipients and informal caregivers continue to be on the winning side.

Acknowledgements

This report was commissioned by the Home and Continuing Care Policy Unit, Health Canada (Contract No. P-654900-04). The views and opinions expressed in this report are those of the authors and not necessarily those of Health Canada. The report benefited from discussion with Linda Lysne, Acting Executive Director, Canadian Caregiver Coalition, and Sandra MacLeod, Senior Policy Analyst, Home and Continuing Care Policy Unit, Health Canada. The authors thank Linda Kay, Centre for Rural and Northern Health Research, for administrative assistance. We also thank Sandy Lemieux for her work on early versions of Appendix 1.

Table of Contents

How Can Telehomecare Support Informal Care?

Examining What is Known and Exploring the Potential

Final Report

1 Introduction

Telehomecare and the broader field of telehealth continues to gain prominence and support. A substantial amount of money has been allocated by federal/provincial/territorial governments to advance telehealth initiatives as demonstrated by the many pilot projects and programs that have been put in place (e.g., CHIPP, First Nations and Inuit Telehealth, NORTH Network, Telehealth Ontario, Smart Systems for Health). Many health care commissions and task forces in Canada have advocated the wider use of telehealth, particularly in rural, northern and remote settings (Kirby & LeBreton 2002b; Ministerial Advisory Council on Rural Health 2002; Romanow 2002). The importance of expanding homecare and supporting informal caregivers has also been given strong support (Kirby & LeBreton 2002b; Romanow 2002). The potential for telehealth to address some of the issues related to the expansion of homecare has not gone unnoticed (Kirby & LeBreton 2002b; Romanow 2002). This report examines the overlap between telehealth and homecare with a special focus on the impact of telehomecare on informal caregivers.[1]

Informal caregivers provide unpaid care to frail, chronically ill or disabled individuals (defined as per Colantonio and colleagues (2001), Hollander and Chappell (2002), CHCHRS (2003a,b) and others). In addition, informal caregivers are not legally recognized by the jurisdiction through licensure, certification or registration (Pong 1999). Informal caregivers are predominately family members (spouses, children, siblings, etc.), but may also include friends/neighbours and volunteers (e.g., meals on wheels) (CHCHRS 2003a,b). Informal care is not synonymous with homecare, though there is a considerable overlap. Most informal care is given in the home, but can also be provided in institutional settings such as hospitals and nursing homes (CHCHRS 2003b). Homecare can be provided by formal health care professionals or support personnel, in addition to informal caregivers (CHCHRS 2003a,b).

Homecare comprises four main types of care: acute care, chronic or continuing care, promotive/preventive care and palliative care (Kirby & LeBreton 2002b: 149; Romanow 2002: 173; Health Canada 2004). Homecare involves four main groups of people: care recipients, health care practitioners, support workers and informal caregivers. Homecare is considered to be "one of the fastest growing components of the health care system" (Romanow 2002: 171). This increase is due, in part, to systematic changes in the delivery of health care, such as improvements in treatment outcomes, bed closures, reductions in length of stay, improvements in homecare services, preference for homecare over institutional care, and so forth (see Health Canada (no date); Kirby & LeBreton 2002b; Romanow 2002 for background and discussion of these issues).

---

[1] With the focus on the intersection of telehomecare and informal caregiving, this report obtains general or contextual information on telehealth, health care, home care and informal caregiving from published reviews and syntheses. Readers are referred to these reviews/syntheses for additional background information.

The increase in the demand for homecare is also due to the aging of the Canadian population. This aging is driven by increased longevity and by the aging of the "baby-boom" generation (36-55 years old in 2001) (Statistics Canada 2002a,b). The projection for a higher percentage of seniors in the population seems reasonable—what is more problematic is anticipating the health care needs of this older population. It is problematic because when baby boomers become seniors, they will likely differ in health status from today's group of seniors. In addition, changes in health care delivery and outcomes may affect the health status of tomorrow's seniors. Therefore, an extrapolation of the health care needs of today's seniors may not be a good estimate of tomorrow's needs (see discussion in Kirby and LeBreton 2002a).

It seems reasonable, however, to expect that the need for homecare will increase as the population ages, even if the exact nature of the care is unclear. Older individuals in the population are over-represented in terms of homecare use. A national survey of Canadian adults (aged 15 years or older), conducted in 2001-2002 as part of the Canadian Home Care Human Resources Study (CHCHRS 2003b), found that 51% of the care recipients were 65 years or older. A study of family caregivers, conducted in 2002 by Decima Research Inc. (2002) on behalf of Health Canada, found that 57% of the care recipients were 65 years or older.[2] Seniors are over-represented in terms of the percent receiving homecare given that approximately 13% were 65 years or older in 2001 (Statistics Canada 2002a,b). An increase in the number and proportion of seniors in the population suggests an increase in future demand for homecare, with implications for informal caregivers.

Health care deinstitutionalization, shorter hospital stays and growth in homecare are also abetted by technological advances. Increasingly, informal care, as well as self-care, are being used to replace services formerly provided almost exclusively in institutional settings and by professionals (see, for example, discussion in Kirby and LeBreton 2002a; Romanow 2002). Various chronic diseases such as arthritis, asthma, cystic fibrosis, diabetes and hypertension are managed, in part, at home. Similarly, various monitoring, caring, treatment and rehabilitation procedures can be handled by informal caregivers. These include blood pressure measuring, physical therapy for arthritis, intravenous chemotherapy, speech therapy for aphasic patients, parenteral nutrition and home dialysis. Telehomecare can be seen as another technological advance that could be used to support caregiving in a home environment.

The implications for informal caregivers are in terms of the care that they would be expected to provide and the physical, mental and financial costs that they might incur in providing this care. For example, 46% of Canadian informal caregivers reported that they had "experienced stress as a result of providing care" and 14% reported experiencing "physical pain or discomfort as a result of providing care" (CHCHRS 2003b: 17). In their summary of the literature on family caregivers of persons with dementia, Schulz and Martire (2004: 241) state that “some researchers have likened caregiving to being exposed to a severe, long-term, chronic stressor.” Kirby and LeBreton (2002b: 145) reported that the 1998/99 National Population Health Survey found that, in Canada, 80-90% of care in the home for frail, chronically ill or disabled individuals was not publicly funded. It seems reasonable to assume that the care and cost burdens fall primarily on the shoulders of the patient and immediate family, but may also extend to other relatives, friends or volunteers.

---

[2] Additional information on care recipients and on informal caregivers is presented in the Results and Discussion section.

This dual burden of care plus costs is expected to increase over time. In fiscal year 2002/2003, there were an estimated 900-4,500 homecare recipients per 100,000 people in Canada.[3] The Canadian Home Care Human Resources Study (CHCHRS 2003a,b) projected a 27-62% increase in the number of homecare recipients over 20 years beginning in 1996. The 50-year projection was for a total of 760,000 to 1,460,000 homecare recipients: an increase of 40-170%.

There are ethical, economic, political, cultural and social implications that result from an increase in the numbers of homecare recipients or an increase in the proportion of care delivered in the home (Arras & Dubler 1995; Hollander & Chappell 2002; CHCHRS 2003a,b; Baranek et al. 2004; Motiwala et al. 2005). From the perspective of informal caregivers, many of these concerns can be encapsulated in a short question: What kind of support is available to informal caregivers? More explicit questions would ask: What is the nature and extent of the political, social and cultural support? What is the extent of the financial support? What is the extent of the clinical and technical support? And for the specific focus of this report: What is the role of telecommunications in providing this support? What are the realized and potential implications of telehomecare for informal caregivers and for homecare in general?

Telehealth is broadly defined as the use of communications and information technologies to overcome boundaries between health care practitioners or between practitioners and service users for the purposes of diagnosis, treatment, consultation, education and information transfer (e.g., Reid 1996; Picot 1998). These boundaries are most often related to geographic distance. Telehomecare is the application of telehealth to provide care to patients and support informal caregivers in the home. Telehomecare in rural areas is particularly relevant because health care practitioners, such as physicians, tend to be scarce in rural areas (Pitblado & Pong 1999).

Telehomecare projects/programs are increasing in number (e.g., Dansky et al. 2001; Demiris et al. 2001; Finkelstein et al. 2004; Young et al. 2004) and are considered by some to be the way of the future (e.g., Darkins and Cary 2000; Yellowlees 2000). Systematic reviews have found support for the clinical efficacy and efficiency of telehomecare, with the caveat that the results were mostly from pilot projects and that they tend to represent short-term clinical outcomes (e.g., Hersh et al. 2001; Hailey et al. 2002; Jennett et al. 2003). Unfortunately, the roles of informal caregivers have not been the focus of most of these studies. For instance, studies of satisfaction with telehealth services in general typically deal with care recipients (e.g., Williams et al. 2001), to a lesser extent with that of health care practitioners and very rarely, if at all, with that of informal caregivers (but see Dick et al. 2004, for a notable exception).

There are a number of unanswered questions and unresolved issues with respect to telehomecare and informal caregivers. For instance, it is not known if informal caregivers will benefit from telehomecare. In addition, it is not clear that telehomecare could live up to its full potential without the support of informal caregivers. For example, some care recipients may need help in hooking-up the telehomecare equipment. As telehomecare expands, more attention will need to be paid to its role in supporting informal caregivers and vice versa.

Telehomecare can be seen as one aspect of telehealth just as informal caregiving can be seen as one aspect of homecare. This report describes the current status of telehomecare through a summary of telehomecare projects in Canada and selected projects from other parts of the world and through a review of the literature that deals with the impact of telehealth on informal caregivers. In addition, ways in which the intersection can grow—how telehealth can be

---

[3] From http://secure.cihi.ca/cihiweb/en/pub_login_prtwg_HC_15-HC_e.html. Note that not all provinces and territories were reporting on this health indicator and not all used the same definition. See website for details.

expanded into other aspects of the informal caregiver's role and how informal caregivers can take advantage of other telehealth applications—are addressed through extrapolation, inference or “informed speculation” based on what is known about the challenges and needs of informal caregivers, and what is known about the strengths and limitations of telehealth in general and telehomecare in particular.

2 Methodology

2.1 Literature Search Criteria

The overall focus of this literature review and synthesis was on studies of telehomecare and informal caregivers (ICGs) with direct relevance to Canada. We focussed on documents published between 1990 and the first three months of 2005. The following research questions were used to guide the search for relevant documents:

(1) Telehomecare studies involving informal caregivers::
  (a) What was the impact of telehomecare on ICGs? How was this impact measured?
  (b) What was the satisfaction, needs, perspective, etc., of ICGs with respect to telehomecare?
  (c) Did telehomecare increase or decrease the burden of care? health or well-being of the ICG?
  (d) Was telehomecare welcomed or feared, desired by the ICG or imposed by others?
  (e) What role did the ICG play in the decision to implement telehomecare? How was their opinion valued? What characteristics of the ICG were considered during the decision?

(2) Informal Caregivers:
  (a) What aspects of informal care giving could be enhanced by telehomecare?
  (b) What aspects might suffer? Or remain unaffected?
  (c) What about a situation when patient care improves but ICGs suffer? Or the opposite?

  In the event that there was little direct evidence, we asked some related questions:
  (d) What are the **parallels** to telehomecare? For instance, are there parallels to be drawn from current homecare practice with the introduction of <u>technology</u> or equipment into the home (e.g., specialized equipment, monitors, intensive care/palliative care beds)?
  (e) Are there parallels in acute and chronic care facilities (e.g., hospitals, nursing homes, long-term care facilities, and homes for the aged)? Parallels in which informal caregivers are trained or exposed to medical devices, monitors, telecommunication equipment, etc.
  (f) What are the lessons that can be transferred to telehomecare?
  (g) Are there needs assessments that address the introduction of technology?
  (h) What ICG education/training is needed, what follow-up support is needed when technology is introduced into the home?
  (i) What are some of the concerns, needs, etc., of ICGs that could be addressed by telehomecare?

We focussed on telehomecare interventions that measured the impact on informal caregivers as well as on the care recipient (CR). One example would be a telehomecare program designed to improve the health of the CR and thereby reduce burden for the ICG. We also focussed on the use of telecommunications to educate or support ICGs. Examples would include telephone support groups, email or web services directed towards the informal caregiver.

2.2 Literature Search Methods

A comprehensive search of published and unpublished (grey) literature was conducted using the following strategies:

I. Search of on-line bibliographic databases using keywords and keyword combinations
II. Screening of abstracts for relevant literature (based on Section 2.1 Literature Search Criteria)
III. Examination of references sections of publications for potentially useful studies
IV. Expert consultation within the telehealth/telehomecare community

The bibliographic databases searched included:

1. Ovid (Ovid Technologies) including: Cumulative Index to Nursing & Allied Health Literature (CINAHL); Journals@Ovid Full Text; Your Journals@Ovid, Books@Ovid, All Evidence Based Medicine (EBM) Reviews (American College of Physicians (ACP) Journal Club, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects (DARE); and Medline
2. EBSCOhost (EBSCO Publishing) including: PsycInfo; Social Sciences Abstracts; and Academic Search Premier (ASP)
3. Telemedicine Information Exchange (TIE)
4. ProQuest Digital Dissertations Database
5. Web of Science (Science Citation Index)
6. Search for additional appropriate databases in the following disciplines: Sociology, Gerontology, Psychology, Medical-Health, and Nursing.
7. World Wide Web using the search engines: Google (www.google.ca), Vivísimo (http://vivisimo.com), Yahoo (www.yahoo.com), and AskJeeves (www.askjeeves.com).
8. Search of specific journals for articles relevant to informal caregivers (i.e., The Gerontologist, Age and Aging)

Titles and abstracts (if available) were screened using the criteria presented in Section 2.1: Literature Search Criteria.

2.3 Project Search Strategy and Methods

The following websites were searched for information on Telehomecare projects or programs:[4]

1. Canada: Health and the Information Highway Division, Health Canada (www.hc-sc.gc.ca/ohih-bsi/res/init_e.html)
2. USA: Telemedicine Programs Database (http://tie.telemed.org/programs/programs.asp)
3. UK: Telemedicine Information Service (www.teis.nhs.uk/)
4. EU: eHealth Best Practice Services, Projects & Solutions Database (www.ehtel.org/SHWebClass.asp?WCI=ShowCat&CatId=9)
5. World Wide Web using Google (www.google.ca), Vivísimo (http://vivisimo.com), Yahoo (www.yahoo.com), and AskJeeves (www.askjeeves.com).

In addition, potential projects were identified from:

6. Search of published and unpublished (grey) literature from the literature search.
7. Consultations with telehealth/telehomecare experts.

---

[4] Search words included: telehomecare; telehome care; tele homecare, tele-homecare; telehome health; in-home telehealth; telehealth homecare; home telecare; home telehealthcare; home telemedicine; home-based telemedicine; telecare; telematic homecare; home telehealth

3 Results

3.1 Literature Search

Tables 1a,b show the number of citations found in major bibliographic databases using the search strategies described above. Some search terms were added (e.g., palliative care, chronic care) and others were dropped as the search strategies evolved. Tables 1a,b present results from the final search strategy as reapplied to all bibliographic databases. Note that the Telemedicine Information Exchange bibliographic database contains only telemedicine-related references and has restricted search capabilities. Table 2 shows the results of the screening process. Appendix 1 contains the literature review.

Table 1a. Number of citations found in bibliographic databases

	KEYWORD GROUPS	*REFERENCE DATABASE*			
# ↓	←GROUP #	OVID DATABASE	EBSCOHOST	PROQUEST DIGITAL DISSERTATIONS	WEB OF SCIENCE
1	telemedicine OR tele-medicine OR telehealth OR tele-health OR telecare OR tele-care OR telecommunication OR tele-communication OR telemonitoring OR tele-monitoring	11751	66874	1224	7637
	#1 with restrictions [a]	16 [b]	2468 [c]	-	205 [d]
2	telehomecare OR tele-homecare OR telehome-care OR home telecare OR home tele-care OR home telehealth OR home tele-health OR home telemedicine OR home tele-medicine OR home telecare OR home tele-care OR home telemonitoring OR home tele-monitoring	570	38	6	85
	#2 with restrictions [a]	0 [b]	1 [c]	-	9 [d]
3	informal caregiver OR informal carer OR family caregiver OR family carer OR spouse caregiver OR spousal caregiver OR unpaid caregiver OR unpaid carer OR home caregiver OR home carer OR uncompensated caregiver OR uncompensated carer OR carer	8553	7980	195	1441
	#3 with restrictions [a]	50 [b]	619 [c]	-	36 [d]
4	support OR needs OR perceptions OR roles OR knowledge deficit OR distress OR burnout OR isolation OR quality of life OR satisfaction OR burden OR respite OR overload OR stress OR depression OR intervention	5,623,863	1,259,734	354732	>100,000
	#4 with restrictions [a]	14817 [b]	82573 [c]	-	62369 [d]

	KEYWORD GROUPS	*REFERENCE DATABASE*			
# ↓	←GROUP #	OVID DATABASE	EBSCOHOST	PROQUEST DIGITAL DISSERTATIONS	WEB OF SCIENCE
5	homecare OR home-care OR home care OR home healthcare OR home-healthcare OR homecare service OR home-care service OR home care service OR home nursing OR home-nursing OR community health care OR domiciliary care OR home care agency OR home care agencies OR home health care agency OR home health care agencies OR respite care	80342	20305	1132	5463
	#5 with restrictions [a]	285 [b]	1514 [c]	-	127 [d]
	COMBINED KEYWORD GROUPS				
	#1 + #3	49	28	0	2
	#1 + #3 with restrictions [e]	0 [b]	1 [c]	-	0 [d]
	#2 + #3	8	2	0	0
	#2 + #3 with restrictions [e]	0 [b]	0 [c]	-	0 [d]
	#3 + #4	7716	5145	150	98
	#3 + #4 with restrictions [e]	50 [b]	424 [c]	-	27 [d]
	#2 + #3 + #4	8	2	0	0
	#2 + #3 + #4 with restrictions [e]	0 [b]	0 [c]	-	0 [d]
	#1 + #3 + #4	47	24	0	0
	#1 + #3 + #4 with restrictions [e]	0 [b]	1 [c]	-	0 [d]
	#1 + #3 + #4 + #5	20	10	0	0
	#1 + #3 + #4 + #5 with restrictions [e]	0 [b]	0 [c]	-	0 [d]
	#3 + #4 + #5	2134	1498	14	10
	#3 + #4 + #5 with restrictions [e]	18 [b]	38 [c]	-	10 [d]

[a] Search narrowed using tools unique to each database. See table notes b-d.
[b] Search limited to Review Articles, Systematic Reviews, and EBM Reviews.
[c] Search limited by document type/form/content type=review, language=English, and population type=human.
[d] Search limited to language=English and document type=review.
[e] The second set of each combination search was conducted with the limited searches, as defined in table notes b-d.

Table 1b. Number of citations found in the Telemedicine Information Exchange bibliographic database (total of 16038 citations)

KEYWORD(S)	*NUMBER OF CITATIONS*	*KEYWORD(S)*	*NUMBER OF CITATIONS*
Telemonitoring	160		
Telehomecare	60	Home telehealth	78
Home health	1306	Home telecare	46
Home	1338	Home telemedicine	52
Home telemonitoring	26	Home telecommunication	0
Informal	37	Informal caregiver	1
Family	235	Family caregiver	20
Caregiver	106	Informal carer	1
Carer	37	Family carer	4
Support	1154	Overload	8
Needs	637	Stress	99
Burnout	3	Depression	59
Burden	54	Intervention	23
Respite	6		
Homecare	97	Home nursing	16
Home healthcare	52	Domiciliary care	2
Homecare service	5	Respite care	3

Table 2. Number of citations selected, screened and reviewed.

STAGE OF SEARCH	TELEHOMECARE CITATIONS	INFORMAL CARE CITATIONS
Keyword search	~1400 citations	~2000 citations
Preliminary screening	~300	~500
Secondary screening	~100	~200
Citations selected for review	68 [a]	12

[a] 48 of the 68 citations were summarized in Appendix 1. The remaining 20 citations contained preliminary results or summaries of information already included in Appendix 1.

3.2 Project Search

The search for telehomecare/telehealth projects that have implications for informal caregivers yielded 30 Canadian and 71 selected international projects (Details are in Appendix 2).

3.3 Description of Informal Caregiving

Informal caregiving is typically defined as unpaid care that is provided to frail, chronically ill or disabled individuals by informal caregivers (predominately family members, but also friends, neighbours and volunteers).[5] Informal care can be given in the home, in health care institutions and during transit (informal caregivers frequently transport care recipients to and from appointments with health care professionals). The next few paragraphs provide a general description of Canadian informal caregiving and informal caregivers (ICGs), the care recipients (CRs) and homecare professionals.[6]

3.3.1 Prevalence

Almost 1 in 5 of Canada's adult population provides some type of informal care. A national survey of Canadians aged 15 years or older, conducted in 2001-2002 as part of the Canadian Home Care Human Resources Study (CHCHRS 2003b), categorized 18% of the 4,208 respondents as ICGs (providing care to seniors or non-seniors) (Table 3). Results from the 2001 Census show that 18% of the Canadian population who were 15 years of age or older provided unpaid care or assistance to seniors in 2001 in the week prior to the census (Statistics Canada 2005). This is a slight increase from the 1996 Census, when 16% reported providing unpaid care to seniors. Results from the General Social Survey suggest that almost 19% of Canadians aged 45 or older and living in the provinces provided some sort of informal care to seniors in 2002 (Cranswick 2003; Statistics Canada 2003).[7] Results from the three surveys are remarkably similar, given that there are differences in the respondent's and CR's age and coverage across Canada. However, a survey that focussed on family caregivers (a subset of ICGs) found a much lower prevalence of about 4% for Canadians aged 18 years or older (Decima Research Inc. 2002).

3.3.2 Socio-Economic and Demographic Characteristics

About two-thirds of ICGs in Canada are female and the majority are middle-aged (mid-30s to mid-50s) (Table 3). A comparison of the published survey responses suggests that family caregivers were slightly older (mid-forties and over) and a higher percentage are female, relative to ICGs as a whole. Please refer to Table 3 for other socio-economic and demographic characteristics, as well as to the original sources for these data and definitions (CHCHRS 2003b; Statistics Canada 2005; Decima Research Inc. 2002).

---

[5] We use the term "informal caregivers" in the generic sense and refer to sub-groups such as "family caregivers" when warranted by the available information.

[6] The description of informal caregiving is meant to be illustrative and not exhaustive. Readers are referred to the original reports for more details, including differences in definitions of care, care recipients and informal caregivers, plus differences in survey methods and analyses.

[7] Territories were not included in the General Social Survey Cycle 16.

Table 3. Selected Characteristics of Canadian Informal Caregivers

CHARACTERISTIC	CANADIAN HOME CARE HUMAN RESOURCES STUDY	2001 CENSUS UNPAID WORK	NATIONAL PROFILE OF FAMILY CAREGIVERS
Source	*CHCHRS 2003b*	*Statistics Canada 2005*	*Decima Research Inc. 2002*
Definition of ICG	15 years or older who were [currently?] caring in the respondent's or CR's home for a family member, relative or friend (child or adult) who has a long-term physical or mental condition or who is frail or disabled, needs care, attention, or similar	15 years or older who had provided unpaid care or assistance to one or more seniors in the week before the census: personal care, visit, telephone call, help with shopping, banking or taking medication, etc.	18 years or older who were currently providing care in respondent's or CR's home to another family member who has a physical or mental disability, is chronically ill or frail (excluding short-term care involved in injuries or illness)
Study characteristics	Conducted Dec. 2001-May 2002 as part of Berger Population Health Monitor Survey 774 (18%) of 4,208 respondents were identified as ICGs.	Conducted mid-May 2001 as part of census, with 1 of 5 households asked these questions 18% were identified as ICGs.	Conducted Feb.-Mar. 2002 by Decima Research Inc. 471 (4%) of 13,252 respondents were identified as family caregivers
Age	24% - 15-29 years 45% - 30-49 years 28% - 50-69 years 3% - 70 years plus average 42 years	10% - 15-24 years 11% - 25-34 years 25% - 35-44 years 25% - 45-54 years 14% - 55-64 years 14% - 65 years plus	11% - 18-34 years 19% - 35-44 years 22% - 45-54 years 23% - 55-64 years 25% - 65 years plus
Gender	62% - female	69% - female	77% - female
Marital status	65% - married 24% - single		
Employment	43% - employed full time		22% - employed FT
Income	37% - total household income of $20,000-49,999		35% - total household income of $25,000-44,000

3.3.3 Care and Cost Burden

The vast majority of ICGs (71%) or family caregivers (92%) cared for one person (Table 4). The average time commitment of family caregivers in Victoria and Winnipeg who provided care to seniors was 4-26 hours/month (Hollander et al. 2002). Between 13-48% of the ICGs experienced some form of stress related to the provision of care (Table 4). ICGs often experience high levels of stress, depression and social isolation from family and friends. In fact, depression rates for ICGS range from 30% to 83% and are higher for particular groups, such as ICGs of individuals with dementia, female caregivers and spouse caregivers (various studies as cited by Eisdorfer et al. 2003). Several factors have been identified that contribute to ICG depression including CR problem behaviour, ICGs' opinion of their own caregiving skills, isolation, family problems, lack of support, and disruption in other roles and activities (various studies as cited by Eisdorfer et al. 2003). Ploeg et al. (2001) asked Canadian ICGs about their needs and the most commonly expressed needs were: social contact, respite, physical care assistance, financial support, information and emotional support. Harding and Higginson’s (2001) summary of interviews with 18 ICGs in the UK echoed the common opinion in the literature that ICGs are typically ambivalent about their own unmet needs.

Between 40 and 68% of the family caregivers felt that they had no choice in terms of looking after the CR (Decima Research Inc. 2002). Family caregivers who felt that they did not have a choice were less likely to report that they were coping very well with the responsibilities (27% for those who felt that they had no choice versus 43% for all respondents).

Almost 36% of Canadian ICGs, aged 45 years or older, reported in 2002 that they had incurred extra expenses in caring for a senior (Cranswick 2003; Statistics Canada 2003). Between 8-17% reported that they had lost income, reduced hours of work or changed work patterns, and 2-3% reported that they had quit or turned down a job in order to provide informal care to a senior. In a separate Canada-wide survey of 471 family caregivers, Decima Research Inc. (2002) found that 44% of family caregivers reported that they had paid out-of-pocket expenses towards the care of their family members.

Transportation was the most frequently mentioned expense, paid by 81% of the 207 family caregivers who reported out-of-pocket expenditures (Decima Research Inc. 2002). Other frequently reported expenditures were: non-prescription medications (71%); medical supplies (54%); prescription medications (43%); and equipment (41%). Expenditures for homecare or home support services were reported by 12-39% of the 207 family caregivers. Forty percent were spending $100-300/month, 12% spending $300-500/month, another 12% spending more than $500/month, while 17% spent less than 100/month (18% did not respond) (Decima Research Inc. 2002). A study on the cost-effectiveness of homecare of seniors in Canada estimated that out-of-pocket expenses averaged $119-565/month for ICGs in Victoria and Winnipeg (Hollander et al. 2002). Purchase of services that were not covered by provincial health insurance plans was $0-290/month. ICG time was valued at $155-937/month, if minimum wage was used, or $435-2,626/month, if a caregiver had to be hired. Maximum total cost to the CR/ICG was $626-3,479/month ($7,509-41,749/year) (Hollander et al. 2002).

Table 4. Care and Cost Burden of Canadian Informal Caregivers

CHARACTERISTIC	CANADIAN HOME CARE HUMAN RESOURCES STUDY	GENERAL SOCIAL SURVEY CYCLE 16	NATIONAL PROFILE OF FAMILY CAREGIVERS
Source	*CHCHRS 2003b*	*Cranswick 2003*	*Decima Research Inc. 2002*
Care burden	71% - cared for one person 17% - cared for two people 8% - cared for 3-8 people		92% - cared for one person 8% - cared for two or more people
Stress	46% - experienced stress as a result of providing care 14% - experienced physical pain or discomfort	ICGs aged 45 years or older: experienced consequences to -sleep (13%) -health (13%) -social activities (31%) -holiday plans (23%)	13-29% - experienced "significant" personal difficulties relating to emotional, physical or financial health 36-48% - experienced "some" personal difficulties relating to …
Health status	78% - ICGs' health was excellent or good, relative to other persons of their age 19% - ICGs were frail, disabled or needed care themselves		

3.3.4 Care Recipients (CRs)

Most CRs were seniors (aged 65 years or older) and were most often the parent or spouse/partner of the ICG (Table 5). A comparison of survey responses shows that ICGs more frequently reported that they looked after their parent and less frequently reported that they looked after their spouse than did family caregivers. None of the sources for these data (CHCHRS 2003b; Decima Research Inc. 2002) provided information on the gender of the CR. Family caregivers were more likely to provide care in their own home than were ICGs—perhaps because family caregivers were three-times more likely to look after their spouse/partners than were ICGs.

Table 5. Selected Characteristics of Canadian Informal Care Recipients (CRs)

CHARACTERISTIC	CANADIAN HOME CARE HUMAN RESOURCES STUDY		NATIONAL PROFILE OF <u>FAMILY</u> CAREGIVERS
Source	*CHCHRS 2003b*		*Decima Research Inc. 2002*
Age	1-6% - in each of the following age classes: 0-4, 5-9, 10-14 20-24, 25-34, 35-44, 45-54 and 55-64 years 15% - 65-74 years 36% - 75 years plus		7-10% - in each of the following age classes: 0-17, 18-34, 35-44, 45-54, 55-64 years 14% - 65-74 years 26% - 75-84 years 17% - 85 years plus
Relationship to caregiver [1]	43% - parent (of the caregiver) 26% - another relative 19% - friend/neighbour 13% - spouse/partner 13% - child 10% - sibling		33% - parent (of the caregiver) 8% - another relative 38% - spouse/partner 17% - child 5% - sibling
Location of care	27% - caregiver's home 62% - CR's home 9% - either or both homes 2% - caregiver's home or institution		77% - caregiver's home 23% - CR's home (NOTE: 97% of care of the spouse/partner is in the caregiver's home, which, presumably is also the CR's home) Crude adjustment suggests: 40% - caregiver's home 23% - CR's home 37% - either or both homes

[1] Totals may be greater than 100% because some informal caregivers care for more than one person.

3.3.5 Nature of the Care Provided

The main type of care provided is helping with activities of daily living: arranging transportation, helping with medication regimen, assisting with personal hygiene and housekeeping/cooking duties (Table 6). Clinical care focused on wound care and the occasional injection.

Table 6. Selected Aspects of the Care Provided by Canadian Informal Caregivers [1]

CHARACTERISTIC	CANADIAN HOME CARE HUMAN RESOURCES STUDY		NATIONAL PROFILE OF FAMILY CAREGIVERS
Source	*CHCHRS 2003b*		*Decima Research Inc. 2002*
Reason for care	63% - CR "is elderly or frail but wants to live in their home" 53% - CR "is not elderly but is physically or mentally ill, disabled or frail in some way"		43% - physical disability 21% - mental disability 18% - both types 18% - other/unknown
Clinical care	*ICGs helped daily/ occasionally/ rarely (inferred):* 1-8% - provide clinical care (change bandages or clean wound, give needles, etc.)		*Family caregivers helped daily/ occasionally/ rarely:* 11-48% - provide clinical care (49-90% - never provided this type of care)
Instrumental activities of daily living	*ICGs helped daily/ occasionally/ rarely (inferred):* 76% - get them to doctor's appointments or to visit friends 61% - cleaning/ housekeeping 56% - assist with medications 46% - help with eating/ cooking 33% - help communicate with others		*Family caregivers helped daily/ occasionally/ rarely:* 89% - drive to destinations 20% - cleaning/ housekeeping 73% - assist with medications 18-35% - help with eating/ cooking 77% - paying bills
Activities of daily living	20% - help with dressing, personal hygiene 18% - help with mobility		48-61% - help with dressing, personal hygiene 59-68% - help with mobility

[1] Totals may be greater than 100% because some informal caregivers provide more than one service or care for more than one individual.

3.3.6 Homecare Professionals

The CHCHRS (2003b: 23-35) provides a summary of the available information on formal homecare workers. CHCHRS estimated that there were over 32,000 home support workers (HSW),[8] [9] over 9,000 registered nurses (RN), almost 3,000 licensed practical nurses (LPN) and almost 3,000 occupational therapists/physical therapists/social workers (OT/PT/SW). Health Canada (1999) cited a 1996 estimate from Human Resources Development Canada (1998) of 75,000 visiting homemakers and 55,000 nurses employed in health and social services settings (excluding hospitals and doctors' offices). There were no estimates for other formal homecare workers such as case managers, respiratory therapists, speech therapists, dietitians, physicians, psychologists, etc. (CHCHRS 2003b).

