



International Union Against Cancer



Reach to Recovery International

# 10th REACH TO RECOVERY INTERNATIONAL CONFERENCE

MAY 13 - 16, 1998, LJUBLJANA, SLOVENIA

*"LOOKING BACK - MOVING FORWARD"*



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## ***“LOOKING BACK- MOVING FORWARD”***

MAY 13 - 16, 1998, LJUBLJANA, SLOVENIA

CONGRESS CENTRE  
CANKARJEV DOM

## ***Abstract Book***



International Union Against Cancer



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## CONFERENCE PROGRAMME

*Wednesday, May 13, 1998*

### **PRE-CONFERENCE DAY:**

9:00 - 12:00

Chairman, Elizabeth Brien (UK); Jeff Dunn (Australia)

Pre-Conference Workshop for National Co-ordinators / Members of the Reach to Recovery International Forum

**CD-E7**

12:00 - 14:00	<i>Lunch</i>	
14:00 - 17:00	<b>Registration</b>	
18:00	<b>OPENING CEREMONY</b>	<b><i>Linhart Hall</i></b>
	<b>WELCOME RECEPTION</b>	<b><i>Klub CD</i></b>

**Thursday, May 14, 1998**

**DAY 1: VOLUNTARISM AND SUPPORT TO PATIENTS**

**Plenary Sessions** ***Linhart Hall***

***Chairman: Mrs. Jackie Wasserman (Canada)***

09:00 - 9:15	Volunteers and the Evolution of Voluntarism (Elizabeth Brien, UK)	
09:15 - 09:35	Communications (Christy Kenneally, Ireland)	
09:35 - 10:10	The Importance of Psychosocial Support For Breast Cancer Patients (Ronnie Kaye, USA)	
10:10 - 10:30	<b><i>Panel Discussion</i></b>	
10:30 - 11:00	<b><i>Coffee Break</i></b>	

***Chairman: Mrs. Tensia Alvirez (USA)***

11:00 - 11:20	The Volunteer and Her Impact on the Patient (Giulia Tarabocchia, Italy)	
11:20 - 11:40	Treatment and Decision Making - Psychosocial Considerations (Zvonka Sevšek, Slovenia)	
11:40 - 12:00	Psychological Benefits of Support Groups (Ivan Kodelja, Slovenia)	
12:00 - 12:20	<b><i>Panel Discussion</i></b>	
12:20 - 13:45	<b><i>Lunch</i></b>	<b><i>Klub CD</i></b>
13:45 - 14:30	<b>Poster Session</b>	<b><i>Foyer I</i></b>
14:30 - 17:00	<b>Roundtables &amp; Workshops</b>	<b><i>Conference Rooms</i></b>



09:20 - 09:40	Increasing Community Awareness (Evelin Smillie, UK)	
09:40 - 10:00	Building Relations and Coalitions Within Your Community (Liisa Elovainio, Finland)	
10:00 - 10:20	<i>Coffee Break</i>	
10:20 - 10:40	Dynamic Planning to Meet Volunteer and Patient Needs (Jeff Dunn, Australia)	
10:40 - 11:10	<b>Panel Discussion</b>	
11:10 - 12:20	Roundtables	<b>Linhart Hall</b>
12:20 - 14:00	<i>Lunch</i>	<b>Klub CD</b>
14:00 - 14:30	Poster Session	<b>Foyer I</b>

**Chairman: Graeme Brien (Australia)**

	<b>Plenary Sessions</b>	<b>Linhart Hall</b>
14:30 - 15:00	Hope For The Future (Ronnie Kaye, USA)	
15:00 - 15:45	<b>"Looking Back - Moving Forward"</b> (Jennie Cook, USA, Elizabeth Brien, UK; Christy Keneally, Ireland)	
15:45 - 16:00	<b>Medals and Awards</b>	
16:00 - 16:20	<b>Invitation to the Next Conference</b>	
	<b>Closure of the Conference</b>	
19:00	<b>FAREWELL DINNER</b>	<b>Hotel Slon</b>

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### **Programme for the accompanying persons**

- The programme for accompanying persons is included in the registration fee for participants and accompanying persons.
- Opening Ceremony and Cocktail Party on Wednesday, May 13 at 18.00 in Linhart Hall
- Sightseeing tour of Ljubljana on Thursday, May 14, at 10.00, meeting point at registration desk in Cankarjev Dom.
- Organ Concert at the Cathedral of Ljubljana and reception in Town Hall on Friday, May 15, at 20.00.
- Farewell Dinner in Kavarna Hotel Slon on Friday, May 15, at 19.00
- Lunches in Klub Cankarjev Dom

# ***Lectures***



Title/type in CAPITAL LETTERS	VOLUNTEERS AND THE EVOLUTION OF VOLUNTEERISM	
	<i>DOUBLE SPACING</i>	
Author(s)	Mrs Elizabeth Brien (McCrum)	
	<i>DOUBLE SPACING</i>	
Institution	Ulster Cancer Foundation	40-42 Eglantine Avenue
Town	Belfast	BT9 6DX
Country	Northern Ireland	

START ABSTRACT

This paper will discuss the history of Volunteers and Volunteerism and the changes which have taken place over the years to what it has presently become.

The paper will, however, focus on Volunteers and Volunteerism relating to Reach to Recovery and the other cancer sites Volunteer Programmes.

From time memorial Volunteers and Volunteerism has been part of human society. Women took the lead in Volunteering work, but this is no longer the case. Because of unemployment men and young people do Voluntary work.

There are many different types of Volunteer work, one of which is the Volunteer Programme like Reach to Recovery, Laryngectomee Volunteers, Prostatic Cancer Volunteers and many others. Some of these Programmes are male orientated as men have begun to take responsibility for their health as well as realising they too need help when they have cancer.

These are all based on the Reach to Recovery Programme with its selection and training of Volunteers..

Volunteer Programmes are totally unique with the strong motivating force being the experience of cancer, being able to share the difficulties associated with the disease, and by doing so helping others.

The paper will take an example of one country which went from the difficulty of Volunteers being accepted by the health and caring professionals to the Health Service (i.e. The Government) now funding the Cancer Organisation to train Volunteers in order to work closely with them.

More and more Volunteers and Volunteerism is being accepted and seen as of tremendous benefit to Society.

## **COMMUNICATIONS**

Christy Kenneally

CKC TRAINING INTERNATIONAL, Dublin  
Ireland

**Communication skills are essential to an effective Reach to Recovery Volunteer. Rather than thinking of technical skills, let us turn our thoughts to the heart of the matter. What is my perception of my role and what is my perception of the woman I will encounter. How can I, given the very real constraints of time and opportunity, meet this person heart to heart and affirm and enable her to draw on her own inner strengths so that she may recognise and recover her sense of wholeness.**

## THE IMPORTANCE OF PSYCHOSOCIAL SUPPORT FOR BREAST CANCER PATIENTS

Ronnie Kaye, M.A., MFCC

Marina del Rey, California 90292 U.S.A.

As with any life situation, there are a fortunate few people who seem to manage the crisis of breast cancer with remarkable grace. They go on about the business of daily living with barely an interruption. They don't get sick from chemotherapy. If they lose their hair, they make wonderful turbans, decorate hats, tie scarves in creative ways. Sometimes they make bold statements by going bald-headed in public — a gesture which takes considerable self-confidence. They are emotionally and spiritually centered, and seemingly unaffected by this life-threatening illness. In a situation that would deplete most of us, they seem to find the inner resources to continue giving to others. Certainly, they exist — these super-survivors. I, however, am not one of them, and neither are the patients that I treat. In fact, the majority of women diagnosed with breast cancer will manifest some degree of distress which will continue long past the end of treatment.

