Electronic Social Support Groups to Improve Health

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To determine the effectiveness of interventions included in the Mandatory Health Programs and Services Guidelines (MHPSG), the following systematic reviews were completed and funded by the Public Health Research, Education and Development (PHRED) Program of the Public Health Branch, Ontario Ministry of Health.

1998 – 1999
- Health Hazard Investigation
  - Emergency Response to Acute Environmental Hazards
  - Strategies to Enhance Public Awareness of Environmental Risks

- Chronic Diseases and Injuries
  - Chronic Disease Prevention
    - Community interventions to Enhance Fruit and Vegetable Consumption
    - Use of Coalitions in Heart Health, Tobacco Use Reduction and Injury Prevention
    - Community-Based Heart Health Programs
    - School-Based Adolescent Risk Behaviour Prevention Programs

- Family Health
  - Sexual Health
    - Adolescent Pregnancy Prevention Strategies
  - Child Health
    - Professionally Led Parenting Groups
    - Peer/Paraprofessional 1:1 Interventions in Improving Maternal/Child Health
    - Public Health Nurse Home Visiting
    - Curriculum Suicide Prevention Programs for Adolescents

- Infectious Diseases
  - Day Care Centre Infection Control Interventions
  - Adolescent STD Prevention Strategies

1999 – 2000
- Health Hazard Investigation
  - Chronic Disease Prevention
    - Postpartum Smoking Relapse Prevention Strategies
    - Cervical Cancer Screening Interventions

- Injury Prevention
  - Anticipatory Care Interventions with Community Dwelling Elderly

- Chronic Diseases and Injuries
  - Chronic Disease Prevention
    - Healthy Feeding in Infants Under One Year of Age
    - Injury Prevention in Children & Adolescents

- Family Health
  - Sexual Health
    - Youth to Youth Peer Health Promotion
  - Child Health
    - Healthy Feeding in Infants

- Infectious Diseases
  - Needle Exchange Programs
  - Online Computer Support Groups for Adults
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The Public Health Branch of the Ontario Ministry of Health released new Mandatory Health Programs and Services Guidelines (MHPSG) in December 1997. Although the MHPSG provide guidelines for a wide range of public health practices in Ontario, the strength of evidence for many of the guidelines has not been summarized in a systematic way.

In 1998-1999, the Public Health Branch provided funding for the Effective Public Health Practice Project (EPHPP). The mandate of the project was to complete 15 summaries based upon systematic reviews of the effectiveness of specific requirements of the MHPSG. In 1999-2000 the EPHPP is completing eight more summaries. Each review is linked to one of the three general standards or three program standards. The reviews summarize the best available research evidence for public health practice in these areas. Research evidence is one piece of information needed to inform decision making in public health. Other factors, such as the local environment, local priorities, and available resources are also important.

The reviews were completed by review groups composed of members of the Ontario Public Health Research, Education and Development (PHRED) Program Health Units as well as representatives from other Health Units around the province. The PHRED Provincial Steering Committee has overseen the project.

Potential review topics were initially identified through a survey of public health practitioners and managers across Ontario. Each review group followed a systematic approach that included comprehensive search strategies and quality assessment of each primary research study selected for inclusion in the review.

One of the primary objectives in completing this work was to ensure that it is relevant to public health practitioners in the field. We contacted all Medical Officers of Health and asked for volunteer experts. The response was tremendous and more than 100 practitioners and managers from over 90% of health units across Ontario agreed to take on the role of peer reviewers for the draft reports.

This project already has had many benefits. Public Health professionals have developed skills in completing systematic reviews and have increased awareness of the importance and feasibility of evidence-based practice. Through this project, we have established new links with the Cochrane Collaboration. We hope that several reviews will be registered with the various Cochrane Review Groups, making them accessible to the international public health community. Finally, the process of completing this project has contributed to the development of a strong province-wide network of public health professionals.
Effective Public Health Practice Project

Summary Statement for Practitioners/Managers

Electronic Social Support Groups to Improve Health

Public Health Mandate

The provision of public health programs addressing social support, peer education, and peer support are mandated under the Family Health and Chronic Diseases and Injuries programs. Public health units in Ontario are “to foster the creation of a supportive environment for health” (Ontario Ministry of Health, 1997). The provision of public health programs addressing social support, peer education, and peer support are mandated under the Family Health and Chronic Diseases and Injuries programs. A further objective under the Equal Access goal, is to “reduce educational, social, and environmental barriers to accessing mandatory public health programs”. Barriers to access, such as literacy level, language, geography, social factors, education, economic circumstance, and physical ability are to be addressed. The provincial mandate also defines the Internet as one strategy to be used for “the provision of information and opportunities for skill development to facilitate the adoption of health-related behaviours for the prevention of chronic diseases”. It is also to be used as a mechanism for community-wide education campaigns for health promotion programs. (OMOH, 1997).

Background

The World Health Organization describes “social networks” as social relations and links between individuals that are vital to the provision of “access to or mobilization of social support for health” (WHO, 1998). Devins and Binik (1996) found that social support is a major intervention to facilitate coping with chronic physical illness. Social support is also believed to positively influence health outcomes, health behaviours and the use of health services.
(Stewart, 2000). Technology has been used in a number of different venues to provide health information in combination with social support. It can address some access barriers, while raising others. Mizsur (1997) located approximately 700 electronic support groups available on the Internet, covering a broad range of health issues. On-line support involves the development of companionship, group membership, and a sense of belonging despite the lack of “knowing” the persons involved.

**Issue**

The World Health Organization (WHO) has clearly identified the importance of social support as a determinant of health and a necessary component of social capital (WHO, 1998). In the 1990s, the provision of social support through virtual/electronic support groups via computer-mediated communication has become a new reality. The Internet has been used to provide emotional, informational, and functional support for a variety of populations to improve health.

**Finding the Answers**

A systematic review was conducted to investigate the nature, use, and impact of electronic support groups (ESGs) on the health of individuals. A total of 39 articles were identified from the electronic search and review of the reference lists. Three were content analyses, which were included in the review but not rated; 24 were relevant and represented 16 distinct studies (as there were multiple reports for some studies). Studies were categorized according to the health issue. They included: cancer (7), caregivers of Alzheimer’s and dementia patients (1), persons living with AIDS (3), parenting (2), substance abuse (drugs and smoking) (2), stress management (1), eating disorders (1), diabetes self-management (1) and sexual abuse (1). Overall global quality ratings for the rated studies were as follows: one paper was rated strong, two were rated as moderate and 13 were weak.

**What’s the Evidence?**

The findings indicated that:

- social support was successfully provided via a computer-mediated communication medium for a broad range of populations and health conditions
- participation in multi-featured ESGs (e.g., those with additional features such as access
to health information and decision support tools) resulted in a variety of positive health outcomes

in studies that investigated multi-featured systems, communication features providing social support were the most frequently used feature, demonstrating their public appeal

no risks were found from the use of ESGs, with the rare exception of flaming (negative or destructive posting of messages), indicating the necessity for monitoring

ESGs were used seven days per week and 24 hours per day, suggesting that they can be a good source of help when traditional services are not available

there was a typical pattern of use found in closed ESGs, where there was heavy use at first, a dropping-off, and then levelling-off period at about 3 to 4 months, indicating that this form of ESG requires time to get established.

Implications for Practice and Research

Given the lack of methodologic rigour in studies found to date, there is a need for systematic planning, development and evaluation of ESGs as an innovative health intervention.

There is a need for further research investigating the nature and impact of on-line electronic social support groups in a variety of populations. School health, parenting, and breastfeeding programs are identified in the Mandatory Health Programs and Services Guidelines to include peer and social support (OMOH, 1997). These may be appropriate starting points for ESG development and research. In addition, there is a need to determine the most effective role for public health practitioners in this medium.

More Sources of Information


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Effective Public Health Practice Project

Highlights for Policy Development

Electronic Social Support Groups to Improve Health

Issue
The World Health Organization (WHO) has clearly identified the importance of social support as a determinant of health and as a necessary component of social capital (1998). In the 1990s, the provision of social support through virtual/electronic support groups via computer-mediated communication has become a new reality as the Internet is being used by a variety of populations to provide emotional, informational, and functional support to improve their health.

Background
The World Health Organization describes “social networks” as social relations and links between individuals which are vital to the provision of “access to or mobilization of social support for health” (WHO, 1998). Devins and Binik (1996) found that social support is a major intervention to facilitate coping with chronic physical illness. Social support is also believed to positively influence health outcomes, health behaviours, and the use of health services (Stewart, 2000). Technology has been used in a number of different venues to provide health information in combination with social support. It can address some access barriers while raising others. Mizsur (1997) located approximately 700 electronic support groups available on the Internet, covering a broad range of health issues. Support on-line involves the development of companionship, group membership, and a sense of belonging despite the lack of “knowing” the persons involved.

Public Health Mandate
The provision of public health programs addressing social support, peer education, and peer support are mandated under the Family Health and Chronic Diseases and Injuries programs. Public health units in Ontario are “to foster the creation of a supportive environment for health” (Ontario Ministry of Health, 1997). The provision of public health programs addressing social support, peer education, and peer support are mandated under the Family Health and Chronic Diseases and Injuries programs. A further objective, under the Equal Access goal, is to “reduce educational, social, and environmental barriers to accessing mandatory public health programs”. Barriers to access such as literacy level, language, geography, social factors, education, economic circumstance, and physical ability are to be addressed. The provincial mandate also defines the Internet as one strategy to be used for “the provision of information and opportunities for skill development to facilitate the adoption of health-related behaviours.
for the prevention of chronic diseases”. It is also to be used as a mechanism for community-wide education campaigns for health promotion programs. (OMOH, 1997).

What’s the Evidence?

A systematic review was conducted to investigate the nature, use and impact of Internet-based electronic support groups (ESGs).