Professional caregivers in four main categories (HSW, RN, LPN, OT/PT/SW) are predominantly females (90%), aged 40 years or older (>50%) and with over 65% having college or university training (CHCHRS 2003b). The nature of the care provided by these professionals and supportive personnel varies according to the occupational group and involves more frequent and more varied clinical care than ICGs. However, as was the situation for ICGs, HSWs were heavily involved in meal preparation and personal hygiene, while LPNs were heavily involved with home making as well as personal hygiene (CHCHRS 2003b).

3.3.7 Summary of Informal Caregiving

The typical ICG is a middle-aged, married woman in good or excellent health with some post-secondary education. The vast majority of ICGs were providing care for one person. The CR was typically the parent or the spouse of the ICG and was 65 years of age or older. CHCHRS did not determine what percentage of the CRs received care from both informal and formal caregivers, though 41% of ICGs reported that there was only occasionally or hardly ever any other support person in the house (CHCHRS 2003b). Decima Research Inc. (2002) reported that 35% of family caregivers said that no one else was available and 25% reported a lack of homecare services. Conversely, 23% of family caregivers reported that some form of formal homecare was received.

The ICG assists with activities of daily living such as getting the CR to appointments or social visits, helping with household chores and meals and ensuring adherence to medication regimen. ICGs remarked that it is their responsibility to provide such care (40-78% of family caregivers said that they had no choice, Decima Research Inc. 2002). ICGs objected to any assumption that it was fully their responsibility or that they all had the ability and resources to provide such care (Decima Research Inc. 2002; CHCHRS 2003b). ICGs would like to have more recognition, support and resources, such as financial relief, employment flexibility, respite care or formal homecare services. ICGs often remarked that their emotional and physical health suffered from the stressful and demanding nature of their caregiving role.

Telehomecare may address some of the need and potentially alleviate some of the problems or concerns raised by ICGs. But telehomecare may also increase the burden of cost, care and stress. The following sections summarize the information in the available literature and lessons learned from selected telehomecare projects and then use "informed speculation" to discuss how telehomecare could be used to support informal care and ICGs.

---

[8] Home support workers were para-professionals that were defined by CHCHRS (2003b: 23) to include personal aides, personal attendants and homemakers.

[9] The CHCHRS (2003b: 24) reports that the Labour Force Survey (Statistics Canada) yielded estimates of 17,000-57,000 home support workers.

4 Telehomecare and Informal Caregivers

This section was organized around five themes that are common to the evaluation of the impact of the broader field of telehealth: *Access, Acceptability, Integration, Quality* and *Benefits & Costs* (Figure 1). These evaluation themes are similar to those proposed by the Institute of Medicine (Field 1996) and have been adapted for use in Canada by the National Telehealth Outcome Indicators Project (NTOIP) (Scott et al. 2003). The evaluation themes presented here incorporate some of the modifications suggested in the ongoing monitoring of NORTH Network (Isaacksz et al. 2003; P. Lindsay, L. Sarsfield and others, NORTH Network, July-August, 2004, personal communication).[10] The Centre for Rural and Northern Health Research (CRaNHR) has adapted these themes for use in an ongoing evaluation of a First Nations telehealth program (Keewaytinook Okimakanak Telehealth Program, http://telehealth.knet.ca). In this report, the focus is on those aspects that relate to the potential and realized impact of telehomecare on informal caregivers (ICGs) and informal caregiving.

The impact of telehomecare on ICGs can be direct or indirect. An example of a direct impact would be the results of a support service that was offered to the ICG. Indirect impact on the ICG could be through the impact on the care recipient (CR) or on the formal care provider—anything that would affect the nature and extent of the care burden would indirectly impact on the ICG. The impacts (direct or indirect) may vary along a positive-to-negative continuum with respect to the effect on ICGs and may be highly sensitive to the context in which telehomecare was delivered. The following sections summarize the available information from the literature (Appendix 1) plus lessons learned from selected telehomecare projects (Appendix 2), organized around the themes of *Access, Acceptability, Integration, Quality* and *Benefits & Costs*.

---

[10] NORTH Network is one of the largest telehealth/telemedicine networks in Canada (www.northnetwork.com).

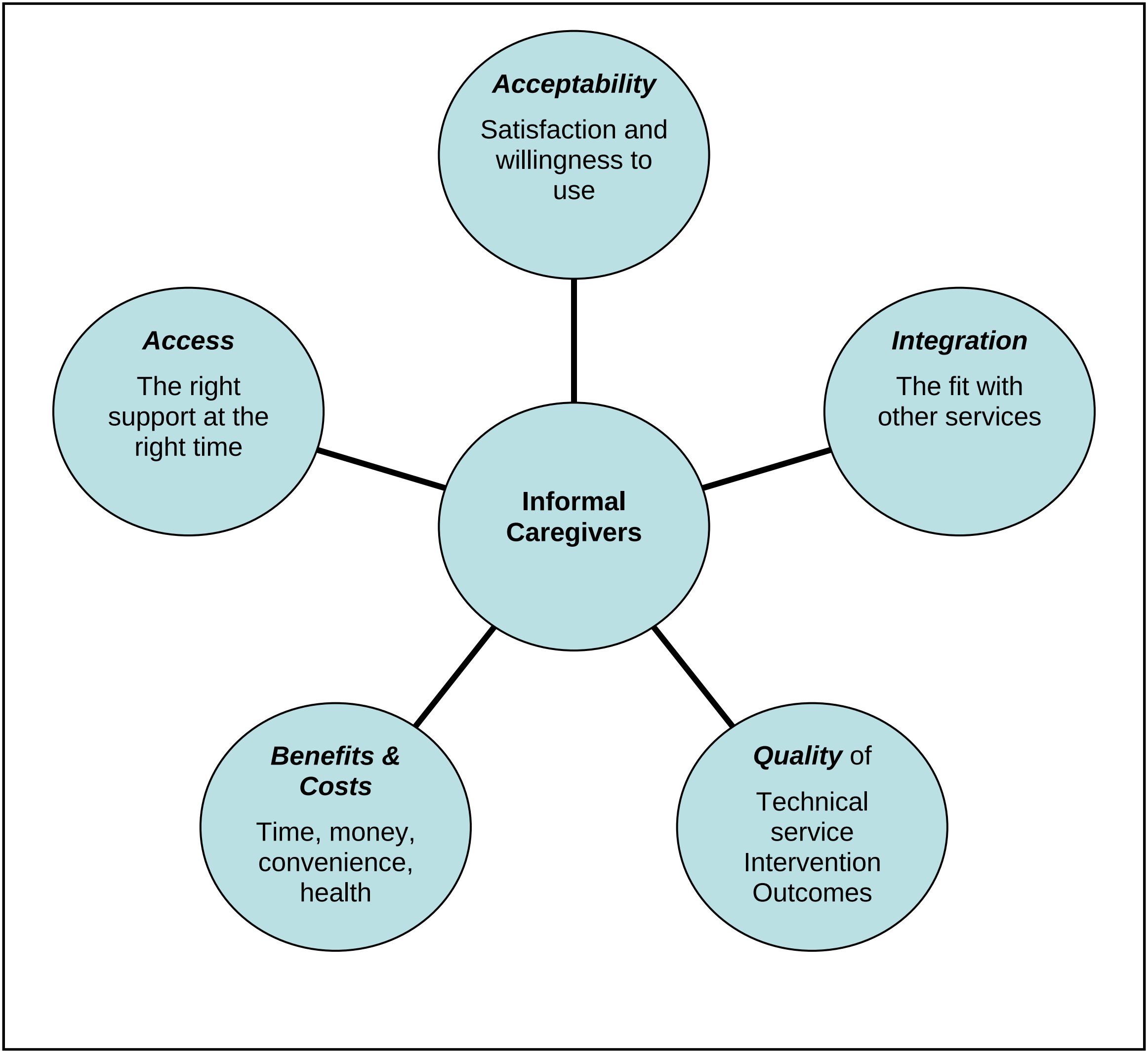

Figure 1. Evaluation themes centered around the impact on informal caregivers

4.1 Access

Access is defined as the availability of the right support services at the right time without undue burden (from the point-of-view of the ICG).

ICGs often face obstacles in accessing health care and support services for themselves and for those under their care. In a Canada-wide study of ICGs of the elderly, Colantonio and colleagues (2001) identified the following barriers to participation in support groups: time constraints, transportation difficulties and lack of respite. Buckwalter and colleagues (2002) summarized telehomecare innovations for rural elders and their ICGs. Their conclusion was that telehomecare offered one way to improve access of ICGs to information, education and decision-making support services.

Access to information and decision-making support provided by telecommunications equipment has been largely inferred from the use of the telehomecare service. For example, Brennan and colleagues (Brennan et al. 1992; Brennan and Moore 1994) describe the use of a home computer connected to a central computer in a study of Ohio ICGs. They found that the 47 ICGs used the computer an average of 92 times over the course of a year to obtain information, help with decision-making and chat with other ICGs. In a comparison of telephone and in-person support groups for 91 ICGs of brain-injured CRs in Edmonton, Brown and colleagues (1999) found no differences in attendance or completion of the program between the telephone and in-person support groups. Unfortunately, all urban family caregivers were assigned to the in-person group while all rural family caregivers were assigned to the telephone group and so differences between the groups may reflect differences between rural and urban populations and not necessarily differences due to the interventions. Very little other comparative information was found, either as a before-and-after comparison of the same ICGs, or as a controlled comparison of telehomecare-users to non-users.

There was some anecdotal evidence on the helpfulness of telehomecare from the perspective of the ICG. For instance, comments from 9 of 14 ICGs and CRs in a Tennessee study suggested that the telehomecare service offered "increased and faster access to healthcare advice" (Dimmick et al. 2000: 130). Similar comments were made by ICGs in a study of a telehospice service for terminally ill patients in Michigan and Kansas (Whitten et al. 2001) and echoed by the parents of children recently discharged from the Hospital for Sick Children in Toronto (Young et al. unpublished). That telehomecare could improve access to care and support services for ICGs seems obvious, even though data are lacking. Of course, the presence of telecommunications equipment in the home does not necessarily entail its use. Whether ICGs find such equipment to be satisfactory or acceptable is discussed in the next section.

4.2 Acceptability

Acceptability is the degree to which ICGs are satisfied with a service or are willing to use it.

Studies of satisfaction may examine different aspects of the ICGs' experience: satisfaction with the equipment and technical support, satisfaction with the quality of the telehomecare consultation compared to a face-to-face consultation, overall satisfaction, and so forth. In two separate systematic reviews of the broader telehealth literature on CR's satisfaction, Mair and Whitten (2000) and Williams and colleagues (2001) found that low sample size and poor study designs limited the generalizability of the results. Almost all studies reported that over 80% of CRs gave telehealth in general the highest satisfaction rating, though the meaning is unclear without a contemporary comparison of satisfaction with telehealth and alternative services and given the methodological limitations.

CRs may be satisfied, but it would not be axiomatic that ICGs would also be highly satisfied. However, the same results (and caveats) seem to apply to ICG satisfaction with telehomecare. For example, in a study of 57 parents of young children in Toronto, Dick and colleagues (2004) reported a mean satisfaction score of 83/100 for the homecare portion of the study. Brown and colleagues (1999) found that the telephone ICG support group tended to rate their sessions slightly higher than the in-person ICG support group (9.2/10 versus 8.5/10). The rating for group size and overall rating was also higher in the telephone group. Anecdotal comments from ICGs in Washington, DC (Buckley et al. 2004) and Ohio (Kart et al. 2002; Kinney et al. 2003) suggested that ICGs were highly satisfied with the telehomecare service.

Parents of very low birth weight infants enrolled in the intervention arm of a RCT, reported high satisfaction with the video-monitoring, information and support system of Baby CareLink (Gray et al. 2000). Grant and colleagues (2000) conducted a RCT on 74 ICGs of stroke survivors that compared the impact of a telephone intervention, telephone contact (no intervention) and the control. They found that satisfaction with health care services was not affected by the telephone intervention, but it did decrease significantly in the control group. In another study, four ICGs gave high marks to various aspects (including satisfaction) of a telehomecare service in Europe (Guillén et al. 2002). In a systematic review of RCTs and/or controlled trials, Krishna and colleagues (2002) found that CRs, ICGs and formal providers gave high satisfaction ratings to a variety of telephone reminder services.

High satisfaction implies a willingness to use and yet not every ICG is eager to use the technology. The adoption of information and telecommunications technology in the home by ICGs may depend on the perceived impact on their care burden, the complexity of the technology and the skill level of the user. For example, Buckley and colleagues (2004) reported some evidence to suggest that ICGs of stroke patients did not choose to participate in a therapeutic intervention if they were at either end of the continuum of their perceived level of burden. That is, ICGs with low burden did not see a need for the service and ICGs experiencing high levels of burden were too overwhelmed by their caregiving responsibilities to take part in the project. This finding was supported by Mahoney and colleagues (2003) who reported on the results of a 12-month RCT that examined the impact of telephone support on burden and anxiety of ICGs of Alzheimer's patients. Subramanian and colleagues (2004) reported that the most common reasons for refusal to participate in telehomecare projects was the lack of perceived additional benefits of telehomecare (32% of those who refused) or that routine health care was sufficient (29%). Colantonio and colleagues (2001a) reported that ICGs wanting to use telephone support services were more likely to be able to leave the CR for up to 2 hours, but conversely, had more hours of caregiving per week and had higher levels of depression.

ICGs may not use the equipment, even if it has the potential to reduce their care burden or otherwise improve their quality of life. This may occur when there is a mismatch between the ICGs' perception of their technological skills and their perception of the complexity of the technology. For instance, Kart and colleagues (2002) summarized the literature on the use of technology by older disabled persons and their caregivers and concluded that the individual was less likely to use more complex technology, unless they possessed matching skills. Goodenough and Cohn (2004) found that the best predictor of videoconferencing use by ICGs was previous use of other types of telecommunications technologies, such as email.

In some studies, ICGs reported that the telehomecare technology was easy to use. For example, CRs and ICGs who participated in a telehomecare demonstration project in Tennessee, which provided teleconsultations for conditions ranging from congestive heart failure to diabetes management, found that the equipment was easy to use (Dimmick et al. 2000). The equipment installed in the home consisted of a video camera, monitor and speakerphone connected through telephone line. ICGs involved in a 2-year telehospice project in Michigan and Kansas also reported that the home videophone equipment was easy to use (Whitten et al. 2001). Czaja and Rubert (2002) reported similar findings in their 6 month study of speakerphone use by family carers. Parents of children on ventilators expressed similar positive response to videophone use in the home (Miyasaka et al. 1997).

In contrast, other ICGs said that they were not comfortable with using telecommunications equipment. Buckwalter and colleagues (2002) cited an article by Whitten (2001) who wrote that some seniors felt uncomfortable with the new technology, had difficulties talking to health care providers via a TV system, that they tended to be less candid and that they felt "emotional distance" between themselves and the health professional.

A study of teletriage services provided by registered nurses (RNs) in northern Ontario found that older persons and those in rural areas were less likely to use the service (Hogenbirk & Pong 2004; Hogenbirk et al. 2005). Anecdotal comments suggest that older persons and rural residents may have felt less comfortable talking with a nurse that they did not know and who did not know the specifics of local service delivery conditions or the patients' health history. Colantonio and colleagues (2001a) reported that those ICGs wishing to use telephone support lines tended to be younger and were more highly educated.

In contrast, Mahoney and colleagues (2001) found that ICGs who regularly used a telephone support service were older than non-users or infrequent users, though frequent users tended to be more highly educated. In addition, Mahoney and colleagues (2003) suggested anecdotally that rural residents were more likely than urban residents to use the telephone support system because other sources of information, advice and support were less readily available to rural residents. It is worth noting that lack of previous experience with telecommunications technology and the perception–-rightly or wrongly—that the technology will not help, seem to be the main impediments to adoption and not age per se (see summary in Magnusson et al. 2004: 229). As such, older people may require different teaching methods due to age-related differences in learning. A client-centered needs assessment may help determine if the technology will prove a benefit or a hindrance to daily life.

In a review of studies of technology-dependent children in the home, Wang and Barnard (2004) summarized the disadvantages reported by the parents. Parents remarked that they felt that they did not have sufficient knowledge and were not properly prepared to provide their children with the technical medical care. In contrast, parents of young children discharged from the Hospital for Sick Children were eager to start the telehomecare program, perhaps because the home was much preferred over the hospital (Young et al. unpublished). The presence of medical equipment in the home was also a continual reminder of their child's condition, a source of worry over possible medical emergencies and the equipment was often considered an unwelcome intrusion into the home environment due to the noise (beeps and alarms) and physical existence. Complaints about the size of the equipment were also noted by Young and colleagues (unpublished).

In some situations, telehomecare was considered to be more acceptable than the alternative form of care, particularly when privacy and anonymity were important to the ICGs and CRs. Family caregivers may be reluctant to use standard health services due to the stigma associated with their relatives' health condition. For example, Brennan and Moore (1994) suggested that family caregivers might not take advantage of offered services because of the social stigma associated with dementia and the lack of privacy and anonymity during office or home visits. It was hoped that the telecommunications equipment would allow the ICGs the anonymity to be more frequent and open in their communications (Brennan & Moore 1994).

Conversely, other ICGs thought that telehomecare interventions would reduce their anonymity and privacy. In one study that examined the receptiveness of a therapeutic intervention provided by RNs using videophones to ICGs at home, ICGs who refused to participate in the study cited concerns about reduced privacy, security and safety (Buckley et al. 2004). A camera in the home was considered by some ICGs as an invasion of privacy because even careful placement of cameras may result in private behaviours becoming observable to others (Buckley et al. 2004; Kart et al. 2002; Kinney et al. 2003). Remotely controlled cameras were a particular issue and the balance between the need for privacy versus the need to monitor CRs for health and safety reasons was raised by several ICGs. Other ICGs were worried that criminals could access the camera thereby facilitate entry into their home. There was also a concern about the possible loss of privacy when talking over the telephone or video conferencing equipment (Kart et al. 2002; Kinney et al. 2003).

Acceptability, willingness to use and satisfaction of ICGs with telehomecare applications could be a function of perceived or actual advantages or disadvantages (discussed in the later section on *Benefits & Costs*) (e.g., Subramanian et al. 2004). These pros and cons include how well the telehomecare service was integrated with other health care and support services for ICGs, CRs and formal health care providers. Issues related to service integration are discussed in the next section.

4.3 Integration

Integration is defined as the degree to which telehomecare services and other health care services work with one another to support the needs of the ICGs or to reduce their care burden or their quality of life.

Many, if not all, telehomecare (and telehealth) services start as pilot projects and are likely to be less well integrated with existing health services. In a synthesis of telehealth projects supported by Health Canada's Health Transition Fund, Pong (2002) captured the feelings of many telehealth proponents who believe that the lack of integration of telehealth into the mainstream health care system could cause telehealth services to fail or become less effective. To be effective, telehealth and, by implication, telehomecare, cannot be layered onto existing health services without careful planning as to how it will become an integral part of health care delivery. Of course, integration is not an issue unique to telehomecare—it is an ongoing issue for the health care system as new knowledge, techniques, processes or organizational structures are introduced and adopted or abandoned.

Evidence in the literature for the integration of telehomecare into mainstream health care and homecare is largely anecdotal (e.g., Dimmick et al. 2000; Eisdorfer et al. 2003), though there is an increasing number of examples of widespread use of telehomecare services in Canada (e.g., Atlantic Health Sciences Corporation: Virtual Interactive Telehealth Assistance; Prince Edward Island-West Prince Health Telehospice/Telehomecare; Canadian Virtual Hospice-Manitoba), the U.S. (e.g., Kaiser Permanente Tele-Home Health; Department of Veterans Affairs; Visiting Nurse Associations of America) and Australia (e.g., CSIRO Hospital Without Walls). Institutional readiness (e.g., Jennett et al. 2004) and stakeholder readiness (e.g., Hebert & Korabek 2004) for the implementation and integration of telehomecare are of considerable interest and importance, though the perspectives of the ICG are rarely reflected in the literature.

4.4 Quality

Quality has several dimensions. This report examined: (1) *Quality of Technical Service*; (2) *Quality of Interventions*; and (3) *Quality of Outcomes*. Some of the pros and cons of the interventions and outcomes are discussed more fully in the section on *Benefits & Costs*.

4.4.1 Quality of Technical Service

Quality of Technical Service relates to the performance of telehomecare equipment and technical support services, plus measures of the match between home and equipment, with emphasis on the impact on the ICG.

Telecommunications infrastructure has varied over time and continues to vary by region (as asserted by Tran et al. 2002). Rivera and colleagues (2003) in Project FOCUS, an southern U.S. telehomecare service that assisted ICGs to develop problem-solving skills, found that while ICG satisfaction with the intervention was high, there were technical obstacles such as poor and lost connections and power fluctuations that disabled many of the units, particularly in rural areas. In another study, nurses and CRs reported similar phone connection problems (Dimmick et al. 2000). Buckley and colleagues (2004) found that ICGs and nurses differed in their evaluation of the technical aspects of the videophones. Nurses reported audio/visual problems in 40-49% of the sessions, while ICGs reported problems in 14-18% of the sessions. Technological malfunctions (service interruptions, jerky images, chopped sounds, temporary or systematic incompatibilities, etc.) continue to be a major irritant for all users. Turn-key operations with built-in redundancies and minimum guaranteed service may help reduce the impact and frequency of these malfunctions.

The equipment chosen for a particular telehomecare intervention should be appropriate to the application. For some applications, a standard telephone will suffice, but more telehomecare services are using videophones or videoconferencing. Some of the other issues that should be considered when telehomecare services are implemented include consideration that more than one individual will use the equipment and that some CRs may experience change in their level of functioning over time (e.g., Kart et al. 2002; Kinney et al. 2003). In addition, technology should be easily adapted to the ICGs' environment, be low cost with a long shelf life, current, easy to learn, and address security, privacy and ethical issues.

4.4.2 Quality of Interventions

Quality of Interventions assesses the degree to which telehomecare service compares favourably to alternative support services provided to the ICG.

There is some evidence to suggest that ICGs consider the telehomecare intervention to be as good as or better than the alternative. Brown and colleagues (1999) found that the telephone support group rated their sessions slightly higher than the in-person support group (9.2/10 versus 8.5/10). A Florida study compared videophone support to no videophone support for ICGs of individuals with prolonged states of reduced consciousness (Hauber & Jones 2002). ICGS in the videophone group (n=5) reported 58% of their needs were met (18% unmet) versus 50% met (28% unmet) in the comparison group (n=4). It may be that the information and support was better received by the ICGs because it was delivered in a more timely and incremental fashion.

Gray and colleagues (2000) conducted a RCT that evaluated the satisfaction[11] of parents whose very low birth weight infants had to stay in the neonatal intensive care unit. Compared to the responses of 30 parents in the control group, the 26 parents in the intervention arm reported significantly higher satisfaction scores for overall quality of care and the environment and visitation policy, while reporting non-significantly higher scores for the six other dimensions.

---

[11] Picker Institute’s Neonatal Intensive Care Unit Family satisfaction survey

The results suggest that the video-monitoring, information and support system of Baby CareLink was more satisfactory than the usual method of educating and informing the parents.

Satisfaction with telehealth service in general could be used as a measure of the quality of the intervention, but only if a controlled comparison was made between the telehealth service and the alternative (e.g., face-to-face instruction). Unfortunately, controlled comparisons were rarely employed in the evaluation of CRs' satisfaction with telehealth (Mair & Whitten 2000; Williams et al. 2001) and, with the exceptions noted above, absent from the measurement of ICG satisfaction with telehomecare interventions. The bottom-line is that information on the quality of the intervention from the perspective of the ICG is somewhat limited and anecdotal.

4.4.3 Quality of Outcomes

Quality of Outcomes is the degree to which telehomecare service directly or indirectly reduces the care or cost burden or improves health outcomes of ICGs.

The majority of the telehomecare literature deals with the impact on the CR and not the impact on the ICG, though there are a few notable exceptions. Results from studies that focus on the impact on ICGs suggest that these telehomecare interventions may be as good (i.e., no different) or better than alternative interventions in terms of the impact on ICGs. For example, Brown and colleagues (1999) reported that there was no significant difference between telephone support groups and in-person support groups with respect to the change over time (first and last day of group sessions, six months after) in family functioning, caregiver burden or distress.[12]

In other studies, there was evidence of a differential impact. For example, Eisdorfer and colleagues (2003) used a RCT to study the effect of three 12-month interventions—one of which involved text and voice interactive computer sessions—on 154 ICGs of Alzheimer's patients randomly assigned among the three groups. The study was one of six studies in the Resources to Enhance Alzheimer's Caregiver Health (REACH) program. ICG depression was significantly reduced in the telehomecare group relative to the other interventions in the six months following cessation of the interventions. The magnitude of this change varied with the ethnicity of the ICGs and their relation to the CR.

Mahoney and colleagues (2003) conducted a RCT to determine the effects of a 12-month computer-mediated telephone intervention on 49 ICGs versus 51 in the care-as-usual group. This study was another in the REACH program. They found that there was no significant effect on bothersome nature of CRs behaviour, ICG depression or ICG anxiety scores for all ICGs. They did find an impact for a subset of ICGs with low to mid mastery scores at baseline: the intervention significantly reduced bother, depression and anxiety. Bother scores were even more reduced for ICGs who were the wives of CRs. Lack of an overall intervention effect may have been because ICGs reported low baseline bother and depression scores and thus there was little room for improvement or because most ICGs had no difficulty in obtaining information and advice from specialists, physicians and nurses such that the potential impact of the intervention was minimized.

Bass and colleagues (1998) reported on the results of a RCT that evaluated the effect of a computer support network (the ComputerLink project) on four types of caregiver strain for ICGs of Alzheimer's patients. The 12-month intervention led to reduced levels of strain for some

---

[12] Please refer to Appendix 1 for a list of the exact instruments used.

family caregivers, particularly those who had more informal support and were spousal carers. Use of different types of the service was associated with differential effects on strain. For example, the "communication" component reduced strain for non-spousal carers or those with higher initial strain, while the "solitary" component reduced strain for spousal carers and those living alone with CRs.

In a RCT (a pilot study with some restrictions on allocation[13]), Grant (1999) compared three interventions that provided social problem-solving skills for 30 ICGs of stroke survivors. The telephone intervention group, relative to home visit and telephone control groups, experienced a significant reduction in depression, more positive problem-solving skills, and greater caregiver preparedness and improved but non-significantly different scores for depression, problem-solving and caregiver preparedness at two and five weeks after the intervention. Interestingly, after 12 weeks, Grant (1999) found that there were no statistically significant differences among the groups.

In a similar, but separate RCT, Grant and colleagues (2002) compared three interventions directed towards 74 ICGs of stroke survivors. They found that the telephone intervention improved problem-solving skills, preparedness, vitality, social function, depression and role limitation related to emotional problems over 18 months relative to the telephone control and care-as-usual control groups. There were no significant differences in caregiver burden. The telephone intervention did not affect positive problem orientation, though this measure was significantly decreased in the care-as-usual group.

Goodman (1990) reported on a RCT with a cross-over after three months that examined the impact of the intervention (Care-Line project) on ICG's use of informal supports as well as social supports, mental health, burden and information. Subjects, who were caring for Alzheimer's patients, were assigned to a peer telephone network or telephone lecture series and then reassigned to the alternative after three months. There were no significant differences between groups before or after the cross-over. Both groups reported that the CRs became more impaired and both groups increased the use of social support. Telephone networks may have substituted initially for emotional and social support from family and friends but only for those ICGs who had telephone networks first and then the telephone lectures. ICGs who had telephone lectures first, used family and friends for emotional and social support throughout both phases of the RCT. Interestingly, the 3-month results (prior to crossover) showed a positive impact by both treatments that levelled off in the final three months.

A synopsis of the findings from RCTs suggest that caregiver depression is reduced by telephone support for ICGs of stroke survivors (Grant 1999; Grant et al. 2002) and may be reduced (Eisdorfer et al. 2003) or unaffected (Mahoney et al. 2003) by telephone-computer interventions for ICGs of Alzheimer's patients. Caregiver burden was not affected by telephone support for ICGs of stroke survivors (Grant 1999; Grant et al. 2002), nor for ICGs of Alzheimer's patients (Goodman 1990). There was partial support for improvement in outcomes such as strain (Bass et al. 1998), bother (Mahoney et al. 2003), problem-solving, preparedness, and social functioning (Grant et al. 2002), quality of life (Chan et al. 2003) or anger (Steffen 2000). For ICG satisfaction, there was evidence for improvement (Gray et al. 2000) or less of a decrease relative to the control (Goodman 1990).

Results are reasonably consistent with a meta-analysis of 78 studies on all kinds of ICG interventions (Sörenson et al. 2002). Sörenson and colleagues found that interventions had a

---

[13] ICGs who lived more than 50 miles away from the study sites were <u>not</u> assigned to the home visit group.

slight to moderate effect on all variables, though there was a stronger effect on ICG knowledge or ability than on ICG burden, ICG depression and CR symptoms. Group interventions were less effective at improving ICG burden and well-being but more effective at reducing CR symptoms than were non-group interventions. In summary, the impact of telehomecare interventions directed towards ICGs seems to be positive over a period of 6-18 months for selected outcomes. Otherwise, there does not seem to be much difference between telehomecare and other interventions in the cited studies.

4.5 Benefits and Costs

Benefits and Costs are defined, from the perspective of the ICG, in monetary and non-monetary terms to include dollars, time, convenience, mental and physical health or well-being and so forth.

Economic evaluations of telehomecare rarely, if ever, consider the impact on the ICG. Some recent economic evaluations of homecare suggest that out-of-pocket costs to family caregivers would average $100-500/month (Hollander et al. 2002), with transportation costs cited as one of the most frequently incurred costs (Decima Research Inc. 2002). Thus, it is likely, by reducing the need for travel, that telehomecare would reduce out-of-pocket costs to ICGs.

ICGs and CRs have reported in a number of studies that they consider telehomecare a convenient and time-saving method of receiving health care services. A U.S. telehomecare program, called Home Touch, provides support to homecare recipients and their caregivers through bi-weekly telehomecare encounters with a homecare nurse (Dimmick et al. 2000). The nine CRs and family caregivers who were interviewed said that telemedicine could save time transporting CRs to appointments and that it was more convenient than a standard homecare visit.

In another study (Goodenough & Cohn 2004), parents of cancer patients were asked to provide their perceptions of the benefits of telehomecare. The statements that they rated the highest were “reducing travel costs” and being “useful for remote communities”. A comparison of rural and urban groups in this study found that rural parents gave higher ratings to the impact of time and distance. Buckwalter and colleagues (2002) reiterated this finding in their review of telehomecare for elders and ICGs in rural communities.

ICGs also reported that telehomecare was convenient in terms of time commitment, in part due to reduced travel requirements, but due to timely access to information and advice from professional health care providers or from other ICGs (Brennan et al. 1995; Dimmick et al. 2000; Buckley et al. 2004). Users and non-users alike appreciated the fact that the service was ready and available should they need to use it (Brennan et al. 1995; Mahoney et al. 2003; Young et al. unpublished). Dimmick and colleagues (2000) also reported that patients felt that there was increased personal attention from nurses who were not in such a hurry to visit the next home. These benefits can also result in a reduction of anxiety for the ICG who can access the information and advice they require as the need arises (Buckley at al. 2004). Asynchronous communication capabilities, in which the sender and receiver do not need to be present at the same time, provide additional convenience for informal and formal caregivers, as well as the patients (e.g., Brennan & Moore 1994).

Another benefit is the reduction in family separation (Young et al. unpublished). One advantage of homecare services is that they provide support to individuals with health conditions, which allows them to stay in their own home. This benefit accrues to the CR, the ICGs and to other family members. In contrast, a literature review of technology-dependent children in the home, found that bringing the CR into the home, surrounded by noisy and cumbersome equipment does not create the ideal home environment for many family members (Wang & Barnard 2004). Dick and colleagues (2004) reported that parents with children who were heavily dependent on technology had a relatively lower satisfaction score for homecare versus hospital care. Family togetherness may suffer when the home becomes a substitute for the acute care ward of a hospital.

Some of the potential benefits of telehomecare may appear in unforeseen areas. For instance, one problem faced by ICGs is that distant relatives may not appreciate the difficulties associated with caring for an individual in the home (Kart et al. 2002; Kinney et al. 2003). Goodenough and Cohn (2004) reported that parents of children with cancer gave videoconferencing to connect family members the highest rating of potential applications. Virtual family visits were also highly valued by seven ICGS in Sweden (Sävenstedt et al. 2003). Similar sentiments have been echoed by First Nations community members in northwestern Ontario (K. Houghton, Telehealth Manager, March 2005, personal communication). Incidentally, telehomecare may take on an expanded meaning in remote areas where community health centres can serve as de facto homes. In such communities, there may be more ICGs available to provide support. This has implications for service delivery, as well as for privacy and confidentiality.

