

Primary care

Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions

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Abstract

Objective To compile and evaluate the evidence on the effects on health and social outcomes of computer based peer to peer communities and electronic self support groups, used by people to discuss health related issues remotely.

Design and data sources Analysis of studies identified from Medline, Embase, CINAHL, PsycINFO, Evidence Based Medicine Reviews, Electronics and Communications Abstracts, Computer and Information Systems Abstracts, ERIC, LISA, ProQuest Digital Dissertations, Web of Science. **Selection of studies** We searched for before and after studies, interrupted time series, cohort studies, or studies with control groups; evaluating health or social outcomes of virtual peer to peer communities, either as stand alone interventions or in the context of more complex systems with peer to peer components.

Main outcome measures Peer to peer interventions and co-interventions studied, general characteristics of studies, outcome measures used, and study results. **Results** 45 publications describing 38 distinct studies met our inclusion criteria: 20 randomised trials, three meta-analyses of n of 1 trials, three non-randomised controlled trials, one cohort study, and 11 before and after studies. Only six of these evaluated “pure” peer to peer communities, and one had a factorial design with a “peer to peer only” arm, whereas 31 studies evaluated complex interventions, which often included psychoeducational programmes or one to one communication with healthcare professionals, making it impossible to attribute intervention effects to the peer to peer community component. The outcomes measured most often were depression and social support; most studies did not show an effect. We found no evidence to support concerns over virtual communities harming people.

Conclusions No robust evidence exists on the effects of consumer led peer to peer communities, partly because most peer to peer communities have been evaluated only in conjunction with more complex interventions or involvement with health professionals. Given the abundance of unmoderated peer to peer groups on the internet, research is required to evaluate under which conditions and for whom electronic support groups are effective and

how effectiveness in delivering social support electronically can be maximised.

Introduction

One of the most promising aspects of the rise of ehealth is the widespread availability of electronic peer to peer community venues, where people with common interests gather “virtually” to share experiences, ask questions, or provide emotional support and self help. Virtual communities are social networks formed or facilitated through electronic media.¹ Although such communities already existed in the era before the world wide web (for example, in bulletin board systems and private networks that enable peer to peer communities), the primary medium for virtual communities today is the internet, in mailing lists, newsgroups or usenet discussion forums, web based discussion forums, and live chatrooms. Virtual communities can be seen as mental health and social support interventions. They often have the function and character of self support groups and are then also called electronic support groups. As of April 2004 Yahoo!Groups (www.yahoo.com) listed almost 25 000 electronic support groups in the health and wellness section. Although plenty of descriptive and anecdotal information exists on the potential benefits² and harms of online peer support,³ we sought evidence—beyond case studies and qualitative work—for the efficacy of virtual communities as stand alone or adjunct interventions in health care and their impact on health related outcome measures.

Methods

Inclusion and exclusion criteria

We sought randomised controlled trials, non-randomised controlled trials, and cohort studies to draw conclusions about effectiveness, as well as before and after studies to draw conclusions about promising interventions. We included studies, in any language,

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Tables A-D and appendixes 1-3 are on bmj.com

published in peer reviewed journals or “grey” literature (dissertations, government reports, etc) that met the following criteria. Firstly, the intervention studied was a virtual community, defined for the purpose of this study as a group of individuals with similar or common health related interests and predominantly non-professional backgrounds who interact and communicate publicly through a computer communication network such as the internet, or through any other computer based tool, allowing social networks to build over a distance. Secondly, the content focus of the virtual community was on health or healthcare issues in the broadest sense, including emotional and social support, health education, or health related behaviour change. Thirdly, the outcomes measured were knowledge, health, psychological or social outcomes, or use of health services. Fourthly, a control group (or a baseline measure) was present and outcome measures were reported.

Search strategy

We searched Medline, Embase, CINAHL, PsycINFO, Evidence Based Medicine Reviews, Electronics and Communications Abstracts, Computer and Information Systems Abstracts, Educational Resources Information Center, Library and Information Science Abstracts, ProQuest Digital Dissertations, and Web of Science (see bmj.com).

