Support Care Cancer (2003) 11:763–768
DOI 10.1007/s00520-003-0536-7

REVIEW ARTICLE

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Support groups for cancer patients

Received: 31 July 2003
Accepted: 20 August 2003
Published online: 15 October 2003

This work was presented as an invited lecture at the 15th International Symposium Supportive Care in Cancer, Berlin, Germany, 18–21 June 2003.

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Abstract Within the last two decades psychosocial group interventions have been developed to help cancer patients cope better with the psychosocial sequelae of cancer diagnosis and treatment. Support groups include a variety of different approaches some of which focus on behavioral aspects and symptoms (e.g. pain, fatigue) and some on the expression of emotions. Most of these support programs are structured and short-term and include elements such as delivery of information, emotional and social support, stress management strategies based on the cognitive behavioral approach and the teaching of relaxation techniques. Beyond individual therapy, group therapies can address cancer-related issues to enable patients to gain emotional support from other patients with similar experiences and to use these experiences to buffer the fear of dying and the unknown future. One of the overall therapeutic targets is the promotion of the patient's individual resources. Therefore, such groups are helpful not only for the patients, but also for their spouses and other family members, in relieving the cancer-related distress. In Germany, support groups are established in rehabilitation clinics as well as outpatient programs and play an important role in palliative and supportive care of cancer patients. Against the background of changes in the patients' role, the increasing availability of information technology (e.g. the internet) and patient advocacy in cancer treatment, support groups may be understood as a mean of empowerment of the patient. The need for group interventions such as outpatient programs for cancer patients is claimed not only by the health professionals but also by the patients themselves. There is some research emphasizing that avoidance of feelings, denial of concerns, feelings of helplessness and social isolation are correlated with poorer health outcome and poorer quality of life. Many empirical studies have provided evidence-based knowledge that structured group interventions for cancer patients improve psychological wellbeing, reduce anxiety and depression, and improve quality of life, coping and mental adjustment. Positive effects on survival have even been reported, but these effects have not yet been proven.

Keywords Psychooncology · Psychosocial intervention · Patient education · Support groups · Coping · Quality of life

Introduction

Over recent decades cancer treatments have become more complex and intense, and treatment regimens are of longer duration. Together with increasing survival rates, invasive therapies have led to higher morbidity of patients. Quality of life and the psychological wellbeing of the patients have become more important as outcome criteria. Therefore medical treatment requires the cooperation of patients, and demands their psychological and social resources in the management of cancer-related distress. In total this development has caused higher awareness of psychosocial needs and interventions as an essential part of cancer therapy.

Against this background, psychosocial group interventions have been developed within the last two decades to help cancer patients cope with the psychosocial sequelae of cancer diagnosis and treatment. Support groups for cancer patients include a variety of different approaches, types and settings covering self-help groups and professionally led support groups. As the nature and the dynamics of self-help groups are different from professionally led groups, the focus of this article is only on those types of support groups led by a professional.

Beyond individual therapy, group therapy can address cancer-related issues to enable patients to gain emotional support from other patients with similar experiences and to use the experiences of others to buffer the fear of dying and the unknown future. One of the overall therapeutic aims is the enhancement of the patient's individual resources. Therefore, such groups are helpful not only for the patients, but also for their spouses and other family members by relieving the cancer-related distress. Support groups also play an important role in palliative and supportive care. Against the background of changes in the patients' role, the increasing availability of information technology (e.g. the internet) and patient advocacy, support groups may be comprehended as a means of empowerment of the patient.

This paper provides an overview of the basic approaches and application of support groups for cancer patients and discusses the empirical evidence against the background of intervention research.

Coping and interventions

One of the most important targets of psychosocial support groups is improvement in coping strategies. Therefore, it may be helpful to summarize the basic knowledge about coping and adjustment of cancer patients. Within the last three decades coping research has shown that coping is a process of self-regulation, at the emotional cognitive and behavioral levels. Patients often use a variety of coping strategies. In many studies it has been demonstrated that problem-focused coping may be associated either at the same time or consecutively in the short term with denial. There is some evidence in the literature that avoidance of feelings, denial of concerns, feelings of helplessness and social isolation are correlated with poorer health outcome and poorer quality of life. Denial and avoidance may be adaptive in the short term, but have been proven to be maladaptive in long-term adjustment. In some studies it has been shown that good coping is associated with the use of multiple and flexible coping strategies, adjusted to the distress situation [1]. But coping is not only an intraindividual process but is also contextual, as the patient is interacting with his or her social environment (spouse and family, friends and next of kin). Social support and the social environment of the patient directly influence the processes of emotional, cognitive and behavioral coping strategies. The increasing knowledge as to how patients cope with cancer-related distress has formed the clinical and empirical basis for the development of different types of psychosocial interventions.