There is some evidence to suggest that telehomecare has the potential to improve continuity of care and care management by permitting more frequent exchange of information (Helgesson et al. 2005; Sävenstedt et al. 2003). For instance, subtle clues can be picked up by the CR, the ICG or the formal care provider as they observe and listen to one another during audio/visual telecasts. This can improve awareness of the CR's health status, the impact on the ICG, concerns of the formal care provider, etc. This increased awareness has implications for improving care management, improving the ICG's or CR's quality of life and so forth.

Telehomecare, however, was not considered the ideal solution for all problems. For example, Goodenough and Cohn (2004) reported that parents gave higher ratings for the usefulness of videoconferencing for psychosocial care or education rather than for clinical uses or treatment planning. Similar qualified support came from a study by Kart and colleagues (2002) who used focus groups to examine how technology could assist family caregivers of relatives with dementia. Technological solutions that are affordable and can meet some of their needs were welcomed by ICGs, though ICGs also noted that technology could neither substitute for their presence nor meet every one of their needs. This finding was echoed in an European study of family caregivers (Magnusson & Hanson 2003).

Some ICGs thought the greatest benefit of telehomecare services would occur if the service augmented, but did not replace home visits (Magnusson & Hanson 2003; Magnusson et al. 2004). The Swedish ICGs might have spoken for many ICGs when they stated that video visits were preferred over telephone calls, but not preferred over in-person visits (Sävenstedt et al. 2003). It may be that this reflects the ICGs' and CRs' initial perception of telehomecare as a second-best service, perhaps because the ICGs have a strong initial preference for face-to-face and an initial reluctance to use technology (Mahoney et al. 2001). This perception seems to be modified as ICGs and CRs become familiar with the telehomecare service (e.g., Dick et al. 2004; Young et al. unpublished). Perhaps one strategy to facilitate adoption of telehomecare is to start the service gradually, with training adapted to the individual and demonstrate its advantages before ICG burden becomes too high.

One unanticipated side-effect of telehomecare may be that it unrealistically raises expectations of the ICG or CR for care services or devices that are not readily available in their community (Magnusson & Hanson 2003). For example, residents in rural or remote areas may learn of services in urban areas that are not available to the same extent in their area. However, the situation may also occur in urban areas when services are available in other political jurisdictions, but are not available or not covered by health insurance plans in the CR's or ICG's jurisdiction. The positive side to this potential side-effect is that in raising awareness, it may also raise the level of advocacy for such services. Such was the conclusion of Magnusson & Hanson (2003) who noted that ICGs preferred to be informed about what was potentially available, rather than being "kept in the dark".

Results from several RCTs, summarized in the section on quality of outcomes, have provided evidence that telehomecare interventions have an impact on ICGs. There is other information from studies that did not employ comparative designs. For example, Davis (1998) used a pre-/post-test study design to assess the impact of telephone-based interventions on 17 ICGs of dementia patients. Davis found that 12 weeks of telephone support did not have any significant impact on ICG problem-solving styles, in the number of problem behaviours displayed by the dementia patients nor in the reactions of the ICGs to those behaviours. However, ICGs' use of social supports and life satisfaction were significantly increased, while depressive symptoms were significantly decreased over time.

Employing a similar pre/post test design, Glueckauf and colleagues (2004) found improved perception of self-efficacy, ability to manage challenging care behaviours and emotional care burden for the 21 ICGs. There was no change in the ICGs' perception of stress-related growth, positive caregiving appraisals or time burden. Strawn and colleagues (1998) reported that a 12-week telephone intervention was associated with reduced stress, stress-related responses and perceived burden of care for 14 ICGs of dementia victims for a time period that started before the intervention to 2 weeks after the intervention ended.

Given the methodological limitations, these comparative and non-comparative studies suggest that telehomecare did have an impact on ICGs for selected interventions and selected circumstances. However, in several comparative studies the telehomecare intervention was no better than the other interventions. In the non-comparative studies, the impact of telehomecare interventions relative to the alternative was not assessed.

5 Discussion

The literature on the impact of telehomecare on informal caregivers (ICGs) dealt mainly with studies of telephone or web-based support interventions for caregivers. For example, studies focused on telehomecare services that provided ICGs with counselling, emotional support, peer support, information, decision-making support, respite, skill building and education. The literature contained little information on the ICGs' perceptions of telehomecare services or the indirect impact on ICGs of telehomecare services that were geared towards the care recipient (CR). In fact, the absence of ICGs in the telehomecare literature is conspicuous given their importance to the homecare delivery system.

The methods used in this study to search and then select the literature for review have some limitations. Our search was limited to articles and, to a lesser extent, dissertations, books and reports published from 1990 to early 2005. The date limitation seems reasonable given that almost all of the telehomecare literature was published during that time period and that rapid developments in telecommunications technology reduce the applicability of older articles. The focus on articles was a function of our reliance on searchable on-line bibliographic databases. These databases varied with respect to the number of dissertations, reports, books or book chapters that they contained. These searches of on-line bibliographic databases were augmented by direct searches of the World Wide Web for projects and related reports. We are reasonably confident that we have identified most of the reports or articles based on these projects. Our search was limited to English-language publications. We have no measure of how many non-English language publications exist in our search domain. The keywords used in our searches were grouped into broad categories and we are reasonably confident that we have identified the vast majority of important keywords. Keyword searches were augmented by checking the literature cited lists of any pertinent references. As a partial check of our completeness, an additional search using “information technology” and similar keywords combined with “caregiver” or “informal care” keywords identified only a few new references.

It is encouraging that the number of citations that we found was comparable with that found by Magnusson and colleagues (2004). They conducted a literature review of studies on the use of information and communications technology in support of family caregivers and frail elderly. They identified about 1,500 articles after the first stage (keyword search). These were reduced to 539 and then to 84 articles at subsequent stages. These final numbers were slightly higher than what we found, but this is not surprising, given that we further restricted our search to citations that described an impact on ICGs.

A caveat on the level of evidence is warranted. Most of the cited articles and reports used descriptive study designs. Very few articles or reports employed comparative designs and those that did had small sample sizes or strict screening criteria for ICG eligibility or examined specific telehomecare applications such that results were not readily generalizable. As an example of the latter point, many of the comparative studies focused on telephone-based educational and supportive interventions for ICGs of Alzheimer’s patients. Of 48 articles summarized in Appendix 1, only 13 (27%) used comparative designs: 23% were randomized controlled trials (RCTs) and 4% were cohort studies. Approximately 42% of the articles used descriptive designs and 10% used pre/post test design with no comparison group.[14,15] Therefore, many of the findings should be considered speculative in nature—the explanations should be viewed as possible rather than as proven.

Proponents of telehealth and telehomecare have long championed the potential of telecommunications technology to improve access to health care services and reduce travel costs (monetary and non-monetary costs). Issues around the quality of technical service and quality of clinical service continue to be resolved by a combination of technological improvements and increased user experience (e.g., Bashshur 1998). Systematic reviews have found support for the clinical efficacy and efficiency of telehomecare, with the caveat that the results were mostly from pilot projects and that they tend to represent short-term clinical outcomes (e.g., Hersh et al. 2001; Hailey et al. 2002; Jennett et al. 2003). An emerging literature suggests that telehomecare interventions directed towards informal caregivers may be as good as or better (in the short-term) than alternative interventions. It seems reasonable to assert that time-sensitive sharing of information (updates on the health/well-being of the CR or the instruction/education of the ICG) is greatly enhanced by telecommunications technology.

---

[14] Other designs included: case reports (8%); literature review (8%); meta-analysis (2%) and informed opinion (2%).

[15] Some articles reported on the same or different aspects of the same study and so percentages are for the articles and not the studies, per se.

The importance of the ICG in providing or arranging homecare necessitates an approach in which telehomecare programs are developed in such a way that they address the needs of the CRs, ICGs, support workers and formal care providers. The typical disjointed approach probably reflects the youth of most telehomecare programs and the traditional disregard of the importance of informal caregivers as an integral part of the health human resources continuum (Pong 1999). It may also be that telecommunications technology was considered only as a new way to deliver established programs. It may require a shift in vision to see telehomecare as a means of re-organizing the existing health care system and to plan accordingly.

A number of organizations are developing guidelines for telehomecare. These include:

1. American Telemedicine Association (www.americantelemed.org/icot/hometelehealthguidelines.htm)
2. US Department of Veterans Affairs (www.va.gov/occ/TH/toolkits.asp)
3. Visiting Nurse Association (www.vnaa.org or www.innovativehcs.com)

Some of these guidelines include explicit evaluation of the role of the ICG with respect to their ability and willingness to use the equipment, as well as their training needs. In addition, these guidelines suggest that the home environment should be assessed for safety, security and other issues (e.g., Williams et al. 2000). Not all of these guidelines mention the ICG. Instead, they typically focus on the patient and mention the ICG occasionally or implicitly as in the phrase “patients and their designates” (Britton 2003; Dansky et al. 1999). It is also not clear what “weight” that the availability, ability and willingness of the ICG has in the decision to implement telehomecare. It may be that the important role that the ICG plays in successful delivery of homecare requires much more explicit consideration and mention so as to help realize the full potential of telehomecare.

One such example arises from the work of Dick and colleagues (2004), who evaluated a telehomecare program for parents and children with serious chronic conditions. Through focus groups with health care providers and parents, Dick and colleagues derived eight key components for developing a pediatric telehomecare service (modified from Table 1, in Dick et al. 2004). These important components included:

1. Develop a selection process to identify eligible children and families;
2. Provide adequate training for parents, children and health care providers;
3. Ensure quality monitoring of service;
4. Develop partnerships between health care providers (e.g., institutional and local levels);
5. Provide for access to emergency care;
6. Recognize the demands placed on parents and intervene as needed;
7. Develop a “contract” between parents and health care providers; and
8. Provide for individualized care of the patient and support of the parent.

There is a great potential for telehealth and telehomecare to re-structure the current health care system. However, the existing level of evidence requires a more cautious approach. Very few studies employed comparative research designs with sufficient numbers of participants or were free of major methodological limitations. Most of the articles and reports in Appendix 1 were descriptive studies. Therefore, much of the evidence is suggestive and inconclusive. An additional concern was noted by Peacock and Forbes (2003) who, in their systematic review of interventions for ICGs of persons with dementia, noted that most studies have been conducted on persons who have already accessed the formal care system. Their concern was about the possible utility and impact of these interventions on those who have not yet asked for or accessed formal care. The concern seems equally relevant to the telehomecare literature, with particular importance for bringing out the full impact of telehomecare. Consider, for instance, the potential impact that early detection of chronic diseases, by means of telecommunications technologies in the home, on the structure and function of the future health care system.

6 Conclusions

The scarcity of evidence, methodological limitations, the apparent or real contradictory findings and the short-term nature of many of the studies all suggest that the science is in its infancy and that implementation of telehomecare may need a cautionary approach, particularly with respect to its potential impact on ICGs. In light of these limitations, the following major findings are noted and implications suggested for further research and consideration.

Findings with support from the telehomecare literature:

- There is a large variety of health and health-education services that could be offered via telehomecare;
- Telehomecare is not a one-size-fits-all solution to the issues and concerns of ICGs;
- Telehomecare has improved access by ICGs to caregiver support services such as education, information, CR care suggestions, ICG self-care help as well as emotional and social support;
- Telehomecare offers an opportunity for more timely and more meaningful communication among CRs, ICGs and formal care providers;
- ICG support services have been readily accepted by most ICGs with a high level of satisfaction;
- Successful telehomecare occurs when the ICGs' technical skill level matches (or is trained to match) the level needed to use the telehomecare equipment;
- Successful telehomecare also occurs when the ICGs and the CRs want the service.

Findings inferred from the general literature on telehealth or informal care:

- From the point-of-view of the ICG, successful telehomecare is likely to occur when:
    - ICG support of all types is built-in right from the start—social, emotional, physical, mental and financial support;
    - The ICG's perspective is sought in the design (e.g., needs assessment) stage;
    - The ICG's feedback is sought on a regular basis during the start-up and operational stages;
    - The impact on ICGs is measured on a regular basis and used to modify the program accordingly.
- Other factors for a successful telehomecare include:
    - Other main players (CRs, support workers and formal care providers) are involved.
    - Technologies and programs are designed and adopted with the needs of CRs and ICGs in mind, rather than driven by the technology developer or vendor incentives.
    - Telehomecare services become integrated with existing health care services, particularly with respect to continuity of care or care management.

Additional recommendations and challenges:

- Policies, guidelines or standards may be needed to determine who has the responsibility for care and under which circumstances should it/can it be transferred to others. Some questions to be answered include:
    - What are the care responsibilities of the CR, ICG, support worker and formal care provider?
    - How much care responsibility can be transferred to ICGs? What is reasonable? How will this be measured? Monitored? By whom?
- Policies, etc., may be needed to recognize the importance of proper assessment of the CR and ICG during the transition from formal care institution (e.g., hospital, nursing home) to home (with telehomecare services) and back again. In other words, telehomecare needs entry and exit policies.
- Policies, etc., may be needed to ensure that the viewpoints of the CR, ICG, support worker and formal care provider are considered during these transitions and during the telehomecare period.
- The quality of the intervention and quality of the outcome (with respect to the impact on the ICG) should be monitored and evaluated, using robust research designs that compare telehomecare to alternatives.
- Economic evaluations of telehomecare programs should explicitly consider the impact on the ICG as well as other users and selected stakeholders.
- CRs who look after themselves are also the ICGs. This poses additional challenges to the success of telehomecare and would be the task of another study.

The need for homecare and thus the role of the informal caregiver is expected to increase as the population of Canada ages over the next few decades. The extent of this care need is unknown and so is the exact role for the informal caregiver, principally because of uncertainties in the future health status of seniors, success of interventions and effectiveness of service delivery. Telehomecare offers an opportunity to improve service delivery, thereby improving the availability of and access to health care and support services. Telehealth (in general) has the potential to change the very structure of the health care system. There are winners and losers with any change and it is incumbent on health service workers (including researchers, providers, administrators, decision- and policy-makers) to ensure that care recipients and informal caregivers continue to be on the winning side.

7 Literature Cited

Arras, J.D. & Dubler, N.N. (1995). Introduction: ethical and social implications of high-tech home care. Chapter 1, pages 1-31 in J.D. Arras, Editor. *Bringing home the hospital: ethical and social implications of high-tech home care*. John Hopkins University Press, Baltimore, MD.

Baranek, P.M, Deber, R.B. & Williams, A.P. (2004). *Almost Home: Reforming home and community care in Ontario*. University of Toronto Press, Toronto, ON.

Bashshur, R. L. (1998). Rethinking the evaluation and priorities in telemedicine. Editorial. *Telemedicine Journal,* 4(1),1-4.

Bass, D,M., McClendon, M.J., Brennan, P.F. & McCarthy, C. (1998). The buffering effect of a computer support network on caregiver strain. *Journal of Aging and Health*, 10(1), 20-43.

Brennan, P.F. & Moore, S.M. (1994). Networks for home care support: the ComputerLink project. *CARING Magazine*, 13(8), 64-70.

Brennan, P.F., Moore, S.M. & Smyth, K.A. (1995). The effects of a special computer network on caregivers of persons with Alzheimer's disease. *Nursing Research*, 44(3), 166-172.

Brennan, P.F., Moore, S.M. & Smyth, K.A. (1992). Alzheimer's disease caregivers' uses of a computer network. *Western Journal of Nursing Research*, 14(5), 662-673.

Britton, B.P. (2003). First home telehealth clinical guidelines developed by the American Telemedicine Association. *Home Healthcare Nurse*, 21(10), 703-706.

Brown, R., Pain, K., Berwald, C., Hirschi, P., Delehanty, R., & Miller, H. (1999). Distance education and caregiver support groups: Comparison of traditional and telephone groups. *The Journal of Head Trauma Rehabilitation*, 14(3), 257-268.

Buckley, K.M., Tran, B.Q. & Prandoni, C.M. (2004). Receptiveness use and acceptance of telehealth by caregivers of stroke patients in the home. *Online Journal of Issues in Nursing*, 9(3), 1-16.

Buckwalter, K.C., Davis, L.L., Wakefield, B.J., Kienzle, M.G. & Murray, M.A. (2002). Telehealth for elders and their caregivers in rural communities. *Family Community Health*, 25(3), 31-40.

Canadian Home Care Human Resources Study. (2003a). Synthesis Report. The Home Care Sector Study Corporation. Available from www.homecarestudy.ca

Canadian Home Care Human Resources Study. (2003b). Technical Report. The Home Care Sector Study Corporation. Available from www.homecarestudy.ca

Chan, D.S., Callahan, C.W., Sheets, S.J., Moreno, C.N. & Malone, F.J. (2003). An internet-based store-and-forward video home telehealth system for improving asthma outcomes in children. *American Journal of Health-System Pharmacists*, 60, 1976-1981.

Colantonio, A., Kositsky, A. J., Cohen, C. & Vernich, L. (2001). What support do caregivers of elderly want? Results from the Canadian Study of Health and Aging. *Canadian Journal of Public Health*, 92(4), 376-379.

Cranswick, K. (2003). General Social Survey Cycle 16: Caring for an Aging Society. Statistics Canada, Ottawa, ON 89-582-XIE.

Czaja, S.J. & Rubert, M.P. (2002). Telecommunications technology as an aid to family caregivers of persons with dementia. *Psychosomatic Medicine*, 64, 469-476.

Dansky, K.H., Palmer, L. Shea, D. & Bowles, K.H. (2001). Cost analysis of telehomecare. *Telemedicine Journal and e-Health*, 7(3), 225-232.

Darkins, A.W. & Cary, M.A. (2000). Telemedicine *and telehealth: Principles, policies, performance, and pitfalls*. Springer Publishing Co. New York, NY.

Davis, L.L. (1998). Telephone-based interventions with family caregivers: A feasibility study. *Journal of Family Nursing*, 4(3), 255-270.

Decima Research Inc. 2002 National profile of family caregivers in Canada – 2002. Final report prepared for Health Canada. Downloaded March 15, 2005 from: www.hc-sc.gc.ca/english/pdf/care/nat_profile02.pdf

Demiris, G. Speedie, S. M. & Finkelstein, S. (2001). Change of patients perceptions of telehomecare. *Telemedicine Journal and e-Health*, 7(3), 241-248.

Dick, P. T., Bennie, J., Barden, W., Daniels, C. & Young, N. L. (2004). Preference for pediatric telehome care support following hospitalization: A report on preference and satisfaction. *Telemedicine Journal and e-Health*, 10(Suppl. 2), 45-53.

Dimmick, S.L., Mustaleski, C., Burgiss, S.G., & Welsh, T. (2000). A case study of benefits & potential savings in rural home telemedicine. *Home Healthcare News*, 18(2), 125-135.

Eisdorfer, C., Czaja, S.J., Loewenstein, D.A., Rubert, M.P., Arguelles, S., Mitrani, V.B. & Szapocznik, J. (2003). The effect of a family therapy and technology-based intervention on ICG depression. *The Gerontologist*, 43(4), 521-531.

Field MJ, editor. (1996). *Telemedicine: A guide to assessing telecommunications for healthcare*. Committee on Evaluating Clinical Application of Telemedicine, Institute of Medicine, National Academy Press, Washington, DC

Finkelstein, S., Speedie, S. M., Demiris, G., Veen, M., Lundgren, J. M. & Potthoff, S. (2004). Telehomecare: Quality, perception, satisfaction. *Telemedicine Journal and e-Health*, 10(2),122-128.

Glueckauf, R.L., Ketterson, T.U., Loomis, J.S. Dages, P. (2004). Online support and education for dementia caregivers: Overview, utilization and initial program evaluation. *Telemedicine Journal and e-Health*, 10(2), 223-232.

Goodenough, B. & Cohn, R.J. (2004). Parent attitudes to audio/visual telecommunications in childhood cancer: An Australian study. *Telemedicine Journal and e-Health*, 10(Suppl. 2), 15-25.

Goodman, C. (1990). Evaluation of a model self-help telephone program: Impact on natural networks. *Social Work*, 35(6), 556-562.

Grant, J.S. (1999). Social problem-solving partnerships with family caregivers. *Rehabilitation Nursing*, 24(6), 254-260.

Grant, J.S., Elliott, T.R., Weaver, M., Bartolucci, A.A. & Giger, J.N. (2002). Telephone intervention with family caregivers of stroke survivors after rehabilitation. *Stroke*, 33(8), 2060-2065.

Gray, J.E., Safran, C., Davis, R.B., Pompilio-Weitzner, G., Stewart, J.E., Zaccagnini, L. & Pursley, D. (2000). Baby CareLink: Using the internet and telemedicine to improve care for high-risk infants. *Pediatrics*, 106(6), 1318-1324.

Guillén, S., Arrendondo, M.T., Traver, V., Valero, M.A., Martin, S., Traganitis, A., Mantzourani, E., Totter, A., Karefilaki, K., Paramythis, A., Stephanidis, C., & Robinson, S. (2002). User satisfaction with home telecare based on broadband communication. *Journal of Telemedicine and Telecare*, 8, 81-90.

Hailey, D., Roine, R. & Ohinmaa, A. (2002). Systematic Review of Evidence for the Benefits of Telemedicine. *Journal of Telemedicine and Telecare*, 8(Suppl. 1), 1-30.

Harding, R. & Higginson, I. (2001). Working with ambivalence: Informal caregivers of patients at the end of life. *Support Care Cancer*, 9, 642-645.

Hauber, R. P. & Jones, M. L. (2002). Telerehabilitation support for families at home caring for individuals in prolonged states of reduced consciousness. *Journal of Head Trauma Rehabilitation*, 17(6), 535-541.

Health Canada. (2004). Information: Home Care. Health Canada online, Downloaded March 18, 2005 from: www.hc-sc.gc.ca/english/media/releases/2004/fmm06.htm

Health Canada. (1999). Human Resource Issues in Home Care in Canada: A Policy Perspective. Home Care Division, Health Canada, Cat H21-148/1999E, ISBN 0-662-27963-8, Downloaded March 18, 2005, from www.hc-sc.gc.ca/homecare/english/pub.html

Health Canada (no date). Home Care in Canada 1999: an Overview. Downloaded March 22, 2005, from: www.hc-sc.gc.ca/homecare/english/profil.html

Hebert, M. A. & Korabek, B. (2004). Stakeholder readiness for telehomecare: Implications for implementation. *Telemedicine Journal & e-Health*, 10(1), 85-92.

Helgesson, A., Johansson, U.B., Walther-Stenmark, K., Eriksson, J., Strömegren, M. & Karlsson, R. (2005). Coordinated care planning for elderly patients using videoconferencing. *Journal of Telemedicine and Telecare*, 11, 85-92.

Hersh, W. R., Helfand, M., Wallace, J., Kraemer, D., Patterson, P., Shapiro, S. & Greenlick, M. (2001). Clinical Outcomes Resulting from Telemedicine Interventions: a Systematic Review. *BMC Medical Informatics and Decision Making*, 1(5), biomedcentral.com/1472-6947/1/5

Hogenbirk, J. C., & Pong, R. W. (2004). An audit of the appropriateness of teletriage nursing advice. *Telemedicine Journal and e-Health*, 10(1), 53-60.

Hogenbirk, J.C., Pong, R. W. & Lemieux, S. K. (2005). Impact of Telephone Triage on Medical Service Use: Implications for Rural and Remote Areas. *Journal of Agricultural Safety and Health*, 11(2), 229-237.

Hollander, M. & Chappell, N. (2002). Final Report of the National Evaluation of the Cost-Effectiveness of Home Care: Synthesis Report. National Evaluation of the Cost-Effectiveness of Home Care. Victoria, BC. Available from www.homecarestudy.ca

Hollander, M. & Chappell, N., Havens, B., McWilliam, C., & Miller, J.A. (2002). Substudy 5 Study of the Costs and Outcomes of Home Care and Residential Long Term Care Services. A report prepared for the Health Transition Fund, Health Canada. National Evaluation of the Cost-Effectiveness of Home Care. Victoria, BC. Available from www.homecarestudy.ca

Human Resources Development Canada. (1998). Job Futures 1997-98: Part 1 Occupational Outlooks. Human Resources Development Canada, Ottawa, ON.

Isaacksz S., Goel V., & Roston B. (2003). Using the balanced scorecard for evaluating telemedicine programs. Appendix Q in Brown E, & Sarsfield L. 2003. NORTH Network Program Phase II Evaluation Report. NORTH Network, Toronto, ON Available from: www.northnetwork.com/webportal/NorthNetworkPortal/ [additional details from P. Lindsay (personal communication, July 2004)].

Jennett, P. A., Hall, L. A., Hailey, D., Ohinmaa, A., Anderson, C., Thomas. R., Young, B., Lorenzetti, D. & Scott, R.E. (2003). The socio-economic impact of telehealth: a systematic review. *Journal of Telemedicine and Telecare*, 9, 311-320.

Jennett, P. A., Scott, R. E., Hall, L. A., Hailey, D., Ohinmaa, A., Anderson, C., Thomas. R., Young, B., & Lorenzetti, D. (2004). Policy implications associated with the socioeconomic and health system impact of Telehealth: a case study from Canada *Telemedicine Journal & e-Health*, 10(1), 77-83.

Kart, C. S., Kinney, J. M., Murdoch, L. D. & Ziemba, T. F. (2002). *Crossing the digital divide: Family caregivers' acceptance of technology*. Oxford, OH: Scripps Gerontology Center, Miami University.

Kinney J.M., Kart, C.S., Murdoch, L.D. & Ziemba, T.F. (2003). Challenges in caregiving and creative solutions using technology to facilitate caring for a relative with dementia. *Ageing International*, 28(3), 295-314.

Kirby, M. J. L. & LeBreton, M. (2002a). The health of Canadians – The federal role. Volume two: Current trends and future challenges. Interim Report of the Standing Senate Committee on Social Affairs, Science and Technology. Ottawa, ON.

Kirby, M. J. L. & LeBreton, M. (2002b). The health of Canadians – The federal role. Volume six: Recommendations for reform. Final Report of the Standing Senate Committee on Social Affairs, Science and Technology. Ottawa, ON.

Krishna, S., Balas, E.A., Boren, S.A., & Maglaveras, N. (2002). Patient acceptance of educational voice messages: a review of controlled clinical studies. *Methods of Information in Medicine*, 41, 360-369.

Magnusson, L., & Hanson, J. (2003). Ethical issues arising from a research, technology and development project to support frail older people and their family carers at home. *Health and Social Care in the Community*, 11(5), 431-439.

Magnusson, L., Hanson, E. & Borg, M. (2004). A literature review study of information and communication technology as a support for frail older people living at home and their family carers. *Technology and Disability*, 16, 223-235.

Mahoney, D. F., Tarlow, B. J. & Jones, R. N. (2003). Effects of an automated telephone support system on caregiver burden and anxiety: findings from the REACH for TLC intervention study. *The Gerontologist*, 43(4), 566-567.

Mahoney, D. M. F., Tarlow, B., Jones, R. N., Tennstedt, S. & Kasten, L. (2001). Factors affecting the use of a telephone-based intervention for caregivers of people with Alzheimer's disease. *Journal of Telemedicine and Telecare*, 7, 139-148

Mair, F. &; Whitten, P. (2000). Systematic review of studies of patient satisfaction with telemedicine. *British Medical Journal*. 320, 1517-1520.

Ministerial Advisory Council on Rural Health. (2002). Rural health in rural hands: Strategic directions for rural, remote, northern and Aboriginal communities. Ministerial Advisory Council on Rural Health, Health Canada, Ottawa, ON.

Miyasaka, K., Suzuki, Y., Sakai, H. & Kondo, Y. (1997). Interactive communication in high-technology home care: videophones for pediatric ventilatory care. *Pediatrics*, 99(1), e1-e6.

Motiwala, S.S. Flood, C.M., Coyte, P.C. & Laporte, A. (2005). The First Ministers' accord on health renewal and the future of home care in Canada. *Longwoods Review*, 2(4), 2-9.

Peacock, S.C. & Forbes, D.A. (2003). Interventions for caregivers of persons with dementia: A systematic review. *Canadian Journal of Nursing Research*, 35(4), 88-107.

Picot, J. (1998). Telehealth Industry, Part 1 – Overview and prospects. Health Industries Branch, Industry Canada, Ottawa, ON.

Pitblado, J.R. & Pong, R.W. (1999). Geographic distribution of physicians in Canada. Centre for Rural and Northern Health Research, Laurentian University, Sudbury, ON.

Ploeg, J., Biehler, L., Willison, K., Hutchison, B. & Blythe, J. (2001). Perceived support needs of family caregivers and implications for a telephone support service. *Canadian Journal of Nursing Research*, 33(2), 43-61.

Pong, R.W. (2002). Sharing the Learning – The Health Transition Fund Synthesis Series: Rural Health / Telehealth. Health Canada, Ottawa, ON.

Pong, R.W. (1999). Preparing for population aging: in search of a new manpower paradigm. Pages 11-23 in Asia-Pacific Conference for the International Year of Older Persons: Conference Proceedings, Volume 1. Hong Kong Council of Social Service and Social Welfare Department. Hong Kong.

Reid, J. (1996). *A telemedicine primer: Understanding the issues*. Innovative Medical Communications, Billings, MT.

Rivera, P.A., Shewchuk, R. & Elliott, T.R. (2003). Project FOCUS: Using videophones to provide problem-solving training to family caregivers of persons with spinal cord injuries. *Topics in Spinal Cord Injury Rehabilitation*, 9(1), 53-62.

Romanow, R.J. (2002). Building on values: The future of health care in Canada. Commission on the Future of Health Care in Canada, Ottawa, ON.

Sävenstedt, S., Brulin, C. & Sandman, P.O. (2003). Family members' narrated experiences of communicating via video-phone with patients with dementia staying at a nursing home. *Journal of Telemedicine and Telecare*, 9, 216-220.

Schulz, R. & Martire, L.M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry*, 12(3), 240-249.

Scott, R.E., McCarthy, F., Jennett, P., Perverseff, T., Palacios, M.F., & Rush, B. (2003). National Telehealth Outcome Indicators Project (NTOIP): Project information and a synthesis of telehealth outcome literature. Atlantic Health Sciences Corporation and Faculty of Medicine, University of Calgary. Available from: www.md.ucalgary.ca/Medicine/Centres/TeleHealth/NTOIP/_resources/InformationDocument.pdf

Sörensen, S., Pinquart, M. & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42(3), 356-372.

Statistics Canada. (2005). Unpaid Work, 2001 Census Technical Report. Statistics Canada, Ottawa, ON 92-397-XIE. (online data tables at www.statcan.ca Catalogue No. 97F0013XCB2001003 Topic-based Tabulations, Canada's Workforce: Unpaid Work.)

Statistics Canada. (2003). General Social Survey Cycle 16: Aging and Social Support Tables. Statistics Canada, Ottawa, ON 89-583-XIE.

Statistics Canada. (2002a). 2001 Census: Age and sex profile: Canada. Downloaded March 17, 2005 from: www12.statcan.ca/english/census01/Products/Analytic/companion/age/canada.cfm

Statistics Canada. (2002b). 2001 Census: Age and sex profile: shifts in the population size of various age groups. Downloaded March 17, 2005 from: www12.statcan.ca/english/census01/Products/Analytic/companion/age/population.cfm

Strawn, B. D., Hester, S. & Brown, W. S. (1998). Telecare: A social support intervention for family caregivers of dementia victims. *Clinical Gerontologist*, 18, 66-69.

Steffen, A. M. (2000). Anger management for dementia caregivers: a preliminary study using video and telephone interventions. *Behavior Therapy* 31, 281-299.

Subramanian, U., Hopp, F., Lowery, J., Woodbridge, P. & Smith, D. (2004). Research in home-care telemedicine: challenges in patient recruitment. *Telemedicine Journal and e-Health*, 10(2), 155-161.

Tran, B. Q., Buckley, K. M. & Prandoni, C. M. (2002). Selection & use of telehealth technology in support of homebound caregivers of stroke patients. *CARING Magazine*, 21(3), 16-21.

Wang, K.K. & Barnard, A. (2004). Technology-dependent children and their families: a review. *Journal of Advanced Nursing*, 45(1), 36-46.

Whitten, P., Doolittle, G. & Hellmich, S. (2001). Telehospice: Using telecommunication technology for terminally ill patients. *Journal of Computer Mediated Communication*, 6(4), 1-16.

Williams, G., Doughty, K. & Bradley, D.A. (2000). Safety and risk issues in using telecare. *Journal of Telemedicine and Telecare*, 6, 249-262.

Williams, T. L. May, C. R. & Esmail, A. (2001). Limitations of patient satisfaction studies in telehealthcare: A systematic review of the literature. *Telemedicine Journal and e-Health*, 7 (4), 293-316.

Yellowlees, P. (2001). *Your guide to e-health*. University of Queensland Press. Queensland, Australia.

Young, N.L., Barden, W., McKeever, P. & Dick, P.T. (no date).Taking the call – bell home: A qualitative evaluation of a pediatric tele-homecare service. Unpublished manuscript January 2005.