Results

Included studies

From all databases combined we identified and screened a total of 12 288 abstracts (see bmj.com). Forty five publications met our inclusion criteria, describing 38 distinct studies: 20 randomised controlled trials, three meta-analyses of *n* of 1 trials, three non-randomised controlled trials, one cohort study, and 11 before and after studies (see bmj.com).

Only six of these studies dealt with “pure” peer to peer interventions.⁴⁻⁹ One study had a 2×2 factorial design (full or control website combined with or without peer to peer group), enabling the comparison of a peer to peer group with a minimal co-intervention with other arms.¹⁰ The remaining 31 studies evaluated complex interventions where the virtual community was only an adjunct to a broader intervention that often included structured psychoeducational components or treatment programmes, entailed giving printed brochures or videos, computers or web television access to participants, incorporated decision support or one to one therapeutic relationships with health professionals, offered personal online diaries, or contained games (see bmj.com). Because of the multiple components within these interventions it is not possible to draw more generalisable conclusions about the value of online peer to peer communication from them.

Virtual communities evaluated as stand alone interventions

The six studies evaluating “pure” virtual communities were before and after studies evaluating web based discussion forums,⁵⁻⁹ a chat room,⁷ or a combination of a chat room and newsgroup,⁸ with one cohort study evaluating mailing lists⁶ and one non-randomised controlled trial evaluating a voice bulletin board system.⁴ We identified no randomised trials evaluating the

effects of peer to peer communities alone. We found one factorial design randomised controlled trial that compared the effects of the different components (including the peer to peer component) of a complex intervention with each other.¹⁰ The reporting of this trial is incomplete, however, as no P values for all comparisons are provided. Of the six studies, only one⁶ dealt with unmoderated venues; the remaining studies all reported some degree of facilitation by a health professional. With one exception, even studies coded as “stand alone” peer to peer interventions therefore had involvement from health professionals, with trained individuals leading the groups as moderators or facilitators by stimulating discussions, formulating questions, or posting topics of interest or educational material on the bulletin boards.

Impact of virtual communities on health and social outcomes

Depression and social support (each used in 12 studies) were the most commonly used measures (table 1). Only three studies, among them a before and after study and a cohort study, found significant improvements in depression scores, and nine studies (among them eight randomised controlled trials) did not find or report an intervention effect on depression. Similarly conflicting are the data for social support measures; five studies found significant effects and seven studies did not.

Measures of healthcare use were obtained in only three studies, with contradicting results: Alemi et al, evaluating a voice bulletin board, reported a significant decrease, Gustafson et al a significant increase in phone calls to providers.^{4 11}

Nine studies focused on structured weight loss or healthy body weight interventions with peer to peer components, again with mixed, but mostly non-significant, results. In one study the internet support group even sustained a significantly smaller weight loss than face to face support groups.¹²

Five studies evaluated communities for diabetic patients; four of them measured glycosylated haemoglobin as an outcome measure, which has repeatedly been shown to be responsive to educational and behavioural interventions in diabetes.¹³ Only one study (a before and after study without control) showed a significant improvement.¹¹

Six studies investigated the effect of smoking cessation programmes that included peer to peer groups. In a factorial design randomised controlled trial¹⁰ the effect of the two main components (psychoeducation programme on the website and peer to peer group) were evaluated separately. Abstinence rates after 1, 3, and 6 months in the arm with peer to peer group and minimal information intervention were slightly higher than in the arm with no peer to peer group and minimal information but no P values were reported (table 2). Abstinence rates were similar in the arm with peer to peer group and full psychoeducational intervention and the arm with no peer to peer group and full psychoeducational intervention. Similar to many other studies in this field, this randomised controlled trial had methodological problems, with more than half of the participants not responding to follow up surveys and low usage of the intervention (less than 10% used the intervention).