Psychosocial interventions with cancer patients

About one-third of cancer patients suffering from significant psychological distress are in need of appropriate psychological interventions [2]. As each stage of the disease has its own issues the need for psychosocial support may change during the course of cancer. The following phases have been identified as stages with high vulnerability for psychosocial distress:

- Before and after receiving the diagnosis
- During acute care and treatment
- During rehabilitation and after-care
- After recurrence
- During palliative care and progressive disease

According to the needs of patients (e.g. struggling with side effects, anxiety and depression) immediately after diagnosis as well as during acute care and treatment, individual therapy and crisis intervention are the most important settings for psychosocial intervention based on the concept of supportive psychotherapy. Individual therapy is indicated when the patient shows a high level of psychological distress or psychiatric disorder. The main focus is on reducing distress and helping the patient with problem-solving strategies. Individual support ranges from individual counseling to individual therapy depending on the therapeutic relationship, the number of sessions and the intensity of the therapeutic processes. Based on the approach of salutogenesis, one of the most important aims is to focus on the personal and social resources of the patient by helping the patient to find orientation and future perspectives as well as to cope with

the cancer- or treatment-related problems. Patients are able to learn to use their own strengths, resources and self-control strategies.

Beyond the scope of individual therapy, group therapies offer a different way of addressing cancer-related problems during all stages of the disease. Within the last two decades a variety of interventions have been developed for cancer which may be used in the setting of individual therapy as well as in group settings. In psychosocial interventions with cancer patients the following methods are used:

- Relaxation, guided imagery
- Health education
- Neuropsychological training
- Behavioral training
- Art therapy, ergotherapy
- Psychoeducation, didactic information

Relaxation is a well-established technique in psychosocial interventions with cancer patients. The most common strategies are autogenous training or progressive muscle relaxation. These techniques are easy to learn but the patient should train using regular exercises to gain the benefit. Besides these techniques, guided imagery [3] is helpful for cancer patients with respect to self-control of psychological distress, psychological pain control and coping with anxiety. Guided imagery is a therapeutic instrument using mental imagination and autosuggestion to focus on problems with the disease or treatment [4].

Health education programs combine elements such as physical exercise, diet counseling and stress management. This type of intervention uses information about the relationship between attitude and health behavior and psychoeducation as structural elements aimed at raising awareness and changing health behavior. Health education programs are provided especially in rehabilitation centers and in outpatient after-care when acute treatment has been finished.

Some cancer treatments such as radiotherapy or high-dose chemotherapy may cause problems in neuropsychological functioning. In particular, concentration, short-term memory and alertness may be affected. Computer-based training programs for improving neuropsychological function may help patients improve in these areas. Such training programs may be carried out as individual or group therapy.

Art therapy is a specific form of psychotherapy using three dimensions: expressive-creative dimension, cognitive symbolic dimension and an interactive analytic dimension. Art therapy involves the use of the fine arts such as painting, sculpture, music or dance as therapeutic media. Medical art therapy may be regarded as primarily non-verbal approaches helping the patient overcome the trauma of cancer diagnosis and find their own resources to cope with cancer-related problems [5]. Art therapy is provided especially in rehabilitation clinics and during after-care and may be integrated as elements into individual or group therapies. It has been shown that through some types of art therapy certain symptoms such as pain (e.g. music therapy), problems with self esteem (sculpture, painting) or body image (dance therapy) may be addressed.

In total, the therapeutic aims of psychosocial interventions with cancer patients are manifold and address problems in all the different phases of cancer:

- Improvement of information about disease and treatment of cancer
- Enhancement of emotional adjustment, quality of life and coping
- Improvement of satisfaction with care
- Improvement of physical health and functional adjustment
- Improvement of disease- or treatment-related symptoms
- Improvement of patient compliance

In some intervention trials, group interventions have been investigated with respect to the effect on improving immune system indicators or increasing length of survival or time to recurrence; this topic is discussed further in the section on intervention research.