The findings indicated that:

$\text{social support was successfully provided via a computer-mediated communication medium for a broad range of populations and health conditions}$$\text{participation in multi-featured ESGs (e.g., those with additional features such as access to health information and decision support tools) resulted in a variety of positive health outcomes}$$\text{in studies that investigated multi-featured systems, those providing social support were the most frequently used, demonstrating their public appeal}$$\text{no risks were found from the use of ESGs, with the rare exception of flaming (negative or destructive posting of messages) indicating the necessity for monitoring}$$\text{ESGs were used seven days per week and 24 hours per day, suggesting that they can be a good source of help when traditional services are not available}$$\text{there was a typical pattern of use found in closed ESGs, where there was heavy use at first, a dropping-off, and then a levelling-off period at about 3 to 4 months, indicating that this form of ESG requires time to get established.}$

Implications

- Given the lack of strong quality research studies to date, there is a need for systematic planning, development, and evaluation of ESGs as an innovative health intervention.

- There is a need for further research investigating the nature and impact of on-line electronic social support groups in a variety of populations. School health, parenting, and breastfeeding programs are identified in the Mandatory Health Programs and Services Guidelines to include peer and social support (OMOH, 1997). These may be appropriate starting points for ESG development and research. In addition, there is a need to determine the most effective role for public health practitioners in this medium.

References


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ABSTRACT

Objectives
This review sought to answer the question: what is the use, nature and impact of electronic support groups in the prevention and promotion of health? Public health units in Ontario are “to foster the creation of a supportive environment for health” (Ministry of Health of Ontario, 1997). The provision of public health programs addressing social support, peer education and peer support are mandated under the Family Health and Chronic Diseases and Injuries programs. The objective under the equal access goal is to “reduce educational, social and environmental barriers to accessing mandatory public health programs”. Barriers to access such as: literacy level, language, geography, social factors, education, economic circumstance, physical ability are to be addressed. The provincial mandate also defines the Internet as one strategy to be used for “the provision of information and opportunities for skill development to facilitate the adoption of health-related behaviours for the prevention of chronic diseases”. It is also to be used as a mechanism for community wide education campaigns for health promotion programs. (Ministry of Health of Ontario, 1997).

Methods
A search of published and electronic literature related to on-line support groups resulted in retrieval of 39 articles. Twenty-four relevant articles were found, three of which were content analyses. The 21 remaining articles were concerned with 16 distinct studies: one study was rated as strong, two rated as moderate and 13 rated as weak.

Results
There were no negative findings on any of the studies beyond “flaming” reported in two articles. In studies that investigated multi-featured systems (information, decision support tools, etc.), communication features providing social support were the most frequently used feature, demonstrating their public appeal. Participation in multi-featured Electronic Support Group, (ESGs) result in a variety of positive health outcomes.

There is a typical pattern of use found in ESGs where there is heavy use at first, a dropping-off and then leveling-off period at about 3- 4 months, indicating that ESGs require time to establish themselves. ESGs were used seven days per week and 24 hours per day, suggesting that they can be a good source of help when traditional services are not available.

Conclusions
The findings indicate that social support can be successfully provided via a computer mediated communication medium to support a broad range of populations and health conditions.
BACKGROUND

Introduction

The purpose of this literature review is to systematically and critically examine on-line social support networks for use by individuals to improve their health. The World Health Organization (WHO) has clearly identified the importance of social support as a determinant of health and a necessary component of social capital (WHO, 1998). The definition of social support has been long debated by researchers and practitioners (Hutchinson, 1999). In the context of this paper, WHO’s broad definition of social support is fitting. It holds that social support is “that assistance to individuals and groups within communities which can provide a buffer against adverse events and living conditions, and can provide a positive resource for enhancing the quality of life.” (WHO, 1998, p. 20). The WHO definition views social support as emotional and informational support and the provision of material resources and services.

Devins and Binik (1996) found that social support is a major intervention to facilitate coping with chronic physical illness. They note that continued social contact has been shown to “produce a significant survival advantage” among individuals affected by chronic diseases (p. 660). Social support is also believed to positively influence health outcomes, health behaviours, and the use of health services (Stewart, 2000).

The Ontario Mandatory Health Programs and Services Guidelines mandate that “boards will foster the creation of a supportive environment for health, including active participation by citizens in decisions which affect their own health” (Ministry of Health of Ontario, 1997). The provision of programs addressing social support, peer education, and peer support are mandated in the Family Health and Chronic Diseases and Injuries Program Standard. The WHO describes “social networks” as social relations and links between individuals which are vital to the provision of “access to or mobilization of social support for health”. Wellman et al. (Wellman, Salaff, Dimitrova, Garton, Gulia, & Haythornwaite, 1996) have described computer networks as social networks. Computer networks can “sustain strong, intermediate and weak ties that provide information and social support in both specialized and broadly based relationships”. The authors also describe the potential for computer-mediated communication (CMC) to support group tasks by increasing participation, for more egalitarian, creative, and “free” communication, with less centralized leadership. Support on-line involves the development of companionship, group membership, and a sense of belonging despite the lack of “knowing” the persons involved.

The provincial Mandatory Health Programs and Services Guidelines define the Internet as a strategy to be used for “the provision of information and opportunities for skill development to facilitate the adoption of health-related behaviours for the prevention of chronic diseases” (p 13). It is also to be used as a mechanism for community-wide education campaigns for many health promotion programs. (Ministry of Health of Ontario, 1997). The provincial mandate’s objective under the Equal Access goal is to “reduce educational, social and environmental barriers to accessing mandatory public health programs” (p 6). Barriers to access, such as literacy level, language, geography, social factors, education, economic circumstance, physical ability are to be addressed. Technology can address some access barriers, while raising others.
Technology has been used in a number of different venues to provide information in combination with social support for health. Gustafson, Bosworth, Chewning & Hawkins (1987) reviewed the potential uses of computer-based health promotion initiatives to enhance individual behaviour change to improve health. The stages of individual problem solving around health decisions include problem exploration, solution exploration, and implementation. Social support is one task within these stages, which are experienced as an iterative process. Thus social support can be sought at any point in the behaviour change process. Gustafson et al. (1998) describe a variety of support systems such as decision analysis programs, interactive interviewing, and project management software, and offer unique applications of computer-based health promotion to support effective problem solving. Lieberman (1997) also describes benefits of computerized interactive video games to indirectly help to garner social support for children with chronic illness. Telephone technology, through the use of voice bulletin boards and teleconferencing, has also been used to provide social support to various groups such as pregnant women who abuse drugs (Alemi, Mosavel, Stephens, Ghadiri, Krishnaswamy, & Thakkar, 1996a; Alemi & Stephens, 1996b; Alemi, Stephens, Miuse, Dyches, Mosavel, & Butts, 1996c), and for survivors of breast cancer in rural Newfoundland (Curran & Church, 1998, Curran & Church, 1999).

**Review Question and Objectives**

In the 1990s the provision of social support through a computer-mediated communication medium became a reality. Despite the claims about the potential benefits of virtual or electronic support groups to provide social support, no reviews of the literature were found to address them. This review will examine electronic support groups (ESG) that use on-line computer-mediated communication (CMC) systems such as e-mail, bulletin boards, and automatic mailing lists.

The main research purpose is to investigate the use, nature and impact of electronic support groups in the prevention of illness and the promotion of health.

Some specific questions of interest that this review addresses are:

- In what circumstances have electronic support groups (ESG) been used?
- What is the nature of the activity that occurs in ESGs?
- How effective are ESG interventions?
- What benefits and risks exist in the use of ESG interventions?
- How do marginalized communities utilize ESG interventions?

Research papers that describe multi-featured interventions (CMC plus information, decision support tools, etc.) that provide multi-features, including a computer-mediated communication (CMC) system for the ESG, will be included as will interventions that offer CMC alone.

**METHODS**

**Search Strategy**

An electronic literature search using the keywords "social support" and "computer" was conducted, using a variety of on-line data bases. The search scanned publications from January 1990 to May 1999 using MEDLINE, CINAHL, CancerLit, Sociological Abstracts, PsycInfo, Nursing Collection, and Health Star. All references were reviewed for other
possible articles, and retrieved as appropriate. All identified articles were entered into the Reference Manager database software.

**Review Procedures**

After retrieving all potentially relevant articles, the first author rated each article for relevance to the review. Criteria for relevance were that the paper had to include the use, nature, or impact of an electronic social support group, and had to deal with health content.

Validity of all articles was then assessed for all relevant articles using a validity review tool developed by the Effective Public Health Practice Group (Appendix 1). All relevant articles were rated for validity (quality) based on six categories: selection bias, study design, confounders, blinding, data collection methods, and the management of withdrawals and dropouts. Each of these categories were independently rated as strong, moderate, or weak by the two authors. Agreement was reached between raters on each separate category where discrepancies were found. Finally, a global rating of strong, moderate, and weak was obtained for each paper based on the criteria listed in Appendix 1. This rating provides an estimate of the degree of confidence that can be placed in the results.

A number of articles reported on findings from content analyses of ESGs. Although they were not included in the systematic review process described above, they are included in the findings. As a public health intervention, ESGs have been scarcely evaluated to date. The authors felt that results from these research papers would offer valuable information about the content and nature of the discourse that occurs in ESGs. Therefore, we include them to enrich the review.

**RESULTS**

A total of 28 articles were identified from the electronic search. A further search of citations was conducted by reviewing references found in the articles pulled from the electronic search for potential inclusion in the review. The search of citations identified 11 more papers that were potentially relevant, totalling 39 articles (Figure 1). Of the total of 39 articles, 24 were research papers. Fifteen were background papers which are listed in Appendix 2. Of the 21 rated research articles, four were grouped and treated as one study (Bass, McClendon, Brennan, & McCarthy, 1998; Brennan, Moore, & Smythe, 1995; Brennan, Moore, & Smythe, 1992; Brennan, Moore & Smythe, 1991); three others were grouped and treated as one study (Gustafson, et al. 1999; Boberg, Gustafson, Hawkins & Chan, 1995; Pingree, Hawkins, Gustafson, Boberg, Bricker, et al., 1996). Therefore a total of 16 different studies were rated. Overall global quality ratings for the rated studies were as follows: one paper was rated strong, two were rated as moderate and 13 were weak. The global quality rating, design, participants, intervention, outcomes and results are included for each study in Table 1, which outlines the quality assessment ratings based on the six.
Out of 16 rated studies, ten studied the use of ESGs within multi-featured systems (such as information resources, decision support tools, and other communication components). The remaining studies offered only CMC features for social support, such as through the use of public bulletin boards, newsgroups, or automatic mailing lists (such as LISTSERV). Of the 16 papers, 11 described ESG interventions that were moderated, one was unmoderated, and for four studies it was unclear. In the majority of studies (n=10), participants in the ESGs were anonymous, in one they were not anonymous, and in five it was unclear. Sixteen research studies were conducted in North America. One cohort study was conducted in Halifax, Canada (Dunham, Hurshman, Litwin, Gusella, Ellsworth, & Dodd, 1998). Interventions for the rated studies are more specifically detailed in Table 2.