Table 1 Summary of most often used outcome measures except smoking and their results

Outcome	Instrument	Study identifier (author, year, first page No; see table A on bmj.com for references)	Design	Significance level*		
Depression	Centre for Epidemiological Studies depression scale (CES-D)	Barrera 2002-McKay 2002	RCT	NS		
		Bass 1998-Casper 1995-Brennan 1995-McClendon 1998	RCT	NS		
		Brennan 1998-489	RCT	Not reported		
		Glasgow 2003-410	RCT	NS		
		Houston 2002-2062 ("pure" peer to peer intervention)	Cohort study	P<0.05†		
		Lieberman 2003-920 ("pure" peer to peer intervention)	Before and after study	P<0.001‡		
		McKay 2001-1328	RCT	NS		
		Tate 2001-1172	RCT	Not reported		
		Tate 2003-1833	RCT	Not reported		
		Winzelberg 2003-1164	RCT	P<0.01†		
		Beck depression inventory	Quick 1999-Thesis ("pure" peer to peer intervention)	Before and after study	NS	
		Medical outcome survey	Gustafson 1999-1	RCT	NS	
Social support	Modified 6 items from interpersonal support evaluation list (ISEL)	Barrera 2002-McKay 2002	RCT	P<0.05†		
		Instrumental and expressive social support (IESS) scale	Bass 1998-Casper 1995-Brennan 1995-McClendon 1998	RCT	NS	
		4 item social support scale adapted from multidimensional scale of perceived social support (MPSS)	Celio 2000-650	RCT	NS	
		5 point scale developed by the authors	Gustafson 1999-1	RCT	P<0.05†	
		6 item social support scale	Gustafson 2001-435	RCT	P<0.01†	
		"Perceived support from friends and relatives"	Hamman 2002-Thesis ("pure" peer to peer intervention)	Before and after study	NS	
		"Number of peer contacts initiated by group members"	Harvey-Berino 2002-103	RCT	NS	
		Perceived social support-friends scale	Hazzard 2002-69	Controlled clinical trial	P<0.05†	
		Medical outcomes study social support survey	Houston 2002-2062 ("pure" peer to peer intervention)	Cohort study	NS	
		"Increased perception of support from peers"	Johnson 2001-E24	Before and after study	P<0.05‡	
		Perceived social support scale	Lacoursiere 2003-Thesis	Controlled clinical trial	NS	
		Online social support scale	Zabinski 2001-129	Before and after study	Not reported	
		Healthcare use	Fewer phone calls to doctors	Alemi 1996-32	Controlled clinical trial	P<0.05†
		More phone calls to providers	Gustafson 1999-1	RCT	P<0.05†	
		Visits to emergency departments	Gustafson 1999-1	RCT	NS	
Non-emergency visits	Gustafson 1999-1	RCT	NS			
Shorter duration of hospital visits	Gustafson 1999-1	RCT	P<0.05†			
Fewer hospital admissions during intervention	Gustafson 1999-1	RCT	P<0.05†			
Doctor's visits	Lorig 2002-792	RCT	NS			
Eating disorder	Eating disorder examination questionnaire (EDE-Q)	Celio 2000-650	RCT	P<0.01†		
		EDE-Q-weight/shape subscale	Winzelberg 1998-339	RCT	NS	
		Winzelberg 2000-346	RCT	NS		
		Zabinski 2001-401	RCT	NS		
		Zabinski 2001-129	Before and after	P<0.05‡		
		Eating disorder inventory (EDI) drive for thinness subscale	Celio 2000-650	RCT	P<0.05†	
		Winzelberg 1998-339	RCT	NS		
		Winzelberg 2000-346	RCT	P<0.05†		
		Zabinski 2001-401	RCT	NS		
		Zabinski 2001-129	Before and after study	P<0.05‡		
		EDI bulimia subscale	Winzelberg 1998-339	RCT	NS	
		Winzelberg 2000-246	RCT	NS		
		Zabinski 2001-401	RCT	NS		
		Zabinski 2001-129	Before and after study	NS		
		Body mass index (BMI)	Winzelberg 1998-339	RCT	NS	
Zabinski 2001-401	RCT	NS				
Zabinski 2001-129	Before and after study	NS				
Weight loss	Body weight	Harvey-Berino 2002-103	RCT	NS		
		Harvey-Berino 2002-1254	RCT	P<0.05†§		
		Tate 2001-1172	RCT	P<0.05†		
		Tate 2003-1833	RCT	P<0.05†¶		
Diabetes control	Glycosylated haemoglobin	Barrera 2002-McKay 2002	RCT	NS		
		Glasgow 2003-410	RCT	NS		
		Hamman 2002-Thesis ("pure" peer to peer intervention)	Before and after study	NS		
		lafusco 2000-1853 ("pure" peer to peer intervention)	Before and after study	P<0.001‡		

For a complete list of all outcome measures and their results see table C on bmj.com.

