How Can Telehomecare Support Informal Care?

Examining What is Known and Exploring the Potential

Final Report
submitted to:
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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.

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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).

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.

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 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 technology 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.

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]
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).

Table 3. Selected Characteristics of Canadian Informal Caregivers

Characteristic	Canadian Home Care Human Resources Study	2001 Census unpaid work	National Profile of <u>Family</u> 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 <u>Family</u> 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.

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.*
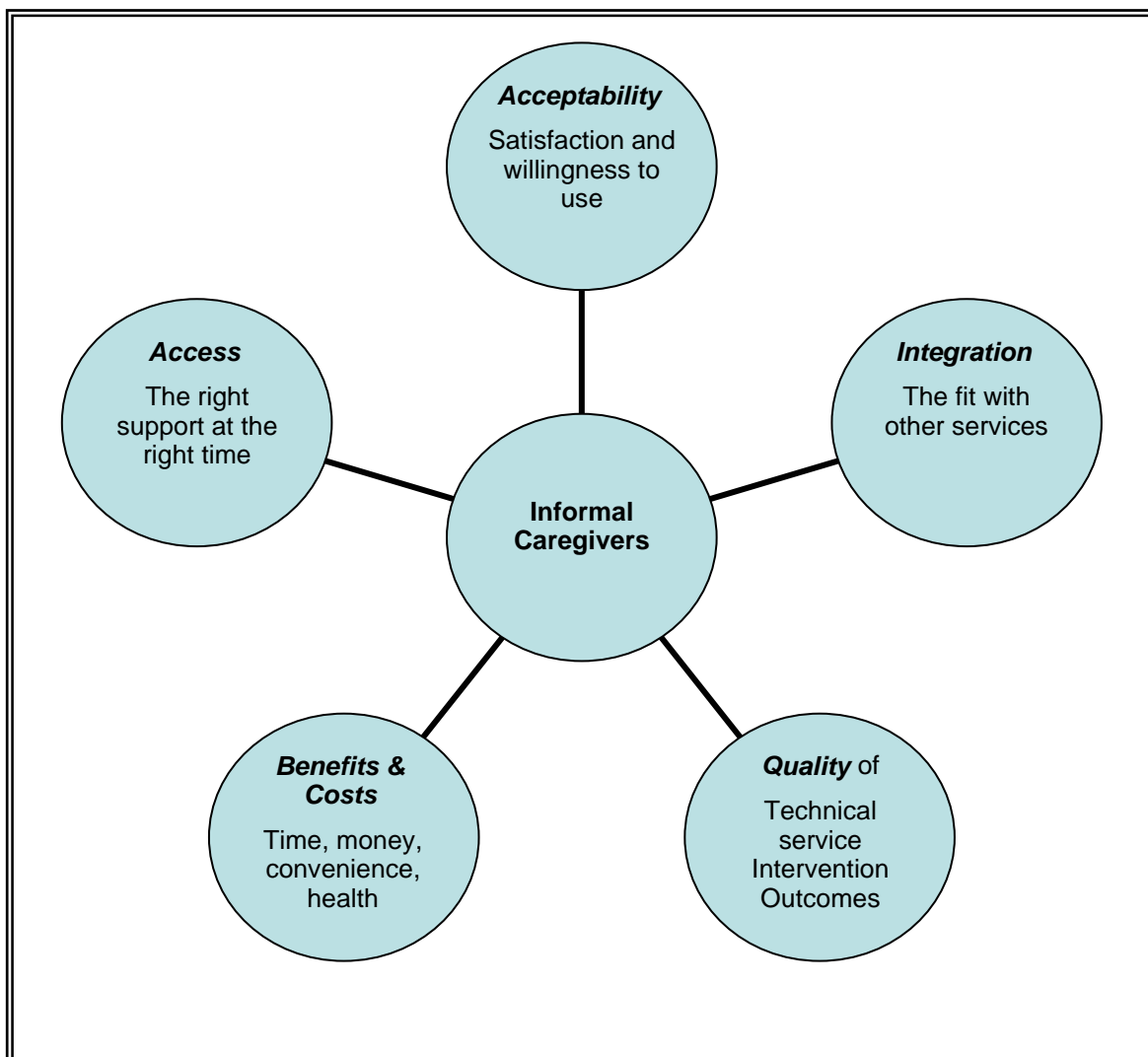

Figure 1. Evaluation themes centered around the impact on informal caregivers

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. 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 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 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.

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.

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[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.

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

[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.

[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

[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.

[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.

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

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

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

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

[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.