Young, N. L., Barden, W., Lefort, S., Nijssen-Jordan, C., Daniels, C., Booth, M., Dick, P T. & The Tele-homecare Team. (2004). Telehomecare: A comparison of three Canadian models. *Telemedicine Journal and e-Health*, 10 (1), 45-52.

8 Appendices

Appendix 1: Telehomecare Literature Summary

Bibliographic Citation	***Study Description[1]***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
Full citation	*Study Design (Design)* *Brief description (Desc:) plus the following, if applicable:* *Project/ Program name: (Proj:)* *Geographic location: (Loc:)[2]*	*Type of care: Acute, Chronic, Preventive, Palliative* *Type of service: Information, Monitoring, Compliance, Support* *Description of: Providers, CR, ICGs, method of recruitment*	*Were ICGs included in the study?* *What were the findings?* *What were the implications for ICGs?* *Abbreviations not defined in the text are listed after the table*
Selected Studies of Telehomecare			
Bass, D, M., McClendon, M.J., Brennan, P.F. & McCarthy, C. (1998). The buffering effect of a computer support network on caregiver strain. *Journal of Aging and Health*, 10(1), 20-43. See also: **Brennan & Moore 1994** **Brennan et al. 1992** **Brennan et al. 1995**	Design: Randomized Controlled Trial (RCT) with Pre/Post Tests Desc: Evaluated use of 12-month computer support network on four types of caregiver strain. The computer support provided a bulletin board, email, Q&A, and a comprehensive encyclopedia for care and support of the CR and ICG. Proj: ComputerLink Loc: U.S.A.	Care: Chronic Service: Support Providers: N/A CRs: Alzheimer's patients. ICGs: n=96. Mean age 60 years, 68% female, 28% African-American. 65% were spouses, 34% were adult children. Provided care for an average of 3 years. Recruitment: ICGs recruited from a university hospital Alzheimer's registry, Alzheimer's Association local chapter and advertisements. Six family carers dropped out during the first year.	Computer support network led to reduced levels of strain for some family caregivers, particularly those who had more informal support and were spousal carers. Use of different components of the service were associated with differential effects on strain: "communication" component reduced strain for non-spousal carers or those with higher initial strain; "solitary" component reduced strain for spousal carers and those living alone with CRs. Computer support may not be as effective at reducing overall strain for those carers who: lack informal support; non-spousal and live with CR only.

---

[1] Unless otherwise noted, studies did not make rural-urban comparisons.
[2] State/Province information is provided when available.

Bibliographic Citation	***Study Description[1]***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
Brennan, P.F. & Moore, S.M. (1994). Networks for home care support: the ComputerLink project. *CARING Magazine*, 13(8),64-70. See also: **Bass et al. 1998**	Design: Descriptive (this article), RCT (main study) Desc: Evaluated ComputerLink – a program that provided information, communication and decision support to ICGs of persons with Alzheimer's disease. Proj: ComputerLink Loc: U.S.A.	Care: Chronic Service: Support ICGs: mean age 61 years, 66% female, 66% white CRs: Alzheimer's disease. 60% spouses, 31% parents, mean time period for care 35 months. Recruitment: 47 ComputerLink and 41 comparison, recruited through three Alzheimer's organizations	Comparative data were not presented in this article. The 47 ICGs in the ComputerLink group used the service an average of 92 times in one year. ICGs used the program the least often to interact with professionals. The experimental group indicated they found the computer network a place to come to communicate and receive support from others who shared similar concerns. Caregivers wrote about instrumental assistance on obtaining services or dealing with a caregiving problem, as well as expressing emotions, moods, and feeling states.
Brennan, P.F., Moore, S.M. & Smyth, K.A. (1992). Alzheimer's Disease Caregivers' Uses of a Computer Network. *Western Journal of Nursing Research*, 14(5), 662-673. Brennan, P.F., Moore, S.M. Smyth, K.A. (1991). ComputerLink: electronic support for the home caregiver. *Advances in Nursing Sciences*, 13(4), 14-27.	Design: Descriptive Desc: ICGs reflect on their use of computer network support service Proj: ComputerLink Loc: U.S.A.	Care: Chronic Service: Support Providers: ICGs: (as above) CRs: Alzheimer's disease. Recruitment: Convenience sample (as above).	Two-thirds of the 47 ICGs used ComputerLink during the week long study period for an average of 2 times/wk at 30 minutes each. Most ICGs learned to used ComputerLink in under 2 hours. ComputerLink requires all communication to be typed, and while the ICGs were creative in their use of capital letters, punctuation, etc., it was the authors opinion that communication was less rich than face-to-face.
Brennan, P.F., Moore, S.M. & Smyth, K.A. (1995). The effects of a special computer network on caregivers of persons with Alzheimer's	Design: RCT with Pre/Post Tests Desc: Evaluated use of a computer-support network on caregiver decision-making confidence and skill and social isolation.	Care: Chronic Service: Support and support. Providers: N/A CRs: Alzheimer's disease. ICGs: n=96, median 64 years	Computer support network significantly improved confidence in decision-making but did not affect decision-making skill or social isolation. 46% of sessions used the public

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
disease. *Nursing Research*, 44(3), 166-172. See also: **Bass et al. 1998** **Brennan & Moore 1994** **Brennan et al. 1992**	Proj: ComputerLink Loc: U.S.A.	of age, 68% female, 28% African-American. 65% were spouses, 34% were adult children, provided care for an average of 3 years. Recruitment: ICGs recruited from a university hospital, Alzheimer's disease registry, local chapter of Alzheimer's Association and advertisements. 6 dropouts during the 1-year study.	bulletin board (mean usage time of 10 minutes), 30% of sessions used private email (6 minutes). Other utilization included: Q&A (14%), encyclopedia (8%), and decision making (1%). Improved confidence in decision-making may have been the result of information exchange among carers rather than use of the decision-making component per se.
Brown, R., Pain, K., Berwald, C., Hirschi, P., Delehanty, R., & Miller, H. (1999). Distance education and Caregiver support groups: comparison of traditional and telephone groups. *The Journal of Head Trauma Rehabilitation*, 14(3), 257-268.	Design: Cohort (analytic) Desc: Compared (rural) teleconferencing vs. (urban) in-person support groups (over 9-10 weeks) for ICGs of individuals with brain injury. Proj: NR[3] Loc: Alberta, Canada	Care: Chronic Service: Support Providers: ICGs: n=91. 88% female, average 48 years of age, 44% were wives, 32% were mothers. Average of 12 years of education. CRs: n=83 adults with brain injuries. 27% female, average 41 years of age, 55% with traumatic brain injury, 31% with stroke, injured for 2.4 years. Recruitment: Caregivers of current or former patients of a Brain Injury Rehabilitation Program were invited to attend the support group (n=52 telephone, n=39 in-person).	Traditional and telephone support groups were compared. Telephone support groups were as effective as traditional face-to-face support groups for ICGs. Satisfaction was high for both groups but the telephone group reported a higher level of satisfaction. No significant difference with respect to the change over time in family functioning (FAD), caregiver burden (CBI) or caregiver distress (POMS). Differences between interventions may be due to differences between rural (telephone) and urban (in-person) participants and may not be due to the intervention, per se.
Buckley, K.M., Tran, B.Q. & Prandoni, C.M. (2004).	Design: Descriptive Desc: Examined factors that	Care: Acute Service: Support	Reasons cited for ICGs refusal to participate in the study included:

---

[3] Not reported in the article.

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
Receptiveness use, and acceptance of telehealth by caregivers of stroke patients in the home. *Online Journal of Issues in Nursing*, 9(3), 1-16.	influence receptiveness, use and acceptance of therapeutic interventions provided by RNs using videophones to ICGs at home. Proj: NR Loc: U.S.A.	Providers: trained telehealth nurses CRs: stroke patients ICGs: min. 40 years of age, mean age 63 years, majority African-American, married, female, middle-income, and homemakers Recruitment: telephone call by the chief investigator, primary ICG of a family member 1st time stroke survivor in the past six months. Of 75 contacted, 21 ICGs agreed to participate.	concerns for personal safety and home security, fear of invasion of privacy, lack of need for services and lack of desire to learn how to use the equipment. ICGs experienced physical difficulties providing care due to their own health problems, economic restrictions, isolation and loneliness, and burnout. ICGs that used the videophones accepted them and were enthusiastic about using them. ICGs experiencing low burden didn't need the service and ICGs experiencing high burden were too overwhelmed by the demands of caretaking to try the service. ICGs were half as likely to report audio/visual problems with the system than were nurses ICGs appreciated timely access to professional advice.
Buckwalter, K.C., Davis, L.L., Wakefield, B.J., Kienzle, M.G. & Murray, M.A. (2002). Telehealth for elders and their caregivers in rural communities. *Family Community Health*, 25(3), 31-40.	Design: Literature Review Desc: Telehealth innovations for rural elders/ICGs. Proj: several described Loc: U.S.A.	Care: Varied Service: Varied Providers: Varied CRs: Varied dementia Recruitment: Varied	Very select Literature Summary: no new results. See: 1. **Brennan et al. 1995**[4] 2. **Davis 1998** 3. **Mahoney et al. 1998** 4. **Wright et al. 1998**
Chambers, M. & Conner, S.L (2002). User-friendly technology to help family carers cope. *Journal of Advanced Nursing,* 40(5),	Design: Descriptive Desc: Questionnaires were used to determine the usability of interactive software designed to provide ICGs with information	Care: Chronic Service: Information, support ICGs: Elderly or disabled, pilot (n=5), mean 59 years old, majority were female.	Comments from all 9 key informants during the pilot were generally positive, with some suggestions on how to improve content and delivery. There was also the suggestion that

---

[4] Bolding indicates that author and article appears in this table.

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
568-577. Chambers, M., Conner, S., Diver, M., & McGonigle, M. (2002). Usability of multimedia technology to help caregivers prepare for a crisis. *Telemedicine Journal and e-Health*, 8(3), 343-347. Chambers, M., Conner, S.L., McGarvey, H. & Diver, M. (2001). User acceptance of a multi-media software application to increase preparedness for caring problems. *Health Informatics Journal*, 7, 152-157. See also: **Hansen et al. 2000** **Magnusson & Hanson 2003**	advice and psychological support Proj: ACTION (Assisting Carers using Telematics Interventions to meet Older persons Needs) Loc: Europe	Evaluation (n=8), majority were female, aged 25-78 years old. Demonstration (n=103), 73% of all 242 respondents were female, 26% were 40-49 years old. Recruitment: Pilot test used 9 key informants, 5 were ICGs. Evaluations by 26 users, 8 were ICGs. Demonstration phase assessed by 242 users, 103 were ICGs.	some of the text was repetitive, and on occasion, patronizing to ICGs. Evaluation findings from 26 users: 70-90% of all users had positive reaction to overall impression, ease of use, satisfaction, etc. Demonstration phase results suggest that all users gave positive scores to the software program for attractiveness, controllability, efficiency, etc. Navigation was given a lower, but still positive score.
Chan, D.S., Callahan, C.W., Sheets, S.J., Moreno, C.N. & Malone, F.J. (2003). An internet-based store-and-forward video home telehealth system for improving asthma outcomes in children. *American Journal of Health-System Pharmacists*, 60(Oct. 1), 1976-1981.	Design: RCT with Pre/Post Tests over 6 months. Desc: Evaluation of patient adherence and disease-control outcomes associated with the use of an internet-based store-and-forward video system for asthmatic children. The RCT compared internet-and-office-based education. Proj: NR Loc: NR	Care: Chronic Service: Monitoring, compliance. Providers: Physicians, case managers. CRs: (n=10), mean 8 years old, 50% female. ICGs: No information Recruitment: CRs recruited from pediatric clinic.	Quality of life survey score (PAQL) increased for ICGs in the virtual visit group and was stable in the office visit group (measured at enrolment and after 6 months) Small sample size (n=10) therefore results are suggestive and not conclusive.
Czaja, S.J. & Rubert, M.P. (2002). Telecommunications	Design: This study was a descriptive study. The full project is a RCT.	Care: Chronic Service: Information and	44 of 76 completed questionnaires at 6 month stage.

Bibliographic Citation	*Study Description*[1]	*Specifics*	*Relevance to Informal Caregivers (ICGs)*
technology as an aid to family caregivers of persons with dementia. *Psychosomatic Medicine*, 64, 469-476. See also: **Eisdorfer et al. 2003**	Desc: Preliminary data on ICGs perception of usability and usefulness of a computer-integrated telephone system designed to help identify and resolve family behaviours affecting care burden. Proj: Resources to Enhance Alzheimer's Caregiver Health (REACH) Loc: Florida, U.S.A.	support Providers: NA ICGs: n=44. Average 68 years old, 77% female, 52% White, 48% Cuban-American. 59% had some post-secondary education, 64% were spouses, 36% daughters, daughters-in-law or nieces, 68% had been providing care for 2-5 years. CRs: Moderately to severely cognitively impaired persons with dementia. Recruitment: NR	Average 10 calls per dyad over 6 months to friends, REACH friends or resources. Average 39 calls per dyad were long distance calls to family members including family conference calls (much appreciated and valued by family carers). 86% found the screen phone valuable, 88% liked using it and 80% were satisfied using it to communicate. 16% had difficulty using the system. Cuban-Americans tended to give more positive responses than White Americans.
Davis, L.L. (1998). Telephone-based interventions with family caregivers: A feasibility study. *Journal of Family Nursing,* 4(3), 255-270.	Design: Pre/Post Tests/ Desc: Outcomes of a 12 week pilot study of a telephone based skill training intervention for ICGs. Proj: NR Loc: NR	Care: Chronic Service: Support and information Providers: Community health nurses ICGs: Mean 57 years old, 75% women, 60% White, and 65% were adult children of the CR. CRs: Dementia, mean 79 years old Recruitment: 17 ICGs with a year or more of caregiving experience.	ICGs showed significant improvements in their use of social support (ISEL), a decrease in depressive symptoms (GDRS) and an increase in life satisfaction (LSI-Z). No significant changes over time in caregivers' problem-solving styles (RPS), in the number of problem behaviours (RMBPC, SPSI-R) displayed by the dementia patients, or in the reactions of the caregivers of those behaviours. Small sample size. No control or comparison groups, so results are suggestive and not conclusive.
Dick, P.T., Bennie, J., Barden, W., Daniels, C. & Young, N.L. (2004). Preference for pediatric telehome care support following hospitalization: A report on	Design: Descriptive Desc: Measured parent preference for a 6-week telehomecare program designed to improve the transition home for children discharged from hospital. THC is	Care: Chronic Service: Monitoring Providers: Nurses CRs: Children discharged from hospital with serious chronic conditions with co-	59% of ICGs indicated a strong preference for telehomecare prior to participation which increased significantly to 71% following the study. No difference between the satisfaction

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
preference and satisfaction. *Telemedicine Journal and e-Health,* 10(Suppl. 2), 45-53.	based on videoconferencing between a health care station and a patient's home using telephone lines, ISDNs or the Internet. Proj: NR Loc: Ontario, Canada	morbidity. 79% were 1 year old or younger, 60% male. ICGs: Parents (n=67), 75% married, 73% post-secondary education, 43% English as first language Recruitment: convenience sample of parents whose children were in-patients from The Hospital for Sick Children (HSC) 10 enrolments during the pilot and 57 during the trial.	for care (derived from Ontario Hospital Patient Satisfaction Survey) delivered in the home to care in the hospital except for parents with children who are heavily dependent on technology who rated hospital care higher than home care. No difference in satisfaction or preference by sociodemographic factors, diagnosis, or clinical circumstance. Overall satisfaction score was 83 out of a possible 100.
Dimmick, S.L., Mustaleski, C., Burgiss, S.G., & Welsh, T. (2000). A case study of benefits & potential savings in rural home telemedicine. *Home Healthcare Nurse,* 18(2), 125-135.	Design: Case Report Desc: Patient-centered interviews (with ICG contributions) to assess a demonstration project for rural patients using a video camera, video monitor, speakerphone, and an electronic interface to a telephone line. Proj: UT Homecare Services and the University of Tennessee Medical Centre provide the service. Equipment provided by Home Touch. Loc: Tennessee, U.S.A.	Care: Chronic and Acute Service: Monitoring Providers: Majority were RNs CRs: n=14, 86% Caucasian, 64% didn't complete high school and 75% had household income of less than $20,000. Recruitment: referrals from physicians in UTMC's integrated health delivery network which were interviewed by a home health nurse to determine patient/ICG interest in participating in the study. (9 ICGs?)	During the CR/ICG interviews, ICGs were asked for their perspective on the advantages and disadvantages of telehealth. ICGs reported the following benefits: Timely and easy access to service, reduced anxiety, convenience, availability of comprehensive and consistent care and increased privacy. In addition, ICGs found that the health care provider's ability to "see" the problem (i.e. a wound) rather than have the ICG describe the problem was a benefit. Both patients and ICGs found the equipment easy to use and depended on the televisits for clinical reasons as well as an opportunity to connect with the outside world. CR/ICGs and nurses reported some problems with phone connections.
Doolittle, G.C., Yaezel, A., Otto,	Design: Descriptive	Care: Palliative	CRs and ICGs reported general

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
F. & Clemens, C. (1998). Hospice care using home-based telemedicine systems. *Journal of Telemedicine and Telecare,* 4(Suppl. 1), 58-59.	Desc: A home telehospice pilot project using the telephone and interactive video equipment. Proj: Collaboration between Kansas University Medical Centre (KUMC) and the Kendalwood Hospice Loc: Kansas and Missouri, U.S.A.	Service: Monitoring Providers: Nurse, social worker, chaplain, and aide CRs: hospice patients, n=6 ICGs: family, n=6 Recruitment: Patients were recruited based on willingness to participate and home location in relation to hospice base stations.	satisfaction with the telehospice system.
Eisdorfer, C., Czaja, S.J., Loewenstein, D.A., Rubert, M.P., Arguelles, S., Mitrani, V.B. & Szapocznik, J. (2003). The effect of a family therapy and technology-based intervention on Caregiver depression. *The Gerontologist*, 43(4), 521-531. See also: **Czaja & Rubert 2002**	Design: RCT with Pre/Post Tests Desc: Examined the efficacy of a 18-month family therapy intervention with/without a computer-telephone support network for ICGs of individuals with Alzheimer's disease. The computer-telephone network provided for conference calls, discussion groups, voice mail/reminders, plus a copy of Alzheimer's Association local directory of resources. Proj: REACH. Intervention includes psychosocial-psychoeducational services, behavioural intervention, environmental modifications, and technology interventions. Loc: Florida, U.S.A.	Care: Chronic Service: Support Providers: NR ICGs: 225 White and Cuban American family caregivers. Mean age 69 years, 75% women, average four years as caregiver, 65% spouses and 27% daughters, 49% had post-secondary education. CRs: Mean age 83 years, 52% female Recruitment: Subjects were recruited from referrals and advertisements. ICGs randomly assigned to therapy (data for 54 of 75); therapy and computer (data for 51 of 77); and minimum phone support group (data for 41 of 73).	Standard therapy plus telephone significantly reduced depressive symptoms (CES-D scale) in ICGs at 6 and 18 months. Therapy alone did not significantly reduce depressive symptoms. Ethnicity and the relationship between ICG and CR influenced the strength of the effect. (Other measures, used as covariates, included: MMSE, ADL, RMBPC and IADL)
Glueckauf, R.L., Ketterson, T.U., Loomis, J.S. & Dages, P. (2004). Online support and education for dementia caregivers: Overview,	Design: Pre/Post Tests Desc: Evaluation of a 16-week caregiver support intervention. Proj: Alzheimer's Caregiver Support Online (AlzOnline), an internet and	Care: Chronic Service: Support, Information Providers: computer-based ICGs: n=21, mean age 64 years, 86% female, 90%	Computer or telephone support was related to decreases in emotional caregiver burden (CAI) and increases in perceptions of self-efficacy (CSES).

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
utilization and initial program evaluation. *Telemedicine Journal and e-Health,* 10(2), 223-232.	telephone-based education and support network. Loc: U.S.A.	White, 62% spouses and the rest daughter's or daughter's-in-law. CRs: Alzheimer's Disease Recruitment: Referrals and advertisements.	There were no significant differences in the ICGs perception of the positive aspects of caregiving (SRG) or perception of time burden. No control or comparison group, so results are suggestive and not conclusive. Internet and telephone groups were pooled prior to analysis.
Goodenough, B. & Cohn, R.J. (2004). Parent attitudes to audio/visual telecommunications in childhood cancer: An Australian study. *Telemedicine Journal and e-Health,* 10(Suppl. 2), 15-25.	Design: Descriptive Desc: Surveys of 100 parents from two regional groups (rural vs. urban) and two childhood cancer groups (leukemia, solid tumour) on their understanding and attitudes toward videoconferencing in specific oncology applications. Proj: NR Loc: New South Wales, Australia Rural/Urban comparisons.	Care: Chronic Service: N/A[5] Providers: N/A CRs: Children with leukemia (43%) and solid tumours (57%). ICGs: 85% were mothers and the majority of 62% were 35-44 years old. Respondents divided into rural (n=44) and urban (n=46) groups Recruitment: Surveys mailed to 215 parents based on referral databases.	Parents gave higher ratings for the usefulness of videoconferencing for psychosocial care or education rather than for clinical uses or treatment planning. The favourite potential application was "contact between separated family members". The best predictor of ratings for future use of video-conferencing was the ratings of use for other communication technologies. There was little evidence of differences between regional groups or cancer types except that rural parents gave higher ratings for the impact of time and distance factors than urban parents. 33% of parents indicated that they would use video-conferencing at least "some of the time". 80% were from rural areas. 33% of parents had previously heard of telehealth, 7% had some experience with videoconferencing during their child's cancer treatment. 36% were interested in receiving more

---

[5] Not applicable.

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
			information about telehealth The highest ratings for perception of the usefulness of telehealth were for "reducing travel cost" and "useful for remote communities". The lowest rating was in response to the statement "relevant to my family's situation" mainly due to low scores from urban parents. Rural parents gave higher ratings than urban parents in general attitudes towards telehealth. Parents gave high ratings to the <u>potential</u> of telehealth especially in terms of savings and benefits independent of their distance to the treatment centre. The results from similar studies show ratings of satisfaction with multidisciplinary pediatric telemedicine consultations to be related to privacy concerns as well as comfort with the equipment and the health care provider.
Goodman, C. (1990). Evaluation of a model self-help telephone program: Impact on natural networks. *Social Work*, 35(6), 556-562.	Design: RCT with Cross-over and Pre/Post Tests Desc: Examines the intervention on perceived use of informal supports as well as social supports, mental health, burden and information. Subjects assigned to a peer telephone network or telephone lecture series and then reassigned to the alternative after three months. Proj: Care-Line, model telephone network program	Care: Chronic Service: Support CRs: Alzheimer's Disease (80%) ICGs: average age 66 years, 75% female, 73% spouses, 75% married, 65% White, 20% African Americans. 63% low to middle incomes (≤ $20k, USD) Recruitment: advertisements and referrals. Matched for age, gender, and	There were no significant differences between groups before the cross-over. There were no significant differences between groups after the cross-over and there were no further improvements. Measures included RMBPC, MHI, CBI, PSSCSC, 10-questions knowledge quiz, satisfaction survey plus a list of family/friend support. Both groups reported that the patients became more impaired and both groups increased the use of social

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
	Loc: U.S.A.	relationship to CR then randomly assigned to network then lectured (n=22) or lecture then network (n=18). There were 41 dropouts.	support. Telephone networks may have substituted initially for emotional and social support from family and friends but only for those ICGs who first had telephone networks and then the lectures. ICGs who had telephone lectures first, used family and friends for emotional and social support throughout both phases. ICGs gained more information through telephone lectures. Results for the first 3 months (prior to cross-over) are presented by **Goodman & Pynoos (1990)**
Goodman, C.C. & Pynoos, J. (1990). A model telephone information and support program for caregivers of Alzheimer's patients. *The Gerontologist*, 30(3), 399-404.	Similar to Goodman (1990) but without cross-over	As above.	After 3 months, both groups gained with respect to satisfaction with social support and perceived social supports for caregiving. No changes after 3 months for burden, ICG-CR relation, distress or mental health. ICGs listening to taped lectures over the phone gained more information about AD and increased their contact with family and friends for emotional support relative to ICGs who participated in telephone networks. See **Goodman (1990)** for 6 month results after the cross-over and a list of outcome measures.
Grant, J.S. (1999). Social problem-solving partnerships with family caregivers. *Rehabilitation Nursing*, 24(6), 254-260.	Design: RCT with Pre/Post Tests Desc: Compared effectiveness of home and telephone social problem-solving skills. Three groups: home visit, telephone	Care: Acute Service: Support Providers: Nurses CRs: stroke survivors with an average age of 71 years,	Compared to the other groups, the telephone intervention group had a significant reduction in depression (CES-D), more positive problem-solving skills (PSI), and greater

Bibliographic Citation	***Study Description[1]***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
Additional descriptive information on the project is found in: Grant, J.S., Elliott, T.R., Giger, J.N. & Bartolucci, A.A. (2001). Social problem-solving telephone partnerships with family caregivers of persons with stroke. *International Journal of Rehabilitation Research*, 24, 181-189	intervention or telephone contact (no intervention) (12-weeks). Proj: NR Loc: USA	53% were males, 60% were African Americans. ICGs: n=30, average age 56 years, wives (40%) or daughters (23%) with an average of 10 years of schooling, 60% were African Americans. Recruitment: Family caregivers who met selection criteria and consented to participate were randomly assigned to groups (ICGs > 50 miles away assigned to telephone or control groups).	caregiver preparedness (PCS) during the intervention and improved but non-significant depression, problem-solving and caregiver preparedness scores at 2 and 5 weeks after patient discharge. Differences, if present, were not statistically significant after 12 weeks. No significant differences for general health caregiver burden (CBS) and satisfaction with healthcare services (CSQ). ICG age and ethnicity may affect the impact of intervention. Some restrictions on allocation meant that rural residents were not assigned to the home visit group.
Grant, J.S., Elliott, T.R., Weaver, M., Bartolucci, A.A. & Giger, J.N. (2002). Telephone intervention with family caregivers of stroke survivors after rehabilitation. *Stroke*, 33(8), 2060-2065. For slightly different pilot test see: **Grant 1999**	Design: RCT with Pre/Post Tests Desc: 18 month study of telephone intervention, telephone contact and control on ICGs of stroke survivors. Proj: NR Loc: Southeastern U.S.A.	Care: Acute and chronic Service: Information and Support Providers: Nurses CRs: n=74, average 74 years of age, 53% female, 74% White-American, 26% African-American. Stroke survivors with moderate levels of disability. ICGs: n=74, average 56 years of age, 91% female, 74% White-American, 26% African-American. 41% were spouses, 36% were daughters. Recruitment: Eligible family carers were randomly assigned to telephone intervention, sham telephone	Telephone intervention increased or improved problem-solving skills (SPSI-R), preparedness (PCS), vitality, social function, mental health and the role limitations related to emotional problems (all SF-36) over 18 months. No significant differences in caregiver burden (CBS). Telephone intervention did not affect positive problem orientation (SPSI-R) or satisfaction with health care services (CSQ), though both measures were significantly decreased in the control group.

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
		interventions and control groups. (There was no 'home-visit' group as per **Grant 1999**) (Data for 63 of 74).	
Gray, J.E., Safran, C., Davis, R.B., Pompilio-Weitzner, G., Stewart, J.E., Zaccagnini, L. & Pursley, D. (2000). Baby CareLink: Using the internet and telemedicine to improve care for high-risk infants. *Pediatrics*, 106(6), 1318-1324.	Design: RCT Desc: Evaluated an internet based program that provided medical, informational and emotional support to families of very low birth weight infants (VLBIs) during the neonatal intensive care unit (NICU) stay using videoconferencing and the internet. Intervention ran for 3-4 months (until infant was discharged home). Survey conducted 1-4 months after final discharge. Proj: Baby CareLink Loc: Massachusetts, U.S.A.	Care: Acute Service: Support, Information and Monitoring Providers: Beth Israel Deaconess Medical Center CRs: VLBIs ICGs: Parents of VLBIs Recruitment: 56 of 176 infants were eligible, then randomly assigned 30 VLBIs to the control group and 26 VLBIs to the CareLink Group.	CareLink group reported significantly fewer problems with quality of care than the control group. For instance, all infants in CareLink group were discharged home whereas 20% of the infants in the control group were transferred to a local hospital before discharge. CareLink group reported significantly higher satisfaction with quality of care and the unit's physical environment and visitation policies. Satisfaction was non-significantly higher for 6 other dimensions of the Picker Institute's Neonatal Intensive Care Unit Family Satisfaction survey. The duration of the infant's hospitalization was similar between the two groups. Infants from families without CareLink tended to stay longer but felt that their stay was too short.
Guillén, S., Arrendondo, M.T., Traver, V., Valero, M.A., Martin, S., Traganitis, A., Mantzourani, E., Totter, A., Karefilaki, K., Paramythis, A., Stephanidis, C., & Robinson, S. (2002). User satisfaction with home telecare based on broadband communication. *Journal of Telemedicine and*	Design: Descriptive Desc: Evaluation of telehomecare services using videoconferencing through broadband networks. Proj: ATTRACT Loc: Europe	Care: Chronic Service: Information, monitoring. Providers: n=13 CRs: n=135 ICGs: results for 4 family caregivers from Belfast for which demographic data were not reported. 80 respondents from Crete and	4 ICGs gave high marks to usefulness of the system, quality of user interface, overall usability and, to a lesser extent, to quality of information. ICGs also gave high marks to different aspects of the communication between patient and doctor. Overall satisfaction was high. Perceived positive effect on patient's

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
Telecare, 8, 81-90.		4 other respondents from Belfast were 23-59 years old and 89% were female. Recruitment: NR.	life. Perceived privacy during use was high. Caveat: small sample size, no comparison or control group.
Hanson, E.J., & Clarke, A. (2000). The role of telematics in assisting family carers and frail older people at home. *Health and Social Care in the Community,* 8(2), 129-137. Additional information in: Hanson, E., Magnusson, L., Oscarsson, T., & Nolan, M. (2002). Case study : benefits of IT for older people and their carers. *British Journal of Nursing,* 11(13), 867-874. Hanson, E.J., Tetley, J., & Clarke, A. (1999). A multimedia intervention to support family caregivers. *The Gerontologist*, 39(6), 736-741. See also: **Chambers & Conner 2002** **Magnusson et al. 1998**	Design: Descriptive Desc: Unstructured interviews solicited feedback on the use of videoconference equipment to assist family caregivers and elderly CRs. Proj: ACTION (Assisting Carers using Telematics Interventions to meet Older people's Needs). Loc: Europe	Care: Chronic Service: Information, support. CRs: Frail elderly. ICGs: n=3, 62 year old female caring for 90 year old father, 73 year old female caring for 75 year old husband. Male in late 80s caring for his wife (in her 80s). Recruitment: Family caregivers looking after frail elderly at home, with little or no formal support services, referred by a medical centre.	Expectations about learning about new services, new ways of coping, how to plan ahead. Initial concerns about invasion of privacy, family caregivers appearance on the screen, self conscious, concerns about technical ability. Information on available services was misleading (raised expectations). Video clips and videoconferencing were well-received. One caregiver said that the equipment was intrusive, and an eyesore. Low participation rate due to reluctance to take on new tasks when their schedule is already busy and demanding. New ICGs with low initial care burden may be most appropriate participants.
Hauber, R.P. & Jones, M.J. (2002). Telerehabilitation support for families at home caring for individuals in prolonged states of reduced consciousness. *Journal of Head Trauma Rehabilitation*, 17(6), 535-541.	Design: Cohort (analytic) Desc: Evaluated the use of videophones to support families caring for individuals with prolonged states of reduced consciousness (10-12 week program). Proj: A service offered by the Traumatic Brain Injury Model	Care: Acute Service: Monitoring Providers: Certified Rehabilitation RNs CRs: Patients in the Traumatic Brain Injury Model Systems Projects of the National Institute on Disability and Rehabilitation and Research	ICGs in the videophone group reported 58% of their needs met (FNQ) (18% unmet) whereas the comparison group had 50% of their needs met (28% unmet). More ICGs in the comparison group felt that the patient required less care at the time of the interview. Small sample size was a serious

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
	Systems Projects of the National Institute on Disability and Rehabilitation and Research. Loc: U.S.A.	ICGs: Family members Recruitment: Participants were recruited from the program (videophone n=6, Comparison n=4).	limitation. Interviews were conducted 3-18 months after discharge from facility.
Health Canada. *Needs assessment for the Canadian Virtual Hospice.* Knowledge Development and Exchange Applied Research. (2002). Final Report December 4, 2002. Downloaded October 5, 2004 from http://www.hc-sc.gc.ca/ohih-bsi/pubs/kdec/on_virt_rpt_e.html	Design: Descriptive Desc: Interviews, focus groups and surveys (n=700) were used to conduct a needs assessment of a palliative care website (conducted in 2002 across Canada). Proj: Canadian Virtual Hospice Loc: Canada	Care: Palliative Service: Information Providers: Various CRs: Various ICGs: Various, n=79 surveys, unknown number of participants in interviews and focus groups. Recruitment: Recruited by palliative care centres/ hospices.	Patients and their families said that the website could provide information/ links for: ▪ emotional, spiritual and mutual support by providing a virtual family (chat rooms, information exchange) or links to sites that offer solace, inspiration, etc. ▪ available financial support and other resources for ICGs and CRs ▪ how to care for the patients ▪ list of questions to ask the formal caregiver ▪ “Ask the Expert” feature ▪ prognosis, problems/complications ▪ medication regimen, side effects ▪ advocacy for the ICG, self-help suggestions ▪ legal requirements and documents (wills, power of attorney) ▪ how to deal with death and the aftermath Patients, families and friends said that the site should focus on patients and families, not providers. The website should contain information in simple-to-read and east to print formats including FAQs, checklists, logbooks, etc. The information should be simple, succinct, viable, trustworthy and appropriate to Canada.