All three content analysis papers investigated automatic mailing list servers. This is an e-mail that is addressed and sent to everyone on the mailing list. The term LISTSERV refers to a specific commercial mailing list server, and is often used incorrectly to refer to any mailing list server (Internet.com, 1999). Klemm (Klemm et al., 1998) conducted content analyses on three unmoderated cancer support groups lists which were ‘managed’ by a ‘list’ owner. Finn & Lavitt (1994) examined five computer-based self-help groups using automatic mailing list servers for sexual abuse victims. The final paper by Sharf (1997) reported on a Canadian automatic mailing list server for cancer patients developed by Jon Church in Newfoundland, Canada.

Of the 16 rated and three qualitative studies, each was categorized according to the health issue, including: cancer (n=7); caregivers of Alzheimer’s and dementia patients (n=1); persons living with AIDS (n=3); parenting (n=2); substance abuse, e.g. drugs and smoking) (n=2); stress management (n=1); eating disorders (n=1); diabetes self-management (n=1); and, sexual abuse (n=1). A summary of findings for each rated article, which follows the health and illness categories outlined above, is included in Table 3.

Cancer

Seven papers dealt with on-line social support groups for cancer survivors including those with breast cancer (McTavish, Gustafson, Owens, Hawkins, Pingree, Wise, et al., 1995; Klemm, Hurst, Dearholt, & Trone, S., 1999; Sharf, 1997; Weinberg et al., 1996; Gustafson et al., 1993) and colorectal cancer (Klemm et al., 1998; Klemm et al., 1999). Five were rated weak. Two were content analyses. Two papers (Klemm et al., 1998; Klemm et al., 1999), involved evaluation of a colorectal cancer ESG, and one compared colorectal cancer content and usage patterns to a breast cancer and a mixed cancer ESG.

Klemm, et al. (1999) in their study of 974 users of three public ESGs, found that information seeking and giving was more likely in men in the prostate cancer groups than in women in the breast cancer ESG. Conversely, women offered encouragement and support more often than men. The interventions in the three ESGs were poorly described. It was unclear if the ESGs were moderated, anonymous, or if other services, such as information resources, were offered at the sites. It was also unknown if other factors may have influenced the content in the discussion. Confounding variables such as demographic characteristics were not gathered. Attribution differences to gender is
questionable, as other variables such as demographics, or the type or stage of cancer may have had an influence on the messages posted. In fact, gender differences were found in the number of information giving/seeking messages when comparing the breast and prostate groups, that were not seen in the mixed group, suggesting that other factor/s may be involved. There does, however, appear to be an association between the type of message posted and gender, which provides an argument for further investigation of gender issues in ESGs.

Klemm, et al. (1998) used content analysis to provide information about the types of messages typically seen in a breast cancer discussion list. This sampling of nine days’ postings during two sampling periods by 97 users of mixed backgrounds (patients, family and caregivers, and health professionals) provided a start to understanding the types of messages posted within a cancer support group discussion list. Most messages were information seeking or giving, personal opinion, encouragement, and support. Sharf (1997) used participant observation in her approach to studying a breast cancer ESG. Like Klemm et al. (1998), she found that information requests and responses were the most common messages. Personal views were second in frequency, while relationships between physician and patient were third, and the provision of psychological support fourth. It may be valuable to differentiate between the content posted by those diagnosed with the disease compared to professionals, family, and friends. No studies investigated differences and similarities in content of messages among types of users.

Klemm (1998) found that more information seeking and giving messages were apparent in their first sampling, whereas support/encouragement was greater in the second sampling of messages from the same group six months later. Further data about the patterns and nature of the relationships formed over time would be useful to gain a more meaningful understanding of this finding.

The two studies rated weak were pilot studies using CHESS (Comprehensive Health Enhancement Support System), a multi-featured program that included a social support element (McTavish et al., 1995; Gustafson et al., 1993). CHESS includes a communication component, e.g., a discussion group (ESG), personal stories (PS), and Ask an Expert (AE), as well as information component, e.g., an instant library (IL), and getting help (GH). It also offers complex decision analysis aids. Although the studies using CHESS for cancer support sampled very small groups, they did provide preliminary data that showed that participants used communication features more often than decision-making and information features. The likely explanation for this finding is that social support is seen as an ongoing process, whereas the need for help with decision-making is likely event based. Weinberg et al. (1996) examined the feasibility of a private BBS system that was used by six cancer patients. They found that use dropped off when patients’ conditions worsened, and during the month of December. The later finding was interpreted as due to the rush of the Christmas season. No other studies identified seasonal variations in use patterns.

Caregivers

Four articles that reported on one large controlled clinical trial on the use of ESGs for caregivers of persons with dementia, primarily Alzheimer’s caregivers, were found. They were grouped and rated as one study. The group of papers was globally rated as strong. Two papers in this study described the results of the controlled clinical trial (Bass et al.,
1998; Brennan et al., 1995) and two reported on feasibility studies conducted in preparation for this larger study (Brennan et al., 1991; Brennan et al., 1992). This study researched a multi-featured support system intervention called ComputerLink. It offered three communication features, including a bulletin board system (BBS), private e-mail, and a question and answer component (Q&A). The BBS and Q&A features were used anonymously by participants and were moderated by a nurse. Other features included decision support tools and an encyclopedia with information related to Alzheimer’s disease.

Groups were allocated to either Computer Link or a control, and measured different outcomes such as caregiver strain, perceived isolation and decision-making. The method of randomization was not described. Their findings are detailed in Table 3. Despite the relatively small sample size in these two reports, the findings provided some evidence that such a system could be useful for reducing strain in some caregivers (Bass et al., 1998) and that the users experienced greater improvement in confidence in their decision-making than controls (Brennan et al., 1995). It is interesting to note that the authors’ hypothesis that more vulnerable caregivers would experience greater benefits was not consistently supported by the research. Findings cannot be attributed to specific features of the intervention. For example, it is unknown what impact the communication features had on the results.

The two early feasibility studies investigated the use of ComputerLink by two groups of caregivers whose average ages were 60 and 68 years (Brennan et al., 1991; Brennan et al., 1992). Both studies measured usage by participants and both conducted a content analysis of the posted messages. All papers reporting on ComputerLink (Bass et al., 1998; Brennan et al., 1995; Brennan et al., 1991; Brennan et al., 1992) provided evidence that participants used the communication components (BBS and Q&A) more frequently than the information and decision support components as was seen in the two pilot studies of cancer ESGs using CHESS (McTavish et al., 1995; Gustafson et al., 1993).

The content of messages was analyzed in three of the four studies in the caregiver category (Brennan et al., 1995; Brennan et al., 1991; Brennan et al., 1992). In one paper (Brennan et al., 1995) over 600 messages were analyzed using deductive content analysis which compared the types of messages in ComputerLink to those typically seen in face-to-face support groups. Findings suggest that dialogue in ESGs is similar to traditional groups.

Use patterns by caregivers showed that there was a wide variability in participants’ use of the system. A wide range of access (three to 590 log-ons) was seen in participants’ use of ComputerLink over one year (Brennan et al., 1995). The feasibility study of 47 caregivers showed that use was greater among younger participants (Brennan et al., 1992). Log-ons occurred at all hours throughout the 24-hour period (Brennan et al., 1995; Brennan et al., 1991; Brennan et al., 1992) which demonstrated that users access support services beyond usual business hours.

**Persons living with AIDS**

Three papers (Gustafson et al., 1999; Pingree et al., 1996; Boberg, Gustafson, Hawkins, & Chan, 1995) that reported on the use of CHESS, for persons living with AIDS, were grouped as one (Table 3). CHESS as was described earlier, is a multi-featured
computer-based program. The group of articles reporting on a controlled clinical trial (CCT) using CHESS was rated as moderate. One paper reported on comparisons of the experimental and control groups (Gustafson et al., 1999) and the other two reported on results of the experimental group (Boberg et al., 1995; Pingree et al., 1996). Two other papers in this AIDS category reported on the use of ComputerLink and were rated weak (Brennan et al., 1994; Brennan et al., 1991).

Along with the many findings outlined in Table 3, Gustafson, et al. (1999) in their CCT found that functioning of AIDS patients improved with CHESS and that this benefit disappeared after it was removed. This finding suggests that those who are isolated and possibly not cognitively stimulated could benefit from such computer-mediated systems. CHESS users had decreased levels of negative emotion and better social support than controls. They were more active in their lives and continued to have strong social supports and improved quality of life across a range of measures. Comments received on a survey question about what people got out of CHESS showed that emergency room and caregiver visits were shorter because users were well-prepared for questions and had clear expectations. Phone calls to health providers significantly increased during and after installation because patients felt more empowered to raise issues that concerned them. The authors suggested that CHESS users had fewer and shorter hospitalization, probably as a result of increased awareness of risks and timely interventions. They also conclude by saying that "similar systems offer the potential for patients to face a wide variety of health care crises, where patient knowledge and action can make a difference" (p. 7).

Boberg, et al. (1995) focused their paper on general use patterns of participants. Their findings indicated that users frequently accessed the system outside of usual business hours. As was seen by caregivers, they also demonstrated a pattern of heavy use in the first weeks, followed by a levelling period, and then steady use. They also gathered information about user perceptions of the system through surveys and focus groups. Methods for the focus groups were poorly described. However, users cited advantages of the ESG, including availability seven days a week and 24 hours per day, anonymity, that the “healthy did not have to face the sight of people in terminal stages”, and that users could relate to people on the content of the discussion rather than race, dress, and sex. Disadvantages included a time lag in getting responses to messages, difficulty in conveying some emotions such as sarcasm, and having to read many messages in which the user was not interested.