In order to understand the importance of psychosocial support for the breast cancer patient, it is vital that we appreciate the true nature of the breast cancer crisis. Right from the moment of diagnosis, we are challenged in both the internal and external aspects of our personal journey. The internal refers to the emotional and spiritual upheaval experienced as we move through diagnosis, treatment, and recovery. The external refers to the way in which breast cancer affects our relationships with others as well as our role in the family, at work, and in society.

If we first look at the social dimension of the breast cancer crisis, we find that women report a wide range of difficulties. Just the diagnosis itself is enough to cause some people to treat us differently — either distancing themselves from us or acting as though we are already dying. Surgery may result in a radical alteration in body image. While trying to adjust to this sudden and unwelcome change, we worry about how this loss of a body part will affect the people in our life. As we move through treatment, side effects can compromise our ability to manage even the normal, everyday tasks that others have come to expect of us... and which we have come to expect of ourselves. People often do not know how to help. They may be much too solicitous, making us feel like worthless invalids, or overly encouraging and optimistic, thus unintentionally discounting our feelings of grief, sadness, anger, and depression. We struggle with our role in the workplace. Concerned about discrimination, we debate about whether to tell our co-workers of our fight with this life-threatening illness. We wind up feeling isolated at work, at home, and in the community because our diagnosis has made us "different."

At the same time that we are trying to maintain our balance socially, we find ourselves confronted by serious emotional and spiritual issues as well, which define the internal aspect of the experience. First, there are the existential issues: fear of death, fear of dying, mortality, vulnerability, and a frantic search for the meaning and purpose of life. In addition, old emotional wounds and unresolved situations tend to be reactivated by the breast cancer crisis. We are assaulted by losses — both old and new — and haunted by relationships that lack closure. We struggle to find some stability on the emotional rollercoaster that sweeps us away. Our priorities undergo a radical shift. It is a time of chaos. It is also a time of tremendous learning.

It stands to reason that support at such a critical time would be beneficial. However, the term "psychosocial support" is somewhat intimidating, and, unfortunately, has come to stand for the type of professional support which is offered by trained psychotherapists and social workers. This definition is far too narrow to encompass the many possible ways of providing desperately-needed comfort and assistance. Clearly, the Reach to Recovery volunteer has a much to offer in this arena. By drawing on her own experiences with breast cancer as well as her Reach to Recovery training, she can validate feelings, provide a safe haven for sharing, listen compassionately, facilitate self-

exploration, offer practical suggestions for adapting to changes in appearance, encourage productive dialogue with family members, friends, co-workers and doctors, and be a role model for successful emotional recovery. Her caring and concern help to soften the harshness of the diagnosis and alleviate the fear of the unknown. She becomes an anchor in a very stormy sea.

I have been asked to defend the importance for psychosocial support for women with breast cancer. One of the complaints that I have heard most often from my patients is about the loneliness of the breast cancer experience. Trying to work through so many profoundly important issues is incredibly challenging. Struggling alone is simply too hard. Women dealing with breast cancer need guidance, support, and an opportunity to share their pain. How can we settle for less?

## THE VOLUNTEER AND HER IMPACT ON THE PATIENT

Giulia Tarabocchia

Clinical Psychology Unit, Cancer Centre  
Trieste, Italy

To have cancer of the breast is a "critical" event in a person's life. The woman goes through a period in which she must absorb and assimilate within herself and her existence the disease and its consequences.

As regards the problems that arise in the woman in this moment of her life the volunteer has the task of giving her emotional support, information and knowledge. She can carry out these tasks particularly because she has already confronted and worked through this experience.

For the same reason the volunteer is also for the patient an example of life and a model to refer to.

The role of the volunteer is certainly founded on the aspect of having been herself operated for a cancer of the breast, which makes possible a reciprocal positive "identification" between the patient and the volunteer. However, certain conditions need to be present and comply with by the volunteer in order that her functions may be effectively performed.

Dealing with different aspects of the patient-volunteer relationship leads also to considerations as regards to the volunteer's training and characteristics.

## TREATMENT AND DECISION MAKING - PSYCHOSOCIAL CONSIDERATIONS

Zvonka Sevšek,

Health Centre, Velenje  
Slovenia

When the women learn that their diagnosis is cancer and later during the treatment, they experience intense feelings of fear, sorrow, anxiety, vulnerability, guilt, hate of themselves and of others, loneliness, shame, envy and anger. The illness does not affect the woman only physically it interferes deeply with her life, emotions, relationships, values, feelings and thoughts, so that emotional healing is usually much slower than physical.

The following characteristic statements of women after they got cancer have been selected from literature:

- Cancer means death sentence. Regardless what I do I am going to die.
- This must be a mistake. The doctors must have made mistake with the diagnosis or this is only a bad dream. When I wake up I will find out that everything is O. K.
- The illness represented a threat to my life plans (marriage, career) more than to my life, I became depressive and scared.
- Why is this happening to me? This is not fair. I became angry because of unfair fate, I relentlessly looked for the reasons of my illness and made illogical conclusions.
- The treatment will disfigure me to such degree that nobody will ever try to approach me. I was scared of losing all my friends; I grieved over the loss of the part of my body, which is the symbol of womanhood.
- The treatment ahead of me is too heavy burden for me. I was afraid that I wouldn't find enough courage to cope with all troubles and agony waiting for me during the treatment.
- How shall I decide about the treatment if I know nothing about breast cancer? When I learned about the diagnosis from my doctor I was so shocked and confused that I didn't understand even the simplest information.
- I felt terribly alone.
- When I fell ill I began to look on life with more realism, I found out what was really important to me and every single day was a precious gift to me.
- I was surprised to learn that some of my friends tried to be with me but they didn't know how to approach to me. When I openly spoke of my feelings and needs, I tore down all the walls between us and I obtained more support and help and I felt more accepted.
- The most important source of hope was my faith in God. When I faced my fears and doubts, I did not feel alone.
- I tried to proceed playing my role of "superwoman", I tried to protect my nearest ones from the truth, I took upon me the responsibilities that were too much for me and I eventually fell into despair and depression.

We can see that the statements of women are very different but they illustrate their capability to act efficiently in a given situation.

The majority of illnesses, cancer too, is basically psychosomatic. They are caused by loosing control over life. Therefore it is very important for curing what we can do for ourselves in order to gain control, not what the doctors can do for us. Herewith I proceed with the choice theory and reality therapy of Dr. W. Glaser which says that the control is the way how to function in order to satisfy our needs

(beside the need to survive there are four more psychological needs:

- need for love and belonging - to be accepted in the society and to be loved, feeling of belonging,
- need for power – over the things, over one’s own body and oneself as well as over other people,
- need for freedom – to choose how we will live, for freedom of expressing ourselves,
- need for fun – game, creativity).

Every man satisfies his need in a different way. We satisfy our needs in relations with others and when these relations are unsatisfactory, when the reality is different from our wishes psychological troubles occur which we try to solve with our behaviour. The patients told me about the feeling of loosing control during medical treatment in the hospital, they were helpless, others decided about what would be happening to them, they could not indulge in the activities that were their relaxation before the illness (sports, travels, etc.), they felt less accepted by the people who were themselves in distress because of their illness.

Figure 1 shows some replies of the women included in the support group about their behaviour after having been told about their illness. For easier understanding the total behaviour is divided into four components: thinking, activity, feeling and physiology.