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
			A printed information kit, access by telephone plus public use computers were all suggested as was to improve access/availability to the information.
Kart, C.S., Kinney, J.M., Murdoch, L.D. & Ziemba, T.F. (2002). *Crossing the digital divide: Family caregivers' acceptance of technology.* Oxford, OH: Scripps Gerontology Center, Miami University. Kinney J.M., Kart, C.S., Murdoch, L.D. & Ziemba, T.F. (2003). Challenges in caregiving and creative solutions using technology to facilitate caring for a relative with dementia. *Ageing International*, 28(3), 295-314.	Design: Descriptive Desc: Focus groups were used to investigate ICG needs that could be addressed through telehealth Proj: Xanboo Smart House Management System supplied the equipment. Loc: Ohio, U.S.A.	Care: Chronic Service: Monitoring Providers: N/A CRs: Individuals with Dementia. ICGs: mean age 63 years, 77% were female, 96% White, 61% had some post secondary education, 42% were spouses, 42% were sons/daughters or sons-in-law/daughters-in-law. Recruitment: Participants were recruited through presentations made by the research team to ICG support groups. 26 ICGs attended the first focus group (before) and 16 of these attended the second focus group (after).	ICGs wanted to maintain a safe environment with as little restrictions as possible and were also concerned with issues related to privacy and security. ICGs suggested that a monitoring system between the patient and distant family members would be beneficial. ICGs also stated that technology could not meet all of their needs (i.e. patient aggressiveness) and was not appropriate in all situations or a substitute for their presence. Respite care at a distance was of interest to ICGs. In considering technology for ICGs, participants advised that solutions should consider the likelihood of multiple users, the changing levels of functioning in the dementia patient. ICG comments in the 2nd focus group were generally positive and supportive of the Xanboo system, but when asked to indicate possible problems, ICGs cited the need for a computer, expense, and the possible interruptions that could be caused by the pager. Participants were generally amenable to having cameras in the home if they could control them. The article summarizes the literature

Bibliographic Citation	***Study Description[1]***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
			on the use of technology by older disabled persona and/or their ICGs and concludes that the more complex the technology the less likely it will be used unless the user has the skills to match the technology. The article lists criteria for technology for ICGs/patients and states that the technology should a) be easily adapted to the ICGs environment, b) be low cost, c) have a long shelf life, d) be current, e) easy to learn, and f) address security and ethical issues.
Krishna, S., Balas, E.A., Boren, S.A., & Maglaveras, N. (2002). Patient acceptance of educational voice messages: a review of controlled clinical studies. *Methods of Information in Medicine*, 41, 360-369.	Design: Literature Review of RCTs Desc: Systematic review of randomized and/or controlled studies of automated voice message delivery systems. Proj: N/A Loc: N/A	Care: Chronic, preventive. Service: Information, monitoring, compliance. Providers: Varied CRs: Varied. In the studies with ICGs, the CRs were children and elders. ICGs: Varied. In the studies with ICGs, these were parents or carers of the elderly. Recruitment: Varied.	CRs, ICGs and formal providers typically gave high satisfaction ratings to a variety of voice mail/telephone reminder services.
Lee, J.H., Kim, J.H., Jhoo, J.H., Lee, K.U., Kim, K.W., Lee, K.Y., & Woo, J.I. (2000). A telemedicine system as a care modality for dementia patients in Korea. *Alzheimer Disease and Associated Disorders*, 14(2), 94-101.	Design: Descriptive Desc: Questionnaires and direct observation of the users were employed to examine the acceptance and reliability of a telemedicine service for dementia patients. Proj: Dementia Telemedicine Center Loc: Korea	Care: Chronic Service: Information, monitoring, support. Providers: n=140 nurses CRs: n=140 dementia patients ICGs: n=620 (cumulative) family caregivers at 2 of 3 sites. N=30 family caregivers at 1 site had access to a tele-education service, 77% female, daughter-in-law,	Specialists noted that family caregivers accepted the system based on visual observation of the family caregivers positive emotional responses. 30 family caregivers and 14 other caregivers responded to a survey about the tele-education service, 89% said that it was helpful and applicable. In comparison to the standard lecture, 145 said that it was better, 32% same, 54% said that it was unfamiliar

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
		daughter/son or spouse of CR (based on 22 of 30 ICGs). Recruitment: Dementia patients recruited from 3 institutions providing elder care.	or boring.
Magnusson, L., & Hanson, J. (2003). Ethical issues arising from a research, technology and development project to support frail older people and their family carers at home. *Health and Social Care in the Community*, 11(5), 431-439. For more information about this service see: Magnusson, L., Berthold, H., Chambers, M., Brito, L, Emery, D., & Daly, T. (1998). Using telematics with older people: the ACTION project. *Nursing Standard*, 13(5), 36-40. Magnusson, L., Hanson, E., & Nolan, M. (2002). Assisting carers using the ACTION model for working with family carers. *British Journal of Nursing*, 11(11), 759-763. Magnusson, L., Hanson, E., Brito, L., Berthold, H., Chambers, M. & Daly, T. (2002). Supporting family carers through the use of information and	Design: Descriptive Desc: Interviews, focus groups and questionnaires were used to explore ethical issues related to both the research and the intervention directed towards family caregivers and elderly CRs. Proj: ACTION Loc: Europe	Care: Chronic Service: Information and support. Providers: Professional carers, health and social care providers. CRs: n=39 ICGs: n=39 Recruitment: NR	Participatory action research was used and generally well-received by the family caregivers, in terms of influencing the project and in terms of knowledge gained during the process. Participants were those, who in the opinion of the local staff/researchers were most agreeable to or enthusiastic about the technology. Participants were happy to use the technology if it was of direct benefit to them in their daily life. Participants emphasized that the service could not and should not replace a home visit. Initial concerns about privacy, personal appearance. Privacy screen or a separate room (preferred) were used. Patient safety conflicted with privacy and consent issues when it came to continuous monitoring. There were competing concerns about 'raising expectations' versus keeping family caregivers and CRs 'in the dark' – family carers preferred to be informed.

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
communication technology – the EU project ACTION. *International Journal of Nursing Studies*, 39(4), 369-381. Magnusson, L. & Hanson, E. (2004). Working with older people and their carers to research and develop responsive ICT support services. *Health Informatics Journal*, 10(1), 83-88.			
Magnusson, L., Hanson, E. & Borg, M. (2004). A literature review study of information and communication technology as a support for frail older people living at home and their family carers. *Technology and Disability*, 16, 223-235.	Design: Literature Review Desc: Review of studies on the use of information and communication technology in support of family caregivers and frail elderly. Proj: N/A Loc: N/A	Care: Chronic Service: Information and support. Providers: Varied CRs: Frail elderly living at home. ICGs: Varied Recruitment: NR	The reviewers identified 3 themes: (1) services for CRs (telemonitoring, e-health records, telecare, smart homes, tele-robotics); (2) services for family carers – most are US-based, geared to dementia or stroke family carers (telephone, tele-computing, on-line chat, websites); and (3) success factors – designed for the user so as to be easily learned, adopted and incorporated into daily life. Training targeted to the elderly. Evidence of cost-effectiveness, sustainable business-plan, coordinated services and interoperability. Proper consideration of informed consent, privacy, personal safety, etc. The review included articles that appear in this table: ▪ **Brennan & Moore 1994** ▪ **Brennan et al. 1992** ▪ **Colantonio et al. 2001** ▪ **Czaja & Rubert 2002** ▪ **Davies 1998**

Bibliographic Citation	***Study Description[1]***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
			▪ **Hanson et al. 1999** ▪ **Magnusson & Hanson 2003** ▪ **Mahoney et al. 2001;2003** ▪ **Ploeg et al. 2001**
Mahoney, D.F., Tarlow, B.J. & Jones, R.N. (2003). Effects of an automated telephone support system on caregiver burden and anxiety: findings from the REACH for TLC intervention study. *The Gerontologist*, 43(4), 566-567. For more information about on this project see: Friedman, R.H., Stollerman, J.E., Mahoney, D.M. & Rozenblyum, L. (1997). Using telecommunications technology to take care of patients. *Journal of the American Medical Informatics Association*, 4(6), 413-425. Mahoney, D.F., Tarlow, B. & Sandaire, J. (1998). A computer-mediated intervention for Alzheimer's caregivers. *Computers in Nursing*, 16(4), 208-216. Mahoney, D.F. (2004). Linking home care and the workplace through innovative wireless technology: the worker interactive networking (WIN) project. *Home Health Care Management & Practice*, 16(5), 417-428.	Design: RCT with Pre/ Post Tests Desc: Determined effects of 12 month computer-mediated automated interactive voice response intervention for ICGs. Proj: Resources to Enhance Alzheimer's Caregiver Health for Telephone-Linked Care (REACH for TLC) – includes weekly caregivers conversation, personal mailbox, bulletin board and respite conversation available through the ICGs telephone. Loc: Massachusetts, New Hampshire, Rhode Island	Care: Chronic Service: Support CRs: Alzheimer's Disease, mean age 78 years, 48% were female, 36% had post-secondary education. ICGs: mean age 63 years, 80% were female, 79% were White, 16% were African American, 45% were retired, 54% were spouses, 38% were child, 61% had post secondary education. Recruitment: advertisements and referrals yielded 143 contacts, 118 were eligible and 100 participants were enrolled and randomly assigned to control (51) or intervention (49) group (stratified by gender and recruitment site). There were 3 dropouts.	There was no significant effect on bother (bothersome nature of CRs behaviour) (RMBPC), depression (CES-D) or anxiety (STAI) scores for all ICGs 6 months after program ended. For ICGs who had low-mid mastery scores (CMS) at baseline, the intervention significantly reduced bother, depression and anxiety. Bother scores were even more reduced for ICGs who were the wives of CRs. Lack of an overall intervention effect may have been because (1) ICGs reported low baseline bother and depression scores and thus there was little room for improvement; and (2) many ICGs had no difficulty in obtaining information and advice from AD specialists, physicians and nurses. Some evidence for greater use among rural participants due to reduced access to other resources. Authors suggest that ICGs might prefer linking to local (known) providers rather than to an anonymous service and that interventions match ICG characteristics and preferences.

Bibliographic Citation	***Study Description*[1]**	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
Mahoney, D.M.F., Tarlow, B., Jones, R.N., Tennstedt, S. & Kasten, L. (2001). Factors affecting the use of a telephone-based intervention for caregivers of people with Alzheimer's disease. *Journal of Telemedicine and Telecare*, 7, 139-148.	Same as above. This paper reports on system use and factors influencing use.	Same as above.	Same study as above, but results are for telephone intervention group only. ICGs averaged 11 calls over 18 months for a total of 55 minutes per user. 93% used the system in the 1st month (average 4.5 calls). Usage declined rapidly to 10-20% for the 5th month and beyond. Monitoring and counselling module and respite conversation module had the heaviest use (mean of 57 and 17 minutes, respectively). Almost half of the ICGs used the system for 2 or more consecutive months. These 'adopters' were significantly older (by 10 years), more highly educated and reported a greater sense of management of the situation than 'non-adopters'. Adopters were more likely to be male and a spouse and were more likely to have been rated as technologically proficient by the trainer. Greater ICG age, high proficiency rating, and secondarily higher education level were associated with longer duration of use. ICGs who experienced technical problems during their 1st call were less likely to become adopters. Non-adopters said that the advice, information or respite service either was not yet or no longer relevant to their care needs. In-person advice from local (known)

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
			experts was preferred over telephone advice from anonymous experts by both ICGs and by the professionals.
Ploeg, J., Biehler, L., Willison, K., Hutchison, B. & Blythe, J. (2001). Perceived support needs of family caregivers and implications for a telephone support service. *Canadian Journal of Nursing Research,* 33(2), 43-61.	Design: Descriptive Desc: Semi-structured interviews were used to identify the perceived support needs of family caregivers of persons living with chronic illness and receiving homecare services and to describe telephone services that would meet these needs. Proj: NR Loc: Ontario, Canada	Care: Chronic Service: N/A Providers: N/A CRs: Mean age was 78. ICGs: n=34, most were spouses, mean age 62 Recruitment: Case managers of a home-care agency identified ICGs who met criteria.	Main needs reported by ICGs included: more social contact, instrumental support (respite, assistance with physical care, financial compensation), informational support and emotional support. Most ICGs indicated that they would use a telephone support service provided by a professional (71%) or another ICG (59%) and believed that telephone support could meet some of their emotional and informational needs. 35% would prefer to initiate calls, 6% would like the service to do so and 38% preferred a combination of the two. 7% preferred to remain anonymous. ICGs viewed peers and professionals as playing different roles in providing telephone support, preferred knowledgeable, well-trained, caring telephone service providers and described a need for after-hours support. Article provides background information on informal caregiving in Canada as well as an assessment of the literature describing interventions for ICGs.
Rivera, P.A., Shewchuk, R. & Elliott, T.R. (2003). Project FOCUS: Using videophones to provide problem-solving training to family caregivers of	Design: Case Report (this article); RCT (main study). Desc: Describes problem-solving skills training for ICGs using videoconferencing.	Care: Chronic Service: Support CRs: persons with spinal cord injuries. CRs & ICGs: age 19-84 years,	Comparative results not yet available, case study and anecdotes were reported in this article. Participant interest and satisfaction was high (no data).

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
persons with spinal cord injuries. *Topics in Spinal Cord Injury Rehabilitation*, 9(1), 53-62.	Proj: Project FOCUS – educates ICGs in problem-solving skills. Loc: Rural areas of Alabama, Tennessee and Georgia	60% female, 30% African Americans. Recruitment: ICGs of patients who stayed at a rehabilitation centre. At publication, 61 ICG/CR dyads had been randomized into intervention (n not reported) and control groups.	Power fluctuations in rural areas caused problems.
Sävenstedt, S., Brulin, C. & Sandman, P.O. (2003). Family members' narrated experiences of communicating via video-phone with patients with dementia staying at a nursing home. *Journal of Telemedicine and Telecare*, 9, 216-220. For more details see: Sävenstedt, S. (2004). Telecare of frail elderly: reflections and experiences among health personnel and family members. Department of Nursing, Umeå University, Sweden. Umeå University Medical Dissertations New Series No. 918 ISSN 0346-6612.	Design: Descriptive Desc: Examined family members' experiences of seeing the patient via videophone. Proj: NR Loc: Sweden	Care: Chronic Service: Information Providers: N/A CRs: n=7, average 78 years of age. Dementia patients in a nursing home. ICGs: n=7, 71% (5) were spouses (70-75 years of age), 1 son and 1 daughter-in-law (33-46 years of age). Recruitment: Family members with more than 2 months experience using the videophone.	Qualitative analysis revealed 2 themes: 1. "To see makes the family member involved": ▪ maintain contact/ communication ▪ part of the caring ▪ see patient's condition ▪ confirm relationship 2. "To see is a different way of communicating": ▪ can be more focused and relaxed ▪ not suitable for severe episodes/state of dementia ▪ should not replace face-to-face visits ▪ better than just the telephone ▪ reliant on nursing home staff to identify best times Study results are limited by small sample size.
Schulz, R., Belle, S.H., Czaja, S.J., Wisniewski, S.R. & Ory, M.G. (2003). Introduction to the special section on resources for enhancing	Design: Meta-analysis Desc: Evaluation of a multi-site intervention trial for caregivers of persons with Alzheimer's disease for interventions designed to	Care: Chronic Service: Information and support Providers: Varied CRs: n=1222, average 79	Results are from a meta-analysis; 9 active treatments and 6 controls over 6 sites for 6 months. Overall, active interventions caused a significant decrease in caregiver

Bibliographic Citation	***Study Description[1]***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
Alzheimer's caregiver health (REACH). *Psychology and Aging, 18(3)*, 357-360. Details obtained from: Belle, S.H., Czaja, S.J., Schulz, R., Zhang, S., Burgio, L.D., Gitlin, L.N., Jones, R., Mendelsohn, A.B., & Ory, M.G. (2003). Using a new taxonomy to combine the uncombinable: integrating results across diverse interventions. *Psychology and Aging*, 18(3), 396-405. Czaja, S.J., Schulz, R., Lee, C.C. & Belle, S.H. (2003). A methodology for describing and decomposing complex psychosocial and behavioral interventions. *Psychology and Aging*, 18(3), 385-395. Gitlin, L.N., Belle, S.H., Gurgio, L.D., Czaja, S.J., Mahoney, D., Gallagher-Thompson, D., Burns, R., Hauck, W.W., Zhang, S., Schulz, R. & Ory, M.G. (2003). Effect of multicomponent interventions on caregiver burden and depression: the REACH multisite initiative at 6-month follow-up. *Psychology and Aging, 18(3*), 361-374. Wisniewski, S.R., Belle, S.H., Coon, D.W., Marcus, S.M., Ory, M.G., Burgio, L.D. &	reduce caregiver burden and depression (2 sites used computers in their active interventions, 3 sites used telephone in the controls). Proj: REACH Loc: U.S.A., 6 sites	years of age. 56% female. 56% Caucasian, 24% Black, 19% Hispanic. Alzheimer's patients with moderate to severe impairment, 60% had fair or good physical health. ICGs: n=1222, average 62 years of age, 81% female. Ethnicity as per CRs. 70% were married/cohabiting, 57% had some post secondary education, 72% had income <$40000, 39% were retired. Average duration of care was 4 years. Recruitment: ICGs recruited from various clinics, social service agencies, physician's offices, advertisements, announcements and community presentations (demographic data from Wisniewski et al. 2003).	burden (pooled p=.022). Neither of the 2 interventions that used computers had a significant effect (p>.091) on burden. Overall, active interventions caused a non-significant decrease in depression (pooled p=.095). 1 of the 2 interventions that used computers significantly decreased depression (p=.012). (Meta-analysis results from Gitlin et al. 2003). NOTE: Pooled results include 3 sites that used telephone-based minimal interventions in the control group.

Bibliographic Citation	***Study Description*[1]**	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
Burns, R. (2003). The resources for enhancing Alzheimer's caregiver health (REACH): project design and baseline characteristics. *Psychology and Aging*, 18(3),375-384.			
Skipwith, D.H. (1994). Telephone counselling interventions with caregivers of elders. *Journal of Psychosocial Nursing*, 32(3), 7-12.	Design: Case reports Desc: 4 case reports of a telephone counselling service for family carers of the elderly. Proj: NR Loc: U.S.A.	Care: Chronic Service: Support Providers: N/A CRs: n=4, 75% female, 75% African-American. ICGs: n=4, average 67 years of age, 100% female, 75% African-American.	Tri-weekly 15-minute telephone calls by nurse-research to each family caregiver. Average of 12 calls. Scheduled calls initiated by nurse, occasionally interrupted by CR. Time spent identifying caregiving problems, suggesting possible solutions and follow-up with suggestions.
Steffen, A.M. (2000). Anger management for dementia caregivers: a preliminary study using video and telephone interventions. *Behavior Therapy*, 31, 281-299.	Design: RCT with Pre/Post Tests Desc: Measured the efficacy of an anger management series and workbook for dementia family caregivers (home view plus weekly telephone sessions or class-based viewing or control (no viewing/ telephone sessions) over 8 weeks. Proj: NR Loc: NR	Care: Chronic Service: Information and support Providers: N/A CRs: n=33, Alzheimer (85%) or dementia patients. ICGs: n=33, average 64 years of age, 76% female, 76% White, 24% African-American. Caring for an average of 3.7 years. 55% were spouses, 36% were adult children. Recruitment: ICGs recruited using announcements/ advertisement, targeting mailings, contact with local organizations and local Alzheimer's Association	Video+/- telephone were compared statistically to the control and not to each other. Examination of scores suggest that scores improved significantly for both video groups relative to control for caregiver anger, depression (BDI) and ability to manage disruptive behaviours (CSES). There was some evidence that home viewing plus weekly telephone sessions many have had a greater impact on depression and ability to manage disruptive behaviours than did class-viewing (statistical significance unknown). Possibly confounding of the impact of home viewing with impact of telephone sessions and small sample

Bibliographic Citation	***Study Description[1]***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
		chapter. There were 5 dropouts.	size precludes definitive conclusions.
Strawn, B.D. Hester, S. & Brown, W.S. (1998). Telecare: A social support intervention for family caregivers of dementia victims. *Clinical Gerontologist*, 18, 66-69,	Design: Pre/Post Tests Desc: Examined the effectiveness of a telephone intervention to reduce stress in ICGs in a 12 week program. Proj: Telecare – consisted of weekly telephone contacts by a Caring Caller. Loc: NR	Care: Chronic Service: Support Providers: Graduate students in clinical psychology ICGs: n=14 CRs: Alzheimer's Disease Recruitment: NR	Psychosocial distress and symptomology (BSI) was increasing during the baseline period, but was significantly reduced during telephone intervention, as well as perceived burden (BI). ICGs said that they highly valued the telephone sessions and were sorry that the project had ended. Anecdotal comments from the 'Caring Callers' suggested that ICGs shared increased self-care, greater effects to reach out to social supports and discussed feelings of loss, anger, and other thoughts or emotions not typically discussed with anyone else. Objective and subjective evidence suggest that Telecare is a cost and time efficient means of providing social support. Small sample size. No control or comparison group, so results are suggestive and not conclusive.
Tran, B.Q., Buckley, K.M. & Prandoni, C.M. (2002). Selection & use of telehealth technology in support of homebound caregivers of stroke patients. *CARING Magazine*, 21(3), 16-21. See also: **Buckley et al. 2004**	Design: Case Report Desc: Describes how telehealth technologies can support home-bound caregivers of stroke patients. Proj: HomeCare & Telerehabilitation (HCTR) Technology Center at CUA Loc: U.S.A.	Care: Acute Service: Support Providers: Nurses ICGs: n not reported CRs: Stroke patients Recruitment: N/A	Two case studies illustrate the benefit of timely sessions between ICG and nurse. Sessions included 2-way information sharing, visual demonstrations, trouble-shooting of care problems, and social interaction/support. Quality of technology not always appropriate for physical assessments of the CR. Videophone technology considered

Bibliographic Citation	*Study Description*[1]	*Specifics*	*Relevance to Informal Caregivers (ICGs)*
			cost effective and useful in providing emotional and informational support. Authors suggest the addition of telehealth visit to in-home visits could improve care to CRs through support of ICGs.
Walsh, S.M. & Schmidt, L.A. (2003). Telephone support for Caregivers of patients with cancer. *Cancer Nursing*, 26(6), 448-453.	Design: Pre/Post Tests Desc: Pilot study to determine the feasibility of conducting a telephone intervention for ICGs over 4 weeks for cancer patients near end-of-life. Proj: Telecare II Loc: Florida, U.S.A.	Care: Acute Service: Support Providers: Nurses ICGs: n = 5, 80% female, mean age 66 years, 80% White. CRs: n=6 cancer patients, 50% female, mean age 75 years. Recruitment: subjects referred by hospice staff.	ICGs experienced less depression (CES-D), despair and disorganization. ICGs experienced higher burden (CBS) due to the CR's increasingly serious condition. No substantial changes in panic, blame, detachment, personal growth (HGRC-EoL) or social support (ISS). Small sample size did not permit statistical testing.
Walsh, S.M., Estrada, G.B. & Hogan, N. (2004). Individual telephone support for family caregivers of seriously ill cancer patients. *Medsurg Nursing*, 13(3), 181-189.	Design: This study was a descriptive study. Full study was a RCT. Desc: Telephone calls were used to describe and explore major sources of concern for family carers of seriously ill cancer patients. Proj: Tele-Care Loc: Florida, U.S.A.	Care: Palliative Service: Information and support. Providers: N/A CRs: n=50, seriously ill cancer patients. ICGs: n=42, > 45 years old, 69% female, 67% White, 7% African-American, 26% Hispanic. 92% were spouses/partners. Recruitment: ICGs recruited from local hospitals and a large regional cancer centre when they visited or accompanied a patient.	One 20-minute phone call every other week over 10 weeks (5 calls per carer). Calls made by nurse-researcher 5 themes: (1) bearing the burden; (2) distressing feelings (depression, resentment, helplessness, worry); (3) coping with uncertainty (seeking support, making decisions, engaging in activities, deception); (4) conditional well-being; and (5) feeling abandoned by others. 84% of participants completed the study and were assumed to have benefited from the telephone calls. 2 carers reported that the CRs resented the time that the carers spent on the phone talking with researchers.

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
Wang, K.K. & Barnard, A. (2004). Technology-dependent children and their families: a review. *Journal of Advanced Nursing*, 45(1), 36-46.	Design: Literature Review Desc: Summary of issues and implications of caring for technology-dependent children living at home. Loc:	Care: Chronic or Acute ICGs: Parents CRs: Technology dependent children Recruitment: Varied	Empirical review of the literature. Child and ICG benefit from lower anxiety as focus moves from illness and helplessness to recovery and functioning (citing Kohrman 1991). ICGs satisfied with seeing the emotional and social growth of the child when at home (citing Diehl et al. 1991; Petit de Mange 1998). ICGs welcome, but are challenged by improved educational opportunities for their child (citing Elder 2001; and others). ICGs may experience adverse health effects when caring for technology-dependent children at home (citing Leonard et al. 1993; and others). Sleep problems, anxiety and depression may be exacerbated (citing McKeever 1991; and others). ICGs may go through a wide range of emotions such as anxiety, anger, guilt, frustration and sorrow (citing Smith et al. 1991; Patterson et al. 1994). Medical equipment may be noisy, physically intrusive and a constant reminder of the child's ill health (citing McKeever 1991; and others). ICGs may experience fear and panic at finding their child dead, in performing technical procedures, etc. (citing Sudela et al. 1993; and others). Reconciling the role of parent and carer with the need to perform painful procedures on the child is a source of conflict and ambiguity to both parent

Bibliographic Citation	***Study Description[1]***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
			and child (citing Carnevale 1990; and others). The ICGs interaction with the healthcare professional may be problematic and unclear because of the conflict roles as parent/medical technician (citing Kirk 1991; and others). Real or perceived shift of responsibility is troubling to the ICG and providers (citing Schachter & Holland 1995; and others). Family dynamics may be affected negatively (citing Patterson et al. 1992; and others). Family income often declines while costs rise (citing Wilson et al. 1998; and others). This is especially difficult for single parent families (citing House 1995).
Whitten, P., Doolittle, G. & Hellmich, S. (2001). Telehospice: Using telecommunication technology for terminally ill patients. *Journal of Computer Mediated Communication,* 6(4), 1-16. Whitten, P., Doolittle, G., Mackert, M. & Rush, T. (2003). Telehospice: end-of-life care over the lines. *Nursing Management*, 34(11), 36-39.	Design: Descriptive Desc: Surveys and interviews were used to examine the impact of a two year Telehospice project that provided palliative services using videophones to connect professional and patients/ICGs. Proj: Michigan/Kansas Telehospice Project Loc: Michigan & Kansas, U.S.A.	Care: Palliative Service: Monitoring, and Support. Providers: Nurses, social workers, spiritual care counsellors and physicians. CRs: 56 participants were patients or ICGs if the patient was too ill to participate. Recruitment: NR	Patients and ICGs made positive comments about the service and were interested in increasing their use of it. They felt that it improved traditional hospice care. Those that declined to use the service did so due to feeling overwhelmed by their caregiving responsibilities. ICGs perceived the equipment to be safe and effective and felt more comfortable with the videophones than the telephone due to the video component and ease of use in case of emergencies. Family caregivers and friends report general satisfaction with Telehospice, perhaps more so than the patients.

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
Wright, L.K., Bennet, G. & Gramling, L. (1998). Telecommunication interventions for caregivers of elders with dementia. *Advances in Nursing Science,* 20(3), 76-78.	Design: Informed Opinion Desc: Describes a theory-based telecommunications interventions model. Proj: Caregiver Interventions via Telecommunications (CIT) model. Loc: U.S.A.	Care: Chronic Service: Support Providers: Nurses ICGs: N/A CRs: Dementia Recruitment: N/A	The CIT model used Riegel's dialectical theory of human development as its conceptual base. The CIT model has the following components: ICG emotional health; ICGs management of CRs problem behaviours; psychotherapeutic interactions (interventions directed towards the ICGs); and family/community support. Model components are linked and focused on the issue of human development, which features ICG actions that lead to concordance, control, adaptation and acculturation. The authors draw from the literature on telephone interventions to discuss the pros and cons of the CIT model.
Wright, L.K., Bennett, G., Gramling, L. & Daley, L. (1999). Family ICG evaluation of telehealth interventions. *The Gerontologist,* 39(Suppl. 1), 67. [Abstract only]	Design: Descriptive Desc: Evaluate ICG satisfaction with an 8 week long pilot telehealth program. Proj: NR Loc: GA, U.S.A.	Care: Chronic Service: NR Providers: Advanced Practice Registered Nurses (APRNs) CRs: individuals with Dementia Recruitment: regular phone n=10, videophone n=5	ICGs preferred in-person contacts opposed to telephone calls but liked the videophones because they could see the nurse and they "liked being on TV". The majority of ICGs did find the calls (videophone or telephone) very or extremely helpful though some ICGs did not attribute their change in caregiving skills to the nurse's teaching. Small sample size. Abstract only.
Young, N.L., Barden, W., McKeever, P. & Dick, P.T. (2005).Taking the Call – Bell Home: *A qualitative evaluation of a pediatric tele-homecare service*. Unpublished	Design: Pre/Post Tests. Desc: Interviews were used to assess a 6-week telehomecare service for children and families during the initial transition from hospital to home. Service used	Care: Acute Services: Support and Monitoring. ICGs: 16 mothers, 4 fathers and 2 adolescents from 16 families	Interviews were conducted prior to discharge, 2 weeks after discharge and 2 weeks after the intervention ended. Main themes: impact on child, on family, on health care experience.

Bibliographic Citation	***Study Description***[1]	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
manuscript.	video-conferencing phones and remote vital signs monitors. Proj: Tele-HomeCare (THC) Loc: Toronto, Canada	CRs: children discharged from hospital, 56% male, most < 1 year old, 50% hospitalized since birth. Recruitment: Purposeful sampling technique used to select a heterogeneous sample from 63 families involved in trial.	THC was successful method of delivering health care remotely and allowed children to be reunited with their families. ICGs perception was that the service enhanced health care in the home.

Bibliographic Citation	***Study Description***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
Selected Studies of Homecare and ICGs			
Colantonio, A., Cohen, C. & Pon, M. (2001). Assessing support needs of caregivers of persons with dementia: Who wants what? *Community Mental Health Journal,* 37(3), 231-243.	Design: Descriptive Desc: Telephone interviews were used to examine the interest of ICGs in support services such as telephone support, newsletters and computer services. Loc: Ontario, Canada	Care: Chronic Service: N/A Providers: N/A ICGs: n=148, mean age 62 years, 70% female, 80% married, mean 13 years of education. Caring for an average of almost 4 years, 100 hours/week, but duration and time were quite variable CRs: 76% had dementia, mean number of functional limitations was 9/14 and mean number of behavioural problems was 3/9. 66% could be unsupervised for 0.5-2 hours if someone else was in the home. Recruitment: Recruited from the Alzheimer Society for Metropolitan Toronto Wandering Persons Registry a non-profit listing.	7% or fewer ICGs had used a telephone support line. 61-66% of those who had not used a telephone support line said that they would be interested in doing so. Those interested in phone support were younger, had more education, cared for individuals with higher needs, and had more hours of caregiving. 24% of ICGs had received a newsletter. 75% of the ICGs who had not received a newsletter said that they would be interested in receiving some. 39% of ICGs owned or had access to a computer. Only 28% of ICGs were interested in receiving information and support via computer. ICGs interested in computer support were younger, non-spousal, unmarried, high levels of education and high levels of depression.
Colantonio, A., Kositsky, A.J., Cohen, C. & Vernich, L. (2001). What support do Caregivers of elderly want? Results from the Canadian study of Health and Aging. *Canadian Journal of Public Health*, 92(4), 376-379.	Design: Descriptive Desc: Used results from the Canadian Study of Health and Aging to assess ICGs interest in various support services. Loc: Canada (National study)	Care: N/A Service: Support Providers: N/A. ICGs: n=188, 72% female, mean age 64 years, 33% daughter and 23% wife, and 82% English. CRs: 43 elderly persons with dementia and 145 without. 63% female.	ICG interest in interventions was 10% for support groups, 41-45% for receiving telephone support, 41% for receiving a newsletter, 15-24% for receiving volunteer support and 15% for support via computer.

