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Developing a free supportive care program for cancer patients within an integrative medicine clinic

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Abstract The cancer patient's journey not only includes a threat to one's life, but the need to face many medical and emotional challenges. The free Cancer Supportive Care Program (CSCP) within the Center for Integrative Medicine Clinic at Stanford University Hospital and Clinics has been identified as a successful model for helping patients to deal with these challenges. Its programs include informational lectures, support groups, chair massages, exercise, alternative modality classes, a Life Tapes Project, an informational website, and a bimonthly newsletter available free to anybody touched by cancer. Now in its third year, this program benefits from a blending of

leadership resources, availability of space, institutional agreement on patient need and funds from private and corporate donations. By presenting the basic premises of the Cancer Supportive Care program and outlining specifics about the program, institutions in various national and international demographic regions may implement similar programs according to their resources and the needs of patients. It is our hope that the CSCP can become a model for the development of similar programs in various parts of the United States and abroad.

Keywords Supportive care · Cancer · Implementation · Integrative medicine

Introduction

Recently diagnosed cancer patients and long-term survivors are faced with an uncertain future. Their well-being, on both physical and emotional levels, is continually threatened by fear, isolation, anxiety, depression, fatigue and pain. These symptoms tend to reinforce one another and constitute reminders of the illness and its implications. Side effects of cancer therapies and the disease itself therefore result in a decreased quality of life (QOL) for the vast majority of patients.

Research indicates that patients who are involved in their own care and who take an active role in their treatment, feel better [4, 6, 15, 16] and in some [5, 8, 10, 14, 17] but not all studies [2, 3, 7, 9] recover better. A randomized study that compared QOL according to the survival of patients in the adjuvant and metastatic settings noted that an increase in QOL included improved mood,

appetite, well-being, and hence a longer survival rate in patients with metastatic disease [1]. This suggests that QOL also plays a role in determining a patient's length of life. Resources and programs that are shown to improve QOL, such as CSCP, are therefore vital to promote both a more meaningful, and potentially a longer life-span for those struggling with cancer.

In January 1999, we initiated a pilot study of the Cancer Supportive Care Program (CSCP) at Stanford Hospital and Clinics to evaluate its impact on the QOL of cancer patients, survivors, family and friends. The study provides evidence that, when complemented with conventional cancer treatments, supportive care programs significantly enhance the QOL for people diagnosed with cancer (Rosenbaum et al., unpublished paper: The CSCP and website for improving the quality of life for cancer patients). It also demonstrates the feasibility of such programs, in that patients are attracted to and make

good use of them. Growing clinical awareness about the importance of integrative therapies makes developing supportive programs such as CSCP a matter of priority and urgency.

Location

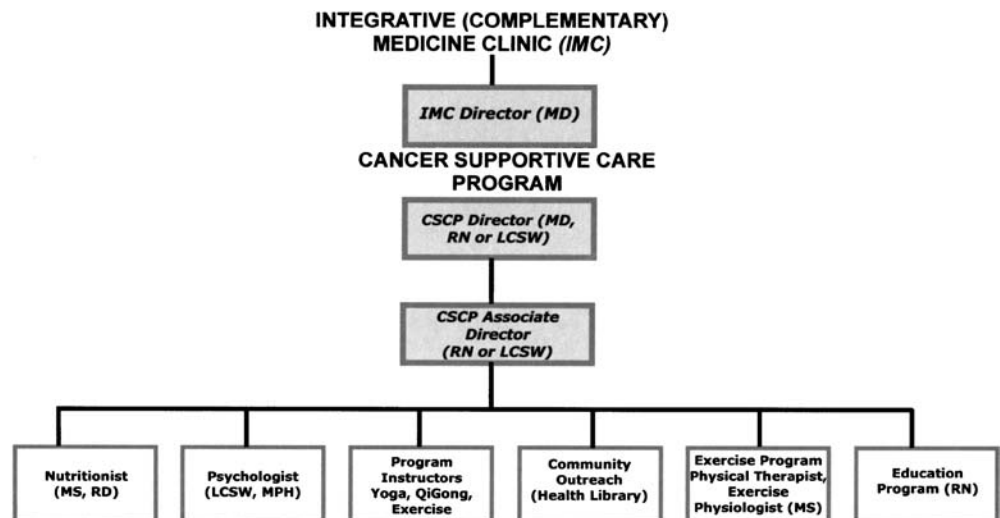
The current CSCP in place at Stanford University Hospital and Clinics offers an array of programs that have been proven successful. These programs may be modified according to resources and population needs of each institution. Information on developing similar CSC programs has been already offered at several cancer centers with much success. Kaiser Hospitals in San Francisco and Oakland have active programs and programs at both the Richard Block Cancer Center in Kansas City and the Comprehensive Cancer Center of Rhode Island are underway. Furthermore, international programs are being initiated in Hong Kong, Israel and Singapore. In sharing information on our current successful program, it is our hope to provide insight and advice into developing similar supportive programs throughout the globe. Future collaborations with other institutions and the sharing of pertinent data will encourage optimal supportive care programs and therefore the most effective impact on the QOL of patients.