Brennan and Ripich, (1994) reported on the findings from 26 persons living with AIDS who were exposed to ComputerLink for six months. Due to the small sample of users and a weak description of context and methods for the qualitatively presented case studies, results cannot be generalized. However, this paper, through its investigation of individual cases, identified interesting areas for further research. The fact that many users lurked (only read) rather than contributed messages, suggested that persons living with AIDS most likely reread existing messages and found suggestions or support in them. This study also identified a similar characteristic pattern of high use in weeks two to three, and then a levelling off of use, as was seen in the Boberg study (1995).

### Other Topics and ESG

A number of articles were found that described and/or investigated the use of ESGs for health topics. These categories fell under the following sub-headings: parenting
(Mickelson, 1997; Dunham et al., 1998), substance abuse (King, 1994; Schneider, Walter, & O’Donnell, 1990), sexual abuse (Finn et al., 1994), stress management (Meier, 1997), and a body weight concerns program (Winzelberg, Barr, Sharpe, Eldredge, Dev, & Constantinou, 1998; Gleason, 1995). Each topic will be briefly discussed.

**Parenting**

Two papers evaluated the use of ESGs for parents. One group consisted of young and single mothers (Dunham, et al. 1998) and the second group was parents of children with special needs (Mickelson, 1997).

The Dunham et al. cohort study, which was rated as weak, described the use of a multi-featured communication system, “Staying Connected”, which included a private anonymous bulletin board, private e-mail and real time chat facilities for young single mothers of children under the age of one year in a Halifax community (Dunham et al., 1998). The paper identified some unique issues related to the use of ESGs with a high risk population of young single mothers. Isolated parents were found to use the service more than those less isolated, supporting the conclusion that this intervention was valuable for those parents most in need. Participation in the ESG was correlated to the age of the infant, indicating that those who had younger infants had increased potential for social isolation. The Sense of Community Scale, which was found to be correlated to system use, was a variable that was not measured in other articles. Qualitative case reports indicate that in one case, women supported each other to escape an abusive situation and another organized a “Staying Connected” party in order to meet members face to face. Two percent of messages in this ESG were considered rude or non-supportive.

Dunham et al. (1998) pointed out some limitations to their research. The methodology was a correlational study, thus findings might be related to these women’s developmental changes rather than the intervention. Therefore, levels of exposure to the intervention (via measures of frequency of use) were also examined in the analysis.

Mickelson’s (1993) cohort analytic study which was rated weak, compared groups of parents with children with special needs including Down Syndrome, developmental delays, and autism who did and did not participate in ESGs. Her paper focuses the report on the concept of social stigma and seeking and receiving support in the two groups. The findings (Table 3) indicated that there are significant differences between the ESG and non-ESG groups in demographics such as education, age, and race, as well as other variables such as the parents’ perception of the social stigma of their child’s condition. Thus as the authors point out “because the samples differed demographically, it is hard to distinguish demographic from communication effects in this study” (p. 175). The author postulated that there may be an additional “communication factor” which occurs with ESGs users as they have access to more electronic information about their child’s special need through the Internet, thus possibly increasing parents’ understanding of their child’s needs.

An interesting discussion was presented about possible reasons that mothers in ESGs perceived more social stigma than others, and why this finding persisted over time. Mickelson wondered if mothers obtain a stronger self awareness of stigma through the sharing of stories. Other reasons may relate to the higher educational level seen in this group and a possible higher expectation for their children. The findings that more males
were found in the ESG is also an area that requires further investigation. Was this a result of more males using the Internet, or more males willing to dialogue about their child's special needs in an anonymous environment? This points to possible gender differences for this population. This research also indicated that parents in ESGs perceived their family and friends less favourably than other parents. Mickelson questioned if this was a result of ESG isolating parents from friends and family through the provision of on-line supports, information, and sympathy. Such issues suggest areas for future investigation.

**Body Image and Food Concerns**

A controlled clinical trial by Winzelberg, et al. (1998), rated moderate, investigated the effectiveness of a multi-featured multimedia program containing content related to eating patterns, body image, and weight concerns with a sample of university women who did not suffer from an eating disorder (Table 3). It also featured an anonymous, moderated e-mail social support group for two groups of up to ten people. The clinical psychologist moderator's role was to reflect concerns expressed by users and make reference to content in the software within the e-mail messages. Limitations of this study were a small sample size, significant differences in experimental and control groups, and the potential for recall bias in participants' recording of their use of the intervention.

The authors claim that the eating intervention was able to minimally support users. They hypothesized reasons for users' failure to use the software, including technical difficulties in installation, the lack of privacy, and the undue attention that could be raised in use of the program in a public place. It was unclear where and how the intervention was used by participants.

The authors felt that the lack of use of e-mail (65 messages by group 1 and 24 messages by group 2 over three months) may have limited the effectiveness of the intervention. There were few supportive emotional messages between participants and they often asked for feedback and support with little response over the three months of use. Gleason (1995) in a background paper, described a similar application of a bulletin board system (BBS) in a women's college to create a virtual space for the discussion of issues pertaining to eating concerns and eating disorders. The "Body Image" BBS was open to all users on campus and confidentiality was not maintained. Gleason anecdotally reported that the BBS provided an opportunity for users to disclose their anger and some users posted personal stories of their struggles. Contrary to Winzelberg et al.'s findings, they consequently received support from others despite the lack of confidentiality in the system.

**Sexual Abuse**

Finn & Lavitt (1994) analyzed the content from 1178 messages from five automatic mailing list servers which were described as self-help/mutual aid groups for sexual abuse victims (Table 3). This study applied a unique approach for researching social support groups not seen in others. Investigating many conferences and comparing patterns of use and interactions yielded interesting data. Unfortunately, content analysis methods were poorly described and there was no member checking, inter-rater or intra-rater reliability reported. However, themes raised in the analysis were clearly supported by examples from the on-line discussions, which added credibility and context to the reported findings.
Research findings identified that the gender mix of groups is associated with varying levels of participation. For example, in female-dominant groups, females had higher participation rates than men and the reverse was true in male-dominant groups. Gender issues raised in the research findings, identified an important area for further research. This study also indicated that naturally occurring ESG groups do seem to evolve developmentally as supported by the observation that the amount of participation is related to the longevity of the group.

**Substance Abuse**

Two studies related to substance abuse included ESGs for smoking cessation and for recovering drug addicts. Schneider et al. (1990) described an RCT, rated as weak, where 1158 smokers were randomly assigned to one of four groups: a full version smoking cessation program (SCP) either including or excluding an ESG, a group with only access to the ESG, and a group with no intervention. The full version intervention offered a mix of information and communication features. This paper demonstrated that although daily rates of smoking increased after using the program, they still remained lower than pre-treatment levels, indicating that “participation in a computerized smoking cessation program, regardless of its nature, can help individuals to reduce their daily smoking intake, even when they do not quit smoking” (p. 150). One focus of this study was related to the results of differences of those who used the forum versus those who did not. It appears that the full version of the program, and the forum, to a lesser degree helped smokers to “become motivated and to learn the skills for self-monitoring” (p. 150).

Some limitations were found in this paper. Use was measured as “accessed more than once” which is a limited measure of intervention exposure. This group of CompuServe users was mostly male, whereas about half of the general population are female. Due to the under-representation of women, the authors correctly caution readers as to the limited generalizability of the findings to a general population. The investigators treated non-responders in the most conservative way possible, by labeling them as “still smoking”.

King’s (1994) retrospective survey of drug and alcohol addicts was rated weak. The author concluded that, for some addicts, the ESG assisted in their recovery. The correlation found in this paper that frequent users reported more improvement is logical as it was assumed that those who perceived that they got something positive out of the ESG would be those who were more frequent users, while those who could find little benefit would not return. It cannot be implied, however, that more frequent use of ESG will result in better improvements for all users, as cause and effect cannot be drawn from this study design. The study also identified that of those who responded to the survey, 58% contacted others that they had met in the ESG by phone, post, or in person. This phenomenon was also seen in the study by Dunham et al. (1998) of single mothers where a small group of users organized to meet outside of the ESG.

**Stress Management**

Meier (1997) reported on a feasibility study, rated as weak, of 11 volunteer social work student participants who partook in a stress management automatic mailing list servers (Table 3). The intervention, which was described in detail, indicated that the moderator took a directive role by assigning topics for discussion and then summarized responses to send out to members. A poor number of postings by users (n= 33) were seen over the
six-week intervention. This may have been too short a time period to obtain full participation in the intervention.

This paper also briefly reported on member preferences about the group format. Users wanted unlimited, rather than time-limited, regularly-scheduled groups. There was a small discussion of group leader roles, indicating that moderators must have a high tolerance for uncertainty to respond to changing role expectations.

**Diabetes Management**

A paper by McKay, Feil, Glasgow and Brown (1998), rated weak, reported on a survey study that reviewed the use of a multi-featured, web-based system to support persons with diabetes who had personal access to the Internet (Table 3). The web site provided information support, a personalized blood glucose monitoring chart, and an on-line social support group. Findings showed that the social support component accounted for 60% of all activity on the site. Demographic characteristics collected during registration of 111 participants onto the site indicated that users were primarily male and that their median age was 43 years, the oldest being 77 years of age. The site served participants internationally. Seventy-seven of the users replied to a satisfaction survey indicating that they found the social support group helpful whether they actively posted messages or were lurkers (readers only) on the system. They found that there was no inappropriate sharing of advice on the site.

**Issues and Themes**

In light of the findings of the studies in each category, some issues and common themes were raised that would help to guide future practice and research directions. The following section further addresses some of the research questions posed for this review.

**Use and Content of the Communication Feature**

Ten of the studies investigated multi-featured programs that all included a communication feature. They indicated that communication features were used more than information or decision-making features (McTavish et al., 1995; Gustafson et al., 1999; Pingree et al., 1996; Gustafson et al., 1993; Boberg et al., 1995; McKay, et al., 1998). The content analyses of the messages are difficult to compare due to the variety of groups that have used ESGs. The purpose of messages, however, has generally been found to offer or obtain support. Dunham et al. (1998), in their ESG work with single mothers, rated all messages and found that 97.9 % of messages gave some sort of support; 56% provided emotional support, 37% provided information support and 37% tangible support. Three studies (Klemm et al., 1998; Klemm et al., 1999; Sharf, 1997) indicated that in public cancer support groups, most messages were for information seeking and giving, to share personal experience, and provide encouragement and support.