Basic concept of support groups

Support groups are provided for cancer patients in various settings and types [6]. As mentioned above, there are groups for health education, relaxation, guided imagery, neuropsychological training and stress management. Further, clinical experience has shown that site-specific groups are helpful for patients (e.g. breast cancer patients) as they allow patients to discuss their problems with peers and facilitate self-disclosure. In the same way, homogeneous groups for recently diagnosed patients or patients undergoing high-dose treatment are designed to focus on their specific problems.

With respect to size, the number of members in support groups ranges from 5 to a maximum of 12 members. The optimal group size has been shown to be about 8 members. The frequency of group sessions is mostly one session per week. If groups are provided as part of inpatient rehabilitation programs the frequency could be more than one session per week. As outpatient groups in the after-care setting, it may be helpful to run these groups in a setting outside the hospital which may decrease the threshold for acceptance of such groups. Depending on its organizational structure the groups could run as closed groups as well as being based on open membership.

Among the variety of support groups we can discriminate two different basic approaches:

– Affectively oriented groups
– Educational groups

Although there is a continuum between these two approaches, affectively oriented groups are more strictly designed as long-term open-ended groups for patients with ongoing or recurrent illness. Working with the group dynamics, they are based on a psychotherapeutic approach working on personal growth and therapeutic processes. Such groups are scheduled for a time duration of at least 4 months up to 1 year. Emotion-focused psychotherapeutic groups are aimed more at the open expression of emotion and sharing of feelings about cancer. As the most important issues dealing with losses, problems with self-image and self-esteem as well as fear of death and dying are discussed. Expressing their feelings and concerns should allow patients to reduce their distress and also give all members the chance to discuss cancer-related problems such as the doctor–patient relationship and interaction with health-care providers. One of the most prominent examples of such an affectively oriented group approach is so-called supportive expressive group therapy [7]. The main topics of this approach are as follows:

– Building bonds
– Expressing emotions
– Detoxifying death and dying
– Redefining life priorities
– Improvement of social support by friends and relatives
– Improvement of doctor–patient relationship
– Improvement of coping

The educational group approach has a short-term schedule from 6 to a maximum of about 16 sessions over 2 to 4 months. These groups are particularly for first-diagnosed patients who are struggling with the problems of cancer diagnosis, treatment and information. Such groups normally have a formal structure with a given agenda using working materials such as paper/pencil techniques or exercises (e.g. relaxation). The main targets are providing patient information and education and improving coping skills. The aspects covered by educational support groups providing information about cancer and treatment include health education, stress management techniques, behavioral training, learning problem solving and self-control strategies such as relaxation (e.g. guided imagery). The main targets are the enhancement of self-efficacy and the empowerment of the patient to cope with cancer-related distress.

The strength of support group approaches is based on peer support and the availability of feedback from group members. Peer support helps diminish the sense of stigma and overcome social isolation. Cohesion of a group is helpful for attaining the goals of group therapy. Cohesion of a group may be defined as the intensity with which patients are able to build bonds with others and develop identification with the group. Another important factor responsible for the effectiveness of group therapies is the relationship between the members and the wish to help other members of the group to cope better. This may be defined as altruism, which is an important coping strategy for some patients who find emotional balance in helping others. The expression of emotion leads to a process of catharsis, which has been demonstrated as a very important therapeutic action. Further, the group setting allows the patients to test changes in behavior within a sheltered framework.

Intervention research in psychooncology

Systematic investigation of the effectiveness of psychosocial group interventions started in the early 1970s and is still a very active field in psychooncology. A recently published review of outcome studies [8] found that, following the first studies published in the early 1970s, there has been an increase in published papers within recent decades until 2000. A lot of studies have shown a benefit with respect to the outcome criteria quality of life and coping, emotional distress and problem solving strategies. How far psychological support influences survival, recurrence or immunological parameters is still an open question. A survey of breast cancer patients [9] has shown, with respect to evidenced-based medicine, evidence levels of I and II in psychosocial interventions in oncology.