Goals

The goals of CSCP include:

1. To improve the QOL for both newly diagnosed cancer patients and long-term survivors
2. To reduce the severity of side effects related to cancer and its treatments

Fig. 1 Staffing of the CSCP program at Stanford Hospital and Clinics



3. To provide supportive activities including psychological support, exercise and complementary and alternative modality (CAM) classes and nutrition, fatigue and pain management counseling for both patients and families
4. To provide cancer patients and their family/friends with education about their illness through lectures, classes, literature, multi-media, website and support groups

Patients

Program participants come from a fairly narrow socio-economic and demographic region in within the San Francisco Bay Area, specifically centered around Stanford University in Northern California. They range in age from 25–75+ although a majority (76%) are in the 50–75 year age bracket. Based on recent 6-month data, of the over 10,500 visits between January 1999 and July 2002, 92% are cancer patients of varying diagnoses (breast, lung, liver, prostate), and varying Karnofsky status. The rest are patients' family members or caregivers seeking help or providing support. Participants are either self-referred as a response to a newsletter, physician encouragement, or feedback from other patients. Although the region tends to be a traditionally affluent area, all programs are offered free of charge. Thus, no patient is barred from participating as a result of financial disadvantage. Patients are encouraged to participate in as few or as many programs as they desire.

Staff

It is possible to implement a supportive cancer care program without hiring additional staff as long as current staff members are willing to collaborate and participate

in the program. By coordinating staff resources already available in most institutions (dietician, nurses, physical therapist, physicians, research associates, statisticians or other available experts) the following have been apparent:

1. An increase in acceptance within the institution regarding credibility of the program
2. Facility in obtaining funding from patients, donors and institutions
3. Improved credibility when presenting data about the program
4. Facility in maintaining resources as staff is more resourceful, efficient and reliable

The program director, which can be a full or part-time position held by a nurse or social worker, may be recruited from within the institution. Staffing of the CSCP at Stanford Hospital and Clinics is shown in Fig. 1. Staffing is provided by a full-time Associate Director (R.N.), three part-time (chemotherapy nurse, dietitian and social worker) and five hourly staff assistants (exercise physiologist, massage therapist and instructors for yoga, qigong, and healing imagery).

Programs

Programs include lectures presented by a variety of healthcare professionals, consultations on nutrition and side effect management, free complementary and alternative medicine (CAM) classes (yoga, medical qigong, guided and healing imagery), support groups, exercise for recovery, and free chair massages to promote positive changes to QOL.

Educational videos of each lecture are offered through the loaning library to patients unable to attend a particular session or meeting. To enable home-viewing, selected CSCP lectures/programs are also shown on the Stanford Library website.

Imagery

Two imagery classes were implemented as part of the CSCP. The purpose of both is to demonstrate that imagery can lead to an increase in QOL for cancer patients via its ability to decrease anxiety and to promote peace of mind. The first, called healing imagery, is offered to any cancer patient that wishes to participate. It is based in the outpatient Stanford Center for Integrative Medicine. The second, called guided imagery, is for in-hospital patients. These include interested oncology and bone marrow transplant patients with more severe health issues than those in the outpatient clinic. It is led by oncology nurses trained in guided imagery and is available to

patients as a 12-week group session, or on a one-on-one basis as needed. The imagery classes are designed to provide comfort and anxiety control, rather than to lead patients to believe that they can control the course of their cancer through images of healing.

Nutrition, chemotherapy and fatigue counseling

Nutrition. Patients are generally self-referred to attend a one-on-one consultation with a registered dietitian. The free evaluation/consultation is specifically tailored to the patient's needs according to their diagnosis, eating habits and symptoms. It allows the patient to discuss concerns regarding nutrition and overall health. Topics discussed often include: maintaining caloric intake to prevent muscle wasting, foods for people with difficulties swallowing, dealing with nausea/vomiting, changes in taste perception and pain during eating. Furthermore, patients are provided with a general packet of information including tips on maintaining health, where to shop for wholesome foods and nutritionally sound foods.

