

**Effects of Web based cancer support resources use on cancer affected people:
A systematic literature review**

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Abstract

To lay the groundwork for understanding the impact of web based support resources use on cancer affected people and devising plans for taking advantage of rapid development of internet technology for health purposes we conducted a systematic literature review. Studies published between 1993 and 2014 that presented empirical data addressing the effects of access to web based support resources on health and psychological aspects of cancer affected people were undertaken in this systematic review. We use the term cancer affected people to refer to people who have ever been diagnosed with cancer. We used Science Direct, Springer Link, IEEE Explore, Google Scholar, and expert consultation to select articles, thirty five (35) of which met the selection criteria. Results showed the use of web based support resources by cancer affected people enabled them to archive health and psychological related benefits. The most common benefits were better confident, enhanced satisfaction and self-esteem, improvement in wellbeing and quality of life, increased optimism, reduction in depression, feeling empowered, become more active in their treatment and experiencing better health status. This review may motivate different health suppliers, such as health care organizations, to develop web based support systems into their care and post-care programs. This review revealed that previous studies extremely focused on websites, online forums, email listservs, bulletin boards and blogs as web based resource, and other web based support resources such as Social Networking Sites have been neglected in past research. This review will help investigators set priorities for future research on Social Network Sites as web based support resource for cancer affected people.

Key words: Systematic literature review, web based support resources, cancer affected people

1. Introduction

World Wide Web is used as a resource for both health related informational and emotional support.¹ Web based information and emotional support resources are static webs (Web 1.0) that support one way information dissemination, and dynamic web (Web2.0 applications) that enables internet users to exchange informational and emotional support via interactive communication.²

Web based resources have capability of convenience, availability and anonymity that foster information and emotional support disseminations.³ Studies have shown cancer affected people, people who have been diagnosed with cancer, use web to search cancer related information and to exchange emotional support.⁴ Studies have suggested that access to web based resources has positive effects on cancer affected psychology and health.⁵

It's important to develop general understanding about the effect of web based resources on cancer affected people to further develop the web based resources for cancer affected people. In addition, given the high prevalence of cancer and suffering resulting from diagnosis and subsequent treatment, it's essential to keep up with new web based technologies that have the potential to positively affect cancer affected people.⁶ A reasonable response to further develop of the web based cancer support resources is: first aggregate and examine the existing web based resources and then make recommendation for future. To this end we conducted a formal, systematic literature review which is a means of identifying, evaluating and interpreting all existing research related to a topic area.⁷

The effects of web based cancer support resource on cancer affected people, which is a summary of this review, is presented in the format of conceptual framework. The result may play an integral role in clarifying the positive consequences, health and psychological aspect, of the use of web based support resources for cancer affected. The latter may inform the design of future intervention trails for applying new web based support resources for improving cancer affected people's health and psychology.

The methodology we employed for the task of summarising and giving structure to evidence is widely cited and proposed by Kitchenham, which includes planning the review, conducting the review and reporting the review.⁸ This method helped us to present a rational evaluation of the research topic. This paper outlines the method of systematic literature review, the findings and the expected contributions and suggestions for future research.

2. Method

Kitchenham's methodology has three phases including planning the review, conducting the review, and reporting the review. Each phase has several steps that are described in detail in the following paragraphs.

2.1 Planning the review

Planning review encompasses identifying the questions that review will address. The present study has carried out a systematic literature to address the following research questions:

RQ1: How does the use of web based cancer support resources impact cancer affected people's health and psychology?

The aim of undertaking a systematic literature review is not only collecting all existing evidence on a research question but also providing an evidence-based guideline for practitioners⁹. Accordingly, this study intended to answer the following questions as well:

RQ2. What are the characteristics of the current studies that focused on the effects of web based cancer support resources on cancer affected people?

RQ3. What type of web based support resources have been used in existing studies?

RQ4. What type of cancer affected people were target population?

RQ5. What research design has been applied in the existing studies?

The second step in planning the review was developing a protocol: Protocol encompasses search strategy (identifying search terms, and selecting essential resources and databases for search), study selection criteria (including area and excluding area), and data extraction strategy and the procedures for extracting the information from each study. The purpose of developing protocol was to decrease the possibility of the researcher's bias.