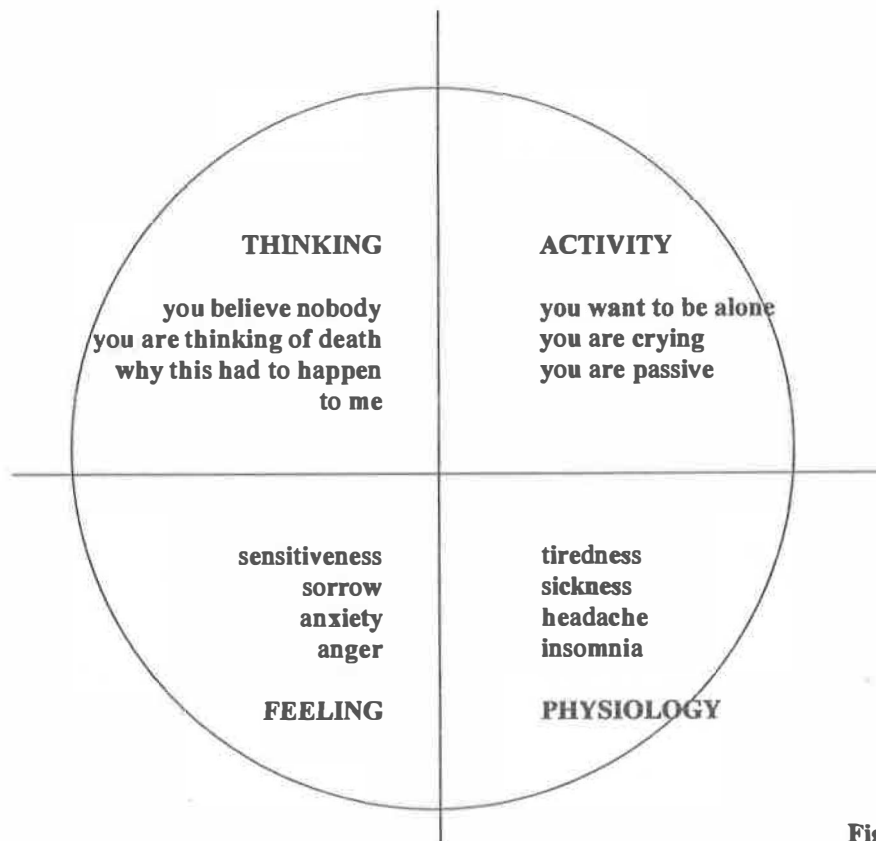


Fig. 1

The needs of patients were poorly satisfied; their relations with others, with their nearest ones, their friends and colleagues fell into pieces. Choice theory supports the explanation that one is internally motivated with pleasure experienced when one or more of five genetic needs have been satisfied or by avoiding the pain when one does not succeed in satisfying those needs. All we can get from real world are information. All our behaviour that concerns in any way the satisfying of our needs is chosen. Consequently, we are able to actually control only our behaviour. Activity and thinking can be chosen while feelings and physical response are the consequence of our actions and thoughts.

Considering this theory it is clear that the patients too have the possibility to choose their behaviour and that they are at least partly responsible for their medical treatment. Let us look how would react the patients from the support group who would in given circumstances assume the responsibility for themselves:



Fig. 2

If the patient wants to be included in the medical treatment process fully and responsibly she should be a partner to specialists or medical staff who ought to encourage her to express her feelings, fears and questions about the course of illness, further treatment and about her possibilities of recovering. If one is better informed about what is threatening one, the analysis of the situation is better and the choice of right solutions is easier, but first of all, one feels less threatened and experiences less stress. In this process however, mutual trust between the patient and doctor is of primary importance.

Leslie Wong, plastic surgeon, says: "It is important to offer comfort to patients and to treat them as partners. The key is in their education, so they can decide upon the method of medical treatment by themselves".

In her book "Talks against fear" the author Anne-Marie TAUSCH describes her experience with her first chemotherapy when she turned down the painkillers. She convinced herself that chemotherapy is something positive that would destroy cancer cells. Author says that one can in a positive way affect one's body and feeling through one's spirit. Pain is not so strong when one thinks of something beautiful. Physical pain is easier endured with proper spiritual mood. "I wouldn't like my body to be strong and my soul weak. Spiritual strength can revive the body and we can find a new way of dealing with pain. Health is a complex, mental and physical condition closely interconnected and affecting one another. Medical science should take it into better consideration."

Of course, the patient needs her nearest ones, her family, friends with whom she can share her feelings and satisfy as good as possible her basic needs through proper relations. Sharing of feelings makes one feeling better and relieved. In this way one can open a route to others how to show their concern and offer their help. Here too, the patient has a choice: she can withdraw or she can try to approach others who equally experience strong feelings. She can find help in a support group or with proper specialists outside her home. When a patient learns about experience of other



patients she will take decisions on medical treatment easier, though it should be emphasised that every patient is person of her own and the course of treatment will be different for everyone.

Let us be reminded that one's activity and thinking is a matter of one's own choice. Maybe the following suggestions found in an article could be the orientation to the patients when taking decisions:

1. The word cancer should be taken as merely a word, the original meaning of the word changed considerably by years. As once scaring diseases such as tuberculosis, smallpox, cerebral paralysis, cancer too will be defeated. Be here when it happens.
2. Accept chemotherapy, radiation and other forms of treatment because they are your friends and defenders. Though they require a certain tax for their effort, they still give more than they take.
3. Co-operate fully in your treatment. Learn all details of your illness, diagnosis, prognosis, conventional and alternative treatment, discuss them openly and sincerely with your oncologist and ask when you don't understand something.
4. Take your illness as a detour in your life, as something temporary and plan your future and make long-term goals. When you recover in your mind it will help a lot to your physical recovery.
5. Express your feelings openly and sincerely to your nearest ones, they are affected too. Comfort them, since they need comfort too.
6. Be comfort also to other cancer patients, be their source of knowledge, courage, understanding and love. Give them hope, hope is their salvation. It will be comfort to you too.
7. Never give up hope regardless your feelings since deep down in your heart you know that your fear is only temporary that there are better times ahead.
8. Don't consider your illness as total sum of your life but as a part of it. Fill your life with other activities that give you pleasure and relaxation. Filling your life with illness means giving up.
9. Keep your sense of humour under any circumstances, laughter relieves your heart and accelerates recovery. This is not an easy task but worth trying.
10. Keep permanent and unshakeable faith in something, a superior being, medical science, your future or anything else, make your faith stronger and it will make you stronger.

What if the patients do not have enough will and energy for such thinking and behaviour? Can volunteers help them to choose the most effective behaviour and reach mental rehabilitation as soon as possible?

I remember one volunteer telling after one of her visits to the hospital: "When I came to the patient, she was desperate. When I tried to reach her she said that it was no use, that her life was finished and there was no use thinking about future. I told her that I understood. Then as if she remembered that the volunteer had the same illness, she asked me if I was operated too. When I told her that it happened nine year ago, her mood changed immediately. It looked like she started to get the energy from me because I had defeated the cancer and she obtained the strength to face the illness. Later on the nurse told me that after my visit the patient ate her lunch for the first time after the operation."

When the patients learn of their diagnoses and in the beginning of treatment their behaviour is inefficient and the volunteer is the one who can help the patient to assume the responsibility for herself and begin with small steps, but nevertheless walk in the right direction.

The source of positive thinking for the patient can be the fact that the volunteer is still alive so many years after the treatment, that she is still active and in spite of possible loss of her breast, she can still live full and happy life, that she has not gave up hope, though the diagnosis had been "cancer", but she had won the battle with the illness.