Bibliographic Citation	***Study Description***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
		Recruitment: Data from a national sample of caregivers from the 1996 second wave of the Canadian Study of Health and Aging.	
Harding, R. & Higginson, I.J. (2003). What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 17, 63-74.	Design: Systematic Literature Review Desc: Review of the effectiveness of interventions for ICGs of cancer and palliative care recipients. Loc: Not applicable	Care: Palliative & Acute Service: Varied ICGs: varied CRs: Cancer and palliative care patients Recruitment: Varied	Literature Review: 22 studies identified, 9 specific to ICGs, but only 6 evaluated the intervention. ICGs needs include: informal support fatigue, finances, anxiety, isolation and information. (reference #10) Priorities are information and psychological support (#8, #11). ICGs report high satisfaction with homecare and find it useful (#17). One-to-one interventions may be too time consuming and costly to be effective (#25). Group work determined to be successful for some ICGs but low attendance due to work, family obligations, lack of respite, ICGs health (#38). One RCT found that hospice care wasn’t used often in the last two weeks of life because the ICG was unable to cope (#16). ICGs appreciate one contact to access a variety of services and the ability to develop familiarity with service providers (#19). Respite – some ICGs are not willing to leave the patient (#57). The available evidence has few evaluations measuring ICG outcomes, small sample sizes, and untested measures (#46). Negative results don’t appear to be published (#48). ICG independence and self-reliance are possible barriers to service acceptance (#58). Challenge to provide ICG interventions may be greater in rural areas (#24). No mention of any evaluation of technology-based intervention for ICGs.

Bibliographic Citation	***Study Description***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
			Authors conclude that the current level of evidence says more about feasibility and acceptability than about effectiveness.
Harding, R. & Higginson, I. (2001). Working with ambivalence: Informal caregivers of patients at the end of life. *Support Care Cancer*, 9, 642-645.	Design: Descriptive Desc: Semi-structured interviews were used to examine services for ICGs. Loc: London, UK	Care: Palliative Service: Support ICGs: n=18, 67% female, ages 23 to 72 years, 72% full-time ICGs, urban residents. CRs: 89% had cancer diagnoses. Recruitment: Convenience sample – ICGs were recruited by Clinical Nurse Specialists	Five main concepts were generated: identity, expectations and the future, appropriate help, respite and mechanisms of coping. ICGs report putting their self-identity and life aspirations on hold. Belief that a nurse in the home is not normal. ICGs express the need for respite but also an unwillingness to leave the caregiving role and also the use of distracting activities to cope but the perceived obligation to provide constant care. Interventions for caregivers need to consider their ambivalence about their needs. Interventions should respect the ICGs current coping strategies, offer appropriate duration and frequency of time away and work through the issues of loss of identity and putting life on hold. Short-term interventions that provide information and skills may be acceptable and appropriate to ICGs. i.e. communication between peers, newsletters and group sessions.
Knight, B.G., Lutzky, S.M. & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *The Gerontologist*, 33(2), 240-248. (See **Sörensen et al. (2002)** for an updated meta-analysis)	Design: Meta-analysis Desc: Review of interventions for ICG distress. Loc: Not Applicable	Care: Varied ICGs: Varied CRs: Varied Recruitment: Varied	20 articles representing 18 studies were analyzed. Overall the meta-analysis found that individual interventions had a larger effect than group interventions for burden and emotional dysphoria. Effect of respite interventions was lower and more variable. Group interventions show a small but positive effect on ICG distress. Social and Health Services other than respite services show no impact on caregiver distress.
Medigovich, K., Porock D.,	Design: Descriptive	Care: Palliative	ICGs reported high levels of care expectations,

Bibliographic Citation	***Study Description***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
Kristjanson, L.J., & Smith, M. (1999). Predictors of family satisfaction with an Australian palliative home care service: A test of discrepancy theory. *Journal of Palliative Care*, 15(4), 48-56.	Desc: Interviews were used to examine family satisfaction, expectations, and perceptions of a palliative home care service. Loc: Perth, Western Australia	Service: Support ICGs: n=55, family member, mean age 61 years, 56% female. 87% were married, 75% were spouses. CRs: Patients with advanced cancer receiving care from a home hospice care service. Recruitment: ICGs that met selection criteria were randomly selected and invited by mail (n=200) to participate in the study and those interested were contacted by phone (n=55).	satisfaction and were positive about the care received although positive perceptions about the care diminished over time. Family satisfaction scores were higher for older family members. Care perceptions and satisfaction levels were lower for family members who reported more family dysfunction. 29% of the variation in satisfaction was explained by the difference between ICG expectation and perception of care received by the patient. 54% of the variation in ICG satisfaction was explained by ICG perception of care. Variance in satisfaction explained by expectations minus perceptions was lower than reported in Canadian studies and may be due to methodological or cultural differences.
Morgan, D.G., Semchuk, K.M., Stewart, N.J. & D'Arcy, C. (2002). Rural families caring for a relative with dementia: barriers to use of formal services. *Social Science & Medicine*, 55, 1129-1142.	Design: Descriptive Desc: Focus groups and semi-structured interviews were used to identify and describe challenges in caring for rural elderly with dementia. Loc: Saskatchewan, Canada Rural perspective.	Care: Chronic Service: N/A Providers: 11 directors of care, 13 nurses and aides, 7 physicians. ICGs: 3 spouses; 9 daughters/daughters in-law, 1 other (only 1 was male). CRs: Dementia. Recruitment: Referral from nursing home directors. Potential participants responded to mail-out.	ICGs reluctant to use services for the following reasons: stigma of dementia, denial by family members, lack of privacy and anonymity, their own independence and self-reliance, the need for a "legitimate" reason to use respite services, guilt, and the higher acceptability of hospital based as opposed to nursing home based respite care. Some under use of services due to lack of awareness. Factors that influence the use of respite services: availability, accessibility, quality or hospitality and usefulness Caregivers supporting a family member with dementia experience a tremendous stress ICGs found health care providers often lacked skills in early assessment and diagnosis and were unaware of available services. Women take on the major responsibility for caregiving.

Bibliographic Citation	***Study Description***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
			Rural cultural values about appropriate behaviour for women promote social isolation and guilt about accepting help with caregiving.
Peacock, S.C. & Forbes, D.A. (2003). Interventions for caregivers of persons with dementia: A systematic review. *Canadian Journal of Nursing Research,* 35(4), 88-107.	Design: Systematic Literature Review Desc: Review of interventions for caregivers of people with dementia. Loc: Not Applicable.	Care: Varied ICGs: Varied CRs: Varied Recruitment: Varied	36 studies, focus on 11 methodologically stronger studies. No one intervention had an overall significant impact on the well-being of ICGs. Case management did not impact ICG depression, (citing Newcomer et al. 1999). Case management increased the likelihood of using formal support services (Newcomer et al. 1999). Education interventions were not sufficient to improve ICG well-being (citing Corbeil et al. 1999; Wright et al. 2001) Psychotherapy benefited the ICG the most by delaying patient institutionalization (Mittelman et al. 1993;1996). A Computer-Networking Intervention revealed that the intervention group increased their decision-making confidence but there was no difference in decision-making skills, social isolation or use of health services **(Brennan et al. 1995**).
Pusey, H. & Richards, D. (2001). A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging & Mental Health*, 5(2), 107-119.	Design: Systematic Literature Review Desc: Review of psychosocial interventions for people with dementia and their ICGs. Loc: Not Applicable.	Care: Chronic ICGs: Varied CRs: Dementia Recruitment: randomized and non-randomized controlled trials (n=30 studies).	Individual interventions that focused on problem solving and behaviour management were the most effective. Technology based interventions improved confidence in decision-making; computer network (**Brennan et al. 1995**); telephone network (**Goodman & Pynoos 1990**). Weak evidence for effectiveness/ineffectiveness of technology-based interventions. Weak evidence for effectiveness/ineffectiveness of group-based interventions or individually based interventions. There is little evidence to support a definitive

Bibliographic Citation	***Study Description***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
			approach to interventions for ICGs of people with dementia. There were methodological weaknesses across all studies including: small sample sizes, lack of random allocation and blinding of the assessment of outcomes, a lot of self-reported measures.
Schulz, R. & Martire, L.M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry*, 12(3), 240-249.	Design: Literature Review Desc: Select summary of dementia caregiving including the health effects of caregiving, and interventions for caregivers. Loc: Not Applicable	Care: Chronic ICGs: family members and friends caring for dementia patients. CRs: Dementia Recruitment: Varied.	Selected literature review – methods not described. Limitations of caregiver intervention research is small sample sizes, limited range of interventions tested, and limited geographical location. “some researchers have likened caregiving to being exposed to a severe, long-term, chronic stressor” (p.241). The literature reports a moderate relationship between patient disability and caregiver distress, moderated by ICG characteristics (gender, personality, etc.), available support services, coping strategies, relationship between ICG and CR, etc. (citing refs # 6-8). The caregiver of individuals with dementia is generally the spouse, daughter or daughter-in-law (#5, #9). Caregiving of dementia patients is more time-consuming and stressful than providing care to individuals with only a physical disability (#10). Female ICGs report more depressive and anxiety related symptoms and lower levels of satisfaction than males (#20, #21). The demands of caregiving may compromise the emotional and physical health of ICGs (#17-28). Five domains of risk for caregivers: safety, self-care and preventative health behaviours, caregiver support, depression and distress, and problem behaviours of the care-recipient. A

Bibliographic Citation	***Study Description***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
			comprehensive approach to case management would assess all five risk areas and develop and intervention that would address them. Early interventions may assist the ICG in avoiding more serious care and personal health problems later in the caregiving period. Response to death is strongly related to the caregiving experience (#54, #55). Interventions that treat the CR and the ICG are likely to have the largest effects (#34).
Sörensen, S., Pinquart, M. & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42(3), 356-372. (An update of **Knight et al. (1993)**)	Design: Meta-analysis Desc: Review of the effectiveness of interventions for caregivers for older adults. Loc: Not Applicable.	Care: Varied ICGs: Varied, mean age 62, 69% females, 86% White, 77% lived with the care receiver, 50% were spouses, 79% were married, and 39% were employed CRs: Varied, mean age 77 years, 64% females, 61% of the studies focussed on care for dementia patients. Recruitment: Varied (n=78 studies)	2 major types of ICG interventions are those aimed at: (1) reducing the objective amount of care provided by ICGs (e.g., respite, improve CRs health); and (2) improving the ICGs well-being and coping skills (e.g. psychoeducation, support, psychotherapy). Meta analysis suggests: • ICG interventions were, on average, of small to moderate effect size • Psychotherapeutic and psychoeducational interventions showed the most consistent effects on all outcomes (burden, depression, well-being, ability/knowledge and CR's symptoms Multi-component interventions positively affected ICG burden, well-being and ability/knowledge but not depression and CR symptoms. Respite interventions positively affected caregiver burden and depression. Supportive interventions were effective for burden and ability/knowledge. Intervention effects were smaller for caregivers of individuals with dementia. Effect size varied by characteristics of the intervention, the ICG, initial level of objective and subjective burden and general study characteristics.

Bibliographic Citation	***Study Description***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
			ICG ability/knowledge may be more strongly affected than burden, depression, uplifts of caregiving and CR symptoms. Care recipient training had a positive affect on ICG's well-being and reducing care receiver's symptoms but not the ICG's burden, depression and ability or knowledge. Group interventions were less effective at improving burden and well-being but more effective at reducing CR symptoms than were non-group interventions. The longer the intervention, the larger the effects for improving ICG depression, but the smaller the effects for improving ability/or knowledge.
Stoltz, P., Udén, G., & Willman, A. (2004). Support for family carers who care for an elderly person at home – a systematic literature review. *Scandinavian Journal of Caring Sciences*, 18, 111-119.	Design: Systematic Review Desc: Identify modes of support for ICGs of elderly CR and assess the scientific evidence. Loc: Not Applicable.	Care: Chronic Service: Support ICGs: Varied CRs:. Varied, but most have dementia. Recruitment: Varied, n=26 studies.	Systematic review of 26 studies found strong evidence for family caregivers who: • wish to satisfy learning needs in caring in peer groups • desire respite care • experience negative emotions, burden, stress and worry when caring for an elder at home. Moderate evidence for family caregivers who: • wish to network in social support groups • fear social isolation • fear loss of control, relationship role changes and loss of reciprocity Moderate evidence also for: • caregiver education programs are a good and effective way to support family caregivers and their CRs Insufficient evidence for: • in-hospital respite care as a good and effective way to support family caregivers and their CRs • ethnical differences in how family caregivers perceive their role • positive thinking and focusing on rewards

Bibliographic Citation	***Study Description***	***Specifics***	***Relevance to Informal Caregivers (ICGs)***
			keep family caregivers going on a day-to-day basis The majority of the studies cited as evidence for the above statements were qualitative, focusing on family caregivers of CRs with dementia.

Abbreviation and description of instruments (e.g., scales, indices, inventories) mentioned in the summary of documents

Abbreviation	Description
ADL	Activities of Daily Living Scale
BI	Burden Interview
BDI	Beck Depression Inventory
BSI	Brief Symptom Inventory
CAI	Caregiver Appraisal Inventory
CBI	Caregiver Burden Inventory
CBS	Caregiver Burden Scale
CES-D	Center for Epidemiological Studies – Depression Scale
CMS	Caregiver Mastery Score
CSES	Caregiving Self-Efficiency Scale
CSQ	Client Satisfaction Questionnaire
FAD	Family Assessment Device
FNQ	Family Needs Questionnaire
GDRS	Geriatric Depression Rating Scale
HGRC-EoL	Hogan Grief Reactions Checklist – End of Life
IADL	Lawton Instrumental Activities of Daily Living

Abbreviation	Description
ISEL	Interpersonal Support Evaluation List
ISS	Inventory of Social Support
LSI-Z	Life Satisfaction Inventory
MHI	Mental Health Index
MMSE	Mini-Mental State
PAQL	Pediatric Asthma Quality of Life
PCS	Preparedness for Caregiving Scale
POMS	Profile of Mood States
PSI	Problem Solving Inventory
PSSCSC	Perceived Social Support for Caregiving and Social Conflict
RMBPC	Revised Memory and Behavior Problem Checklist
RPS	Rational Problem-Solving Inventory
SF-36	Short Form Health Survey
SPSI-R	Social Problem Solving Inventory - Revised
SRG	Stress-related Growth Scale
STAI	State Anxiety Inventory

Appendix 2: Telehomecare Project Summary

Project/Program	***Project/Program Description**[1]*	***Specifics***	***Relevance to Informal Caregivers***
Project/program name, geographic location and URL(s) from which information has been obtained	*Brief description of project/ program*	*Type of care: Acute, Chronic, Preventive, Palliative* *Type of service: Information, Monitoring, Compliance, Support* *Description of: Providers, Clients, ICGs, method of recruitment*	*Were ICGs included in the project/program?* *What were the implications for ICGs?* *Additional references[2]*
Canada			
Atlantic Health Sciences Corporation (AHSC): Virtual Interactive Telehealth Assistance Links (VITAL) - Hospital to Home Monitoring New Brunswick, Canada http://209.217.71.106/cgi-bin/starfinder/9481/hihinit.txt http://www.ahsc.health.nb.ca/Programs/Telehealth/telehealth.shtml http://www.ahsc.health.nb.ca/Programs/Telehealth/vital.htm http://www.ahsc.health.nb.ca/Programs/Telehealth/Telehomecare.pdf Start date: Spring 1997 End date: developed into an	Embracing technology as a process enabler the AHSC embarked on a provincial research and development project based out of the New Brunswick Heart Centre (NBHC) at the Saint John Regional Hospital Facility. Virtual Interactive Telehealth Assistance Links or (Vital), as the project became known, was successfully transitioned from project to program in 1999 VITAL is a solution to a problem of triaging patients from around the province (or Quebec, Nova Scotia, Prince Edward Island and Maine) who need to go to	*Care*: Acute *Service*: Teletriage, Triage of patients who need to go to the New Brunswick Heart Centre for assessment/ treatment, monitoring *People*: General population, cardiac patients	Training sessions are provided to the caregivers prior to the patient's discharge. Upon discharge, the telehealth unit is sent home with the patient and caregiver Caregivers are given teaching sessions during the patients post-op hospital stay to learn how to install and use the equipment comfortably.

---

[1] Text is quoted directly or paraphrased from that on the website(s)

[2] Bolded references were summarized in Appendix 1

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
ongoing program in 1999 Active program	the New Brunswick Heart Center for assessment/ treatment Allows cardiologists, heart surgeons and cardiology nurses to monitor their patients' condition in the patients' homes during the six week post-operative period Hospital to Home Monitoring Program is offered to the majority of eligible post-op cardiac surgery patients		
Cardiac Home Ambulatory Monitoring Project (CHAMP) / Integrated Cardiac Home Monitoring Pilot Project Scarborough Hospital-General Division, Ontario, Canada http://209.217.71.106/cgi-bin/starfinder/9481/hihinit.txt http://www2.itssti.hc-sc.gc.ca/B_Pcb/HTF/Projectc.nsf/EnglishAll/3A8C1677C092F79C852567DF00639831 Start date: Not specified End date: January 2001	Randomized control trial of the home monitoring of patients with congestive heart failure after their discharge from hospital Study's primary aim was to see if more intensive, cost-effective monitoring at home could lower readmission rates and improve patient outcomes, functional status, and the cost-effectiveness of the cardio-respiratory program	*Care*: Acute, Preventive, early detection, early release from hospital *Service*: Home diagnostic monitoring, education, compliance, maintenance *People*: Patients with congestive heart failure	The team aimed to quantify how the quality of life and life style for patients and their families are affected Guidelines outlined how monitoring should be implemented, how the patient and families should be educated and supported and the level of integration that is required from the hospital
CLSC of the Future: Telehealth and Tele-home Care Project Manitoba and Quebec, Canada http://209.217.71.106/cgi-bin/starfinder/9481/hihinit.txt http://www.cefrio.qc.ca/english/projets/proj_33.cfm Start date: 2002/03/06 End date: The initiative has no fixed end date	Pilot project that gave travelling home care workers fast and simple electronic access to patient clinical data, treatment supports and scheduling information The project included tele-surveillance technology to support the independent living of people who would otherwise be	*Care*: Chronic *Service*: Monitoring *People*: Initial pilot involving 1100 urban and rural patients gradually expanded to include 35,000 CLSC patients in the Quebec administrative region	This project introduced a combination of enabling technologies, intervention and management processes that aimed to improve the use and distribution of clinical and management information, thus widening the range of care and maximizing the effectiveness of personnel involved in supporting patients in their own home

Project/Program	***Project/Program Description[1]***	***Specifics***	***Relevance to Informal Caregivers***
	institutionalized Project intended to respond to a trend toward community-based care in a variety of settings		
Enabling Home Care Clients to Self Manage through Tele-Technology St. Elizabeth Health Centre, Markham, Ontario, Canada http://209.217.71.106/cgi-bin/starfinder/9481/hihinit.txt http://www.saintelizabeth.com/foundation/welcome.html Start date: 1999/01/13 End date: 2000/09/29 (end of Pilot project) Continued as an active program	Using video-conferencing technology to bring medical expertise into the homes of diabetics Build and develop an interactive web site for diabetic patients being cared for at home Clients taught how to use the web site through a 'learning lab' to support their care at home Easy to use equipment lets diabetics learn how to monitor their condition and manage their own care, all under the supervision of trained health care providers	*Care*: Chronic *Service*: Monitoring, education information *People*: Diabetic patients, family caregivers, caregivers	Instead of replacing human contact, technology enabled the human touch to be the right touch at the right time and the success of this early endeavour led to the evolution of @ *YourSide* suite of Technology Solutions Responding to one of the greatest needs of family caregivers, SEHC launched a web-based eLibrary to provide helpful information and advice over the Internet. The eLibrary can be accessed at www.saintelizabeth.com @ *YourSide Caregiver Support* is an interactive web-based solution designed to support and assist caregivers, including family members, friends, neighbours and volunteers Key features include comprehensive caregiving information, message centre, monitoring tools for caregivers to record and track their own health and well being as well as those of their loved ones, and links to other helpful websites and additional resources
Home Telehealth Pilot Project Nova Scotia, Canada http://209.217.71.106/cgi-bin/starfinder/9481/hihinit.txt http://hth.marchnetworks.com http://hth.marchnetworks.com/pdf/HomeTeleHealthReportExecutiveSummary.pdf	Pilot project implemented and evaluated a web enabled home telehealth service that enabled remote nursing visits and vital sign monitoring The pilot project also evaluated the impact of the home telehealth solution on the delivery of home care including	*Care*: Chronic Palliative *Service*: Monitoring *People*: target audience is adults (18+ years olds)	As part of the pilot project, an independent evaluation The Home Telehealth Pilot Project was conducted. The impact of home telehealth on informal caregivers was not addressed

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
Start date: August 2001 End date: February 2002	quality of care provided (client, nurse, and family satisfaction) and operational efficiencies (cost, time savings, administrative efficiency, etc.) Gathered feedback on the usability of the home telehealth solution Partnership between March Networks, We Care Home Health Services, and Aliant, and with funding support from CANARIE - was undertaken to demonstrate the utility and value of home telehealth in Canada		
Hospital for Sick Children's Tele-Homecare Project (Tele-Homecare Project: An Integrated Transition Between Hospital and Home) Ontario, Canada http://209.217.71.106/cgi-bin/starfinder/9481/hihinit.txt http://www.sickkids.on.ca/telehomecare/default.asp Start date: 2000/06/01 End date: 2002	Cohort study that examined the impact of telehomecare services on children and families and assessed the impact of technology on the patient and family Goals included to support the child/family in the transition between hospital and community; to successfully move the care of children who are stable but require a higher level of monitoring than that which is available in the community into their home; and to enhance the collaborative partnership between the family, community providers, and hospital providers	*Care*: Acute, intermediate intensity care needs *Service*: Monitoring *People*: Children (0-12), Youth (13-17), families	Hospital based clinical support was available to children and parents 24 hours a day, seven days a week by nurses at the Bell Home Tele-Monitoring Centre For more details see: **Dick et al. 2004** **Young et al. 2005**
Integrated Call Centre for Improved Teletriage and Home Monitoring Ontario, Canada	Development and evaluation of an integrated call-centre, whose primary service is home-monitoring	*Care*: Acute, Chronic *Service*: Teletriage, Cardiology Home-monitoring, primary	Patient/caregiver information/ education

Project/Program	*Project/Program Description*[1]	*Specifics*	*Relevance to Informal Caregivers*
http://209.217.71.106/cgi-bin/starfinder/9481/hihinit.txt http://www.changefoundation.com/tcf/TCFBul.nsf/0/d1b3a329d92a14f8852569ab00574a05?OpenDocument Start date: 2000/11/01 End date: 2002/10/31	Using their telephone, patients logged important clinical findings such as weight, vital signs and ECG. A nurse assessed the information daily to determine if the patient's condition is stable	care, decision support, information & knowledge sharing *People*: Adults (18+ years old)	
Minoyawin Distributed Homecare Resources (MDHR) Pilot Project Northern Ontario, Canada http://209.217.71.106/cgi-bin/starfinder/9481/hihinit.txt http://www.changefoundation.com/tcf/tcfbul.nsf/eb2d6f6074fe4c9c052567180004b916/8db18bf0f3c62100852569ab005cc92e!OpenDocument&Highlight=0,keewaytinook http://health.knet.ca/programming.html Start date: November 2000 End date: initiative has no fixed end date	Remote First Nations health service that addressed the quality improvement needs of local caregivers in five isolated First Nations Purpose of the project was to extend the standard homemaker training protocol to include the use of the Internet and telephone support Adopted a distributed networking-call centre/web-enabled support strategy to address the emergent and on-going learning and quality improvement needs of local caregivers in five isolated First Nations	*Care*: Acute, Chronic *Service*: Distributed networking-call centre/web-enabled support strategy, On-going learning *People*: Aboriginal people, Health care professionals	Focused on delivery of homecare services by front-line homemaking staff in each First Nation Toll free help line to deliver homemaker training to five remote First Nations in Northwestern Ontario
National Pilot Project for Telemedicine in Nephrology Corporation hospitalière Beauséjour, New Brunswick, Canada http://209.217.71.106/cgi-bin/starfinder/9481/hihinit.txt http://www2.itssti.hc-sc.gc.ca/B_Pcb/HTF/Projectc.nsf/EnglishAll/74313EB747F4147F85256816006DA32F	Creation of a distance education program to improve the renal health of persons with hypertension or diabetes Set up of a videoconferencing teaching program for Aboriginals at risk of chronic renal failure	*Care*: Chronic, supervised dialysis treatments *Service*: Monitoring, distance education, training, support *People*: Aboriginal people, hemodialysis patients	One key findings included the project leaders identified that teledialysis improved clients' quality of life by reducing travel, thereby allowing them to spend more time with their families

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
Start date: 1998 End date: Not specified			
Stakeholder Readiness for Telehomecare Diabetic Support Alberta, Canada http://209.217.71.106/cgi-bin/starfinder/9481/hihinit.txt http://www.fp.ucalgary.ca/telehealth/PC-0025.pdf Start date: 2001 End date: 2002	Qualitative methodology was used to explore the perceived attributes of using telehomecare technology as well as organizational strategies that may be useful if telehomecare is selected as a service delivery option	*Care*: Chronic *Service*: Support, disease management, education *People*: Diabetic adults in receipt of homecare, health care professionals	Program cited as providing reassurance to clients and caregivers Nurses noted they had developed close relationships with clients and their informal caregivers and felt they gave need support and interaction, especially since many of their clients were isolated in the community For more information see: Hebert, M. A. & Korabek, B. (2004). Stakeholder readiness for telehomecare: Implications for implementation. *Telemedicine Journal & e-Health*, 10(1), 85-92.
Tele-Home Care: Multi-Centre Canadian Modeling Component Alberta, Canada http://209.217.71.106/cgi-bin/starfinder/9481/hihinit.txt http://www2.itssti.hc-sc.gc.ca/B_Pcb/HTF/Projectc.nsf/ExecSum/NA0161/$File/NA0161.pdf Start date: no date indicated End date: no date indicated	Comparison of three regionally produced models of tele-home care The project developed a 'blueprint' for a core Canadian tele-home care service that could enable higher-intensity care in the home for up to six months after hospital discharge Project team recognized the potential of this model to address health care delivery challenges in rural and remote regions of Canada	*Care*: Not specified *Service*: Monitoring, assessment *People*: Children,	Project findings included: Potential to improve quality of life for both patients and caregivers Benefits associated with increase feelings of support and reduction in family disruptions may result in improvements in the quality of life of families Perceived need of education and social support for patients and caregivers (families), perceived benefit of caregiver learning and reassurance around patient care at home and reduced parent anxiety and stress Families truly believe it is their responsibility to care for family members with support from the health care system

Project/Program	*Project/Program Description*[1]	*Specifics*	*Relevance to Informal Caregivers*
			Improvements in the integration of care that may benefits the patients, the system…and family caregivers Families report no difficulties in managing the technology, that they are please to be in familiar surroundings with their whole family, and that there is a substantial relief of anxiety that comes from knowing there is a familiar face at the other end of the phone line when ever they need the nurse
Using the World Wide Web to Deliver a Cardiac Rehabilitation Program to Patients at Home /CHESS (Comprehensive Health Enhancement Support System): A Pilot Project – Use of a Computerized Patient Education & Support System for Patients with an Acute Cardiac Event British Columbia, Canada http://209.217.71.106/cgi-bin/starfinder/9481/hihinit.txt http://www.providencehealthcare.org/paul/paul.htm Start date: 1999/01/13 End date: 2000/09/29	Cardiac rehabilitation program Patients conferred with cardiac specialists The Comprehensive Health Enhancement Support System (CHESS™) is a computer-based system of integrated services designed to help individuals cope with a health crisis or medical concern.	*Care*: Acute, rehabilitation *Service*: Provision of patient information, supportive care *People*: Adults (18+ year olds)	Not specified within retrieved material
West Prince Telehospice (Prince Edward Island – West Prince Health Telehomecare) Prince Edward Island, Canada http://209.217.71.106/cgi-bin/starfinder/9481/hihinit.txt http://www.gov.pe.ca/infopei/oneli	Project created opportunities to deal with the overwhelming demand for home based care using information technology Objectives: To determine the degree to which "home based teletechnology" will	*Care*: Palliative *Service*: Information, *People*: General population	The Project aimed to: Strengthen the bonds between the patient, the family and the team members providing support Provide support for the caregivers and patients Be a service designed to give the dying

Project/Program	***Project/Program Description[1]***	***Specifics***	***Relevance to Informal Caregivers***
sting.php3?number=17045 http://www.digitalgrp.com/press/oct_1_2000.html http://www.canhealth.com/apr0.html Start date: 1999/01/13 End date: 2000/09/29 2001 shift from Telehospice to Telehomecare	enhance the provision of Palliative Care services to rural Islanders and Canadians. To determine the particular needs which can be served through the use of technology. To determine the modifications and additions to the care/technology mix which would result in +effective and higher quality service. To determine other Home Care applications for this technology		person and their family the kind of reassurance and support which is crucial when the choice to die at home has been made When a dying patient can be cared for professionally via an inexpensive Telehospice network at home rather than at the hospital, the benefits to the patient, to his or her family and to provincial health care costs are obvious. “I’ve have the daughter of one patient already tell me how grateful the family is that we’ve been able to leave her mother at home and yet still know and see what her condition is”
East York Telehome Care Project Ontario, Canada www.telehomecare.ca/reports/FinalCANARIEreportforpartners.doc Start date: April 1, 2003 End date: March 31, 2004	Project strategic objectives included: Carry out large scale THC project with individuals with CHF, COPD, diabetes, across health sectors and providers Explicate the process and concerns of users and providers by developing a midrange theory of THC experience over its duration Evaluate costs, accessibility, health outcomes and satisfaction for users and providers with traditional community care Establish best practice guidelines, policies and standards for THC	*Care:* Chronic *Service:* Remote and in-home visits, descriptive study, RCT, training *People:* Patients accessing an integrated health system, health care professionals	One elderly woman, acting as a caregiver to her husband, with her own health problems, felt that THC was more than she could manage Patients and caregivers found it was easy to learn to use the THC equipment and did not report any technical problems Family members noted they took comfort in having the technology so readily available to monitor the patient’s condition and to allow for increased understanding and empowerment of patients through knowledge acquisitions and improved disease self-management
Distributed Team-Based Learning in Telehealth and Telehomecare Ontario, Canada	The goal of this project is to develop online learning materials for health care professionals working in telehomecare The results of the project join the	*Care:* Not applicable *Service:* Education, on-line learning *People:* Health care	Canada will benefit because telehomecare is an emergent practice particularly relevant for home-based care for chronically ill patients, and those living in rural and remote areas

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
http://www.telehomecare.ca/elearning/index.html Start date: End date:	suite of telehealth courses offered by Centennial College, and enable the College to further build interdisciplinary bridges with other medical teaching institutions to meet the growing demand of education and training for this emerging area of healthcare practice Part of the East York Telehomecare Project, but can be seen as a standalone project inasmuch as it was developed before the eHealth project and had emerged out of longstanding interests in telehealth and online learning at Centennial College, specifically and among the East York community partners more generally	professionals	Often the burden for transportation and accompaniment to appointments falls on family members, who must take time off paid work for this task.
TeleMedisys Remote Monitoring Targets Chronic Disease Management Pilot Project Québec, Canada http://www.canhealth.com/mar99.html Start date: early 1999 End date: upon pilot project completion it will be rolled into a regular program almost immediately	Following its recent launch of a remote cardiac-patient monitoring program, Telemedisys Inc. of Montreal is exploring ways that distance monitoring can improve management of chronic diseases Also plans to launch a trial with cystic fibrosis patients	*Care:* Chronic *Service:* Monitoring, disease management, compliance *People:* People with chronic diseases, children	Not specified within retrieved material
University of Ottawa Heart Institute Ontario, Canada http://www.ottawaheart.ca/UOHI/	Patients considered at high risk for re-admission or with special needs are monitored by a nurse with Telehome monitoring	*Care:* Acute *Service:* Monitoring, self-care education *People:* Patients	Not specified within retrieved material