The third step of planning the review was reviewing the protocol: In this step, three independent experts with expertise in conducting systematic literature reviews assessed the protocol, and any ambiguities in the protocol were rectified.

2.2 Conducting the review

The review was conducted in the following three steps.

2.2.1 Conducting search strategy

In this step a set of search terms were used for addressing the research questions of this study. The search terms were selected through breaking down the research question into mediation and outcome.

Evidence from literature showed that various terms such as 'online support communities', 'virtual support communities' and 'online support resources' were applied in the literature for web based support

resources.¹⁰ Moreover, terms cancer patients and cancer survivors were used for people affected by cancer. Accordingly, 'cancer survivors', 'cancer patients', 'online support communities', 'virtual support communities' were also considered as search terms.

First an inductive search was conducted through searching the above terms in four major electronic databases: Science Direct, Springer Link, IEEE Explore and Google Scholar. In addition, a manual search of specific conference proceedings and journal papers since 1993 was conducted. The mentioned databases were selected because they were known to introduce empirical studies and to have been used as sources for other studies in the information system field. Studies that were published from 1993 to 2014 have been considered in this review because 1993 was the time that the web became available for free to the public.¹¹ This search initially identified 725 articles. Next, a deductive search was manually conducted; the list of references from review papers and book chapters were reviewed and experts were consulted to identify further items, and additional sources of evidence were added to the search results.

2.2.2 Study selection

The objective of this step was to filter the relevant studies from the initial pool of 725 articles in the previous step. This stage includes two main activities:

Study selection criteria. To address the research questions we identified the number of articles that present data arguing the impact of web based cancer support resources on health and psychological aspect of cancer affected people. Inclusion and exclusion selection criteria were used to filter those studies that provided direct evidence for the research questions of this study. Two inclusion selection criteria were used: (1) empirical studies that explicitly report the effects, health or psychology improvement, of access to web based support resources on cancer affected people (2) studies that were peer-reviewed or were published as peer-reviewed work. The exclusion criteria that were used in this study were: (1) studies that did not report an implicit consequence, health or psychology improvement, from using web based support resources (2) studies that were not written in English, and (3) studies that focused on young cancer affected people.

Study selection process. Firstly, abstracts of all 725 papers were reviewed. Using the exclusion criteria, 633 studies were excluded from this study and only 92 articles were retained. The full texts of these 92 articles were then reviewed carefully and the two inclusion criteria were used to filter the most relevant papers. This resulted in only 31 articles. Secondly, a deductive search was conducted by reviewing the reference lists of the chosen 31 articles. This resulted in finding 4 additional articles.

2.3 Data extraction

The 35 included studies were abstracted. For this purpose, data extraction forms were developed to effectively record detailed methods and results from each study to address questions presented in the current study. Data was extracted by one of the researchers and checked by another, and when there was a disagreement the issue was discussed until agreement was reached. The data extracted from each study were:

- The source (journal or conference) and full reference.
- Classifications of web based cancer support resources that were used in the existing studies.
- Summary of the study including the main research questions and the answers.
- Research design that was applied and people who were the study population.

2.4 Data synthesis

Information that could cover the research questions of the current study were synthesised and stored in data extraction forms. Data was tabulated to show:

- Reported consequences, health and psychological benefits, from using web based support resources (addressing SRQ1).
- The characteristics of reviewed articles (addressing SRQ2).
- Type of web based cancer support resources that were used (addressing SRQ3).
- Target population and type of cancer that was used (addressing SRQ4).
- Applied research design in studies under review (addressing RQ5).

3. Reporting the review

This section summarises the result of the study and discusses the answer to research questions.

3.1 Search results

Table 1 shows the results of the search procedure. We identified 365 empirical studies that explicitly report the effects of web based support resources use on cancer affected people.

As can be seen from table 1, Psycho-Oncology journal, health communication, and Journal of

General Internal Medicine published 2 studies. Other journals published 1 study, thus it appears that there is a need to encourage other journals to publish studies related to the using web based cancer support resources by cancer affected people .