It helps to the patient if she can talk to someone having similar experience with the illness as herself, that this someone is not a specialist, physician or nurse with whom she often feels helpless and dares not ask the right questions. Often the patient does not understand the answers. The volunteer is a woman who takes her time for the patient, who paid a visit to her though in the first days after the operation the patient is often convinced that everybody deserted her. A visit of a volunteer can change the feelings of the patient in positive direction and convince her that she matters still.

The volunteer is often asked questions by the patient about further treatment. Though the volunteer cannot answer these questions, she can encourage her to ask the doctor or medical staff. She can motivate the patient to read the literature from this field to obtain additional information on her illness and be an equal partner in the treatment process.

Immediately after the treatment the patient is the most anxious to know how she will replace a possibly lost breast to face the people again. Seeing the volunteer showing no signs of her loss can reassure her and restore her self-confidence. She sees that after the operation and treatment she will be able to preserve her womanhood and attractiveness.

The patients often ask another question: what and to what degree they will be able to work after the treatment, will they still be useful at home and at work. Usually these questions are asked by the women who have done the majority of work at home and who are now afraid that they will be no longer able to take such care of others as before. Experience of the volunteer can give them hope that they will be able to live as normally as before.

With her personality the volunteer shows to the patient that self-pity is no good, that she should face the illness and cope with it and that she should reach to recovery with great hope.

I think that we can conclude that the volunteers really fulfil their mission: offering of practical and psychological help to the patients affected by breast cancer and to help them find the right decisions and stimulation for recovery and quality life.

## PSYCHOLOGICAL BENEFITS OF SUPPORT GROUPS

Ivan Kodelja

Health Centre Nova Gorica, Slovenia

### ABSTRACT

For human complete personality growth the life in a group is indispensable. Man simply cannot be alone. The need to belong to another human being is very strong in the very beginning of life since we find ourselves in a group immediately after being born. The man exists only in relation with another human being, therefore without a group there is no individual.

Psychological problems of an individual occur and are expressed in a group – primarily in the family or in other groups. Severe trauma or sudden illness such as cancer or stress related to breast operation is expressed among other things also in patient's retiring from the society and complete withdrawal. She often reacts depressively. It is understandable that we cope with such troubles (we solve them) in a group that is there where they are expressed.

Support group is a place where the patient gets the opportunity to confess and to study her feelings. Emotional happening in the group is the most important. In the group the patients learn from one another. Those experiencing severe emotional distress after breast operation are usually maladjusted socially. They are occupied with their own problems so that sometimes they have troubles to understand others. When they see that other patients have similar feelings and problems they find normal contact with other people (group members) again. Those patients who have successfully overcome the crisis after breast operation are the greatest help.

Group is the place where the patient after breast operation can get well. Entering the group is a free act. In a good group there is no place for duress and authoritarianism. In the group the patient is capable of complex rehabilitation. It is understandable that "chit-chat" and "gossip" don't belong there; the members develop their own feelings for the emotions of others with the purpose of self-help.

In Slovenia the Support groups (11 groups) meet once a month. The purpose of all these groups is complex rehabilitation of women after breast operation. In some centres, in Nova Gorica too, the women can join Small groups (6 to 8 patients), where they learn relaxation techniques and they train visualisation and imagination. Here they get mutual support and concrete help in solving of personal distress after the operation as well as stimulation for healthier way of life. Our support group is of medium size and open; about 35 active patients. The membership is increasing, more and more patients are active. This year we had our 10<sup>th</sup> anniversary. Our group is led by a volunteer co-ordinator; professional mentor of group is a psychologist.

### What is a Support Group?

Everybody is member of different groups since life in a group is easier and, what is more important, less dangerous. Balance of one's own mental system is not sufficient for a man, it should be sought in one's family, in the circle of one's friends, among the colleagues, etc.

For human complete personality growth the life in a group is indispensable. Man simply cannot be alone. The need to belong to another human being is very strong in the very beginning of life since we find ourselves in a group immediately after being born. The man exists only in relation with another human being, therefore without a group there is no individual.

Group is older than an individual, only in a group human SELF can develop. It enables to a man to make the long and difficult way from frailty and dependence to independence. A person estranged from the society can find the way back to the society through the group.

Group is a good imitation of family. It is a fact that one always carries inside a part of content or discontent related to the experiences in one's family. Later responses are usually the reflection of emotional happening in the family. **Therapeutic group (Support group)** in the widest sense of the word is defined by the characteristics of primary groups. Primary group is for example a family, a harmonic neighbourhood, and similar. Primary groups are

characterised by direct relations, strong emotional bonds, solidarity and readiness for help in distress. As a rule primary groups are small.

Belonging to primary group is of special importance for mental health. Of course, in a group it is impossible to achieve such intimate atmosphere as, for example, in a couple, but the group forces the individual to reach the experience of WE which means more safety and less fear.

### Why Group Therapy?

Psychological problems of an individual occur and are expressed in a group – primarily in the family, but also in other groups. Severe trauma, sudden illness such as cancer or stress related to breast operation are expressed in a patient in the form of retiring from the society and complete withdrawal; the patient often reacts with depression. So it is understandable that such disturbances should be coped with (solved) in a group; that is there, where they show.

Support group is the place where a breast cancer patient can recover after breast operation. Here she finds the opportunity to speak out and to study her feelings. Emotional happening in the group is the most important. In the group the patients learn from one another. In the group a patient is listened to by everybody, they try to put themselves in her place. By verifying her emotions and experiencing the reactions of others the patient begins to verify the reality more clearly.

Those patients experiencing severe emotional distress after breast operation are usually maladjusted socially. They are occupied with their own problems so that sometimes they have troubles to understand others. When they see that other patients have similar feelings and problems they find normal contact with other people (group members) again. The patients who have successfully overcome the crisis after breast operation are of greatest help to them.

In a group or through it the cancer patients can find the way to complete recovery. In a group the patients face themselves and are reflected in others. Basic support gives them the feeling of safety, acceptance and opportunity to do something for themselves.

If the patient finds an opportunity in the group to speak about her personal problem and feels to be accepted by other members, she will make progress as a personality. Gradually developing belonging to the group enables the patient to better fit in emotionally, to exchange the standpoints, views and experience. Thus she experiences that important emotion of unconditional acceptance and belonging which is the condition for complete recovery.

Through positive emotional orientation and basic support the patient will begin to see the world in more optimistic colours. She will take better care of her appearance, she will be better company, she will become physically and emotionally stronger and she will be able to help others and herself better.

Joining the group is a free act since the group ceases to exist as soon as one of the members is there against her will. In a good group there is no place for duress and authoritarianism, it is also possible to abandon it anytime.

Basic characteristic of the group is that it lives **here and now** and not “there and tomorrow”. The group solves the present problems, not the future or past ones. In the group there is mutual understanding and support, joint creativity and co-operation. In the group they don't blame a third person who doesn't exist, they are busy with themselves. It is understandable that “chit-chat” and “gossip” don't belong there; the members develop their own feelings for the emotions of others with the purpose of self-help.

We issue from the fact that high level of emotional stress increases the susceptibility to illness. In supportive approach to medical treatment we want to transform gradually the negative emotions into positive thinking and optimistic view and into more care for oneself. This has important effect on the very process of recovery.

I can summarise from my own experience in leading of small groups that those patients who have totally involved themselves in emotional happening in the group have recovered the best. With their personal contribution these patients have succeeded in giving something to the group and getting an equal share from it.

With some patients who had only “half included” themselves in the group and with some of them who hadn't succeeded to make connection at all the recovery process prolonged and sometimes even interrupted. On the other hand, those patients who fully lived with the group and did a lot for themselves most often completely defeated the illness and they are now capable to help to others.

