Cancer peer support programs: do they work?

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CRD summary
This review examined the effectiveness of volunteer-delivered peer support programmes for patients suffering from cancer. The authors concluded that there were consistent positive benefits of 'real life' peer support, but these conclusions do not fully reflect the findings from the randomised controlled trials. In addition, a lack of methodological rigour in all included studies further weakens the reliability of the conclusions.

Authors' objectives
To examine the effectiveness of volunteer-delivered cancer peer support programmes.

Searching
Cancerlit, PubMed, PsycINFO, CINAHL, the Cochrane Library and DARE were searched. The search strategy used pertinent search terms, which were reported in the review. Reference lists were checked, the journals Cancer and Cancer Practice were searched, and three experts who have published widely in this field were contacted. Only papers published in English-language peer-reviewed journals between January 1980 and February 2002 were included in the review.

Study selection
Study designs of evaluations included in the review
The review included only evaluation studies, defined as 'a systematic acquisition and assessment of the activities, characteristics or outcomes of a (programme)'. Both formative (e.g. needs assessments) and summative (e.g. outcome evaluations) studies were included. The reviewed studies included needs assessments, exploratory and purposive interviews, participant observation, focus groups, surveys with and without a comparison group and RCTs.

Specific interventions included in the review
Studies of cancer peer support programmes were eligible for the review. These were defined as peer support programmes provided by volunteer cancer survivors to cancer patients. Only support programmes in which it was clearly articulated that the role of the health professionals was facilitative non-directive were included. The interventions actually reviewed included support groups, one-to-one visitor programmes, computer support groups, telephone support groups and support services, the exact nature and process of which were not reported in the review. Most of the studies were of small (6 to 57) groups of participants, although a few were larger (157 to 350 participants) and one was of multiple groups (54 Florida Man to Man groups).

Participants included in the review
Studies of patients with cancer were eligible for the review. Studies of programmes directed at adolescents or caregivers were excluded. The included studies were of patients with breast cancer, prostate cancer, melanoma, Hodgkin’s lymphoma and all cancers. Most of the participants were highly educated, middle class, married and younger than the at-risk population (with the exception of prostate cancer). The age range of the study populations were from mid 20s, 30s or 40s to 70s. With the exception of one telephone and one internet group, support groups that were not specific to breast cancer or prostate cancer generally comprised about 70 to 80% females. Around half of the participants were employed either full- or part-time, but race or ethnic origins were not reported in most studies. The time since the diagnosis of cancer ranged from 3 to 8 years for 39 to 69% of the participants.

Outcomes assessed in the review
Inclusion criteria for the outcome measures were not specified. The outcome measures reported in the review varied; generally they pertained to patient satisfaction, improved knowledge, perceived benefits, perceived experiences, particularly in relation emotional, psychological needs and quality of life. Qualitative data were included. The randomised controlled trials (RCTs) used measures of quality of life, body image, psychological morbidity, and...
How were decisions on the relevance of primary studies made?
Two researchers with experience in systematic reviewing and oncology and supportive care independently reviewed the abstracts of relevant articles. Any disagreements were resolved by consensus.

**Assessment of study quality**
The scientific quality of each included study was assessed using the Program Evaluation Accuracy Standards as the basis for assessing scientific quality. This involved checking that:

- the programme or intervention was thoroughly described;
- the evaluation design was appropriate to the programme's objectives;
- the method of participant selection was discussed and response rates were reported;
- the participants and non-participants were described;
- the information sources and measures were described and reliability and validity were presented;
- the methods of data collection were described;
- the data analysis was appropriate; and
- the conclusions were justified.

The authors did not state how the papers were assessed for quality, or many reviewers performed the quality assessment.

**Data extraction**
The authors did not state how the data were extracted for the review, or how many reviewers performed the data extraction.

For each of the RCTs, the review authors calculated effect sizes for peer support versus control where sufficient data were provided. A reference for the methods used was cited in the review.

**Methods of synthesis**
How were the studies combined?
The studies were combined in a narrative. The results, in terms of the benefits of the interventions reviewed, were summarised separately for the RCTs and the studies of other designs.