Project/Program	*Project/Program Description*[1]	*Specifics*	*Relevance to Informal Caregivers*
TH_TeleCare.do Start date: unknown End date: Ongoing		considered at high risk for re-admission or with special needs	
River Valley Health EMPcare@home New Brunswick, Canada http://www.andyscott.ca/releases/release_18-2_03_04.htm http://www.canhealth.com Start date: piloted in 2004-2005 End date: 12 month duration	River Valley Health will expand its renowned Extra Mural Program (EMP) to include access to telehomecare The initiative includes the development of the necessary tools and networks to implement the telehomecare services	*Care:* Chronic *Service:* Management, prevention, monitoring *People:* individuals of all ages in their homes, nursing homes, special care homes, day cares and schools	This system of monitoring on a daily basis will help EMP caregivers identify warning signs of changes in a patient's conditions
Home Plus (Dialysis) Toronto, Ontario (Sunnybrook) http://www.sunnybrookandwomens.on.ca/foundation/news/newsdialysis Start date: January 2004 End date: Ongoing	Home Plus, a pilot project at Sunnybrook and Women's College Health Sciences Centre, is providing dialysis patients who typically would not be eligible for home dialysis The Home Plus program is built around the patient and their needs. It provides a complete system of care, increasing home care support and providing patients with access to their medical information	*Care:* Chronic, acute *Service:* Monitoring, support, information *People:* Dialysis patients	The project will enable the hospital to send medical information electronically to the patient, home health professional and family members The hospital will be able to focus on providing patients and families the best care possible in the comfort of their home
Home Telehealth Diabetes Management Pilot Project Toronto, Ontario (Sunnybrook) http://www.sw.ca/news?id=284 Start date: 2004 End date: Ongoing	The pilot project will test the delivery of multidisciplinary diabetes care in patient's homes using eHealth solutions The project has two phases, the first phase is a five month pilot which will be a spring board to launch a randomized controlled trial to determine the efficacy of eHealth technology versus traditional care delivery.	*Care:* Chronic *Service:* Monitoring *People:* Diabetic patients	Researchers will study and assess patient and provider reactions to the technology and the change in health care delivery
Tele-homecare Technology for	The main objective is to implement	*Care:* Chronic,	The program aims to overcome the

Project/Program	*Project/Program Description*[1]	*Specifics*	*Relevance to Informal Caregivers*
the Chronically Ill Patient Ontario, Canada http://www.bce.ca/en/social/universityresearch/researchprojects/telehomecare/ Start date: unknown End date: unknown	a distinct telehealth program to achieve the goal of "supervised autonomy", which increases individuals' independence without decreasing the necessary continual support and specialist supervision Home Nocturnal Hemodialysis / Remote Assisted Nocturnal Hemodialysis is a superior alternative to conventional renal replacement therapy. The University of Toronto is a pioneer of this renal replacement modality	ambulatory care *Service:* Monitoring, instant messaging, virtual clinic *People:* Hemodialysis patients	perception of being socially isolated and receiving sub-standard care and to provide a sense of community to geographically diversely located individuals
Health Support Interventions for Impaired Elderly and their Caregivers - Supporting Family Caregivers Online Ontario, Canada http://www.klaru-baycrest.on.ca/KLARU_-_CANARIE_July_03.htm http://www.canarie.ca/conferences/telehealth/presentations/elsa_marziali.ppt Start date: unknown End date: unknown	Website to help individuals cope with the challenges and isolation of caring for a chronically ill family member Developed by the Baycrest Centre for Geriatric Care in Toronto The website uses video conferencing and other interactive tools to provide support and disease-specific information to people caring for stroke victims, or those with Alzheimer's or Parkinson's	*Care:* Chronic *Service:* Information, support, training, education *People:* Caregivers, spousal caregivers, informal caregivers	This online caregiver support network has received positive reviews from the 72 caregivers from Alberta and Northern Ontario who participated in the trial The website will be particularly useful for caregivers living in rural and remote areas, and can be adapted for use by other caregiver groups Caregivers experience reduced stress related to their caring of spouses A functional, effective, secure, and scalable web-based tool has been developed for support of family care-givers of patients with dementia
Capital Health plans pilot project with Telus - HomeSitter Alberta, Canada http://www.capitalhealth.ca/NewsAndEvents/Features/Video_mo	The Capital Health authority expects to do pilot projects this year using Telus's new HomeSitter service to monitor frail, elderly people who receive home care but are on their own much of the day	*Care:* Various *Service:* Monitoring, support, information *People:* Frail elderly people in danger of falling are likely candidates, as well as	Capital Health is working with TELUS to identify cameras and other devices that will provide the level of quality medical professionals will require for specific applications such as supporting an aide or family member who is doing wound care, monitoring adults at risk of

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
nitoring.htm http://www.capitalhealth.ca/NewsAndEvents/NewsReleases/technology_partnership_home+monitoring+++.htm Start date: 2005 End date: Ongoing	With the video system home-care staff might notice a client is in trouble and send someone out to help before something serious, such as a fall, occurs TELUS HomeSitter is an Internet-based remote home monitoring solution that allows residential customers to stay in touch with what's going on at home when at work or on vacation	people with dementia who might wander out of the house	wandering and possibly monitoring children receiving care in a home setting
Telehomecare Pilot Project Prince Edward Island, Canada http://www.tbs-sct.gc.ca/rma/dpr/02-03/VA-AC/VA-AC03D-PR_e.asp?printable=True Start date: January 2003 End date: 2006	On January 9, 2003, the Ministers of Veterans Affairs and the Prince Edward Island Department of Health and Social Services jointly announced a Telehomecare Pilot Project. This partnership will result in expansion of the provision of telehomecare service to eligible Veterans and other homecare clients throughout Prince Edward Island. Building upon the Telehospice Pilot Project initiated by Prince Edward Island's West Prince Health Region in April 2000, the partners will develop an operational plan for the continued expansion of the telehomecare service from 2003 to 2006.	*Care:* Palliative *Service:* Instruction, education *People:* Seniors	It is intended that the one-on-one contact between healthcare providers and seniors will provide emotional support and comfort to anxious patients and their families It is expected that the knowledge gained from this project will be transferable to other regions of Canada
Canadian Virtual Hospice Manitoba, Canada www.virtualhospice.ca/ Start date: 2001	The Canadian Virtual Hospice is an interactive network designed to facilitate information exchange, communication, and mutual support between and	*Care:* Palliative *Service:* Information, professional consultation, support *People:* All ages	This project will enable professional and informal caregivers to conduct interactive consultations with experts in palliative care through a web-based forum

Project/Program	*Project/Program Description*[1]	*Specifics*	*Relevance to Informal Caregivers*
End date: Ongoing	among patients, their friends and family, health care providers, and palliative care volunteers The Canadian Virtual Hospice is an excellent example of how information and communications technologies (ICTs) can be harnessed to deliver health information, services, and expertise over short and long distances		At the core of palliative care is collaboration among patients, their families, and the team providing care. Patients and family members are an integral part of making care decisions
Telehome Care in Northwestern Health Services Region (Project #2) Alberta, Canada http://www.health.gov.ab.ca/about/HIF/overviews.html Start date: Unknown End date: Unknown	To put in place a telehomecare service within region to expand and streamline service delivery to clients in homecare system To provide information about telehomecare to facilitate decisions regarding the future investments in this technology	*Care:* Not specified *Service:* Information *People:* Not specified	One objective of the project is client/provider satisfaction, willingness of care providers and clients to use service
Programmes for Autonomy and Communication for the Elderly (PACE) Ontario, Canada http://www.fp.ucalgary.ca/telehealth/CST2002Report-Final.pdf Start date: 1997 End date: Ongoing	PACE is using videoconferencing to establish a virtual residential village, as a tool for intergenerational programs and for medical follow-up in seniors' homes allowing early hospital discharge	*Care:* Chronic *Service:* Follow up, compliance *People:* Seniors	Not specified within retrieved material
Multi-Purpose Intelligent Patient Distance Monitoring Quebec, Canada http://www.cst-sct.org/resources/CST01Summary.pdf Start date: Unknown End date: Unknown	A pilot project with a High-Risk Pregnancy Clinic has provided a technological feasibility evaluation as well as some strong indications that the technology could be generalized to more chronic and severe patient categories As a result, the Anna-Laberge	*Care:* Acute *Service:* Monitoring *People:* High risk pregnancy clinic clients	Not specified within retrieved material

Project/Program	*Project/Program Description*[1]	*Specifics*	*Relevance to Informal Caregivers*
	Hospital is currently deploying the technology to complex medical and surgical problems requiring long term monitoring in different departments of the hospital. Moreover, they are setting up a Monitoring Centre to provide centralized support and services		
Intelligent Distance Patient Monitoring - The Intelligent Clinical Follow-up in Residence (SCIAD) Verdun, Quebec, Canada www.newittech.com Start date: Unknown End date: Unknown	The Intelligent Clinical Follow-up in Residence (SCIAD) offers a solution supplements and tested which makes it possible to establish a clinical relation between the patient in residence and the professionals of health in institution or private clinic through an electronic bond, Bi-directionel and made safe SCIAD allows an intensification of the care residence while supporting the integration of service thanks to the information which it makes available, in an immediate way, with all the speakers. It makes it possible to maintain, if not to improve the health of the patients and thus to reduce the visits to the urgency, the number and the duration of the hospitalizations and to better coordinate the interventions in the network of health	*Care:* Not specified *Service:* Follow-up *People:* Not specified	Not specified within retrieved material
Chronic Wound Management in the Community and Acute Care	A component of the Nova Scotia Telehealth Network (NSTHN) has been providing wound management care via	*Care:* Acute *Service:* Monitoring *People:* Clients with	Ongoing monitoring by local facility-based nurses has provided accurate and timely diagnostic information and resulted in direct and indirect cost

Project/Program	*Project/Program Description*[1]	*Specifics*	*Relevance to Informal Caregivers*
Dartmouth, Nova Scotia, Canada http://strategis.ic.gc.ca/epic/internet/inict-tic.nsf/en/it07546e.html http://www.gov.ns.ca/health/telehealth/activities.htm#wound Start date: Unknown End date: Ongoing	telemonitoring in a cost-effective and efficient way — the management of both acute and chronic wound care by endostomal nurse specialists This program facilitates the transition of chronic wound care from acute care facilities to community care through discharge case conferencing between the enterostomal therapist, acute care nurses and community based nurses such as the V.O.N.	wounds	savings for caregivers, patients, and the health care system without sacrificing quality
United States			
Kaiser Permanente Tele-Home Health Research Project Sacramento, CA, USA http://xnet.kp.org/permanentejournal/sum00pj/abstractstext.pdf http://www.hometelecare.info/publica_4.htm Start date: May 1996 End date: October 1997	Evaluated the use of remote video technology in the home health care setting as well as the quality, use, patient satisfaction, and cost savings from this technology	*Care*: Chronic *Service*: Assessment, monitoring, triage *People*: Newly referred patients diagnosed as having congestive heart failure, chronic obstructive pulmonary disease, cerebral vascular accident, cancer, diabetes, anxiety, or need for wound care were eligible for random assignment to intervention	Study concluded that remote technology has the potential to effect cost savings when used to substitute some in-person visits and can also improve access to home health care staff for patients and caregivers. This technology can thus be an asset for patients and providers For details see: Johnston, B., Wheeler, L., Deuser, J. & Sousa, K.H. (2000). Outcomes of the Kaiser Permanent tele-home health research project. *Archives of Family Medicine*, 9, 40-45
TeleHomeCare Demonstration Project Minnesota, USA http://hhc.sagepub.com/cgi/reprint	TeleHomeCare was a demonstration telemedicine project focused on the delivery of home health care to elderly	*Care:* Chronic *Service:* Support, training *People:* Congestive	Training materials were developed so that the HHC nurses can teach either the patients or their caregivers how to use the equipment.

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
/13/3/219 http://www.ntia.doc.gov/top/conferenceworkshops/nfp2001/powerpoint/finkelstein.ppt http://ntiaotiant2.ntia.doc.gov/top/details.cfm?oeam=276098031 http://www.telehomecare.umn.edu/about.html http://ntiaotiant2.ntia.doc.gov/top/docs/eval/pdf/276098031e.pdf Start date: October 1998 End date: September 2002	homebound patients who are receiving care for either congestive heart failure, chronic obstructive pulmonary disease, or chronic wound healing Patients and their families often need help with medication dosing, symptom management, anxiety with daily cares, support for caregivers, and assessing the need for a physician visit	heart failure patients, family caregivers	
National Laboratory for the Study of Rural Telemedicine - ResourceLink Iowa, USA http://tie.telemed.org/programs/ProgramListings_t2.asp?ID=46 http://telemed.medicine.uiowa.edu/TRCDocs/services/telehome.html http://www.uihealthcare.com/depts/nursing/news/awardsandstories/murray.html Start date: January 1998 End date: Ongoing	The National Laboratory currently provides telepsychiatry, telemedicine to children with disabilities, pediatric echocardiography, diabetes home care, desktop videoconferencing for early detection and treatment of stroke and myocardial infarction The resourceLink process uses a 13-inch television with a small camera mounted on top, and a standard telephone line. A resourceLink nurse calls the patient at an appointed time and they visit face-to-face via the telemedicine connection. At the same time, the nurse can monitor blood pressure, heart rate, and weight through peripheral monitoring devices	*Care:* Chronic *Service:* Monitoring *People:* Elderly clients, the service is aimed at patient populations frequently seen by physicians and often admitted to hospitals, including those with heart disease, diabetes and psychiatric illnesses	Many of the patients face difficult socioeconomic conditions and poor family support
National Laboratory for the Study of Rural Telemedicine - Patient-Centered Multimedia	This project uses emerging technologies to deliver high-quality, content rich multimedia	*Care:* Chronic *Service:* Education *People:* People with	24 hour access to a lively electronic resource full of searchable text, motion video and animation that explains

Project/Program	*Project/Program Description*[1]	*Specifics*	*Relevance to Informal Caregivers*
Education for Individuals with Diabetes Mellitus: A Model for Chronic Disease Self-Management Iowa, USA http://telemed.medicine.uiowa.edu/TRCDocs/Projects/multimedu.html Start date: Unknown End date: Ongoing	educational experiences to supplement existing diabetes education both in the hospital setting and in the home	diabetes	what's happening
Upper Peninsula Telehealth Network Michigan, USA http://www.mgh.org/telehealth/ http://www.mgh.org/telehealth/telehome_print.html Start date: 2000 End date: Ongoing	The Upper Peninsula Telehealth Network (UPTN) provides core services in professional/staff education, the medium for clinical consultations, the medium for administrative meetings, deployment of telehome care systems, community education, and video conferencing services for community groups/businesses Telehome Care is available through six home health agencies whose parent organization participates in the Upper Peninsula Telehealth Network. These six agencies serve patients in eight counties	*Care:* Chronic *Service:* Monitoring *People:* focus is patients with Chronic obstructive pulmonary disease (COPD), Congestive heart failure (CHF), Diabetes and Stroke recovery	Not specified within retrieved material
University of Tennessee Telemedicine Network Tennessee, USA http://gsm.utmck.edu/telehealth/projects.htm http://telehealth.hrsa.gov/pubs/report2001/eval.htm#box9 Start date: 1998	UTTN offers services to home care agencies and other health care providers in the development and operation of a telehealth program Experience with traditional home care agencies, hospice services, and other health care facilities in providing home care and	*Care:* Chronic *Service:* Disease management *People:* patients from UTMC's integrated health delivery network	UT Home Touch Study researchers conducted in-depth interviews and monthly surveys with nine of the 14 patients, as well as their caregivers Family caregivers were also asked about the benefits and disadvantages of telemedicine. Overall, caregivers perceived the following benefits: saved time in transporting patient; reduced

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
End date: Ongoing	disease management services UTTN has published in journals including Home Healthcare Nurse and Telemedicine Journal and eHealth Researchers conducted the 'Home Touch' Study		anxiety; 'just-in-time' health care available; added value of being able to visualize wound; reduced time to get medical help; more convenient than an in-home health care visit; comprehensive, consistent care available; and increased privacy For more details see: Dimmick, S.L., Mustaleski, C., Burgiss, S.G., & Welsh, T. (2000). A case study of benefits & potential savings in rural home telemedicine. *Home Healthcare Nurse,* 18(2), 125-135.
Metropolitan Jewish Health System Telemedicine Project New York, USA http://tie.telemed.org/programs/ProgramListings.asp?ID=401 Start date: January 1998 End date: Ongoing	Began providing home care services via telemedicine to King County, New York in January 1998. They are providing both follow-up care and home monitoring telemedicine, which uses two-way audio/video technology to allow the home monitoring of patients	*Care:* Not specified *Service:* Follow up, monitoring *People:* Not specified	Not specified within retrieved material
Kansas Care, Inc. Ohio, USA http://tie.telemed.org/programs/ProgramListings.asp?ID=404 http://www.kansascare.com/telemed.html Start date: 1996 End date: Ongoing	Home telemedicine system is a service component offered to home care patients Clients are evaluated by a clinician to determine appropriateness for program criteria eligibility.	*Care:* Not specified *Service:* Cognitive evaluation, medication monitoring, blood pressure and pulse assessment, view wounds and syringes, assess heart, lung and bowel sounds *People:* All ages	Not specified within retrieved material
Dementia Caregiver Telehealth Support Project (AlzOnLine) Florida, USA	The project emphasizes the use of template tools, web-based services, audiovisual	*Care:* Chronic *Service:* Support, information, website	The project provides specific resources and tools to caregivers of elderly persons with dementia by capitalizing

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
http://elderaffairs.state.fl.us/doea/english/GLR/sops2005/Program%20Descrip%202.pdf http://tie.telemed.org/programs/showprogram_t2.asp?item=2622 http://www.alzheimerresourcecenter.cc/OnlineResources.html http://www.liebertonline.com/doi/pdf/10.1089/tmj.2004.10.223 http://www.alzonline.net/index.php Start date: July 2000 End date: Ongoing	communication, and toll-free telephone support to consumers. Its intent is to utilize technological advances to enhance prospects of meeting the emotional support and information needs of homebound caregivers Study evaluating initial program evaluation conducted	*People:* Homebound caregivers	on developments in telecommunications technology The purpose of this website is to provide caregivers of elder of persons with progressive dementia web-based resources and services to help those in their care to age in place, in an elder-friendly environment, with security, dignity, and purpose Study results suggest that online cognitive-behavioral intervention (i.e., the Positive Caregiving classes) may lead to substantial reductions in negative caregiver appraisals of burden, and concomitant increases in perceived self-efficacy for key caregiving behaviors
Telehomecare Project Philadelphia, PA, USA http://ntiaotiant2.ntia.doc.gov/top/details.cfm?oeam=426097030 http://www.smeal.psu.edu/ebrc/publications/res_papers/2003_07.pdf http://www.hetinitiative.org/sub-call_for_proposals/cfp-grantee_info.html http://ntiaotiant2.ntia.doc.gov/top/details.cfm?oeam=426097030 http://ntiaotiant2.ntia.doc.gov/top/docs/eval/pdf/426097030e.pdf Start date: October 1997 End date: June 2000	The Pennsylvania State University, along with its partners, will use an innovative technology, telehealth, to provide home health services to insulin-dependent diabetics in Philadelphia County, Pennsylvania. While there is an increasing use of telecommunications technology in health care, its diffusion into home care, the fastest growing sector of the health care industry, has been slow This study investigated the effects of telehomecare on patients and nurses in a large, urban, home health agency. The TeleHomecare Project is a partnership of Pennsylvania	*Care:* Chronic *Service:* Monitoring *People:* Diabetic patients	Not specified within retrieved material

Project/Program	***Project/Program Description[1]***	***Specifics***	***Relevance to Informal Caregivers***
	State University, The Visiting Nurses Association of Greater Philadelphia, and American Telecare, Inc. (ATI)		
Georgetown University Medical Center - MyCareTeam http://www.toolbase.org/tertiaryT.asp?DocumentID=3240&CategoryID=1751 http://telemedicine.georgetown.edu/ Start date: Unknown End date: Ongoing	Georgetown University Medical Center's Web-based system is one of several new tools that use telecommunications technology-computers, the Internet and interactive television-to improve and expand home health care services for the elderly and others with chronic disease Georgetown will test a telehomecare device to see if better coordination of patients care is cost effective. More than 600 patents will take part in the Georgetown study MyCareTeam, an Internet-based application designed to monitor and provide homecare management for people with diabetes and other chronic diseases	*Care:* Chronic *Service:* Monitoring *People:* Elderly and others, people with Diabetes	Not specified within retrieved material
Georgetown University Medical Center – MindmyHeart http://telemedicine.georgetown.edu/ Start date: Unknown End date: Ongoing	MindmyHeart is a Medicare demonstration project awarded to the Georgetown University Medical Center to study the effects of intensive case management of Congestive Heart Failure (CHF) patients by care managers using home monitoring technologies	*Care:* Chronic *Service:* Monitoring *People:* CHF patients	Not specified within retrieved material
Long-term Home Care Telehealth Project at NYLCare of New York	A long-term home care telehealth project at NYLCare of New York that achieved 100% reduction in	*Care:* Chronic *Service:* Monitoring,	Not specified within retrieved material

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
New York, USA http://www.informationfortomorrow.com/successstories.htm Start date: Unknown End date: Unknown	hospitalizations of the CHF patient participants. The project has involved regular telephone calls from nurses to elderly patients, in which patients reportedly felt a sense of "caring" by practitioners who called. This more frequent contact effectively raised the rates of patient compliancy	compliance *People:* CHF patients	
The Use of Home-Telehealth Technology in New York New York, USA http://www.atmeda.org/Forum2004/Presentations/Rodat.pdf Start date: 2004 End date: Ongoing	In early 2004, HCA established a Home Telehealth Technology Task Force to evaluate the utilization of technologies applicable to the home environment and home care specifically. Over 40 providers from across the State participated in the Task Force The first step HCA took was to survey the membership to determine the current use of home telehealth technology that allows monitoring of various vital signs from a distance. HCA also surveyed those providers who have not yet implemented such technologies to determine their readiness	*Care:* Acute, Chronic, Palliative *Service:* Monitoring, disease management, care management *People:* Spouses, caregivers, care providers	The technology assists the informal caregiver in a variety of ways. There are children with elderly parents who are paying for the monitoring as it allows them the peace of mind for those periods of the day when they or another caregiver cannot be with their parent. Spouses, and other caregivers, often participate in the telehealth "visit," and are able to ask the nurse questions. Anxiety is greatly reduced in those patients and their caregivers with the telehealth equipment since their condition can be monitored on a more frequent basis
SUN Home Health Services Northumberland, PA, USA http://www.suncare.org/telehomecare.htm Start date: Unknown End date: Unknown	Some patients need more monitoring to manage their care: telehomecare allows us to access those patients for more visits without traveling great distances," explains Donna Jenkins, RNC, Director of Home Health. "Telehomecare is	*Care:* Chronic, acute *Service:* Monitoring *People:* All members of the community	Not specified within retrieved material

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
	especially helpful in our most rural areas," Jenkins adds, "and patients needing help late in the night can have access to the RN very quickly by calling the Health Information and Referral Center (IRC) where a nurse 'connects' with them via telehomecare."		
Shepherd Center: Telehomecare for the Spinal Cord Injury / Brain Trauma Population http://www.atmeda.org/Forum2003/Presentations/Grogg.ppt http://www.shepherd.org/shepherdhomepage.nsf/Home?OpenForm Start date: 1995 End date: Ongoing	Main focus is POTS communication Prevention/treatment of pressure sores Remote evaluation of home accessibility/rehabilitation for occupational therapy, referred to as virtual OT	*Care:* Chronic, acute, rehabilitation *Service:* Prevention, treatment, follow-up care, monitoring *People:* Patients spinal cord injuries, brain trauma patients	Not specified within retrieved material
HCP Telehomecare Project New York, USA http://www.chcforum.org/pdf/04sweeneyrls.pdf http://www.nyshcp.org/pdf/hcny0205.pdf Start date: 2004 End date: Ongoing	An initial allotment of $50,000 in Federal funding was secured by Congressman John E. Sweeney (R-Clifton Park) to support a telehomecare demonstration project in the Capital District, according to the New York State Association of Health Care Providers, Inc. (HCP). HCP is a statewide trade association representing the full spectrum of home care and hospice agencies in New York	*Care:* Chronic *Service:* Not specified *People:* Frail elderly and disable patients	Not specified within retrieved material
GlucoMon Wireless Device for Mobile Patient Diabetes Monitoring Texas, USA	GlucoMON™ is the first wireless device for automatically transmitting hypoglycemic test results from a child's self-test	*Care:* Chronic *Service*: Monitoring, compliance *People:* Diabetes	Every day, the GlucoMON mobile monitoring system is making a huge difference in the lives of families living with diabetes

Project/Program	*Project/Program Description*[1]	*Specifics*	*Relevance to Informal Caregivers*
http://tie.telemed.org/programs/showprogram.asp?item=2630 http://www.shoppinglinker.com/press/glucomon.html http://www.diabetech.net/ Start date: 2002 End date: Ongoing	glucose meter from anywhere to anywhere. The real benefit delivered in their initial service is to provide a timely remote connection between parent and child and to understand compliance to the expected glucose-testing regimen	patients, children	Beyond providing independence to patients with the most chronic forms of the disease, it is delivering peace of mind to those who care for them day in and day out
Asthma In-Home Monitoring (AIM) Hawaii, USA http://tie.telemed.org/programs/showprogram.asp?item=2839 http://www.pacifichui.org/projects/whitepapers/030804_AIM.pdf Start date: November 2001 End date: August 2004	The AIM project aimed to demonstrate the feasibility of an Internet-based "virtual visit" network to monitor and train pediatric asthmatic patients in their homes using PCs for image and audio observation, training and data capture The purpose of the project was three-fold: to ascertain whether "virtual" visits improve patient outcomes; determine if parents and families prefer virtual visits; and establish whether virtual visits are a cost-effective alternative to standard office-based management of asthma	*Care*: Chronic *Service*: Monitoring, patient education, case management *People*: 120 pediatric asthmatic patients	One anticipated outcome of the AIM project was to reveal if parents and families prefer asthma in-home monitoring and management compared to intensive office-based asthma case management Project results are not yet posted
Department of Veterans Affairs Projects/Programs	VHA delivers care into the home using new information technology based systems (home-telehealth) that facilitate the clinical coordination of care. VHA has individual home-telehealth programs that are exemplary but there is no unified strategy for a VHA-wide implementation of home-telehealth. http://www.va.gov/occ/Docs/Recommendations_06-20-2002_v-4.pdf		
VA Connecticut Healthcare System home telemedicine program Connecticut, USA http://www.va.gov/telehealth/toolkits/hometelehealth/9b_lesson_of_the_month-	Optimize care to some of their homebound patients by allowing clinicians to monitor physiologic data from patients' homes using the Internet Patients receive Web-based education, questionnaires and	*Care:* Chronic *Service:* Monitoring, education, disease management *People:* VA clients	Not specified within retrieved material

Project/Program	*Project/Program Description*[1]	*Specifics*	*Relevance to Informal Caregivers*
home_telehealth.pdf Start date: 1997 End date: Unknown	disease management surveys		
Rural Home Care Project Florida, USA http://www.liebertonline.com/doi/abs/10.1089/153056203766437525 Start date: 2000 End date: Ongoing	One of eight clinical demonstration pilots in an initiative of the Veterans Health Administration (VHA) Sunshine Network in Florida and Puerto Rico In this project three care coordinators collaborate with primary care providers in the management of high-risk, high-cost veterans with multiple chronic diseases such as diabetes and heart failure. The project staff uses home telehealth devices to monitor and educate patients to prevent health crises	*Care:* Chronic *Service:* Monitoring, education, *People:* VA diabetes and heart failure patients	Not specified within retrieved material
TeleHomecare demonstration project at the James A. Haley Veterans' Hospital (JAHVH) Tampa, Florida, USA http://www.prnewswire.ca/cgi-bin/stories.pl?ACCT=105&STORY=/www/story/02-16-1999/0000871061 Start date: 1999 End date: Unknown	The JAHVH project involves placing a user-friendly AVIVA(TM) Single Line TeleHomecare System in more than 100 patients' homes to connect them via ordinary telephone lines to a nurse or physician located at JAHVH	*Care*: Not specified *Service*: Not specified *People*: VA clients	Not specified within retrieved material
Care/Home Telehealth Program (CCHT) at the VA Greater Los Angeles Healthcare System **http://www.ehcca.com/presentations/cahealthit2/2_01_2.pdf** Start date: September 2004 End date: Ongoing	Care coordination/home telehealth (CCHT) provides ongoing assessment, help arranging services, education, and emotional support for frail patients with complex clinical needs in their home	Care: Chronic Service: Monitoring, support People: High risk patients with diagnoses such as heart failure, COPD,	Not specified within retrieved material

Project/Program	***Project/Program Description*[1]**	***Specifics***	***Relevance to Informal Caregivers***
	environments at frequent intervals using telehealth technologies. The goal of CCHT is make prompt interventions for issues that might otherwise be neglected and cause avoidable acute care episodes or long-term institutional care	and diabetes mellitus with co-morbidities, a variety of other frail or homebound patients, especially patients with geriatric syndromes	
Visiting Nurse Associations of America Projects/Programs	Visiting Nurse Associations (VNAs) care for patients of all ages from infants to the elderly and offer comprehensive services that begin with maternal/child health programs and end with hospice care. VNAs provide a broad range of essential home health care and support services to patients in the security and comfort of their homes. These services can include telemedicine. New medical technologies and specialized services are routinely provided in the home by VNAs. These can include infusion therapy, telemedicine and nutritional therapy. http://www.vnaa.org/vnaa/g/?h=HTML/HomeHealthCareServices.html		
VNA Care Network Massachusetts, USA http://www.americantelecare.com/aboutus_PR_CareNet.html http://www.vnacarenetwork.org/index.html Start date: Unknown End date: Ongoing	Telehomecare program with future plans of interfacing to VNA Care Network's clinical information system	*Care:* Chronic, acute, palliative *Service:* Monitoring *People:* All ages	Not specified within retrieved material
VNA Telehome Care Program Senora, CA, USA http://www.tghospital.com/vna.html Start date: 1998 End date: Ongoing	Telemedicine enables a nurse or therapist to visually assess, interact and problem solve a patient's health care issue A small computer is placed in a patient's home enabling nurses to assess wounds, a caregiver's ability to perform wound care, teach patients about their medications, assess for compliance, teach about disease	*Care:* Chronic, acute, palliative *Service:* Monitoring, compliance, education *People:* All ages	Caregivers/patients only have one button to push to activate the computer Caregiver's ability to perform wound care is assessed

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
	process of a related illness and much more		
TeleHomecare for Heart Failure, Hypertension and Diabetes Program (Southeast Michigan VNA) Michigan, USA http://tie.telemed.org/programs/showprogram.asp?item=2553 http://www.vna.org/myh_diseaseMgt.aspx Start date: May 2004 End date: Ongoing	TeleHomecare Monitoring for Heart Failure Program sets the standard for improved care of the homebound patient while helping physicians more effectively utilize their time and resources Designed to proactively detect subtle changes in the patient's weight, pulse and blood pressure, VNA uses remote monitoring technology to augment the traditional team approach between the physician, the patient and the nurse for enhanced quality of care	*Care:* Chronic, acute, palliative *Service:* Monitoring, compliance *People:* All ages	Not specified within retrieved material
VNA Cincinnati http://www.enquirer.com/editions/2004/08/08/loc_loc1anursing.html Start date: 2000 End date: Ongoing	Pilot program for patients with congestive heart failure run by the Visiting Nurse Association The program seeks to augment live home visits with remote checkups using the videophone system	*Care:* Chronic *Service:* Monitoring *People:* Patients with CHF	System lets caretakers conduct checkups from remote sites
American Telecare Inc. Partnerships	American TeleCare, Inc., based in Eden Prairie, Minnesota, is the established leader in the telehealth industry providing solutions to enhance key health care customer applications, such as clinic-to-clinic, provider to patient home and doctor-to-doctor. American TeleCare's telehealth solutions combine sophisticated, leading technology with sound clinical expertise to develop easy-to-use systems for patients and health care providers. American TeleCare products incorporate live audio and video communication with integrated electronic medical peripherals that enable health care professional to conduct remote patients assessments and monitoring. http://www.americantelecare.com/		
Presbyterian Home Healthcare Services (with American TeleCare Inc. and McKesson	A team of professionals closely monitors the patients' condition and progress, reporting to the	*Care:* Chronic *Service:* Monitoring *People:* Home health	Individualized attention helps patients and their families learn about safe, appropriate care, as they increase their