Brennan, Moore & Smyth (1995) deductively conducted a content analysis of 622 messages in a caregiver ESG. The themes were taken from research in face-to-face caregiver support groups. Findings indicated that the top themes were related to the group and its members as a social support system, information about the care recipient’s situation, and the emotional impact of caregiving. In the eating disorder study,
Winzelberg et al. (1998) found that self-disclosure and the provision of emotional support were the most common purposes seen in e-mail messages. Self-disclosure was also identified in message content by Brennan et al. in their AIDS feasibility study (1991). In summary, it appears that participants in ESG often offer support in the content of their messages. Despite this promising finding, however, it is felt that computer-mediated communication tools should be viewed as an adjunct to other means of communication rather than as a replacement (Pingree et al., 1996).

Flaming, where rude or threatening messages are posted, has been identified as a potential risk of ESGs. However, few studies reported on this occurrence. In Dunham’s study of single young mothers, 2% of messages were considered rude or non-supportive (Dunham et al., 1998). Another article that reported on public bulletin boards for sexual abuse survivors cited that out of over a thousand messages read, approximately 17% of them were considered destructive interactions (Finn & Lavitt, 1994). Sexual abuse survivors in this study identified flaming as one reason for leaving an ESG. The differences in incidence of flaming or negative messages may be associated with the type of ESG. For example, public versus private, and moderated versus unmoderated ESGs require further study to investigate if these factors have any effect on flaming incidence.

Usage Patterns

Most studies investigated usage patterns of ESGs. Many found that ESGs were accessed at all times of the day and after business hours (Boberg et al., 1995; Brennan et al., 1994; Brennan et al., 1992; Brennan et al., 1991). This finding may indicate that these services meet client needs that either are not available at other times of the day or are available only when or where it is inconvenient for users to access them.

Characteristic usage patterns over time were seen in closed ESGs (those made available only to study participants), indicating that there may be a pattern of initial high use in the first few weeks, with a subsequent drop, and finally a stabilization of use after about three to four months (Brennan et al., 1995; Boberg et al., 1995; Brennan et al., 1994; Weinberg et al., 1996). Measuring use for too short a time creates the risk of interpreting a drop in use as indicative of an unsuccessful program. These patterns were not described in studies that investigated public ESGs, as individuals do not typically all join a group at the same time or remain for the same amount of time. A network that is formed in a private or closed ESG may show typical stages of group use patterns due to the nature of their formation. This observation deserves further investigation.

Studies indicate that there was great variability in use by participants in ESGs. Brennan and Ripich (1994) reported great variability in use of ComputerLink by persons living with AIDS; the average number of log-ons was 297 times per user although one user logged on 1300 times. This degree of variability was seen in other studies. Wide ranges of length of log-ons ranged from 0.8 to 15 hours per week (King, 1994). In one study, single young mothers were rated as low, moderate, and high users to help researchers deal with the widely skewed findings of frequency of use (Dunham et al., 1998). In another study, caregivers logged on from three to 590 times (Brennan et al., 1995). The degree of variability of use leads one to question the benefits gained and possible risks encountered by those who are low versus high users.
There is an assumption that frequency of use as measured by number of log-ons and/or postings relates to a proportionate amount of benefit gained by the user in ESGs. This has been challenged by qualitative descriptions of individual cases found in one study rated as weak. Brennan & Ripich (1994), in their feasibility study of ComputerLink for persons living with AIDS, identified a strong leader in the ESG who posted many messages and logged on frequently but had increased social isolation scores and increased depression. Despite the quantitative scores which indicated deterioration in his emotional condition, he identified that the ESG was his most important support group. Brennan & Ripich also found through another case interview, that a low user became more compliant with medications, had not missed a doctor’s appointment, and remained clean and sober. The participant attributed these changes to the use of the ComputerLink system. Further rigorous qualitative case studies would help in understanding how to better interpret use statistics in ESGs. Similarly, some argued that lurking (only reading messages) was perceived positively by users (McKay et al., 1998) and was a source of support. Research outcomes should be compared for active participants compared to passive lurkers in electronic environments.

**Factors that Appear to Impact System Use**

**Effect of Group Size**

Winzelberg et al. (1998) in their eating disorders intervention experienced low use of their communication system. They speculated that the arranged group size of 10 users per group may have been too small to create a supportive environment. This was not the experience seen in a feasibility study of two breast cancer support groups of 10 and 15 people who posted 456 times over 50 days, and 1,131 times over 70 days respectively (Gustafson et al., 1993). In the study by Weinberg (1996), a small group of six female breast cancer patients logged on 158 times over three months.

**Point of Access**

In all of the studies that had good degrees of use, participants were logging on at home. It was unclear if the Winzelberg et al. study participants were logging on in a public or private space, the former possibly reducing use.

**Design of Communication System and Use of Moderators**

The Winzelberg et al. study also used an e-mail intervention rather than a threaded discussion or bulletin board. The design of the intervention may have been a factor influencing the amount of use. Moderator issues may have also affected use as this study incorporated defined topics for discussion. A similar situation may have been present in the study by Meier (1997) who investigated a small group of university social work students in an ESG related to work stress management. This study also reported problems with user participation and retention. The moderator also listed weekly topics for discussion. Typically users in other studies defined their own issues for discussion. Cudney & Weinert (2000), in their recently published paper, describe the role of a “nurse monitor” in an ESG for rural women suffering with chronic illness. The authors also outline their established guidelines for the support group, issues of confidentiality, the use of disclaimers to protect against litigation, and policies for potentially harmful communications. Research is missing, however, to answer if moderator-driven topics are a help or a hindrance to ESGs.
Personal Motivation for Use of ESGs

It could also be hypothesized that cancer or AIDS patients who have been diagnosed with a serious illness are motivated and are in need of social support. Pingree et al. (1996) states that persons living with AIDS have a multi-faceted, life-threatening disease, thus motivation is perceived to be high. This situation can be likened to other conditions such as breast cancer, situations where individuals perceive a social stigma, stressful life events, or isolating situations. This is further supported by the work of Bass, et al. (1998) who reported that the use of communication functions was related to reduced caregiver strain for those who reported more strain at the start of the study. In the Winzelberg et al. (1998) eating disorder study, those who were diagnosed with anorexia or bulimia were considered ineligible. Thus, participants who agreed to participate may have felt less of a need for support and were less motivated, resulting in lower use of the ESG. Similarly, the study by Meier (1997), investigating work stress of social work students, may have also reported on a less-motivated group. Three of the participants indicated that the motivation to participate came from the opportunity to improve their computer skills rather than an interest in the topic.

Further research that investigates what motivates people to participate in such groups would be valuable. This would assist practitioners in knowing where to best apply ESG interventions. For example, are health promotion and prevention topics less well suited for ESGs than acute or chronic illness oriented groups? Do health promotion and prevention topics need to be managed differently from chronic disease ESGs?

ESGs Within Multi-featured Systems

Most studies were designed to use multi-featured programs that include communication and information features and in some case a decision support system (Brennan et al., 1995; Brennan et al., 1991; Brennan et al., 1992; Gustafson et al., 1993; McTavish et al., 1995). Some were moderated, others were user-led. Some studies involved professionally moderated groups while others are organized by participants themselves. In addition, design interfaces have changed dramatically over the past decade. Thus, without a clear description of interventions, it is difficult to make comparisons or interpretations about the overall impact of ESGs on health. Pingree et al. (1996) argue that their success is probably a result of “combining the high standard of integration of content and technology” (p. 348).

With the use of complex systems, it is difficult to differentiate the impact of separate features of the systems. One study attempted to separate the impact of the communication component from other system features (Schneider et al., 1990). They designed a two-by-two intervention comparing those with and without access to a discussion forum and with and without access to a full smoking cessation program. The findings indicated that the use of the discussion forum did assist in increasing smoking abstinence rates. Further studies investigating separate effects of communication features would be valuable.

ESG Use by Elderly, Disadvantaged, and Isolated

Pingree et al. (1996) in their report of a CCT of CHESS users indicated that a computer system could be used well by minorities and disadvantaged populations. Those with lower education levels used the information and decision features more than the more
Educated users. CHESS was able to provide users with an anonymous communication system which was well used. However, the authors identified a number of limitations in their study. They pointed out that their sample was of a slightly higher educational level than the general HIV/AIDS population in the state. They also identified a small sample size and the limited power of the findings. However, that being said, the research showed promise in the potential power of CMC to provide a source of electronic support to disadvantaged populations.

Dunham et al.’s study (1998) found that concerns about lack of formal education and previous computer experience was unfounded in the study of young single mothers. They found that those who were most isolated, as measured by an absence of caregiving assistance and the presence of either an older male partner or parent who actively restricted social contact with peers, used the system most consistently. McTavish et al. (1995) demonstrated in a feasibility study that CHESS was well received by a group of impoverished Chicago women of colour with cancer. In a feasibility study, the use of ComputerLink by caregivers was not affected by education, race, length of time caregiving, or the relationship to the patient. However, higher use of ESGs was related to a younger age (Brennan et al., 1992). Boberg et al. (1995) also reports that use of CHESS was higher among younger persons living with AIDS and those who were isolated.

Access Issues

It is important to note that most of the studies addressed in this review, provided users with computers to overcome access problems (closed ESGs). Those who did not (Klemm et al., 1998; Klemm et al., 1999; King, 1994; Finn et al., 1994; Mickelson, 1997), investigated the general use of public ESGs. The less-controlled ESG environment represents web cohorts where rigorous research is much more difficult to design. These studies did, however, better investigate the actual population of Internet users but result in under-representation of certain populations who have access problems.