How were differences between studies investigated?
Heterogeneity was not formally assessed, but differences between the studies were discussed in the text.

**Results of the review**
A total of 21 studies were included in the review. Of these, two were needs assessments, four were exploratory and purposive interviews, one was participant observation, one was of focus groups, three were surveys with a comparison group, five were surveys without a comparison group and three were RCTs.

The main methodological flaws in all studies were: a lack of a theoretical framework; an inadequate description of the programme; response rates calculated on the basis of those approached and not the eligible population; a lack of information on non-participants; and the use of instruments and measures that were not validated. The five qualitative
studies used appropriate methodology for the analysis. The quality of the RCTs varied; all tested for baseline differences and all reported on the delivery of and compliance with treatment (though not in detail). Two of the RCTs used an intention-to-treat analysis, whereas the third RCT did not.

Findings from RCTs.

The RCTs found that peer support groups did not improve quality of life. One study found that, in the short term, the effects of the peer support intervention were adverse rather than beneficial. However, these effects had disappeared at the long-term follow-up. One small RCT found that an 8-week programme resulted in a significant reduction in activity level and non-significant improvements in depression, interpersonal problems, anxiety, personal habits, treatment problems and life disruption, but worsened life satisfaction, self-competency and social competency. A third RCT found improvements in psychological morbidity at 12 months compared with baseline, but slightly worse outcomes in comparison with routine care and nurse support. It should be noted that in all three RCTs the groups studied were set up by the researchers for the purpose of studying them, thus it is possible that their findings do not represent the effects of more naturally generated peer support groups.

Findings from other studies.

High participant satisfaction was reported, but this finding is likely to be biased as there was a lack of feedback from non-respondents and drop-outs. Perceived benefits by patients were reported in terms of emotional needs. Telephone and internet support groups were reported to be of benefit to patients with less common forms of cancer and to those patients who could not easily or did not want to participate in a face-to-face intervention. The peer support programmes presented were helpful in improving the patients’ knowledge of their disease. Information and education was rated more highly than the emotional support benefits of the intervention by a majority of men in prostate cancer groups. The availability of peers with whom to exchange information and experience helped patients to identify their medical problems, and this improved their relationships with their health care providers.

Authors’ conclusions

The authors found that the available studies revealed consistent positive benefits of ‘real life’ peer support, but this did not include the findings from the RCTs. The lack of methodological rigour in all evaluations (including the RCTs) and non-validated outcome measures weakens the reliability of the conclusion that peer support can have a positive impact in cancer patients.

CRD commentary

The research question was well formulated and clearly defined. However, as the authors stated, identifying which interventions are peer led from the poorly reported details in published papers is difficult and it is likely that some studies were included or excluded in error. The range of electronic databases and other sources searched was appropriate, as was the limitation of the searches to 1980 onwards given the relatively recent development of peer support. Some studies might have been missed because of the restriction to journals published in English.

A good level of detail of each of the primary studies was tabulated in the review; some missing information may reflect poor reporting in the original articles. The quality assessment tool used was appropriate given the broad range of study designs included, and the results from this assessment and the conclusions drawn were incorporated into the review findings. It was not always clear from the review which studies were providing qualitative data only and which provided a mixture of qualitative and quantitative data. The narrative synthesis was inevitable given the nature of the available studies. The authors’ conclusions do not reflect the findings from the RCTs as much as they do the findings of the other study designs. This may be justified, in part, by the fact that the interventions studied in the RCTs may not be as representative of real peer support groups as those in the other studies. However, based on the information provided in the review, it is unclear how valid this justification is.

Implications of the review for practice and research

Practice: The authors stated that peer support for cancer patients has been shown to improve coping skills, reassurance and a sense of normalcy, reduction in isolation, information sharing, a better understanding of the experience and the
future, and a greater confidence in talking to physicians.

Research: The authors stated that practitioners and researchers should work together to fully document the nature of peer support interventions and the participants who receive them. Records of people who are eligible for a peer support intervention but who do not attend, or drop-out, should also be kept. Evaluation studies should use standard validated tools for the outcome assessment.

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