Chemotherapy: Enhancing Your Experience. This is a one-and-a-half hour class tailored to meet the needs of those adults undergoing chemotherapy. The class is open to newly diagnosed patients, recurrent patients, caregivers, and family. This educational class will help patients understand the potential side effects of the drugs they are receiving and learn the specific management techniques that will ensure an effective and manageable experience. Knowing what to expect, when to expect it and how to manage potential physical or emotional side-effects of treatments is an important step in the recovery process. The class is followed by a question and answer period to address individual needs according to diagnosis. One-on-one consultations with an oncology nurse are available by appointment.

Fatigue management. The goal of this program is to teach individuals and families about cancer-related fatigue as well as appropriate self-help strategies to manage fatigue. This unique program affords chemotherapy patients the opportunity to meet one-on-one with an experienced Oncology Nurse, to discuss individual situations and experiences and to explore strategies for diminishing fatigue. This is an on-going program offered twice monthly in collaboration with the Cancer Center at Stanford.

Life tapes project

In January 2002, the Life Tapes Project first presented at ASCO in 1977, was re-introduced [11]. Using video, rather than audio, recordings of interviews with family

members, the goal is to produce a lasting legacy of a patient, while building communication and relationships with loved ones. Interviews of patients and their families/friends are moderated by a trained psychologist. Discussions about family life story, genealogy, early years, meaning of life, writing an ethical will, or other topics initiated by the patient are encouraged. Families are presented with a professionally edited videotape and DVD of the interview free of charge.

Lectures

Lectures presented by nurses, geneticists, dietitians, physicians and other health experts are scheduled monthly and cover topics pertinent to cancer patients in the community. Topics are chosen according to feedback from patients. They provide participants with knowledge, coping skills and emotional support to make informed decisions about their disease management and well-being.

Lecture topics include:

- Anxiety and depression
- Benefits of exercise
- Fatigue
- Insomnia and sleep problems
- Mucositis (mouth care after treatment)
- Nutrition
- Pain Control
- Pharmacological control of treatment side-effects
- Sexuality and intimacy
- Vitamins and supplements
- Ways of coping with psychological problems (the mind-body connection)

Educational materials

To provide patients with knowledge of disease and encourage self-initiated education – booklets and literature are made available. These include extensive hand-outs covering nutrition and coping with chemotherapy. Literature on complementary modalities includes topics such as hypnosis, massage, acupuncture, biofeedback, herbal therapies and Traditional Chinese Medicine. The extensive literature offered includes booklets, videos, and our books *Inner Fire* [12] and *Supportive Cancer Care* [13].

Newsletter

A bimonthly newsletter is sent to all participants of CSCP. Article topics include: What's new at CSCP, Frequently Asked Questions, Tips from the Health Library, New Opportunities in the Community, Upcoming Lectures and more.

Website

In addition to the Stanford website (www.cscp.stanford-hospital.com) which offers information on program schedules, the website www.cancersupportivecare.com was launched in May 1999 and provides education, support, and up-to-date information on various aspects of cancer to a worldwide audience. It was specifically designed to allow all people, regardless of physical disability, type of computer or location to access important cancer information.

The site has been nationally recognized for its pioneering ability on several levels:

- 1) It is accessible to the blind, to patients suffering from chemotherapy-induced vision changes, to people with bifocals and the colorblind. It does not induce nausea in sensitive patients like some web sites.
- 2) Individual topics, rather than the entire site, can be printed, either single or double sided.
- 3) It is designed for people with access to a 28 K modem, making it accessible to older computers and worldwide audiences.
- 4) It is accessible to people with lymphedema or with limited mobility who cannot use a mouse.

Both technical papers written by researchers/doctors and those from a patient's or nurse's perspective are included in the website. The modules are thus geared to a wide range of patients: those seeking technical scientific information and those who wish a more personal view. New modules are being added approximately every 2 to 4 weeks. There are currently 27 modules including our most recent ones: Osteoporosis, Clinical Oncology Issues and Post Breast Therapy Pain Syndrome. We encourage cancer institutions, with prior consent, to link their website to cancersupportivecare.com (contact Alexandra Andrews at www.cancerlynx for more information).

Specific recommendations for implementing a program

Required resources

1. Suitable room/rooms to accommodate lectures, physical classes, patient consultations, and other programs
2. A budget to provide patients with information, pamphlets, mailings, payment for hourly staff and other ensued costs
3. Staff members willing to work together and with patients to ensure efficient, comprehensive programs and support

For institutions that would like to set up similar programs and would like to collaborate with the Stanford CSCP, the following would be appreciated:

- a. The use of the CSCP logo alongside your logo on all letterhead or literature
- b. A brief acknowledgement to the CSCP on all literature

Additional information and assistance for institutions implementing a CSCP in collaboration with Stanford can be obtained from Holly Gautier at +1-650-7234268.