All P values refer to a within group comparison (before and after a peer to peer intervention or complex intervention with peer to peer component) or a between group comparison between an arm with peer to peer intervention or complex intervention and an arm without peer to peer intervention or complex intervention. A significant finding usually means significant differences in favour of a peer to peer intervention (or intervention with peer to peer component), unless otherwise indicated.

*NS=non-significant at P<0.05 level.

†Differences between groups for randomised controlled trials, controlled clinical trials, cohort studies.

‡Differences within groups (before and after, person to person intervention).

§Favouring face to face support over internet group. ¶When considering control group (peer to peer support) as before and after design.

Table 2 Summary of outcome measures for smoking and their results

Smoking	Duration of abstinence, measured	Study identifier (author, year, first page No; see table A on bmj.com for references)	Design	% abstinent (of all participants who started the intervention)
	For 7 days at 3 months	Feil 2003-189	Before and after study	18%
	For 7 days at 4 and 12 weeks after enrolment	Johs-Artisensi 2002-Thesis	RCT	4%, 30% (NS)*
	For at least 3 months	Schneider 1986-274	Before and after study	31%
	For at least 3 months	Schneider 1986-277	Before and after study	25%
	After 1, 3, and 6 months	Schneider 1990-141 ("pure" peer to peer intervention)	RCT	6.8%, 5.5%, 9.3% (NR)†
	In the past week at baseline, after the intervention, and 1 month after intervention	Woodruff 2001-239	Before and after study	7.7%, 15.4%, 23.1%

*NS=not significant at P<0.05 level. Compared with brochure only (18%, 32%). Authors also report 24 hour abstinence rates.

†Abstinence rates at each of the three points in time in the arm with peer to peer group and minimal psychoeducational intervention, compared with abstinence rates in the control arm (no peer to peer group and minimal psychoeducational intervention), which were 3.6%, 2.9%; and 7.6%. NR=significance level for this comparison not reported.

Quality of studies

Among the 20 randomised controlled trials, only three trials described their randomisation methods in sufficient detail to permit the ascertainment of allocation concealment. One randomised controlled trial had used a clearly inappropriate randomisation method, using the last digit of the Compuserve ID to determine the intervention.¹⁰ All studies were necessarily unblinded and most outcomes self reported. Intention to treat analysis had been conducted for only eight randomised controlled trials.

Discussion

Despite extensive searches in the health, social sciences, communication, and informatics literature we failed to find robust evidence on the health benefits of virtual communities and peer to peer online support. In 31 studies investigators evaluated complex interventions, making it impossible to draw conclusions on the effectiveness of "pure" electronic peer to peer interactions as used daily by millions of people participating in internet discussion groups or mailing lists. The six studies that investigated peer to peer communication as stand alone interventions tended to have less than optimum research designs with few participants.

Possible explanations

The absence of evidence does not mean that virtual communities have no effect. Several explanations are possible for the lack of studies and evidence. Firstly, there is little commercial or professional interest in evaluating "pure" virtual communities and "unsophisticated" peer to peer interventions such as mailing lists, as opposed to more complex interventions or interventions led by health professionals. Secondly, studies investigating "natural" self helping processes are difficult to recreate in controlled research environments. Many studies seemed underpowered, and only five provided sample size calculations or justifications. Another possible explanation for the failure of many authors to show an effect of virtual communities is that participants may need to have the intrinsic desire to communicate with other people in order for virtual communities to be beneficial. Participants in self help groups may be a self selected subgroup in whom self help processes are effective, and researchers "recruiting from the street" may be looking at the wrong populations. A third possible (but related) reason could be lack of participants' "compliance." Some investigators reported that the virtual community component

was not heavily used,^{5 14-16} making it difficult to show an effect.

No negative effects reported

It has been argued that online relationships are less valuable than offline ones and detract from social involvement with friends.¹⁷ Concerns have also been raised over quality,¹⁸⁻²⁰ extreme verbal inhibition and aggression,^{21 22} hoaxes and spam,²³ encouragement of suicide,²⁴ and privacy issues²⁵ on internet groups. In studies included for this review, no negative effect or harm has been reported. Also here the absence of evidence does, however, not mean that such harm does not exist.