Loneliness, withdrawal, retiring from social midst and excessive emotional suffering sometimes border to mental illness while physical response in such emotional state surely degrades patient's health. Sometimes even the efforts of group members and therapist do not suffice to help the patient to initiate the recovery process in her. Even then one should not despair; the steps are small.

Successfully recovered and well integrated - one could say ex-patients succeeded to obtain the best from the group during the treatment. They have helped themselves the most by beginning to live a more full life. Some of them have become qualified to pass **the good** over to other patients in need since they can understand them well. These ex-patients are you, **the volunteers**, who are ready to share unselfishly your good experience of treatment process with others.

### **How to enter a Group?**

Immediately on learning her diagnosis and even more after the operation the patient is overcome by fear and distress. These emotions are related at first mainly to fear of death, then to the concern about her appearance and about further sex life. Patient's self-confidence drops and the fear of relapse and loneliness occur. She experiences severe fear and sorrow as well as impotence, shame and anger.

When the worst crisis is over, since the patient has met the volunteer who has offered her the most needed support as rehabilitated former patient herself, then, if she wishes, she can enter the **Support group** of women after breast operation. At first she is enabled to meet those patients who underwent the operation and the following crisis more or less successfully.

After a month or sooner depending on the possibilities the patient can enter the **Small support group**. Here she gets the opportunity to exchange her experience and feelings; she can listen to other women whom similar destiny has befallen. Probably the most precious is the feeling that she is not alone in distress. In such surrounding very close friends are made soon.

Patients decide to work in the Small group of their free will, only some of them have a previous interview with the therapist. The most precious incentive for the patient is a positive experience related by others at the group meeting.

The meetings are once a week and last for an hour or an hour and a half, usually 8 to 12 meetings, the group is partly open. In the group the patients usually analyse the most pressing feelings and conflicts, feelings of guilt and various fears related to cancer. They discuss their role as women before, now and in future. With respect to the duration of such group the goals are limited, the emphasis is given to better adjustment of group members to their surrounding.

During the meetings the patient is introduced into the techniques of physical and emotional relaxation such as Autogenic training and similar techniques as well as visualisation or imagination. On one side this makes patient's participation in the group easier and offers her the possibility of successfully including in a long-term complex treatment on the other side.

The emphasis is on the development of patient's ability to overcome the illness by her own strength. There is supportive atmosphere in the group so in horizontal level (among the group members) as in vertical one (therapist – group member).

In Nova Gorica 11 Small groups operated in the last 10 years. Our **Large group** (Northern Primorska 35 – 40 patients) meets once a month. In this group too, basic emotional atmosphere is supportive.

### **How to lead the Support Groups?**

The quality of a group usually depends on the group **leader (conductor) or therapist**. A good leader should weaken his position and strengthen the position of group, he should be more of a co-ordinator than guide. If the members learn relaxation techniques and imagination it is right if the leader himself introduces them to the mentioned techniques. At the same time the leader should not ignore the happening in the group, he should understand it correctly and sometimes even explain it. The most precious thing is the going on between the group members; i.e. making comparisons, verifying, feeling together. Positive emotional orientation and supportive attitude of the therapist give to the group members more hope and expectation, more basic feeling of acceptance and safety.

Group leader should leave the group members talking, he should encourage the group to participate actively and he should give advantage to the contribution of members over his own contribution. He should encourage prudence, patience, understanding, ability of expressing oneself, independence and susceptibility to new experience.

**Good leader...**

- attracts the least possible attention
- does not impede the initiative of individual members
- knows how to turn the discussion into the right direction by minimum interfering
- creates proper atmosphere so that the members can disclose their intimate thoughts.

The leader should have strong and realistic personality. He should know how to listen to any group member. The leader should not be susceptible to the danger of misusing the group for his (her) own needs. The leader should replace the subordination by co-operation of equals at equal terms. Leader's self-assurance originates from modesty. The right leader is **not above the group but in the group.**

Leader proposes, explains, discusses, summarises. He does not hide his own mistakes; he does not believe himself to be omniscient. He is liable to the group; he shares his responsibility with the group.

**Where and how do we meet?**

Some of you experienced the activity in **Small group** where you obtained mutual support, acceptance and understanding as well as concrete help. Some of you have learned relaxation techniques and other "oriental" techniques, you have practised visualisation and imagination, and some of you have been listening to interesting lectures while all of us enjoy to participate in social meetings either on New Year's Eve or at some other opportunity. **Support groups** from different centres in Slovenia (there are 11) meet monthly while once a year we meet at the **Pan-Slovenian Meeting** of women after breast operation "New Spring of Life" at the Congress Centre Cankarjev Dom in Ljubljana.

You volunteers who visit the patient after breast operation unite into **Supervision groups** together with your leader with the purpose to solve promptly the situations occurring at your work with the patient. All of you are included in the **Large Group of Volunteers of Slovenia** in order to qualify additionally for your work. Occasional **Group meetings with medical staff of the hospital** where you operate give new dimensions to your and their experiencing and are support to both.

You, the volunteers are usually the first who inform the patient of the existing Support Group in your place. You should offer her a possibility and a way to include in it. It is right that later, **ever several months** after the operation the patient who is coming to regular checks is informed of the group work. Verbal invitation is very precious, but she should get proper information also elsewhere (in dispensary, internal newsletters, and newspapers).

The purpose of teamwork gains more and more support in the world and today's presence of all of you in this **Mega group** and your experiences are additional proof that this is the right way.

The intention of joining into groups is not to feel sorry for one another or to gain compassion and pity; on the contrary, the intention is to encourage one another so that each and every one of us would find a healthier and more optimistic view of life.

## MEDICAL UPDATE

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### Introduction

Breast cancer is the most frequent cancer of females in the developed world. Its incidence in West-European countries and North America is around 100 per 100,000 population, and is still on increase. Most women will develop the disease at an age of 60 to 69 years. Taking into account the trend of population aging world-wide, it is realistic to expect an increase in breast cancer incidence in the following years, more so since most risk factors associated with the etiology of breast cancer, such as sex, familial predisposition, early menopause, late menarche, age at first birth, and breast-feeding cannot be influenced significantly. Therefore it is expected that approximately a million women world-wide will be affected by this disease in the first decade of the next millennium. Apart from the unpleasant fact that breast cancer will have become a problem encountered by a large number of women all over the World, the fact that an enormous progress has been made in the last decades in the field of secondary prevention and treatment of breast cancer remains indisputable. Encouraging advances can be witnessed also in the field of chemo-prevention of breast cancer.

### Secondary prevention (screening)

Several randomized studies have shown that an active screening of precancerous and cancerous lesions in the breast in women after 50 years of age decreases breast cancer mortality by 30 to 40% (2). Therefore, many developed countries have introduced screening as a part of their regular public health policy program. Screening may include only mammography or a physical examination combined with mammography. In the last few years, the value of mammography for screening purposes has been enhanced by technical improvements that provide better visualization of the breast parenchyma with less exposure to radiation, as well as by greater availability of well-trained mammographers. Unfortunately, in the countries where screening has already been introduced, it has become apparent that only a part of female population will respond to the invitation, and that those who do are always one and the same. Thus, a large proportion of females fails to attend a preventive breast cancer examination, despite the active screening programs. Therefore, at present, the main endeavors of health care promoters and screening organizers in those countries are directed into improving the attendance of women in screening programs.