Table 1. Web based cancer support resources studies

Stud	Author(s)	Journal
S1	Gustafson et al ¹²	Journal of Psychosocial Oncology
S2	Weinberg et al ¹³	Social Work with Groups
S3	Weinberg et al ¹⁴	Health & Social Work
S4	Klemm et al ¹⁵	Computers in Nursing
S5	Gustafson et al ¹⁶	Quality in health care: OHC
S6	Gustafson et al ¹⁷	Journal of General Internal Medicine
S7	Gustafson et al ¹⁸	Journal of General Internal Medicine
S8	Fernsler and Manchester ¹⁹	Cancer practice
S9	Shaw et al ²⁰	Journal of health communication
S10	Shaw et al ²¹	Health Education Research
S11	Shaw et al ²²	Health Communication
S12	Wise et al ²³	Patient education and counseling
S13	Fogel et al ²⁴	Health Psychology
S14	Fogel et al ²⁵	Psycho-Oncology
S15	Fogel et al ²⁶	Cyberpsychology and Behavior
S16	Lieberman et al ²⁷	Cancer
S17	Winzelberg et al ²⁸	Cancer
S18	Meier et al ²⁹	Med Internet Res
S19	Owen et al ³⁰	Annals of Behavioral Medicine
S20	Changrani et al ³¹	Prim Psychiatry
S21	Hoybye et al ³²	Psycho-Oncology
S22	van Uden-Kraan et al ³³	Qualitative Health Research
S23	Beaudoin and Tao ³⁴	CyberPsychology & Behavior
S24	Vilhauer et al ³⁵	Women & health
S25	Høybye et al ³⁶	British journal of cancer
S26	Rodgers et al ³⁷	Journal of ComputerMediated Communication
S27	Shim et al ³⁸	Journal of Communication
S28	Lobchuk et al ³⁹	Cancer nursing
S29	Stephen et al ⁴⁰	Social Science & Medicine
S30	Bender et al ⁴¹	Patient education and counselling
S31	Campbell et al ⁴²	International Journal of Web Based Communities
S32	Osei et al ⁴³	Nursing
S33	Vlahovic et al ⁴⁴	Conference on Human factors in computing systems
S34	Wiljer et al ⁴⁵	Journal of Cancer Education
S35	Vilhauer ⁴⁶	Palliative and supportive care

3.2 The characteristics of current studies on web based cancer support resources

Table 2 summarises the study characteristics. While we searched for papers published from 1993, there were few academic studies that focused on the web

based cancer support resources. As can be shown in table 2, the earliest study was published in early 1994.

Table 2. Characteristics of reviewed articles

ID	Date	Country
S1	1994	USA
S2	1996	USA
S3	1996	USA
S4	1998	USA
S5	1999	USA
S6	2001	USA
S7	2005	USA
S8	1996	USA
S9	2000	USA
S10	2007	USA
S11	2007	USA
S12	2008	USA
S13	2002	USA
S14	2003	USA
S15	2004	USA
S16	2003	USA
S17	2003	USA
S18	2007	USA
S19	2005	USA
S20	2008	USA
S21	2005	Denmark
S22	2008	Netherland
S23	2007	USA
S24	2009	USA
S25	2006	Denmark
S26	2007	USA
S27	2011	USA
S28	2014	USA
S29	2014	Netherland
S30	2104	Canada
S31	2013	UK
S32	2013	USA
S33	2014	USA
S34	2011	Canada
S35	2013	USA

It is apparent from data in Table 2 and chart 1 that publishing studies on web based cancer support resources for cancer affected people had fluctuation with upward and downwards trend. It suggests that there is a need to provide an overview of the effect of web based support resources use on cancer affected people and encourage more researchers for investigating further web based intervention for cancer affected people.

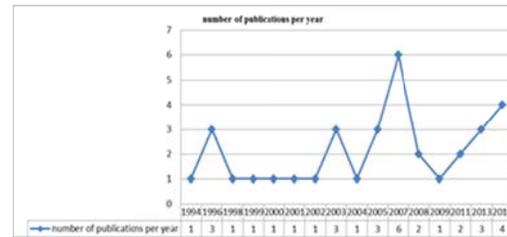


Chart 1. Publication trend of reviewed studies

Table 2 and Char 2 shows that in overall the set of studies are dominated by American researchers, so that majority (n=28) of existing studies were conducted primarily in the USA and the remaining studies were conducted in countries like Canada, Denmark and Netherland. None of the studies was conducted in a developing country, which shows a lack of research in this area in these countries. Further studies should be conducted in order to enhance the understanding of developing countries about the positive impact of web based cancer support recourses.