Schneider, Walter & O’Donnell (1990) in their study conducted in 1987 of a smoking cessation program indicated that females were under represented in their sample. This no doubt was a reflection of the low Internet use by females in general during this time. Similarly, in Mickelson’s 1993 study of public ESGs for parents with special needs children where computers were not provided to users, users were more likely to be slightly older, married, White, completed college, and employed full-time. She also found that proportionately more men were found in the sample of ESG users than in the comparison group of parents in the local community. In the last decade there have been major changes in computer access in Canada for various populations with increasingly more people accessing the Internet (Dickinson & Ellison, 1999). This leads researchers to consider access issues as an important variable in the study of ESGs for the general public. Current studies are needed that address these significant changes in computer and Internet access.

Implications for Research

The paper by King (1994) identified the difficulties researchers have in attempting to use web cohorts. The difficulties in identifying the denominator (number of actual ESG users) in public ESGs creates a significant problem. However, an article published in
Epidemiology discussed the possible benefits of web cohort samples (Rothman & Walker, 1997). They described the potential for web cohorts to have to “sign in” for participation in research including personal demographic data including information about next-of-kin for the purposes of follow up with drop outs. Automated e-mail messages could be used to provide updates of the research and to keep current lists of users. The access to cohorts could be efficient and inexpensive. Kushi et al. (1997) submitted a letter to the editor which disputed the benefits of web cohorts. They questioned the profile of respondents and their representativeness of the cohort of interest. Other questions relate to the potential for respondents to falsify survey responses, the reliability of web-based surveys, as well as the accuracy of calculating response rates.

It is strongly recommended that authors clearly define the interventions in ESGs to assist in meta analysis of research findings. Descriptions should include a clear role of moderators if they are used, as well as a detailed description of the context of use of the ESGs, whether or not the members are anonymous, and the type of medium used (e.g., e-mail, threaded discussion, text or graphical interface). This is increasingly more important as technologies improve and there are more effective and easier ways for users to interact with computers that will ultimately influence ESG use.

An interesting case study included in the background articles, reported on an elderly caregiver ComputerLink participant who was labelled a “champion” user (Brennan et al., 1995). This was a one-page conference proceeding of a case study. The findings do direct researchers to consider qualitative descriptions of cases as an approach to learn more about ways that individuals are impacted by use of such systems and the nature of the ESG environment. Further qualitative study is warranted to better understand patterns of dialogue and uses of ESGs by participants, and the differences between moderated and unmoderated groups. The role of moderators in ESGs has not been explored nor has the effect of anonymity. Except for Gustafson et al.’s work (1999), no studies have examined the cost effectiveness of ESGs. Such studies are necessary to examine the full potential of ESGs. In particular, research is needed to examine the most effective means for public health practitioners to use ESGs to promote health and prevent illness.

**Implications for Practice**

From the research conducted to date investigating the impact of ESGs, social support can be successfully provided via this medium. In the ten studies that investigated multi-featured systems, communication features providing social support were most frequently used. ESGs were used seven days per week and 24 hours per day, suggesting that they can be a good source of help when traditional services are not available.

There is a typical pattern of use found in closed ESGs where there is heavy use at first, a dropping off, and then a levelling-off period; ESGs need to operate for at least three to four months for the group to stabilize into a regular pattern of use.

ESGs have been shown to support a broad range of populations and health conditions. They have been successfully used by a variety of populations: young and old, male and female, rich and poor, highly and poorly educated, minority groups, as well as the isolated. The application of ESGs has shown positive results for a variety of health
situations including persons with severe acute and chronic diseases, as well for those looking to improve their lifestyles.

The strongest studies in this review indicated that participation in multi-featured ESGs result in a variety of positive health outcomes such as improved quality of life, reduced length of hospital stays, increased levels of active life, more active participation in their own health, reductions in emotional strain, and higher experienced social support. Among the many benefits of ESGs, content analyses demonstrate that ESGs are used by participants for information sharing, to offer and obtain emotional and informational support, and to share personal experiences. Self-disclosure was also noted as a reason to participate in ESGs.

There is a high variability of use of ESGs among all populations. High use should not be equated with more ESG benefit. Lurkers (readers only) and low users were shown to gain benefits from ESGs as did high users.

No risks were found from the use of ESGs, with the exception of flaming (negative or destructive on-line interactions). The incidence of flaming was reported in two studies and although it was a rare occurrence, it is a serious issue that requires attention.

**CONCLUSIONS**

The findings from this review that investigated the use of ESGs in health are promising and demonstrate a wide range of benefits for users in need of social support with evidently few risks. However, this body of research is young, and there still remain many questions to answer and phenomena to understand through the use of both quantitative and qualitative research methodologies. The current body of research supports the need to continue to investigate ESGs in the fields of health promotion and illness prevention, acute and chronic illness, and with adults and youth populations. Mizsur (1997) located approximately 700 ESGs available on the Internet, covering a broad range of health issues. In 1998, 4.3 million Canadian households (36% of all households) had at least one member who used computer communications regularly, up from 3.5 million households in 1997 (Dickinson & Ellison, 1999). Researchers are challenged to continue to apply rigorous research methods to investigate ESG use in a rapidly growing and changing world of computer and Internet technology for the provision of social support to improve health.
**FIGURE 1: Results from Search Strategy**

- Total Articles Retrieved: \( n = 39 \)
- Background Articles: \( n = 15 \)
- Relevant Research Articles: \( n = 24 \)
  - Quantitative Research Articles: \( n = 21 \)
    - 4 articles grouped as one study;
    - 3 articles grouped as one study
  - Content Analysis Articles: \( n = 3 \)
- Total 16 Studies
  - Strong Quality: \( n = 1 \)
  - Moderate Quality: \( n = 2 \)
  - Weak Quality: \( n = 13 \)
## TABLES

Table 1: Quality Assessment of Rated Studies
Table 2: Intervention Design Criteria
Table 3: On-Line Social Support Included Studies
<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Global Rating</th>
<th>Selection Bias</th>
<th>Study Design</th>
<th>Confounders</th>
<th>Blinding</th>
<th>Data Collection</th>
<th>Withdrawals</th>
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<td>Private Communication System (Restricted to Study Participants)</td>
<td>Public Communication System (e.g. BBS)</td>
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<td>Anonymous</td>
<td>Private E-mail feature</td>
<td>Decision Support Tool</td>
<td>Question and Answer by Professional</td>
<td>Encyclopedia &amp;/or Dictionary Information</td>
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<td>Brennan (1991) AIDS</td>
<td>Computer Link; Bulletin board for participants in experimental group</td>
<td>Yes</td>
<td>Nurse</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes - Nurse</td>
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<tr>
<td>Brennan (1994) AIDS</td>
<td>Computer Link; Bulletin board for participants in experimental group</td>
<td>No</td>
<td>Yes</td>
<td>Nurse</td>
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<td>Yes</td>
<td>Yes - Nurse</td>
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<tr>
<td>Dunham (1998) Single young parents</td>
<td>Staying Connected: For participants in experimental group</td>
<td>No</td>
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<td>Yes</td>
<td>No</td>
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<td>No</td>
<td>Yes</td>
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<td>Unsere</td>
<td>Yes</td>
<td>No</td>
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<td>Author/ Topic</td>
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<td>Gustafson (1993) Breast cancer</td>
<td>CHESS: Bulletin board for participants in experimental group</td>
<td>No</td>
<td>Yes Trained facilitator</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>King (1994) Recovering substance abusers</td>
<td>No</td>
<td>Prodigy Medical support</td>
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<td>Unsure</td>
<td>Unsure</td>
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<tr>
<td>Klemm (1999) Cancer</td>
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<td></td>
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<td>Unsure</td>
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<td>McKay (1998) Diabetes</td>
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<td>Unsure</td>
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<td>No</td>
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<tr>
<td>McTavish (1995) Breast cancer</td>
<td>CHESS Bulletin board for participants in experimental group</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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</tr>
<tr>
<td>Meier (1997) Stress management</td>
<td>Yes- listserv for study participants</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
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<tr>
<td>Mickelson (1993) Parents with developmentally delayed children</td>
<td>No</td>
<td>Four UseNet groups</td>
<td>Unsure</td>
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</table>