### Chemo-prevention

Reviewing the results in a number of breast cancer patients who have been in the last ten years receiving adjuvant hormonal therapy with tamoxifen, an anti-estrogen, it has been found that tamoxifen exerts an additional protective effect by preventing cancer development in the contralateral breast (3). In those patients, the incidence of the second breast cancer was found to have decreased by 30% or more, depending on the dose and duration of treatment. Moreover, tamoxifen exerts a favorable effect on the content of lipids in the blood, thus decreasing the occurrence of atherosclerosis, and on bone metabolism, which reduces the risk of osteoporosis. Based on the above observations it can be concluded that presently tamoxifen can be regarded as a promising drug for chemoprevention of breast cancer. Such treatment would be indicated particularly in women at risk, i.e. in those with positive familial history, with preexistent benign breast diseases, or women with unilateral breast cancer. On the other hand, tamoxifen also has its adverse effects: thus, the patients who have been receiving tamoxifen for more than two years are at a 3-fold higher risk of developing endometrial cancer. Nevertheless, most of the cases are diagnosed as precancerous lesions or early stages of endometrial cancer, which do not endanger the patient's life and can be effectively managed by an adequate gynecological follow-up and treatment. It is therefore believed that the potential benefits of tamoxifen most probably outweigh its drawbacks, however, in order to be able to draw a definitive conclusion on the indications and justification of preventive tamoxifen use, we have to wait for results of several clinical studies that are being carried out in a couple of thousands women worldwide. Apart from that, new hormonal medications with anti-estrogen effect are coming into use; while closely resembling tamoxifen by their pharmacological properties these new drugs have the advantage of being more selective in their effect and thus exerting less side effects on the endometrial mucosa (4).

## Genetics

The discovery and identification of BRCA-1 and BRCA-2 genes have posed a number of dilemmas in both scientific and lay public (5). Mutation of these two genes, and possibly of some others as well, is known to be associated with a higher risk of breast cancer and also of some other types of cancer so in individual patients as well as in their family members. Unfortunately, the determination of these genetic changes still triggers a number of unresolved scientific and ethical questions. The sensitivity of the test is low, which results in a high rate of false-negative findings, and associated with that, the patient's false expectations. On the other hand, a dilemma such as e.g. what advice should be given to a woman with positive BRCA gene mutation is by all means very difficult. Some are in favor of bilateral prophylactic mastectomy in those patients, although the severe psychic and physical sequelae entailed by such a procedure should not be ignored. The absurdity of such intervention becomes even more apparent in view of the fact that even a prophylactic mastectomy cannot ensure a absolute protection against breast cancer. Although very rarely, women have been reported to develop metastatic breast cancer after prophylactic mastectomy. Further, what advice should be given to women regarding protection against other malignant diseases such as ovarian and colorectal cancers, which are also rather common in this population of women at risk. The question remains whether it makes sense to burden those women with genetic tests and information while we are unable to offer them a reliable method of cancer prevention; in view of this fact, burdening of patients' with awareness of their increased risk of cancer seems justified only as far as it raises their alertness to any physical change in their bodies: they are likely to submit themselves to regular medical checks, and the attending physicians will be more scrutinizing and alert. Thus, if cancer cannot be effectively prevented, at least it can be detected at an earlier stage and as such treated with a fair chance of cure.

## Treatment

In the last decades, one of the main advances in the treatment of breast cancer has been the broad acceptance of less mutilating surgery. The results of two large randomized clinical trials carried out in Milano and in the States in the 80's have shown that in patients with operable breast cancer a conservative surgery in combination with irradiation offers a chance of cosmetically acceptable breast preservation without compromising the patients survival (6,7). Those favorable results led to increasing use of conservative breast surgery worldwide. Thus, nowadays, partial mastectomy is considered a method of choice in patients with operable breast cancer whenever the size of the breast relative to tumor size enables radical tumor removal at a reasonably acceptable cosmetic result. Even now, the rate of patients treated by conservative breast surgery vary substantially from one geographic area to another (8), being influenced by several different factors, such as socio-economic characteristics of the environment, cultural background and tradition, as well as differences in education and general knowledge of both the patient and the surgeon alike. By means of systemic treatment prior to surgery, so called neoadjuvant chemotherapy, the rate of patients in whom breast preservation is feasible, can be further increased (9). On the other hand, thanks to new advances in breast reconstruction surgery, the prospects of patients who are considered unsuitable for breast conservation have improved as well; now these patients are offered a chance of immediate breast reconstruction.

An important step towards a more effective treatment was made in the past decades when adjuvant systemic therapy was introduced into the treatment of breast cancer. Chemotherapy, particularly in premenopausal women, and hormonal therapy, particularly in postmenopausal women, have decreased the mortality rates by 30% (3), the effect being comparable with that of mammographic screening. The question remains, however, whether the use of adjuvant systemic therapy should be restricted exclusively to patients with positive axillary lymph nodes, whose risk of recurrence and thus also the absolute benefit from such treatment is greater, or should this treatment approach be also practiced in patients with negative axillary lymph nodes and a lower risk of recurrence. In order to avoid that a large number of patients be unnecessarily exposed to various adverse effects of systemic treatment, in the past few years, an intensive research has been directed into identifying biological properties of the primary tumor which would help us to differentiate biologically more aggressive tumors from less aggressive ones, and based on those findings, treat the patient accordingly (10). It is surprising, however, that the patients are ready to accept a toxic therapy even when the expected benefit is small, which is in contrast with what many doctors and nurses would believe (11). Also, the tolerance of treatment related side effects varies greatly from one patient to another. While patients in a certain cultural environment regard their loss of hair as a major disaster, those in other environments will overcome this inconvenience with a wig and will not be unnecessarily bothered by it. Even drugs with relatively low toxicity, such as tamoxifen, are not completely devoid of side effects. It is, however, up to individual patients whether they are ready to tolerate adverse reactions, or they find these so disturbing that they would rather deprive themselves of the favorable effects of drug. Indisputably, the adjuvant systemic therapy has proved its outstanding effectiveness and thus justified its role in the treatment of high-risk patients. On the other hand, the trend of adjuvant systemic therapy being introduced into the treatment of low-risk patients introduces a totally new approach to decision making: in the future, the patient and her physician together will have to discuss



all possible benefits and drawbacks of systemic treatment and decide whether it should be used or not. In the choice of treatment, a greater relevance should be attributed to the priorities of each individual patient.

Despite the progress achieved so far, the effectiveness of systemic therapy for breast cancer requires further improvement. There are new promising approaches to treatment including new agents such as taxanes, aromatase inhibitors, pure anti-estrogens, as well as monoclonal antibodies (e.g. her-2-neu antibody) and highly-targeted agents that should be pursued vigorously. The preliminary results of high-dose chemotherapy with peripheral stem-cell support are promising and should be explored further. Exploration of all these treatment modalities together with a better application of known treatments opens a wide range of possibilities for further improvement of treatment.

One of the greatest advances of the past few years was made by all of us concerned with the treatment of breast cancer patients when we had finally realized that the treatment success cannot be identified with the bare effect of therapy on the tumor or the patient's survival. Instead, an essential parameter in the evaluation of the effectiveness and suitability of a particular treatment modality is also the quality of patient's life during and after therapy. Considering the shift of biological aging into more advanced age groups, there are more and more women who are amidst their active life period when affected by cancer. Many of them strive to return back to full life and their daily activities already during the course of therapy, but by all means after the treatment is completed. Therefore, it is all the more important that we seek such effective methods of treatment that would offer them this possibility.

### Conclusion

A review of the progress that has been achieved in the last century in the field of breast cancer allows for a certain optimism. The previously fatal disease has become curable in a majority of patients. Moreover, cure is achievable even without mastectomy in a large proportion of patients. Screening programs make possible breast cancer detection at the earliest stages when the chances for cure are very high, and the chemoprevention has become a reality. Ever newer and more effective methods of treatment by means of targeted agents, monoclonal antibodies, vaccines and genetic treatment are the harbingers of a new era which is expected to ensure that all women with breast cancer could be cured.