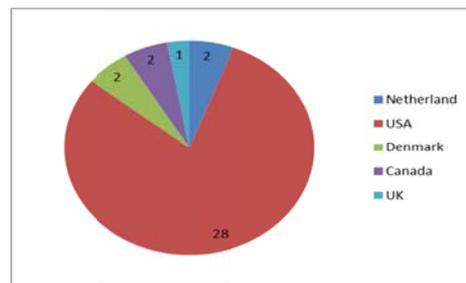


chart 2. Location of the studies

3.3 What kind of web based support resource has been used as a sampler and who were the study population?

With respect to type applied of web based support resource in the published studies; as shown in Table 3, the majority of studies examined the impact a of web based support resources such as chat rooms ,discussion forums, blogs and websites on cancer affected people. Despite the increase in use of Social Networking Sites, the latest web 2.0 application, by cancer affected people ⁴⁵ none of the studies focused on the impact of Social Networking Sites use for the health and psychological purpose of cancer affected people. This is becoming more important as currently there is a rapid growth in the emergence cancer related Social Networking Sites ⁴⁶ Therefore, special attention should be paid to the users of other categories of web based support recourses.

In addition as can be seen from table 3, majority of published studies have extremely used women with breast cancer as their sample for studies. However, web based cancer support resources attract people with other cancer. To illustrate, a recent research demonstrated widespread web based cancer support resources are emerged that enables people affected

by ovarian cancer to develop peer and mentor relationship for informational and emotional purposes.⁴⁷ Future studies are encouraged to consider other populations affected by cancer, men and women cancer, to test whether previous findings generalise to other populations.

Tables3 Target population and type of web based cancer support resource

ID	Target population	Type of Online support resource
S1	Breast cancer affected people	Health enhancement support system(CHESS)
S2	Breast cancer affected people	Bulletin board
S3	Breast cancer affected people	Bulletin board
S4	Prostate and breast cancer affected people	Internet cancer support group(ICSG)
S5	Low income breast cancer affected people	CHESS
S6	Low income breast cancer affected people	CHESS
S7	Low income breast cancer affected people	CHESS
S8	Various cancer affected people	Home based computer support group
S9	Breast cancer affected people	CHESS
S10	Breast cancer affected people	CHESS
S11	Breast cancer affected people	CHESS
S12	Breast cancer affected people	CHESS
S13	Breast cancer affected people with recent diagnosis	General Internet use
S14	Breast cancer affected people with recent diagnosis	General Internet use
S15	Breast cancer affected people with recent diagnosis	General Internet use
S16	Breast cancer affected people	Online cancer forum
S17	Breast cancer affected people	Home based computer support forum
S18	Various cancer affected people	Cancer listservs
S19	Early stage breast cancer affected people	Online coping group
S20	Early stage breast cancer affected people	website
S21	Breast cancer affected people	Email list
S22	Breast and arthritis cancer affected people	Electronic support group
S23	Various cancer affected people	General Internet use
S24	Metastatic breast cancer affected people	Electronic support group
S25	Various cancer affected people	Online chat rooms, discussion rooms
S26	Breast cancer affected people	Online discussion boards
S27	Gynaecologic cancers	Online support groups
S28	Breast cancer affected people	Electronic support groups
S29	Various cancer affected people	synchronous groups using live chat
S30	Breast cancer	Online communities
S31	Prostate cancer	Online forum
S32	Prostate cancer	Electronic cancer support group
S33	Breast cancer	Discussion board
S34	gynaecologic cancer	Computer based group
S35	Breast cancer	Mailing list

3.4 What research design has been employed in the current studies?

With respect to research design, most of reviewed studies used a cross-sectional research design, they have not employed a long-term follow-up approach, hence they are unable to show the long-term impact of the use of web based cancer

Support resources on cancer affected people. Future studies need to employ more longitudinal investigations.