It should be noted that the concepts and program implementation presented in this article and the cancer supportive care program website, provide a guide to make similar programs easier to implement. However, while CSCP has met the needs of patients in the Bay Area region, other institutions may adapt the program according to the financial support, patient and family needs and resources available. It is further possible to develop similar programs independently, that is without affiliation to the CSCP at Stanford, the use of the CSCP logo or resources. This information is also available from the cancer-supportivecare website.

If your institution would like to be affiliated with the CSCP at Stanford, a start-up kit with the following information will be provided:

- Website (www.cancersupportivecare.com). Your institution, hospital or cancer center will be offered a link to the cancer supportive care site. This will not only provide patients with quick access to information about cancer and therapies (already in place on the CSC site), but to programs available throughout the United States and abroad.
- An introductory booklet of the CSCP lecture topics used at Stanford. These topics can be tailored to patients' needs. Videotapes of individual lectures presented at Stanford may also be borrowed to identify appropriate format and level of lectures.
- The cancer supportive care books *Cancer Supportive Care* [13], and *Inner Fire* [12] will be available for use in your introductory lecture series, together with selected brochures and pamphlets.
- *Grant proposals*. Funding is critical to ensure staff and supplies. Contributions made by patients or companies are the surest way of securing money for the program. The start-up advice and help disk on how to request funding may help save time and effort in developing a grant proposal.
- *Videos*. A video library and copies of programs of interest may be linked from The Health Library Video Collection www.med.stanford.edu/healthlibrary/resources/videos.html and used as part of the supportive educational program to improve QOL program.
- Limited back-up support from our staff. An attempt to provide initial guidance or advice regarding adminis-

- tration, nutrition, nursing, physical therapy and website with the understanding that the implementation of a new program is often daunting and uncertain. Our hope is to facilitate the transition as much as possible.
- Graphic templates. CSCP logo and some graphics support will be provided.

Conclusion

Though still in continual development, the CSCP at Stanford has received positive feedback over the past 40 months from both participating patients and other institutions using it as a template. Visits currently number over 10,500, and many patients repeatedly return. There has been progressive implementation of programs as patient needs, additional resources and program staff are identified.

The implementation of similar supportive care programs both nationally and internationally will allow for comparison of current observations with a larger demographic sample; hence more diversity in ethnicity, socioeconomic background and level of illness. By compiling data on current and future exercise, support, and educational programs, as well as on the CSC website, improved local and worldwide access to useful supportive care information may promote an improved QOL for individuals coping with cancer.

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Appendix: ten steps to the implementation of a cancer supportive care program

1. Determine the goals and vision of your institution's program
 - a. What are patients' needs within institution's demographic region?
 - Physical release/exercise
 - Spiritual
 - Social connections
 - Education about illness/lectures
 - b. Available funding
 - How many staff can funding support?
 - Is institution willing to contribute funds?
 - Patients?
 - Grant proposals?
 - c. Who are interested medical team participants and their specialties?
 - Program director (M.D., R.N. or M.S.W.)

2. Obtain program approval

Submit proposal to institution to obtain program approval.

3. Meet with interested members of medical team

- a. What expertise can they contribute?
- b. What are patients' needs?
- c. How to develop program within context of institution and patient population
- d. Pertinent lecture topics
- e. Questionnaire development; how can responses be used to improve program or rate its impact on participants

4. Pilot program

A pilot program of lectures or other series that can easily be advertised and coordinated.

5. Solicit funding for program

- a. Foundations, corporations, patients, institution
- b. Submit grant proposals (assistance with grant writing is available by requesting a CSCP disk) using pilot information and vision of project
- c. Open houses as fund raisers
- d. Obtain sponsors for events
- e. Form a board of directors to help oversee project funding

6. Incorporate CSCP literature

If institution would like to be affiliated with the Stanford CSC Program, Supportive Care Program brochures,

posters, flyers, books, videos, etc. may be incorporated into your resource center

7. Prepare methods for advertising campaign

- a. Brochures
- b. Flyers
- c. Website

8. Begin campaign to enlist interested patients

- a. Flyers in doctors' offices
- b. Solicitations from participating health team members
- c. Posters
- d. E-mail announcements
- e. Website
- f. Promotional freebies with institution program name and logo
- g. Radio promotions
- h. Newspaper or local bulletins
- i. Hospital resource center
- j. Personal contacts

9. Incorporate programs/lectures

Incorporate new programs/lecture topics according to patient feedback on questionnaires.

10. Determine the statistical impact of the program

Use data to:

- a. Encourage more participants
- b. Ensure project funding
- c. Write articles, attend conferences, poster sessions

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