Since Spiegel et al. [10] and Fawzy et al. [11] have reported a significant effect of psychological group interventions on survival as an outcome measure, there has been increasing research interest in the evaluation of psychological interventions and their influence on survival and time to recurrence, and the recent research concerning the relationship between survival effect and group interventions, which aimed at overcoming some of the methodological weaknesses of the previous trials, has been reviewed [12]. On the role of immunological factors as mediators between psychosocial factors and cancer progression, although improvements have been made in research methodology, the results are still inconclusive. In a Canadian trial, the effect of a 35-session, structured group intervention in 66 patients with metastatic breast cancer, randomly assigned to either the intervention or control condition, was investigated [13]. In an Australian randomized trial, the effects of a 12-session cognitive-behavioral intervention in 122 women with metastatic breast cancer were studied [14]. Five years after randomization, an effect on survival was not demon-

strated in any of the studies. The only predictors were the well-known biological prognostic factors. The first replication of the study of Spiegel et al. [10] did not find any effect of supportive-expressive group therapy in women with metastatic breast cancer on survival [15]. Investigation of the effect of psychosocial interventions on survival or recurrence is still an active research field. Further studies are to be expected which will provide information about the outcome in terms of survival and recurrence. At the moment, two large multicenter trials replicating the Spiegel intervention are underway, and results are expected within the next 2 years [16].

Irrespective of whether an effect on survival can be achieved by psychological interventions, the psychobiological mechanisms involved are largely unknown. The assumption of psychoneuroimmunological pathways mediating the mind–body connection is emphasized by many psychooncologists and patients, but is unproven as yet. A meta-analysis of 85 intervention studies of various chronic diseases has yielded only modest evidence to support the hypothesis of an immunological response to psychological interventions [17]. Yet it would be premature to conclude that the immune system is unresponsive to psychological interventions. Important conceptual and methodological issues need to be resolved before any definitive conclusions can be reached.

In contrast, there is strong empirical evidence derived from many controlled trials, as well as meta-analyses, demonstrating that psychological interventions improve cancer patients' quality of life by reducing psychological symptoms and distress, by enhancing psychological adjustment, and by improving functional adjustment and rehabilitation [18, 19]. Six to eight sessions are usually sufficient to improve a patient's quality of life, not only in the short-term, but lasting 3–12 months [20, 21]. In the future more attention should be paid to interventions aimed at changing health behavior and symptom management.

There are some studies showing that moderating variables such as patients' motivation or the timing of the intervention may influence outcome. From the results derived from a recent study, Cunningham et al. concluded that a small, highly motivated minority among cancer patients, those who become highly engaged in psychological work, may possibly benefit in terms of prolonged survival [22]. In the same direction, there may be some indication from other research that interventions are most effective when administered to patients during critical events (e.g. diagnosis, recurrence) and times of high distress [23].

What is needed in the future are large-scale studies with rigorous methodology to obtain conclusive results on the efficacy of such interventions and on the mediating pathways involved. Beyond the aforementioned evidence, little is known about which type of intervention is best suited to which patient. Therefore, there is a clear need for comparative studies investigating the differential effects of various interventions (e.g. cognitive-behavioral vs supportive-expressive) on patients' quality of life. Although there has been an increase in systematic research in group therapy, most of the results are based on breast cancer patients. Only a few studies have been published in which patients with hematological diseases, melanoma or cancer at other sites have been investigated. There is also the need for studies including patients with tumors at various sites. From a methodological point of view, the internal validity and methodological quality of intervention studies should be improved, as there is still a lack of randomized studies [8]. Waiting groups offer the possibility of overcoming ethical problems as well as problems of acceptance of randomization by the patients.

Summary and conclusions

Support groups are a very important way of providing psychosocial support for cancer patients and their families. Support groups are an economic way of helping patients cope with cancer and manage cancer-related distress. Such interventions are easy to implement in different areas and settings of cancer treatment taking into account the special needs of the particular group. Although a high level of empirical evidence has been demonstrated, there is still a gap between the research and clinical practice. In most European countries, there is a lack of psychooncological units and psychooncological support is available only to a minority of cancer patients. In Germany support groups are well established within inpatient rehabilitation programs, whereas there is still a lack of such programs for patients during after-care and during acute-care treatment. Support groups are complementary to individual therapy, offering unique means of providing professionally guided peer support in various phases of cancer treatment. They are helpful in providing information and improving problem-solving skills. Moreover, such groups allow us to identify unmet psychosocial needs of our patients. All these support group approaches should be integrated into a comprehensive medical care system. They help the patients increase their participation in decision making and improve their knowledge and ability to cope.

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