

Short communication

Support for cancer patients: the Bahrain experience

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دعم مرضى السرطان: تجربة البحرين
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الخلاصة: يعتبر السرطان، وهو مرض يتفادى الناس الحديث عنه، ثاني أكبر أسباب الوفيات في البحرين. وقد قامت جمعية مكافحة السرطان البحرينية بتشكيل مجموعة لدعم مرضى السرطان في عام 1993 بهدف مساعدة المرضى وأسرهم على التأقلم مع هذا المرض، وتوعية الجمهور بأهمية التبكير باكتشافه. وتضمنت خدمات هذه المجموعة عقد ندوة أسبوعية على مدى ساعتين لتشجيع المرضى على التعبير عن شعورهم ومخاوفهم، وتوزيع كتيبات إعلامية، والقيام بزيارات للمرضى في المستشفيات وفي منازلهم. كما قامت المجموعة بتنظيم الأنشطة الترفيهية للأطفال المصابين بالسرطان. ويمكن للمرضى والأسر حث هذه المجموعة على مناقشة مشاكلهم. وتهدف هذه الورقة البحثية إلى الإفادة من تجربة البحرين في دعم مرضى السرطان وأسرهم وأصدقائهم.

ABSTRACT Cancer, a disease people avoid talking about, is the second leading cause of death in Bahrain. The Bahrain Cancer Society established a support group in 1993 with the goals of helping patients and their families cope with this disease and increasing public awareness concerning early detection. Services provided by the group include a weekly 2-hour session to encourage patients to express their feelings and concerns, distribution of informational booklets and visits to people at home and in hospital. Furthermore, the group organizes recreational activities for children with cancer. Patients or their families can also page the group to discuss their problems. The main goal of this paper is to share the Bahrain experience of supporting cancer patients, their families and friends.

Soutien aux patients cancéreux : l'expérience de Bahreïn

RÉSUMÉ Le cancer, maladie dont les gens évitent de parler, est la deuxième cause de décès à Bahreïn. La Société bahreïnienne de lutte contre le cancer a mis en place un groupe de soutien aux patients cancéreux en 1993 avec pour objectifs d'aider les patients et leurs familles à faire face à la maladie et de sensibiliser au dépistage précoce. Les services fournis par le groupe comprennent une session hebdomadaire de 2 heures visant à encourager les patients à exprimer leurs sentiments et leurs préoccupations, la distribution de brochures d'information et des visites à domicile ou à l'hôpital. Par ailleurs, le groupe organise des activités récréatives pour les enfants cancéreux. Les patients ou leurs familles peuvent aussi contacter le groupe par alphanpage pour discuter de leurs problèmes. Le présent article vise principalement à faire partager l'expérience de Bahreïn en matière de soutien aux patients cancéreux, à leurs familles et leurs amis.

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Received: 13/06/04; accepted: 24/11/04

Introduction

In Bahrain, cancer is the second leading cause of death after circulatory heart disease. However, with improved cancer services, the 5-year survival rate may increase. The reported number of cancer cases has increased over the past 5 years. This is because of improvements in early detection as well as extended life expectancy, leading to an increase in the number of elderly people, who are more prone to cancer than the younger age group [1].

Diagnosis of cancer, a life-threatening disease, initiates a period of crisis accompanied by considerable psychological distress such as fear and anxiety. The following is a quote from a patient talking about her reaction when she was informed by her physician that she had been diagnosed with cancer: "The first time I heard that I had breast cancer, I panicked. I could not stop crying. Why me, I am still too young to leave my children? All I could think about was my husband and children and how my family was going to take it if I died."

A diagnosis of cancer makes patients feel emotionally distressed, angry and uncertain about the future [2]. In addition 25% of patients experienced depression at the time of diagnosis [3], and approximately 50% may experience depression and anxiety while receiving anticancer treatment [4,5]. Furthermore, the psychological effects of cancer can affect the quality of life and increase the length of hospitalization [6]. Thus, living with cancer is an experience of great suffering for the patient, mainly arising from his reminiscence of a healthy past. Therefore, most people do not like to discuss or talk about cancer; and as soon as they hear someone has got cancer, they believe that this person will suffer and die. For these reasons, patients and their families seek available resources to help with coping

with cancer diagnosis and treatment in order to restore their overall equilibrium.

Coping with cancer

A major illness like cancer may have a devastating impact, not only on patients but also on the immediate family and others with whom the patient has a relationship. Many patients report that a confirmed diagnosis, or even waiting for the result of a biopsy, provokes feelings of uncertainty and fear of death and dying, prompting them to reorder the priorities in their life. These patients go through the common stages of reaction such as denial, bargaining, depression and guilt.

Most cancer patients will require prolonged treatment; so coping with the disease is an exhausting process. Support groups are an important source of help for people coping with the emotional and physical impact of cancer [7]. Furthermore, it has been shown that cancer support groups help to prolong survival [8], decrease psychological symptoms and reduce the number of visits to hospital or oncology clinics [9]. Patients with cancer need help, and patients with strong support systems have better coping mechanisms. Face-to-face (traditional) support groups are used to help patients deal with their illness by fostering effective coping mechanisms [10]. This also helps people feel less lonely and they are able to express a positive change in attitudes towards their illness [11]. Access to a support group may thus serve as an effective psychotherapeutic tool for the coping process.