Table 4. Research design of reviewed studies

ID	Research design
S1	Pre-post Interview
S2	Qualitative interview
S3	Qualitative interview
S4	Qualitative content analysis
S5	Pre post Interview
S6	Pre-post Interview
S7	Pre-post Interview
S8	Cross sectional survey
S9	Pre post Interview
S10	Pre-post Interview
S11	Pre-post Interview
S12	Pre-post Interview
S13	Cross- sectional Survey
S14	Cross- sectional Survey
S15	Cross- sectional Survey
S16	Pre post survey
S17	Pre post survey
S18	Qualitative content analysis
S19	Randomized control trial
S20	Randomized control trial
S21	Qualitative interview
S22	Survey and interview
S23	Cross- sectional survey
S24	Survey and interview
S25	Randomized control trial
S26	Qualitative-Longitudinal
S27	Qualitative
S28	Quantitative
S29	Qualitative
S30	Mixed method
S31	Qualitative
S32	Quantitative -Longitudinal
S33	Qualitative Content analysis
S34	Qualitative Interview
S35	Content analysis

3.5 What is reported health and psychological benefits derived from the use of web based cancer support resources?

With respect to the health and psychological consequences resulted from the use of web based cancer support resources, the most common benefits that were reported were: increase in hope, catharsis, better empowerment, fewer negative emotions, better health care participation, better self-reported quality of life, less loneliness, improvement in emotional wellbeing, reduction in depression and reaction to pain, better emotional wellbeing, better confident, increased optimism and control, satisfaction, enhanced self-esteem and social well-being.

Taken together we were able to assemble the building blocks for a preliminary conceptual framework of web based cancer support resources and cancer affected people (Figure1). This framework suggests that web based cancer support resources have the positive effects on health and psychological aspects of cancer affected people. Yet this preliminary framework does not show, and does not intend to show, the factors that mediate the relationship between web based support resources and health and psychological aspect of cancer affected people. In addition examining the level of causality between factors has left it for future research to discuss and empirically investigate.

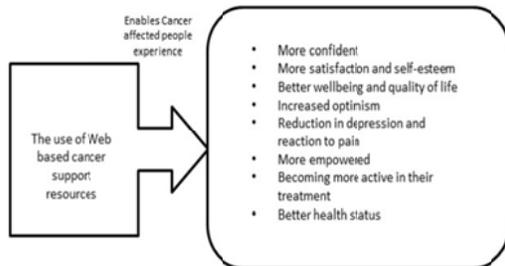


Figure 1. Conceptual framework of web based support resources and cancer affected health out come

4. Conclusion

This study demonstrates inconclusive evidence for positive effects of the use of web based support resources on cancer affected people. Two main contributions may be drawn from this review. Firstly, contributions to the literature; the result of this review has implications for the development of better understanding of the positive and integral role of web based support resources for improving cancer affected health and psychological purposes. So as findings demonstrated that access to web based resources is likely to lead to cancer affected people experiencing higher level of wellbeing and quality of life, reduction in depression and reaction to pain, wanting to become more active in their treatment and experiencing better health status.

Secondly, this study has practical implication; so as the current study highlighted health related benefits resulted from the use of web based cancer support resources in the format of a conceptual framework. This provides evidence to further web based support resource interventions for health and psychological purposes and may motivate different health suppliers, such as health care organisations, to develop web based support systems into their care and post-care programs.

Moreover this study suggests existing studies have limitations that pave the road for future studies. For example, this review showed that existing studies have narrowed the web based cancer support resources to websites, online forums, email listservs, bulletin boards and blogs. It is now apparent that the effect cancer related Social Network Sites have not been investigated for the health and psychological aspects of cancer affected people. Future studies need to investigate the effect of Social Networking Sites as web based support resources for the health and psychological purpose of cancer affected people.

Furthermore, this study revealed that the majority of published studies have extremely used one subset of the cancer affected people, women with cancer, as their study population. The latter suggests an urgent need of investigating the effect of web based support resources on the other categories of type cancer affected people.

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