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**"BREAST CANCER CONTROL: ROOM FOR OPTIMISM, TIME FOR ACTION"**

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**ABSTRACT NOT ARRIVED**

## HORMONE REPLACEMENT AFTER BREAST CANCER TREATMENT

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We are such stuff/ As dreams are made on  
The Tempest, W.Shakespeare

### Summary

A majority of young women who were treated for breast cancer will sooner or later bear the heavy burden of menopause or climacteric disorders which will be either due to cancer treatment or will develop as a natural consequence. It has been recognized that, in comparison to non-hormonal treatments, hormone replacement therapy (HRT) is far more successful method of treatment of menopause disorders. Breast cancer is often hormone-related malignancy; therefore, questions concerning HRT and its risks of having a stimulating effect upon further tumor growth in women who have been treated for breast cancer deserve careful argumentation. The era of dogmatically denying women who previously had breast cancer any form of HRT is probably at an end.

### Introduction

Recovery is a state that every woman with the confirmed diagnosis of breast cancer and her doctor would wish to attain. According to some research results, women even two years after they have been treated for breast cancer wish to be acquainted with the prognosis of the disease and treatment possibilities. Wishing to have among our patients as many successfully cured women as possible, a number of different treatment methods were developed, such as surgery, chemotherapy, irradiation and hormonal treatment. As aggressive treatment methods usually have adverse effects, particularly in cases where several treatment procedures are involved, the quality of life of patients is, beside complete remission, another objective which is gaining in importance.

In Slovenia, breast cancer is the most frequent malignant disease in women. In view of complete rehabilitation of women after therapy, the fact that more than 35% of the women with the confirmed diagnosis of breast cancer are younger than 55 years should not be disregarded. This is the termination of the reproductive period in a woman's life and beginning of climacteric disorders. A typical menopause symptom is the termination of menstrual cycles. In women of the developed world this most often happens at the age of around 50, whereas in women of the developing or least-developed countries it may occur even earlier. The menopause may occur earlier also in women who have been treated for breast cancer. It may arise as a consequence of the impaired function of the ovaria because of physical or mental stress, treatment with cytotoxic or hormonal drugs or irradiation. In such cases the menopause is often referred to as premature. We often decide on additional treatment with cytotoxic drugs in a great number of praemenopausal women who have been surgically treated for breast cancer. Cytotoxic drugs have an inhibitory effect on the function of the ovaria; hence, in majority of women, they induce the cessation menses and, consequently, premature menopause. We assume that sudden premature menopause causes more intense climacteric disorders than gradual cessation of the ovarian function. Similar disorders may also arise from hormonal therapy.

### What is Menopause?

The term menopause actually refers to the last menstrual period. A woman is referred to as post-menopausal when no periods have occurred for 1 year. However, symptoms associated with the decrease in oestrogen levels and cessation of periods can commence some years before menstruation actually finishes. This timespan is therefore known as the peri-menopause or climacteric. In some women, reduced secretion of female sex hormones, particularly oestrogens, which is due to the decline of ovarian function, may cause serious mental and physical troubles. Similarly, less intense disorders due to hormonal oscillation, may sometimes occur just before the menstrual cycle or after pregnancy. A clue difference, though, should not be disregarded: in menopause, the decline of female sex hormones is a process that is irreparable. In any woman who has reached the menopause, no inherent upsurge in the

secretion of sexual hormones will ever happen again. The effects of the deficiency in sexual hormones may become apparent several years later. That is why we distinguish between early and late menopause disorders. Early menopause symptoms are disorders that arise before or during the menopause and persist only a few years. A typical characteristic of late menopause symptoms is that they occur several years after the last menses, even ten years or more later.

#### Early and Late Symptoms of Menopause

Early symptoms, often referred to as acute or transient menopause symptoms, occur as disorders in menstrual cycles or as vague changes typical for the period following the menopause. After the complete cessation of menstruation, the disorders, either mental or physical, become more acute. The most common disorders which are typical for this period are physical disorders related to the disturbed functioning of body temperature regulators; hence, these disorders are often called vasomotor symptoms. In this period, mental disorders are less frequent and are therefore less taken into account because they may arise also in any other period in the life of a woman (though not to the same extent).

Most common vasomotor symptoms are periodic hot flushes, night sweats, palpitations, and blushings. Periodic hot flushes are most common climacteric symptoms in West-European women. Up to 80% of women suffer hot flushes. The length of time that a woman may experience hot flushes appears to vary greatly, from 1 to 11 years. The frequency of flushes also varies, ranging from many times a day to weekly or less. Interestingly, 80% of Japanese women have never experienced hot flushes and scarcely any Indonesian and Mexican woman suffered from them. It is assumed that the cause lies in the food, rich in phytoestrogens (e.g. soya) which can replace at least a part of the lacking oestrogens in the female body.

Other physical menopause-related disorders are fatigue, headache, itching and sharp stinging pains in the vagina and the associated problems during sexual intercourse or urinating, pains in the back and joints.

Psychological symptoms are numerous and often unpleasant: insomnia, lower concentration, lower memorizing, and decision-making capabilities, lack of self-confidence and willpower, fear, weepy mood, irritation, introversion, anxiety, depression. It seems that these psychological changes are stronger in women who suffered from trauma stresses in the past or have been fighting against conflict situations throughout their lives within their more intimate circles, such as family and office or in a wider social environment.

It is undoubtedly true, that the decrease of sex hormones in female can bring about serious mental and physical disorders. To what extent these problems will influence upon every day life of a woman in menopause or will outgrow normal limits into conflict situations, depends upon the family and social environment. With the lifetime becoming longer and with the improvement of social and cultural circumstances the traditional way of thinking in the Western World has changed and this specific period of the life of a woman is no more regarded as the process of getting old and senile.

Late effects of the lack of female sex hormones are observed in different parts of the body; in most cases, they do not affect reproductive organs, yet they influence upon the development of disease which are the common cause of death of a great number of women. These are cardiovascular diseases and osteoporosis. The above disturbances can be alleviated, if not prevented, with the replacement of female sex hormones. HRT is definitely one of the biggest achievements in medicine in the last 25 years. Its beneficial effect has been proved in preventing early climacteric disorders as well as of their more remote consequences, such as osteoporosis-related bone fractures (50%) and cardiovascular diseases (20-40%). Furthermore, the fact that it might reduce the risk of developing Alzheimer's disease and colorectal cancer should not be ignored. Like most things in life, for some women HRT has its drawbacks, the most important of which is a possible increased risk of breast cancer. Women taking HRT for five years or more are at increased risk of being diagnosed with breast cancer. However the breast cancers found in women on HRT are tended to be smaller, less aggressive and easier to treat, and very important, taking HRT did not increase the death rate from breast cancer.

#### Climacterium: a Problem Posed to Women with Breast Cancer History

There are little records on the personal experiences of women with breast cancer history undergoing climacteric changes following the treatment. Our experience, that is the experience of medical staff involved in treatment, is based on many years' clinical routine work and endless endeavours to be successful and efficient. According to our practice we may conclude that the menopause and its related problems are more painful for the women with personal history of breast cancer than for others without such history. Throughout the rest of their lives they carry along mental and physical consequences of the disease and treatment, which is definitely a bitter experience, a sad and dim memory, involving fear and insecurity.