Table 2: Intervention Design Criteria for Rated Studies
<table>
<thead>
<tr>
<th>Author/ Topic</th>
<th>Private Communication System (Restricted to Study Participants)</th>
<th>Public Communication System (e.g. BBS)</th>
<th>Moderated</th>
<th>Anonymous</th>
<th>Private E-mail feature</th>
<th>Decision Support Tool</th>
<th>Question and Answer by Professional</th>
<th>Encyclopedia &amp;/or Dictionary Information</th>
<th>Other Features</th>
<th>Length of Intervention</th>
<th>City/ Country</th>
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</thead>
<tbody>
<tr>
<td>Schneider (1990) Smoking cessation</td>
<td>Compuserv subscribers participants in experimental group</td>
<td>No</td>
<td>Yes - Psychologist</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>-Chat -complex behavioural program</td>
<td>Up to 6 months</td>
<td>US-based</td>
</tr>
<tr>
<td>Weinberg (1996) Breast cancer</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>3 months</td>
<td>US-based</td>
</tr>
<tr>
<td>Winzelberg (1998) Eating disorders</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Educational software -eating, weight, nutrition and exercise</td>
<td>Approx. 7 months</td>
<td>California, US</td>
</tr>
</tbody>
</table>
Table 3: On-Line Social Support Included Studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Design/Quality</th>
<th>Participants</th>
<th>Intervention</th>
<th>Outcomes</th>
<th>Results/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>McKay, Feil, Glasgow, &amp; Brown (1998)</td>
<td>Cohort Study</td>
<td>N = 111 diabetes patients</td>
<td>Diabetes management</td>
<td>Demographic characteristics of participants</td>
<td>Users were mostly male, median age 43 years, oldest 77 years, international</td>
</tr>
<tr>
<td></td>
<td>Weak Rating</td>
<td>N = 70 Survey respondents</td>
<td>1996 internet web site offering</td>
<td>Utilization of features</td>
<td>Participants used the social support component most often (60% of all activity)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Moderated social support group</td>
<td>Satisfaction</td>
<td>Participants (writers and lurkers) found social support helpful</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Information on diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Personalized blood glucose monitoring</td>
<td></td>
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</tr>
<tr>
<td>Mickelson (1993)</td>
<td>Cohort Analytic</td>
<td>N = 109 parents (non-ESG users)</td>
<td>Parenting</td>
<td>Interview surveys demonstrate that parents using ESGs reported</td>
<td>Parents from ESGs were more likely to be slightly older, married, White, had completed college and employed full time than other parents</td>
</tr>
<tr>
<td></td>
<td>Weak Rating</td>
<td>N = 102 parents (ESG users)</td>
<td>ESGS in four USENET groups</td>
<td>• More stress and stigma associated with their child</td>
<td>ESG parents’ children were more likely to have Down Syndrome and autism whereas non-ESG parents’ children were more likely to have developmental delays</td>
</tr>
<tr>
<td></td>
<td></td>
<td>All with child diagnosed with autism, developmental delays or Down Syndrome, aged between birth and seven years</td>
<td></td>
<td>• Perceived family and friends as less supportive than those of the non-ESG users</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>The more frequently public postings were made</td>
<td>Self-selection bias</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• The more stress parents perceived (p&lt;0.10)</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• The less available they perceived their spouse (p&lt;0.05)</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• The greater their fear of rejection by casual friends (p&lt;0.05)</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Design/Quality</td>
<td>Participants</td>
<td>Intervention</td>
<td>Outcomes</td>
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</tr>
<tr>
<td>Meier (1997)</td>
<td>Cohort Study</td>
<td>11 Master’s-level social work students</td>
<td>Stress management</td>
<td>Post-intervention satisfaction survey demonstrated that members viewed listserv group as a safe place to vent feelings and get meaningful support</td>
<td>Scope of discussion topics</td>
</tr>
<tr>
<td></td>
<td>Weak Rating</td>
<td></td>
<td>Moderated, anonymous, and listserv group</td>
<td></td>
<td>• Response to e-mail topics suggest the scope and sequence of topics were appropriate for participants</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Member retention was problematic – four dropped out</td>
</tr>
<tr>
<td>Study</td>
<td>Design/Quality</td>
<td>Participants</td>
<td>Intervention</td>
<td>Outcomes</td>
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</tbody>
</table>
| Schneider, Walter & O'Donnell (1990) | Randomized Controlled Trial | Weak rating | N=1,158 smokers members of CompuServe Divided into four groups  | Smoking cessation program  
|                            |                |              | Full version • personalized, comprehensive behavioural program               | Full version of the program with the Forum resulted in higher abstinence rates than the control at three months (p= <0.08)  
|                            |                |              | Control version • devoid of most full version features and greatly shortened  | Smokers who did not quit smoking, regardless of treatment group, did cut down on their amount of smoking at one month follow up; their daily rate increased after, but still remained lower that pre-treatment levels at six months  
|                            |                |              | Stop smoking Forum • an exchange of comments, a written-out group discussion where smokers could share experiences and observations, and encourage each other | Significant positive correlation between ESG usage rate and self-reported improvement in recovery program (p<0.05)  
|                            |                |              |                                                                              |                                                                                                                                                                                                          | Control subjects without access to the Forum had especially low abstinence rates  
|                            |                |              |                                                                              | Non-responders assumed to be still smoking                                                                                                                                                | Under-representation of females in study population  
|                            |                |              |                                                                              | Self-reported abstinence rates  
|                            |                |              |                                                                              | Those with the full version were more likely to access the program more than once (64.7% vs. 58.9% p<0.05)                                                                                     | 60% of those registered accessed the system more than once  
|                            |                |              |                                                                              | No difference in access rates between Forum vs. non-Forum groups                                                                                                                                  | No difference in access rates between Forum vs. non-Forum groups  
|                            |                |              |                                                                              |                                                                                                                                                                                                          |  

Table 3: On-Line Social Support Included Studies
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<tr>
<th>Study</th>
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</tr>
</thead>
<tbody>
<tr>
<td>King (1994)</td>
<td>Retrospective Survey</td>
<td>71 alcohol and drug addicts on Prodigy</td>
<td>Alcohol &amp; drug abuse ESG Electronic support groups (ESG) which uses and electronic bulletin boards</td>
<td>Positive correlation between usage of ESG and self-reported improvement in recovery program</td>
<td>Self-report of improvement in recovery</td>
</tr>
<tr>
<td></td>
<td>Weak rating</td>
<td></td>
<td></td>
<td>Significant positive correlation between number of hours per week respondent used ESG and reported perceived improvement in recovery (0.46 p&lt;0.01)</td>
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<tr>
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<td></td>
<td>Improvement in recovery positively associated with total number of months of ESG use (0.40 p&lt;0.001)</td>
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<td></td>
<td>58% respondents reported they had made personal contact (phone, in person) with members met in ESG</td>
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<td></td>
<td>Personal contact showed a significant positive correlation with the length of recovery program time (0.40 p&lt;.01) and the number of months of ESG use (0.46 p&lt;.0001)</td>
<td></td>
</tr>
<tr>
<td>Study</td>
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<tr>
<td>Winzelbeg, Barr, Taylor, Sharpe, Eldredge, Dev &amp; Constantinou (1997)</td>
<td>Controlled Clinical Trial</td>
<td>57 U.S. undergraduate females</td>
<td>Eating disorder intervention</td>
<td>Experimental group demonstrated improvements only on the Body Shape Questionnaire compared to controls (p&lt;0.29)</td>
<td>Most common purpose of e-mail message posting was:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n= 27 experimental group</td>
<td>Experimental group</td>
<td>Effect size of the intervention was 0.50 for body image measures and &lt; 0.30 for eating attitudes &amp; behaviour measures which are 1/2 to 1/3 as powerful as psychotherapist-driven interventions</td>
<td>• Self-disclosure</td>
</tr>
<tr>
<td></td>
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<td>n= 30 control group</td>
<td>Student Bodies package</td>
<td></td>
<td>• Provision of emotional support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Students with bulimia and anorexia ineligible</td>
<td>• Student Bodies Software (psycho-educational intervention related to body image, eating patterns, weight concerns)</td>
<td></td>
<td>Some differences reported between experimental and control (Eating Disorder Examination Questionnaire and Weight and Shape sub scales)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Moderated by clinical psychologist, anonymous e-mail support group</td>
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<td>Participants were paid to participate</td>
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<tr>
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<td>Control group</td>
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<td>Delayed intervention</td>
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<tr>
<td>Study</td>
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<td>Intervention</td>
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<tr>
<td>Dunham, Hurshman, Litwinn, Gusella, Ellsworth &amp; Dodd (1998)</td>
<td>Cohort Study</td>
<td>Single mothers between 15-20 years of age with young infants (at least one &lt; one year)</td>
<td>Young Single Mothers’ Parenting Support Group</td>
<td>Parenting stress decreased in the mothers who participated regularly in the computer-mediated social support network</td>
<td>Close, personal relationships and a sense of community developed from the e-mail exchanges</td>
</tr>
<tr>
<td></td>
<td>Weak rating</td>
<td>N = 50; 48 subjects completed the study</td>
<td>Computer-mediated social support network (Staying Connected) offered three forms of social communication</td>
<td>Factors that accounted for differing participation were</td>
<td>Differences in sense of community scale were correlated to participation (more participation=higher sense of community) (r=0.48, p&lt;0.002)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1. Public forum</td>
<td>• The infant’s age (younger infants=more participation)</td>
<td>98% of the postings provided positive social support; 2% were coded as rude and non-supportive</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2. Private e-mail message exchanges</td>
<td>• Social isolation—measured by Adult Control and Absence of Caregiving Assistance (high isolation=high participation) this accounted for 26% (p&lt;0.008) of the variance in mother’s participation</td>
<td>Highly skewed distribution of use</td>
</tr>
<tr>
<td></td>
<td></td>
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<td>3. Text-based teleconferencing</td>
<td></td>
<td>• high use (34% of mothers)</td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
<td>• moderate use (20%)</td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
<td>• low participation (46%)</td>
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<td></td>
<td>Personal face-to-face exchanges occurred as a result of meeting on-line</td>
</tr>
</tbody>
</table>

Table 3: On-Line Social Support Included Studies
<table>
<thead>
<tr>
<th>Study</th>
<th>Design/Quality</th>
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<th>Outcomes</th>
<th>Results/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bass, McClendon, Brennan, &amp; McCarthy (1998)</td>
<td>Controlled Clinical Trial Strong rating</td>
<td>N=96/102 primary informal caregivers of Alzheimer’s disease patients n=47 experimental group n=49 control group</td>
<td>Alzheimer’s Caregivers Experimental group ComputerLink System that included - A public bulletin board - Private mail - Question-answer segment facilitated by a nurse Control group Placebo training experience identifying local services and resources</td>
<td>ComputerLink enhanced caregivers’ decision-making confidence (p&lt;0.01), however no improvements/changes in actual decision making skills or perceptions of social isolation were noted as a result of ComputerLink access</td>
<td>Significantly reduced emotional strain was experienced by caregivers with more informal support (family and friends) and for spousal caregivers Effects of solitary and communication functions - Use of communication function related to reduced strain for caregivers who reported more strain at start of study and non-spouse caregivers (adult children) - Use of solitary functions related to reduced strain for caregivers living alone with care receivers and for spouse caregivers ComputerLink use did not vary with education, race, length of time of caregiving, or relationship to care recipient</td>
</tr>
<tr>
<td>Brennan, Moore &amp; Smyth (1995)</td>
<td>Feasibility Study</td>
<td>Care recipients in both groups declined in health status</td>
<td>The mean age of ComputerLink users differed significantly (users: 56.5 yrs non-users: 66.4 yrs)</td>
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</table>