Support group in Bahrain

The cancer support group was established in 1993 by a television broadcaster and cancer victim. The Bahrain Cancer Society was formed 1989 with a mission to support cancer patients. The group is now a committee

under the Bahrain Cancer Society. It is composed of a small group of volunteers, some of whom are cancer survivors, their relatives and friends, and other people involved with cancer patients such as doctors, nurses and social workers. Cancer survivors often feel a desire to share their experiences with others. The support group plans gatherings of individuals in face-to-face encounters. The meetings are held regularly and are designed to accomplish common goals: to help people cope with cancer, provide emotional support, offer information on cancer and its treatment, facilitate psychosocial adjustment and increase public awareness about preventive measures against cancer.

Reasons for seeking a cancer support group

People seek support groups because they want to belong to a group sharing the same problems, and because they need to get support from others with similar experiences. This process will also enhance their security and comfort in coping with their disease. People may also seek a support group to get assistance in formulating a plan of action during a stressful time.

In Bahrain, women use the support group more than men: the Bahrain Cancer Society records show that around 90% of their attendees were women (unpublished report, Bahrain Cancer Society, 2005). Men may feel they are stronger and think they can cope on their own. Samarel et al. studied a group of women attending a cancer support group and found that the women reported that the group helped them to verbalize their feelings, reduce loneliness and gain useful information [17].

In addition, over the past 2 years (2004, 2005) the Bahrain Cancer Support Group has provided telephone support; during 2005 they received approximately 1000

calls. The majority of callers were suffering breast, colon, lung or kidney cancer.

Non-Bahrainis attend the group sessions more often than Bahrainis, possibly due to lack of family support systems. Patients join to find answers to their questions and concerns about the disease process, treatment and prognosis. Some cancer patients ask for assistance and advice on how to inform their children. When children are properly and accurately informed, their uncertainty, fear and anxiety will be reduced. Accurate information, for example will explain when one of the family members goes bald suddenly.

Finally, attending group meetings is an affirmation of the patient's need to face reality, restore self-esteem and find hope.

Methods of supporting cancer patients

The Bahrain cancer support group generally uses the traditional method of face-to-face support group meetings. People are allowed to verbalize their feelings, which will help them feel better and more able to cope with their illness, which will in turn decrease distress. Other choices are available regarding means of receiving support. Individuals can contact the group by pager, or they can come to a weekly 2-hour group meeting at one of the local hospitals. Those who prefer not to join the weekly sessions may receive support via telephone. The support group is designed to meet the need for reassurance of worth, answer questions and concerns and provide guidance or required information. They distribute booklets in Arabic or English with information related to the diagnosis and treatment of cancer. Support group members visit patients on national and religious holidays and generally spend time with them and distribute gifts. The group organizes recreational activities for children

who have cancer and their families. These include drawing competitions for greeting cards that are sold by the Bahrain Cancer Society for fund raising. Other activities include musical events or dinner parties in restaurants, which may help reduce stress, anxiety and fear.

The group may assist in putting people in touch with the Bone Marrow Donor Registry in San Francisco, California; providing prostheses for patients who are unable to afford their own; raising funds for patients who need treatment abroad; and visiting and giving condolences to the patient's family on their death.

Group dynamics

The support group deals with a variety of topics during their meetings. The topics reflect the attendees' experiences and feelings and what they want to share with the group. This enables patients and their families to decrease their psychological trauma and adopt an effective coping behaviour.

During support group meetings, the side-effects of chemotherapy are discussed and patients share their feelings and experiences. For example, one lady who received support before starting chemotherapy and then experienced fewer side-effects stated, "I never realized with my busy life that there were people to help me face the disease and have a positive attitude, which helps a lot while I am taking my chemotherapy."

This is a dialogue illustrating how patients support each other sharing a common experience: One patient stated, "I can't stop crying. I look at myself in the mirror most of the time. I am a weak person. I cry anytime, anywhere." Another one responded, "I understand your pain, I have been through the same experience, but look at me: I got hair and wear a prosthesis. I look normal." A third patient responded, "I can get some more hair, but I can't get another life."

Someone also stated, "I am lucky to be alive, taking care of my family."

The cancer support group respects patients' religious backgrounds and encourages their faith. The group increases hope in cancer patients by focusing on patients' belief in themselves, their individual abilities, relationships with others and active involvement, while acknowledging that they also have a future. This allows patients to see things around them differently. One patient reported, "The support helped me enjoy my life today. I see how nice it is to walk on the seaside and enjoy the sea and watch the sunset." Another explained his reasons for coming to the group session, "I feel weak today. I came to the meeting to get the spiritual energy that I need."

The following statement reflects the taboo of cancer: "My neighbour is my friend. She started to hide from me once she knew that I was a cancer patient. She does not like to visit me. When I discussed this with her, she said, 'I do not like to see you suffering like my daughter. Then you will leave like my daughter'."

It is also one of the responsibilities of the support group to recognize dying patients, meet their spiritual needs and try to support them in order to assist them to die peacefully and with dignity. This is a quote from a patient, expressed just a few hours before she died: "Stay with me. I feel that someone is here when you hold my hand."

Conclusion

Hope is considered an important factor for people coping with cancer. Support groups may give hope and act as sources of information for cancer patients, their families and significant others. The Bahrain Cancer Support Group encourages people to share their feelings and provides an atmosphere

of courage, humour and hope. The group now needs to realize its full potential by developing an active volunteer support network in order to continue being a significant resource. In addition, public awareness of

the group needs to be enhanced and more people encouraged to use the service, both within and outside the network. No one need suffer alone.

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