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
Information Solutions) New Mexico, USA http://www.americantelecare.com/aboutus_PR_McKesson.html http://www.phs.org/facilities/homecare/home.shtml Start date: Unknown End date: Ongoing	physician and modifying treatment if necessary	and hospice clients	functional independence and learn to manage their medical needs
Palliative Home Care Florida, USA http://www.americantelecare.com/aboutus_PR_StarBanner1.html Start date: Unknown End date: Ongoing	Home TeleHealth System A member of Hospice of Marion County's Healthcare Alliance, Palliative Home Care has placed monitors in several patients' homes It's the first private home health care agency in Central Florida to use the monitors	*Care:* Palliative *Service:* Monitoring *People:* Home nursing clients	Not specified within retrieved material
Windom Project Minnesota, USA http://www.americantelecare.com/aboutus_PR_startribune.html Start date: 2001 End date: Ongoing	The Windom project uses five telemonitors and 11 video telephones and was begun two years ago with a $120,000 Bush Foundation grant administered by the state It's one of a handful of such programs in Minnesota Telemonitors are most often being used with older patients who have chronic diseases that need careful monitoring, and the technology is changing how patients are treated The program is operated by Good Samaritan Communities of Windom, a campus with a nursing home, senior apartments and home health care	*Care:* Chronic *Service:* Monitoring *People:* Nursing home, senior's home clients and home health care clients	With periodic video visits that supplement in-home nursing care, officials with several of the experimental programs say telemedicine clearly benefits some patients. And it can help a patient's spouse as well - Spouse feels safer

Project/Program	*Project/Program Description*[1]	*Specifics*	*Relevance to Informal Caregivers*
Baptist South Miami Home Care (BSMHC) Florida, USA http://www.americantelecare.com/aboutus_PR_Baptist.html Start date: Unknown End date: Ongoing	Telehomecare, technology-enabled home health care delivery, allows for the remote provision of care, monitoring, and education to patients in their homes BSMHC uses live audio/video with medical peripherals including a telephonic stethoscope, blood pressure meter, scale, and glucose meter BSMHC has initially decided to focus on its heart failure population, given that group's risk and cost to home health and the hospital system	*Care:* Chronic *Service:* Monitoring, education *People:* Heart failure patients	Not specified within retrieved material
HHC Health & Home Care New York, USA http://www.americantelecare.com/aboutus_PR_HHC.html Start date: 2002 End date: Ongoing	HHC Health & Home Care, a division of New York City Health & Hospitals Corporation, has implemented the first home telehealth program that targets patients who are HIV positive	*Care:* Chronic *Service:* Provision of care, monitoring, education *People:* HIV patients	Not specified within retrieved material
New Ulm Medical Center Home Health http://www.americantelecare.com/aboutus_PR_NewUlm.html Start date: 2001 End date: Ongoing	Goal of preventing hospital readmissions among its patients with congestive heart failure The community that NUMCHH serves is in a rural, agricultural area whose patients often reside far from the medical center	*Care:* Chronic *Service:* Monitoring *People:* CHF patients	Not specified within retrieved material
United Kingdom			
Assisting Carers using Telematics Interventions to meet Older persons Needs (Action)	Use of domestic TV and sophisticated hardware to bring information to patients and carers The main aim of ACTION project	*Care:* Chronic *Service:* Information and support *People:* Patients and	Further research and development work with the videophone in the Swedish ACTION project is concerned with facilitating communication between care providers and patients and their

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
University of Sheffield, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=421 http://www.stakes.fi/tidecong/512magnu.htm Start date: January 1997 End date: October 2000 (not clear if program is still active)	was to support frail older people and their families to maintain or enhance their quality of life via the use of user-friendly information and communication technology in the comfort of their own homes The ACTION on-line information database and tele care support service consisted of six components: multimedia caring programmes, videophone, Internet services, call centres, senior service centres and education modules.	carers	families. Care planning between hospital and primary health care services has been preliminary tested via use of the videophone with positive results The main purpose of the project is the empowerment of family carers Both family and professional carers are involved at all stages of the development and decision making process to insure that the project is user driven and user friendly. The project is attempting to explore in a cross-cultural manner, the invisible nature and associated problems of family care giving For more details see: **Chambers & Conner 2002** **Hanson & Clarke 2000** **Magnusson & Hanson 2003**
Assistive technologies to support dementia sufferers in the community (Support dementia sufferers) Gwent Healthcare NHS Trust, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=1312 Start date: March 2003 End date: January 2005	The use of technology based on telecare with appropriate domiciliary care packages may provide the means to manage some of the risks associated with the increasing number of dementia sufferers, who wish to live independently in their own homes. All elements of care need to be considered in order to promote independence and dignity in one's own home. Despite the considerable potential offered by technology there has so far been very limited exploitation of the	*Care:* Chronic *Service:* Assessment and monitoring *People:* Dementia patients, caregivers	The project will focus on six clients and their carers living independently in the Blaenau Gwent Community Clients and carers will be fully involved in the assessment process using the MMSE, CADI and CASI rating scales. This will determine how they perceive their quality of life at the start of the project, 6 months and 12 months into the project

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
	opportunities that they present		
BT/Anchor Telecare Project Anchor Trust, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=161 http://www.housingcorplibrary.org.uk/housingcorp.nsf/AllDocuments/F67D787EFB1B0F9280256AB9003E22FE/$FILE/Telecare.pdf Start date: September 1997 End date: January 1999	Homes were monitored through a variety of passive sensors linked to dispersed alarm unit Analyses were performed centrally and messages automatically sent to carers The project sought to investigate the feasibility of using new technology to monitor the lifestyle of older people, what their views towards this technology would be, and, if technology could effectively provide support, what implications this would have for housing, care and support providers The project did not set out to create a finished, polished product, but rather to learn the issues which must be addressed if successful products are to be bought to market which have a positive benefit in supporting older people's desire to remain as independent as possible	*Care:* Chronic *Service:* Monitoring *People:* Older people, carers, home support/domiciliary care patients	The Lifestyle Monitoring Telecare System was the result of a two-year project funded by a Housing Corporation Innovation and Good Practice grant and British Telecom (BT) and trialled by BT with Anchor Trust. The project took a practical and incremental approach to the development of the technology trialed, as a system had to be developed that met the requirements of providers and users and had the technical feasibility to be delivered in a cost-effective manner A number of key issues emerged from the trial including that providers must ensure that the system is easily understood by users and carers alike,
Child Sleep Monitoring at Home Great Ormond Street Hospital for Children, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=1222 Start date: January 2002 End date: February 2002	The project aimed to transfer sleep monitoring of selected patients from hospital to home and to reduce monitoring failures	*Care:* Chronic *Service:* Monitoring *People:* Children	The home monitoring program aimed to provide diagnostic data in a more normal environment which is convenient to the patients and their families
Development of devices for use	The new devices attempt to	*Care:* Chronic	A new phase of research examines

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
in a smart house for people with dementia (Gloucester Smart House) Bath Institute of Medical Engineering Ltd, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=1327 http://www.bath.ac.uk/bime/projects.htm http://www.healthcare.pervasive.dk/ubicomp2004/papers/final_papers/adlam.pdf Start date: May 2001 End date: April 2004	emulate the way a carer would respond to the person they are caring for. A smart house uses sensors to monitor the behaviour of its occupants and their interaction with appliances. The house responds by controlling supporting devices, and by providing reminders The outcome of the project will be a fully equipped demonstrator smart home to enable care professionals to see the potential of the technology for themselves, together with an understanding of installation costs, and the establishment of links with potential manufacturers of the successful designs	*Service:* Monitoring, support *People:* People with dementia, carers	'intent to wander' amongst people with dementia. The most suitable technology for a prompting or dissuading devices is an infrared or ultrasonic sensor. In the Smart House, a bedside light comes on when a person with dementia rises from their bed during the night. A text message is sent to the carer and a prompt will be given to the individual to remind them to return to bed Implementation of smart homes for dementia patients is underway
Falkirk Mobile Emergency Care Service Epilepsy Monitoring Project (Falkirk MECS Epilepsy Monitoring) Falkirk Council, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=1253 http://www.icesdoh.org/downloads/ICT-Older-People-July-2003.pdf Start date: January 2001 End date: Ongoing	Provision of body-worn tilt detectors and in-bed seizure monitors registering alerts through the community alarm service to indicate potential seizures and prior agreement with the service users about seizure management assistance and childcare arrangements where necessary Monitoring of people with epilepsy in their own homes to provide an early response to help manage seizures linked to Mobile Emergency Care Service (MECS)	*Care:* Chronic *Service:* Monitoring *People:* People with epilepsy	Service users express feelings of security which they did not hitherto have
Foetal Monitoring John Radcliffe Hospital, UK	Automated transmission of physiological data collected	*Care:* Acute *Service:* Monitoring	Empowers (educates) patients and local care givers

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
http://www.teis.nhs.uk/jsp/search/activity.jsp?project=81 http://www.medicine.ox.ac.uk/ndog/tmr/ Start date: Unknown End date: Ongoing	remotely at home, and transferred back centrally for analysis	*People:* Pregnant teenagers	
Going Home, Staying Home Foyle Health and Social Services Trust, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=1258 http://www.tunstall.co.uk/splash/downloads/6_2_31going_home_staying_home_project_Fold_HA.pdf Start date: December 2001 End date: Ongoing	The project is a partnership between Fold Housing, Foyle Health and Social Services Trust (FHSST) and Northern Ireland Housing Executive (NIHE) The purpose of the project is to offer support to older people in the Foyle Trust area by supplying a range of assistive technology, monitoring an support services	*Care:* Chronic *Service:* Monitoring, support *People:* Clients over the age of 65	Patients and their families are totally reassured that the service is enabling them to lead as normal and healthy a life as possible
Home Comforts Project The Disability Resource Centre, South Ayrshire Council, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=1259 http://www.south-ayrshire.gov.uk/news/2003/home_comforts.htm http://www.south-ayrshire.gov.uk/committees/publications/2004/sj290404/5.pdf Start date: August 2001 End date: June 2002	Technology was used to complement other forms of support - the main areas of application are in safety, security, environmental control, daily living and communication. The range of technologies used was quite large but all were "plug and play". The technology was person-centred rather than providing a "Smart House" The Pilot Project aimed to maintain or regain independent living at home, mainly for elderly clients (thus delaying or preventing admission to residential care). In addition it aimed to prevent delayed discharge from hospital	*Care:* Chronic *Service:* Support *People:* Original client group was to be over 60's living in Ayr. Referrals broadened this out somewhat, to include people of all ages living in different areas of South Ayrshire	The evaluation demonstrated how positive an impact technology can have on both service users and carers quality of life The project evaluation showed that through the use of technology and support the following were achieved: increased independence, increased security cost savings, positive health outcomes and positive social care outcomes

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
	Modern technology equipment supplied to Home Comfort service users include fall detectors, door entry systems, smoke detectors, front door openers, big button phones, bed monitors and voice annunciators		
Intensive Homecare and Sydenham Court (Intensive Homecare - Sydenham Court) South and East Belfast Health and Social Services Trust, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=1272 http://www.sebt.n-i.nhs.uk/index3.html Start date: January 2002 End date: Indefinitely	Sydenham Court is purpose built accommodation (24 self-contained flats) for adults with cognitive impairment The project's platform is based on the Attract project which demonstrated "proof of concept" for using video conferencing technology in a rehabilitative setting from the service provider to the clients home SEBT is aiming to enable a person to maintain their independence for longer utilizing discrete technology Clients care is delivered at agreed times throughout the day	*Care:* Chronic *Service:* Provision of care *People:* Adults with cognitive impairment, individuals who are on the verge of institutional care	Intensive Homecare offers real choice and is presently providing care to around 125 individuals who would otherwise be in a nursing home or continuing care in hospital
Introducing Assistive Technology Into Older People's Homes: Feasibility, Acceptability, Costs And Outcomes Age Concern Institute of Gerontology King's College London, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=1268 http://www.fastuk.org/project_details.php?Ref=183	Concerned with the introduction and use of a wide range of AT in existing (older) housing occupied by older people, as opposed to new building initiatives	*Care:* Chronic *Service:* Assistive *People:* People over the age of 70	Assistive technology assists other family members in their own right Findings from the research support the view that given careful selection of adaptations and AT to match the needs of a user and their preferences, these can not only enhance quality of life but can do this in a cost effective way Details of the research are still being published

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
http://www.fp.rdg.ac.uk/equal/AT/REKISummaryv1.3comp.pdf Start date: October 2000 End date: July 2003			
Millennium Homes: A Technology Supported Domestic Environment For Frail And Elderly People Brunel University, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=1265 Start date: August 2000 End date: January 2003	The "Millennium Home" used a variety of environmental sensors, connected to a small computer, to monitor the state and activity of the "tenant" Typically they detect occupancy of the bed and other furniture, use of the lavatory, state of locks and doors, gas and water taps, movement in the rooms, and door and bed temperature If the software detects a potentially dangerous situation, the system will first attempt to remove the danger by speaking to the tenant. If this negotiation fails, it will call a volunteer supporter by telephone	*Care:* Chronic *Service:* Monitoring *People:* frail and elderly people	Not specified within retrieved material
Northampton Safe at Home Project Northamptonshire County Council, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=1270 http://www.tunstall.co.uk/splash/downloads/6_2_14Safe%20at%20Home%20Dementia%20Project%20-%20Northampton.pdf Start date: April 2000 End date: unknown	This project put into practice some of the lessons learnt from the ASTRID project The general objective of the project is to explore whether the use of assistive technology can help a small group of people with dementia to continue to live in their own homes - avoiding or delaying admission into institutional care The Safe at Home Project was established to look closely at the potential for new or Smart technology in helping to meet the	*Care:* Chronic *Service:* Smart Technology, monitoring *People:* Dementia patients, carers	Most unpaid or informal carers thought that technology had helped to address behaviour by the person they cared for that worried them. They also felt that it had helped them by reducing their own feelings of anxiety about the person they cared for Evidence from the Safe at Home evaluation has indicated that the ability to show what recommended technologies can do to relatives and unpaid carers is particularly helpful in de-mystifying technology A demonstration house in Northampton has been established to allow potential

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
	needs of people with dementia in their own homes in conjunction with other homecare services		users, carers and local professionals to visit and test the appropriate technologies before agreeing to them being installed in their own homes
Opening Doors for Older People Initiative West Lothian Council, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=1255 http://www.dass.stir.ac.uk/curr-proj/documents/PilotEvaluationofOpeningDoorsforOlderPeopleinwiredWestLothianMay02.pdf Start date: January 1999 End date: March 2003	West Lothian Council put technology packages into older people's homes to support them in the community, whilst closing residential homes formerly owned and managed by the Council To provide an innovative form of housing for older people with support needs that will sustain independent living through effective physical design, focused individual care planning and the efficient use of new technologies	*Care:* Chronic *Service:* Home security and support *People:* Frail older people	Interviews with 3 carers before and after technology installation The sample of family carers was small, and conclusions are tentative at this stage. All were involved in arduous forms of care, and all expressed difficulties with their work, including health problems of their own Carers emphasised the importance of people staying in their own homes, and felt that technology would help with the safety and security aspects of this. When the technology was installed, they felt reassured that their relative was indeed safer, but explained that the stresses of caring continued Plan to develop on-line learning materials for staff, users, and carers
People at Home and in Touch Durham County Council, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=1256 http://www.durham.gov.uk/durhamcc/usp.nsf/web/pages/CFD637B5BB85FFE580256CD7003F2317?opendocument Start date: August 1998 End date: March 2004	The aim of the People at Home and in Touch project was to: Conduct research into and investigate the feasibility of Information and Communication Technologies (I.C.T.s) or other assistive technologies that may help older people remain in their own homes, live more independently and improve their quality of life	*Care:* Chronic *Service:* Support *People:* Frail and elderly people	Study objectives included to use Information and Communication Technology to improve communication between vulnerable people in the community and their carers
Remote Home Monitoring of Patients (@HOME) King's College London, UK	The objective of the project is to equip clinics with state of the art infrastructure, which will allow for	*Care:* Chronic *Service:* Monitoring, surveillance	@HOME aims to provide information services regarding the recovery of the patients to the patients themselves and

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
http://www.teis.nhs.uk/jsp/search/activity.jsp?project=1273 http://a7www.igd.fhg.de/projects/home/home.html Start date: January 2001 End date: Ongoing	continuity in patient treatment at home and, often, a faster dispatch of patients By the end of the project, the @HOME platform aims to enable hospitals to perform remote regular and reliable health monitoring of patients residing and recovering at their homes and will promptly advise the clinic staff in case of an emergency Finally, the system will be validated via clinical trials on two pilot projects	*People:* To evaluate the smart dispenser, the team is tested it on people recovering from surgery and people suffering from chronic mental illnesses	their carers/ relatives The system will automatically trigger the alarm if the readings of the patient show an abnormality. Finally, the information loop will close with feedback to the patient and the (non)specialised carers at home (family, nurses etc). Such services do not currently exist. @HOME is one of the pioneering attempts by breaking technological ground and validating the product by conducting clinical trials
SMART Rehabilitation: technological applications for use in the home (SMART) Sheffield Hallam University, UK http://www.teis.nhs.uk/jsp/search/activity.jsp?project=1319 http://hsc.shu.ac.uk/smart/ http://www.fastuk.org/project_details.php?Ref=664 Start date: November 2003 End date: November 2006	Research will focus upon the development of "SMART" monitoring systems for hospital or home based rehabilitation. The technology or device must: (1) Provide quantifiable functional benefits for the person with stroke. (2) Improve the efficiency of the therapist or carer's ability to assist The research aims to investigate the efficacy of home-based therapy through the use of advanced sensor technology The system will employ monitoring systems that will provide both therapeutic instruction and support information	*Care:* Acute and chronic *Service:* Monitoring, therapeutic instruction, support *People:* Older people with stroke and their carers	Improve the efficiency of the therapist or carer's ability to assist
Broomwell HealthWatch TeleMedical Monitoring Services Manchester, UK	Subscribers to the HEALTHWATCH Tele-Medical Service are constantly monitored for a wide number of life-	*Care:* Chronic *Service:* Monitoring, *People:* Cardiac	Not specified within retrieved material

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
http://www.broomwellhealthwatch.com/desktopdefault.aspx?tabId=4 Start date: Unknown End date: Ongoing	threatening conditions from the comfort of their own home or office Symptoms can be immediately analysed by a 24-hour call centre Subscribers can be expertly advised, immediately, by a qualified nurse or doctor, at any time, day or night, and the appropriate action can be recommended without delay	patients	
Australia			
CSIRO Hospital Without Walls / A Home Telecare System Incorporating Vital Signs Monitoring Australia http://www.csiro.au/index.asp?type=achievement&id=Services_Telehealth&stylesheet=sectorRecentAchievement http://internet.csiro.au/Iapps/HOW1.htm http://www.centie.net/docs/Telemedicine_in_CSIRO.pdf http://www.atmeda.org/news/2000_presentations/Homecare/Wilson.pps Start date: 2001 End date: Ongoing	CSIRO's Hospital Without Walls initiative aims to develop a range of technologies to allow elderly and chronically ill patients to be cared for more effectively in their own homes The "Hospital Without Walls" project has developed wearable wireless devices which monitor the movements and some cardiac functions for patients as they move about their homes Other applications in chronic disease, telerehabilitation and aged care are being considered.	*Care:* Chronic *Service:* Monitoring, alerts, measurement *People:* Elderly and chronically ill patients	Data are recorded in a home computer which maintains contact via telephone lines an the Internet with a server computer, which in turn provides clinicians, nurses and other caregivers with regular information about the vital signs of the patient at home via a distributed information system
CSIRO – The Hospital Without Walls – Gait and Activity Analysis with a Wireless Home Telecare System	System which assisted the elderly or the sick to live a normal, independent lifestyle while their indicators of well-being were	*Care:* Chronic *Service:* Monitoring *People:* Elderly	System was well tolerated The system needs further refinement and testing to improve its reliability

Project/Program	*Project/Program Description*[1]	*Specifics*	*Relevance to Informal Caregivers*
Sydney, Australia http://www.americantelemed.org/news/2002_presentations/wilson.gait.ppt Start date: Unknown End date: Unknown	continuously monitored		
Renal Telemedicine to the Home – The Queen Elizabeth Hospital (TQEH) Adelaide, South Australia http://www.jma.com.au/renal_home.htm http://puck.ingentaselect.com/vl=2116473/cl=32/nw=1/fm=docpdf/rpsv/cw/rsm/1357633x/v6n1/s12/p59 Start date: 1998 End date: Unknown	At The Queen Elizabeth Hospital (TQEH) in Adelaide, South Australia, suitable patients were trained in the Home Dialysis Unit before commencing dialysis at home Case study conducted by John Mitchell & Associates	*Care:* Chronic *Service:* Monitoring *People:* Renal dialysis patients, carers, care providers	Within the case study the patient and his carer identified a range of benefits of the telemedicine link Most important, it saved a trip to Adelaide on one occasion when the patient experienced chest pains and severe cramp while on dialysis Other benefits included a sense of increased support; an ability to solve problems more easily and quickly; and a sense that help was more easily at hand than simply using a telephone The patient and his carer felt that the videoconferencing link to the hospital provided them with significant and improved service The equipment could be used by staff to observe patients and their carers carrying out procedures such as haemodialysis and measuring blood pressure
Centre for Online Health (COH) - Paediatric Palliative Care / Telepaediatric Videophone Project University of Queensland, Brisbane, Australia http://www.uq.edu.au/coh/index.html?page=18401&pid=18388 http://www.uq.edu.au/sft/?page=1	Designed, built and tested a portable, Internet-based videophone that uses the home telephone line for IP videoconferencing Services will be provided directly to the home by the specialist palliative care team at the RCH using the videophone	*Care:* Palliative *Service:* Clinical, psychosocial, educational, monitoring *People:* Paediatric patients	The videophone will provide web-based videoconferencing access to specialist at the Royal Children's from the families home minimising the need for travel, linking local health professionals visiting the home to provide care with specialists, and providing links to information and education resources via the web

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
3415&pid= Start date: Unknown End date: Ongoing	Support health care delivery to patients and families in rural and remote areas of Queensland		
Centre for Online Health (COH) - Telemedicine-Enabled Homecare University of Queensland, Brisbane, Australia http://www.atmeda.org/news/2000_presentations/Homecare/Yellowless.ppt Start date: Unknown End date: Unknown	Ethnographic and social exam of home and present health delivery systems, IP/TCP browser based information environments, personalised GUI's and interfaces for elderly/disabled, telemetry and monitoring devices, mobility, voice recognition, emergency access	*Care:* Chronic *Service:* Monitoring, prescribing and supply of health products *People:* Elderly and disabled	Not specified within retrieved material
Demonstration home telecare system Australia http://www.mja.com.au/public/issues/179_05_010903/cel10001_fm.html Start date: Unknown End date: Unknown	Locally developed Home Telecare System which integrates a range of e-health services and advanced ICT applications 30 to manage chronic disease at home Key design specifications included low relative cost, modularity (pick and choose), simplicity of use, clinically relevant vital-signs monitoring, highly automated scheduling, provision of patient feedback, access to information services and very limited use of wearable devices to promote user compliance A clinical trial was carried out over at least 3 months in metropolitan Sydney and in Wagga Wagga (a regional centre) with 22 patients aged 58–82 years. Some patients were monitored	*Care:* Chronic, acute *Service:* Monitoring, education, compliance, *People:* All patients had a primary diagnosis of chronic heart failure and/or chronic obstructive pulmonary disease	Not specified within retrieved material

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
	continuously for more than 8 months		
Europe			
Nestor Healthwatch – Chronic Disease Management Hatfield, Hertfordshire http://www.ehtel.org/SHWebClass.ASP?WCI=ShowDoc&DocID=5000 http://www.ehtel.org/SHWebClass.ASP?WCI=ShowDoc&DocID=5002 Start date: Unknown End date: Ongoing	Nestor Healthwatch is an e-Health provider that remotely monitors vital signs such as blood pressure, pulse, weight, oxygen saturation, and peak flow, as well as 12 lead ECGs and rhythm strips via a mobile or land based telephone Healthwatch nurses deal with clients in distress, respond to alarms and emergency calls and offer advice and reassurance to individuals instantly Healthwatch provides COPD and CHF management programmes for subscribers in the community Each programme provides daily monitoring of vital sign data and weekly proactive monitoring of subscribers' disease/social state All programmes are tailored to fit the subscriber's individual needs	*Care:* Chronic *Service:* Monitoring *People:* COPD and CHF patients	Online medical website provides subscribers, nurses, and physicians with real-time access to medical information and vital sign data from any location via the World Wide Web. Individual passwords and read-only Internet sites assure the security of the subscriber's medical information
Telematic Management of Insulin Dependent Diabetes Mellitus **http://aim.unipv.it/projects/tiddm/** Start date: January 1996 End date: December 1998	The T-IDDM project was concerned with the design, implementation and testing of an intelligent telemedicine service to assist Insulin Dependent Diabetes Mellitus (IDDM) patients, providing the physician with a decision support tool for improving management of patients according to the best	*Care:* Chronic *Service* Monitoring, consultation*:* *People:* Diabetes patients	Not specified within retrieved material

Project/Program	***Project/Program Description*[1]**	***Specifics***	***Relevance to Informal Caregivers***
	current medical practice		
Social Alarms for Europe in the 21st Century (SAFE 21) European Union http://pricepartnership.com/safe21/factshee.htm http://www.hc-sc.gc.ca/ohih-bsi/pubs/1998_interc/interc_e.pdf Start date: December 1996 End date: November 1999	Safe 21 is a pan European research and development project which will take social alarms into the 21st century. It is run by a consortium of 8 organisations, with financial support from the European Commission The project was aimed at integration of care and security for elderly European people at home The project aimed to build on existing social alarms systems which provide an emergency response to a call initiated by a user	*Care:* Chronic *Service:* Integration of care and security *People:* Elderly patients	It was expected that the broader and more effective capability of social alarm systems will release many family carers to participate socially and economically in the community Automatic telephone call to a control centre which provides staff with the caller's details, including relatives or friends to contact
Medical Diagnosis, Communications and Analysis Throughout Europe – MEDICATE (Part of the Trans European Telecommunications Network Initiative (TEN-TELECOM) London and Barcelona http://www.ehto.org/ht_projects/tentelprojects.html http://www.ehr.chime.ucl.ac.uk/docs/UCL-ComponentReport-M-v2%201.pdf Start date: January 1999 End date: December 2000	MEDICATE is an innovative telemedicine project for monitoring asthma patients in their own homes Asthma sufferers used a portable monitoring device to record their breathing patterns and send the data via a modem and their normal telephone line to a central Disease Management System The data is processed and results sent to the patient's consultant using a secure Internet connection	*Care:* Chronic *Service:* Monitoring *People:* Asthma patients	Not specified within retrieved material
Telecommunications-based Home Care Services for European Citizens (TEN-	The overall objective of the project was to launch services supporting continuity of	*Care:* Not specified *Service:* Not specified *People:* Not specified	Not specified within retrieved material

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
CARE) (Part of the Trans European Telecommunications Network Initiative (TEN-TELECOM) http://www.ehto.org/ht_projects/tentelprojects.html http://europa.eu.int/information_society/activities/eten/cf/project/index.cfm?mode=detail&id=TEN_CARE Start date: January 1999 End date: June 2000	healthcare and home telecare		
TeSAN: Homecare Telemedicine Network in the Veneto Region Italy http://tie.telemed.org/europe/citations2.asp?citation=4523&key=0519583115&page=1&pagecount=6 Start date: 2002 End date: Ongoing	A telemedicine/ telemonitoring service has recently been added for newly discharged hospital patients Vital signs are taken at home by the patient or caregiver and transmitted transtelephonically to the call-center operator who inputs the data into a computer and transmits to the physician	*Care:* Chronic *Service:* Monitoring, clinical telemetry *People:* Newly discharged hospital patients	Not specified within retrieved material
MobilAlarm – Validating European Mobil Alarm Services for Inclusion and Independent Living European Union http://www.empirica.biz/empirica/themen/telecare/projekte_en.htm http://www.mobilalarm-eu.org/ Start date: 2004 End date: 2005	The MobilAlarm project will test an innovative, location-independent alarm and teleassistance service which enables older people, chronically ill, and other persons at risk to initiate an alarm call whenever and wherever he/she needs or wants to do so The project will analyse the European market for such services in general, and in particular it will develop and test business models in three distinct	*Care:* Chronic *Service:* Alarm service *People:* Older people, chronically ill and other persons at risk, disabled people	Not specified within retrieved material

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
	markets		
Hospital Managed Care of Children in Their Homes (SABH) Stockholm, Sweden http://strategis.ic.gc.ca/epic/internet/inict-tic.nsf/en/it07546e.html http://ceres.ingentaselect.com/vl=7097792/cl=57/nw=1/fm=docpdf/rpsv/cw/rsm/1357633x/v7n5x1/s13/p32 Start date: 1998 End date: 1999	A hospital-managed project for the advanced care of children in their homes was established in Sweden The aim was to provide an alternative to inpatient paediatric care by providing hospital-at-home care to stable infants and children using mobile units based on advanced information and communication technology The Karolinska Hospital children's ward and emergency room referred children to SABH care	*Care:* Chronic, acute *Service:* Advanced care *People:* newborn infants with congenital malformations, premature infants in need of oxygen therapy and tube feeding, children with severe burns injuries, patients in advanced post-surgical care, multi-handicapped children with acute complications, children who were failing to thrive, oncological patients and those requiring terminal care	A medical care plan was drawn up by the physician and nurses responsible for the patient in the hospital, together with the parents and the patient Lower personnel costs were due to the fact that, within SABH, parents take over a great deal of the care of their children from staff The framework of the project created new working relations and a new allocation of responsibility has emerged between parents and their children in their home and the clinical personnel
"HausTeleDienst" - A CATV-based interactive video service for elderly people http://www.empirica.biz/empirica/themen/telemedizin/documents/HTDPaper.pdf Start date: 1991 End date: Ongoing	The overall aim has been to prove the ability of frail elderly and mobility-impaired persons to live independently, and to demonstrate strategies for reducing load on social and health care service resources	*Care:* Chronic *Service:* Remote care, information and assistance, emergency, counselling, training and exercise *People:* Elderly	The system enables service staff to provide support for non-professional care-givers who have to carry out tasks such as bathing, or changing clothes Correct care techniques are often unknown by family caregivers with no training. Remote advice can enable them to fulfil even more difficult tasks Personalised help could be offered, creating a feeling of security and integration
Telesupport for Peritoneal Dialysis Patients at Home: Pilot Study Germany http://www.atmeda.org/news/200	Aim of the project was to explore the possibility of improving home care for dialysis patients (initially only for CAPD patients) by adding video-based support	*Care:* Chronic *Service:* Compliance, support, monitoring *People:* Peritoneal dialysis patients	Not specified within retrieved material

Project/Program	*Project/Program Description*[1]	*Specifics*	*Relevance to Informal Caregivers*
0_presentations/Homecare/Stroetmann.ppt Start date: Unknown End date: Unknown			
Application in Telemedicine Taking Rapid Advantage of Cable Television Network Evolution – ATTRACT Five locations in Europe http://www.ehto.org/ht_projects/initial_project_description/attract.html http://www.schin.ncl.ac.uk/rcgp/scopeEPR/refh/ref3ma13.htm Start date: 1998 End date: 2000	A multimedia interactive network, integrating broadband health telematics applications, to facilitate to health professionals and patients at home an optimal environment for cost-effective care services, using existing and emerging cable television infrastructures	*Care:* Not specified *Service:* Not specified *People:* Not specified	Not specified within retrieved material For more details see: **Guillén et al. 2002**
Home Telecare Management System – (EPIC) Europe http://www.ehto.org/aim/volume2/epic.html http://healthinfo.montana.edu/ruralhealth/whitepaper/home_telecare.html Start date: 1995 End date: 1998	The chief aim of the EPIC project was to improve the quality of community care provided to vulnerable people through the development of an information system for integrated care, which supports the sharing of information between health and social care professionals These home based telecare services brought the appropriate technology and services to anyone who needed assistance related to healthcare and/or social problems at home	*Care:* Chronic *Service:* Training, information, advice, monitoring *People:* Elderly and disable patients	Not specified within retrieved material
TopCare Germany http://www.topcare.info/homenav.html Start date: Unknown	Innovative telematic communication technologies and modern vital sign monitoring is applied in TOPCARE in order to enhance post-clinical treatment	*Care:* Acute, chronic *Service:* Monitoring *People:* Post clinical treatment patients	Not specified within retrieved material

Project/Program	***Project/Program Description***[1]	***Specifics***	***Relevance to Informal Caregivers***
End date: Ongoing	in an out-patient setting, foster the communication between patient at home, practitioners and clinics, and to provide electronic assistance in documentation management for improved quality assurance The overall objective of TOPCARE is to develop technical devices and telecommunication structures and to lay the organisational groundwork		
Home Rehabilitation Treatment – Dialysis (HOMER D) Athens, Greece http://www.ehto.org/ht_projects/initial_project_description/homer_d.html http://www.ehto.org/ht_projects/html/dynamic/62.html Start date: January 1996 End date: 1999/2000	Novel telematics services for isolated patients undergoing home treatment for kidney failure. The ultimate goal of HOMER-D project was to develop telematics monitoring services (TMS) for supporting patients who need home haemodialysis (HHD) or satellite haemodialysis (SHD)	*Care:* Chronic *Service:* Rehabilitation, monitoring *People:* Patients with kidney failure, health care professionals	Not specified within retrieved material