Table 3: On-Line Social Support Included Studies
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<tr>
<th>Study</th>
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<tbody>
<tr>
<td>Brennan, Moore &amp; Smythe (1991)</td>
<td>Feasibility Study</td>
<td>Feasibility Study</td>
<td>The mean age of ComputerLink users was 68 years</td>
<td>84</td>
<td>Participants reported using the network primarily for contacting others in a similar situation, obtaining information, emotional support, and for encouraging others Being able to contact from home, receiving numerous response and getting answers quickly facilitated participation</td>
</tr>
<tr>
<td>Fernsler &amp; Manchester (1997)</td>
<td>Survey Weak rating</td>
<td>54 Cancer Forum participants</td>
<td>84</td>
<td>Participants reported using the network primarily for contacting others in a similar situation, obtaining information, emotional support, and for encouraging others Being able to contact from home, receiving numerous response and getting answers quickly facilitated participation</td>
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<tr>
<td>McTavish, Gustafson, Ownes Hawkins et al. (1995)</td>
<td>Survey Weak rating</td>
<td>Eight impoverished African-American women with breast cancer in Chicago</td>
<td>Breast Cancer Support CHESS</td>
<td>Perceived limitations to the ESG were cost, time restraints and technical skills</td>
<td>Limitations Small sample therefore cannot be generalized to population Preliminary data show that poorly educated African American women were able to use CHESS</td>
</tr>
<tr>
<td>Study</td>
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<tr>
<td>Klemm, Hurst, Dearholt, &amp; Trone (1999)</td>
<td>Survey Weak rating</td>
<td>N=379 men and women from 3 Internet Support Groups</td>
<td>Three cancer internet support groups</td>
<td>Main content categories of 1,541 messages</td>
<td>Significant difference in type of message posted by gender (p&lt;0.0001)</td>
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<tr>
<td></td>
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<td>• Breast cancer group</td>
<td>Information giving/seeking</td>
<td>Info seeking ranked first for prostate and mixed groups</td>
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<td></td>
<td>• Prostate cancer group</td>
<td>Personal experience</td>
<td>Personal experience ranked first for breast cancer group</td>
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<td></td>
<td>• Mixed cancer group</td>
<td>Encouragement/support</td>
<td>Web cohorts therefore can not tell differences between groups</td>
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<td>Personal opinions</td>
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<td>Thanks</td>
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<td>Humour</td>
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<tr>
<td>Weinberg, Schmale, Uken &amp; Wessel (1996)</td>
<td>Survey Weak rating</td>
<td>Six women with breast cancer</td>
<td>Breast Cancer Support Computer-mediated support group via a private bulletin board over three months</td>
<td>Participants used the network primarily to discuss their medical and personal concerns rarely did the group members give factual or objective information made favourable statements about the group</td>
<td>Members' physical condition affected the amount of their network use</td>
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<td>Gustafson Wise, McTavish, Taylor et al. (1993)</td>
<td>Surveys of two Pilot Studies</td>
<td>1. 10 women with breast cancer</td>
<td>Breast Cancer Support CHESS</td>
<td>Examined usage patterns over a period of 50 days; 10 participants used 456 times in 50 days; 20 participants used CHESS 1,131 times in 70 days</td>
<td>Respondents preferred CHESS to other social services because of anonymity, freedom to express oneself, comprehensiveness, provision of support for many women</td>
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<td></td>
<td>Weak rating</td>
<td>2. 15 women with breast cancer</td>
<td>A multi-featured, anonymous program including • Questions and answers • Instant library • Ask an expert • Getting help/support • Discussion groups • Personal stories • Decision aids • Action plan</td>
<td>Examined preference for CHESS versus other support services</td>
<td>Focus of study was for user testing to aid CHESS program design</td>
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<td></td>
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<td></td>
<td>Discussion Group service used most often whereas decision support programs used least often</td>
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<td>Anecdotal reports that CHESS empowered women</td>
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Table 3: On-Line Social Support Included Studies
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</table>
| Brennan, Ripich & Moore (1991) | Survey Weak rating | N=26 men and women with AIDS                      | Persons Living with AIDS Phase 1  
  24 hour access to the FreeNet, a free, public access community computer network | Compared FreeNet use with Computer Link Log-ins occurred at all hours of the day and night | Anecdotal evidence reported an impact on cognitive, emotional and behavioural levels (increased confidence to confront physician re more information) More emphasis on self-disclosure Viewed computer network as a “safe space” FreeNet Major benefit according to participants was its rapid, easy access to a diverse social group ComputerLink Major benefit cited was its privacy and comprehensive clinical focus |
| Brennan & Ripich (1994)  | Controlled Clinical Trial Weak rating | N=51 men and women with AIDS  
  n=26 experimental group | Persons Living with AIDS ComputerLink  
  • Bulletin board  
  • Private mail system  
  • Decision support module  
  • Encyclopedia  
  • Question and answer forum | Communication features accessed most often; Private mail used most often (6,086 times); Forum posted 749 messages and users read messages more than 4,000 times The Encyclopedia and the Decision Support Module received little attention | Reports on experimental group Patterns of use settled into a “characteristic patterns of access” after two to three weeks; first week used three or more times per day, then, one to seven times per week. Importance of anonymity stressed |
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<tr>
<td></td>
<td>Controlled Clinical Trial</td>
<td>N=219 persons living with AIDS in Southern Wisconsin</td>
<td>Persons Living with AIDS CHESS - A multi-featured program including Communication • Discussion group (ESG) • Personal stories (PS) • Ask an expert (AE) Information • Instant library (IL) • Getting help/support (GH) • Analysis services • Decision aids • Action plan • Risk assessment</td>
<td>Two month follow up (cohorts 1,2,3) • Significantly more active life (p=0.034) • Decreased levels negative emotions (p=0.0013) • Better social support than controls who stayed the same or got worse than controls (p=0.074) • Cognitive functioning improved with CHESS (p=0.053)</td>
<td>CHESS Utilization Communication features used most (79% of all uses) There was little overall difference in CHESS use by demographically different groups (p&lt;0.01); Subjects rated CHESS very positively in terms of usefulness and ease of use Communication features Average use once per day • High variability in use patterns • Use distributed unevenly over time; (heavy use for first four weeks, gradual decline from week 5-11 followed by steady level between week 12 &amp; 26) • 34% of uses occurred between 9 p.m. and 7 a.m. when few other resources are available</td>
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<td>Gustafson, Hawkins, Boberg, Pingree, Serlin, Graziano, &amp; Chan (1999) (continued)</td>
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<td>Outcomes less than 3 months reported for Cohorts 1, 2, 3.</td>
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<td>Outcomes more than three months reported for Cohort 1.</td>
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<td>Quality of Life</td>
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<td>• Improved across a range of measures at three and six month implementation and maintained at nine month follow up</td>
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<td>• Where CHESS removed at three months, benefits not maintained in follow up</td>
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<td></td>
<td>• Focus on use and acceptance of CHESS</td>
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<td>Hospitalization</td>
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<td>• Control group number of hospitalizations increased during intervention period (p = 0.02)</td>
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<td>• When CHESS group hospitalization did occur, it was significantly shorter (p = 0.009)</td>
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<td>• No differences remained after CHESS was removed</td>
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<td>• Length of hospital stay lower for CHESS group and remained lower after CHESS removed</td>
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<td>Ambulatory Care Utilization</td>
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<td></td>
<td>• CHESS users had shorter visits than controls during intervention period (p= 0.043) however, no difference in number of visits to caregivers/ER noted</td>
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<td></td>
<td>• CHESS users significantly more likely than controls to phone providers during (p = 0.013) and after (p=0.094) computer installation</td>
</tr>
</tbody>
</table>

Table 3: On-Line Social Support Included Studies
REFERENCES


APPENDICES

Appendix 1: Quality Assessment Tool for Quantitative Studies
Appendix 2: Background Papers Reference List
Appendix 1:

Quality Assessment Tool For Quantitative Studies

COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?
   1  Very likely
   2  Somewhat likely
   3  Not likely
   4  Can't tell

(Q2) What percentage of selected individuals agreed to participate?
   1  80 - 100% agreement
   2  60 – 79% agreement
   3  less than 60% agreement
   4  Not applicable
   5  Can't tell

B) STUDY DESIGN

Indicate the study design
   1  Randomized controlled trial
   2  Controlled clinical trial
   3  Cohort analytic (two group pre + post)
   4  Case-control
   5  Cohort (one group pre + post (before and after))
   6  Interrupted time series
   7  Other specify _______
   8  Can't tell

Was the study described as randomized?
   No
   Yes

If NO, go to component C

If Yes, was the method of randomization described? (see dictionary)
   No
   Yes

If Yes, was the method appropriate? (see dictionary)
   No
   Yes

RATE THIS SECTION STRONG MODERATE WEAK
See dictionary 1 2 3
C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?
1 Yes
2 No
3 Can’t tell

The following are examples of confounders:
1 Race
2 Sex
3 Marital status / family
4 Age
5 SES (income or class)
6 Education
7 Health status
8 Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?
1 80 – 100%
2 60 – 79%
3 Less than 60%
4 Can’t Tell

D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?
1 Yes
2 No
3 Can’t tell

(Q2) Were the study participants aware of the research question?
1 Yes
2 No
3 Can’t tell

E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?
1 Yes
2 No
3 Can’t tell

(Q2) Were data collection tools shown to be reliable?
1 Yes
2 No
3 Can’t tell
F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and reasons per group?
1 Yes
2 No
3 Can’t tell

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).
1 80-100%
2 60-79%
3 less than 60%
4 Can’t tell

G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?
1 80-100%
2 60-79%
3 less than 60%
4 Can’t tell

(Q2) Was the consistency of the intervention measured?
1 Yes
2 No
3 Can’t tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?
1 Yes
2 No
3 Can’t tell

H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)
community organization/institution practice/office provider client

(Q2) Indicate the unit of analysis (circle one)
community organization/institution practice/office provider client

(Q3) Are the statistical methods appropriate for the study design?
1 Yes
2 No
3 Can’t tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?
1 Yes
2 No
3 Can’t tell

RATE THIS SECTION STRONG MODERATE WEAK
See dictionary 1 2 3
GLOBAL RATING

COMPONENT RATINGS

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<table>
<thead>
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<th>A</th>
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GLOBAL RATING FOR THIS PAPER (circle one)

1 STRONG  (four STRONG ratings with no WEAK ratings)
2 MODERATE  (less than four STRONG ratings and one WEAK rating)
3 WEAK  (two or more WEAK ratings)

WITH BOTH REVIEWERS DISCUSSING THE RATINGS:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No  Yes

If yes, indicate the reason for the discrepancy

1 Oversight
2 Differences in interpretation of criteria
3 Differences in interpretation of study

FINAL DECISION OF BOTH REVIEWERS (circle one):

1 STRONG
2 MODERATE
3 WEAK
Appendix 2: Background Paper Reference List