In view of the wide variation in interventions, measurement tools, and populations studied, and the lack of methodological rigour in the majority of studies reviewed, the effect of online support groups on health related outcomes and healthcare resource use remains unclear.

Limitations

Only one database (LISA) has a subject heading for virtual communities; we may therefore have missed more complex ehealth systems or interventions that have peer to peer components if these were not evident from the abstract or title. However, we are unlikely to have overlooked studies evaluating "pure" electronic peer to peer interventions, and the paucity of such studies is striking.

Another concern is publication bias, which we attempted to minimise by including five dissertations. Their inclusion in this systematic review proved to be crucial. Interestingly, the four dissertations with "negative" (non-significant) findings remained unpublished whereas the one dissertation with positive results was published as a journal article.

Implications for future research

Virtual communities are promising interventions, used everyday by millions on the internet. Little is known about the conditions and factors (of the group or individual) influencing outcomes. Whether virtual communities benefit from professional (or laypersons') moderation or facilitation is not clear either. With the exception of two studies, all investigators used professionally moderated or facilitated groups, or the level of moderation remained unclear. It is not clear whether virtual communities can substitute or complement face to face support groups. One study compared a computer mediated (voicemail) support group with a face to face group, noting that participation rates were significantly higher in the virtual

What is already known on this topic

Thousands of electronic health related peer to peer support groups in the form of mailing lists, chat rooms and discussion forums are available on the internet

Anecdotal evidence shows that electronic peer to peer self help groups might be beneficial interventions, although some also warn of the dangers of such groups

To our knowledge, no systematic synthesis of the effects of peer to peer support groups has been conducted to date

What this study adds

Numerous controlled studies with peer to peer components have been conducted, but only a few evaluated the effect of peer to peer groups alone

Most studies failed to show an effect, or effects were confounded by potential effects of co-interventions

Quantitative studies with factorial design or evaluating pure peer to peer interventions are needed to provide robust evidence on the effects of peer to peer support groups

group,⁴ but another study showed that virtual groups may be less effective than face to face groups to sustain weight loss.¹³ In terms of the outcome measures used, future studies should also include measures of resource use, as it is currently not clear whether participation in a peer to peer group reduces or increases the use of health care.

Given the abundance of unmoderated peer to peer groups on the internet, researchers must focus their efforts not only on sophisticated professionally led systems, but shift their attention to consumer led, self help venues. Perhaps in this way the research community can best help consumers to help themselves, a guiding principle of support groups regardless of the venue in which they occur.

Contributors: See bmj.com.

Competing interests: None declared.

Note about process: While GE has the same departmental affiliation and works (with AS and CR) in the same centre as Alejandro Jadad, guest editor of this theme issue, it was submitted to the *BMJ* in the normal way, and Jadad neither played any part in the decision making over this paper, nor was he involved in conception or conduct of this study.

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Corrections and clarifications

Recurrent hypoglycaemia in a diabetic patient as a result of unexpected renal failure

In this Lesson of the Week by Malvinder S Parmar (10 April, pp 883-4), the first sentence of the final paragraph should read: "In chronic, progressive renal failure the physician is aware of the risk of hypoglycaemia and adjusts the dose of insulin or hypoglycaemic agents accordingly."

Poor more likely to smoke and less likely to quit

In this News Extra article on bmj.com by Roger Dobson (17 April) we reported on a study published in the *Journal of Public Health*. A reader wondered if this was a mistake and whether the journal was not in fact the *Journal of Public Health Medicine*. The *Journal of Public Health Medicine* seems to have changed its name, however, from the March 2004 issue—to the *Journal of Public Health*. The correct reference to the news article is the *Journal of Public Health* (2004;26(1)13-8).

Efficacy and safety of antidepressants for children and adolescents

When the references were renumbered to take account of a new reference in this clinical review by Jon N Jureidini and colleagues (10 April 2004, pp 879-83), a reference in the table escaped our notice. The reference for the FDA (Food and Drug Administration) data on funding of trials should be numbered 21 (not 20, as published).