It should always be remembered that the symptoms of menopause which do not occur with typical and easily discernible indications, such as hot flushes and excessive sweating, bring about countless troubles, frequently

persistent distress which seems to have no way out. Why? Because, on the one hand, physicians are not cautious enough and do not recognize them and, on the other, patients do not draw adequate attention to them because they are often unable to assign them to the inevitable changes occurring in their bodies.

The women with personal history of breast cancer after successful treatment and rehabilitation, having full support and understanding of the family, colleagues, and wider environment are nevertheless vexed with unrecognizable menopause problems originating from true psychophysical disturbances out of which they do not find their way in spite of every professional medical help. Numerous subjective and objective psychophysical disorders, which are distressing the patients, e.g. fatigue, anxiety, pains in the joints or in the bones, headache, palpitation and formication, require further examination in order to exclude eventual breast cancer spread or development of new malignancies. Despite numerous examination findings no explicate answer can be provided. Further examinations without confirming the conclusions additionally aggravate the patient's psychophysical condition. The vicious circle seems to be closed. Excessive investigations are scaring and exhausting and hardly any optimistic answer adds to the patient's anxiety.

It is important to know that frequent cause of climacteric disorders of some women with personal history of breast cancer is often related to her mental state. Most frequent mental disturbances, which are relentlessly piling up, are the following: disability to adapt to environmental changes which result in stress, drop in concentration, memorizing, and decision-making capabilities, lack of self-confidence and willpower, introversion, anxiety. Due to the increasing lack of self-confidence and understanding for her own problems, the patient with such problems is running away from her work and public life into solitude, looking for release in sick leaves. Unfortunately, she feels overburdened also in the family circle; she is less and less capable of establishing sincere contacts even with those who are most close to her, and is fighting a losing battle also in this important area. Being aware of her disastrous and inappropriate reactions, many a woman after breast cancer treatment has not enough strength to help herself out of troubles. Tired and fed-up as she is, she cannot go on any more and, at this point, the fact that the cancer is cured, hardly matters at all. Not so far ago, one of my patients described her mental distress addressing me with the following words: "Doctor, please, make me a human being again!" A lot of women who are destroyed to that extent are able to pick bits and pieces of their personality only if given professional help by a psychiatrist or psychologist.

It is therefore very important that the therapist as well the patient are aware of the possibility that the troubles which occur in spite of successful treatment and rehabilitation may intertwine significantly with developed menopause symptoms.

#### Non - Hormonal alternatives and Hormone Replacement Therapy in Women after Breast Cancer Treatment

The data available at present are insufficient to confirm the safety of HRT in women with the history of breast cancer. Normal breast tissue is a hormone dependent tissue and in the majority of breast cancer cells hormone receptors are present.

Despite the fact that HRT is the most effective treatment method for both the immediate and long-term complications of menopausal symptoms, there are some non-hormonal alternatives also available. Hot flushes and night sweats can be reduced by simply avoiding aggravating factors like coffee, stress and alcohol. Both clonidine and propranolol have been used for the management of vasomotor symptoms. For those women with osteoporosis, bisphosphonates and calcium supplements are effective treatment options. Sexual dysfunction is not uncommon problem. Supportive counselling is the mainstay of management. Vaginal lubricants are useful but it must be remembered that local vaginal oestrogen preparations are probably absorbed into the systemic circulation.

Only after unsuccessfully non-hormonal treatment and in case of very grave menopausal symptoms we might consider using HRT in women with breast cancer history. The decision whether to start with HRT have to be made only on an individual basis. The expected benefits and the possible side effects have to be discussed among doctor and affected woman. HRT may be applied only after a thorough talk with the patient and after her consent to treatment. In order to be able to evaluate the effectiveness of the therapy, HRT should be carried on at least for three months. After a three month treatment, the effectiveness of therapy needs to be evaluated on the basis of a thorough conversation with the patient. If the treatment results are really favourable, the patients themselves usually ask to continue with the therapy. The restored psychophysical state after HRT brings these women back to normal life which means a lot to them, if not everything. If the treatment results are not so good, we may decide to stop HRT. We should be aware that all women on HRT should certainly have regular breast exams, including mammograms of the affected and the opposite breast as well as follow up exams due to previous breast cancer history.

The most suitable type of the replacement hormone is specifically selected for each patient. Every first or second year of administration, the doses of recommended replacement hormones are regulated to meet individual patient's needs. We usually prescribe the lowest acceptable doses of replacement hormones that a woman needs after breast cancer surgery to manage climacteric disorders.

Irrespective of the proved effectiveness of the replacement hormones we should bear in mind that they are not a magic drug and that they can have, though not very often, unpleasant adverse effects, such as increased risk of venous thrombosis, sickness, tension in the breast, more intense vaginal discharge, "heavy" legs and spasms in the legs.

In view of early detection and successful treatment of breast cancer some would suggest that we should focus also on the question of long-term HRT of women after breast cancer treatment in order to prevent late effects of the deficiency of sex hormones. The risk of pathologic fractures due to osteoporosis and cardiovascular disease are the two most frequent causes of death in elderly women with breast cancer history and without progression. However, our concerns that long lasting HRT could worsen the prognosis of the disease, prevent us from the routine use of HRT women with breast cancer history. Fortunately, new synthetic oestrogen are now being developed which have beneficial effects of the natural oestrogens on skeleton and heart, but probably not stimulate the breast's cells. It will be a major advance if it proves possible to offer women without a fear of breast cancer.

### Conclusion

Any decision regarding HRT in women who have breast cancer must weigh the risks against benefits and should include the views of the patients. HRT should be advised and has to be applied with one and the same objective - to make life more endurable, better, and more pleasant.

Various groups are conducting prospective trials to examine the effects of HRT in women with breast cancer, which will further facilitate the decision in favour of the use of HRT or against it. New promising drugs with less effect on the breast epithelium are underway.

How to reach recovery? So far, in some rare cases it may also be by HRT!

### Recommended Literature

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## PAIN SYNDROME AFTER BREAST CANCER TREATMENT

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### ABSTRACT

Pain is an experience of human physical and psychological suffering. In the last twenty years medical science explained many problems about the occurrence, transfer and perception of pain. It is still impossible to be sure to what degree it is the consequence of tissue damage or of fear, ignorance, worry and painful experience in the past. The influence and readiness of the society to help prevent and to cure the pain is of great importance. Though modern medicine disposes of efficient curing methods to make patients comfortable, these are not available to many who need help, unfortunately neither to women with breast cancer and chronic pain after either surgery or radiation and chemotherapy. Since there is no visible reason for pain, the physician who is told of it often says to the patient that she should accept it and live with it. This usually triggers additional stress, especially in the regions where there is no pain treatment clinics available where the patient could go for help by herself. In these institutions pain is treated multidisciplinary by specialists of different medical profiles such as: anaesthesiologists, neurologists, neurophysiologists, orthopaedists, psychologists and psychiatrists. When a patient is treated by a family doctor without sufficient experience in such treatment, the effects are poorer. Family doctor usually prescribes analgesics (painkillers) which have little effect on such pain and sedatives. The patient increases the number of pills and is soon stigmatised as drug addict by her surroundings. The present curing method preserves aesthetic appearance of operated breast but additional radiation and chemotherapy damage invisibly the subcutaneous tissue and nerves. 30% of patients suffer such severe pain that otherwise healthy women become incapable to carry on with their profession. Pain is accompanied with special psychological condition, depression, insomnia, forgetfulness and social isolation. Pain therapists dealing with this problem are unanimous that these troubles are real, not imaginary. Nowadays our knowledge to prevent such condition is quite comprehensive and we would like to share it with our colleagues – breast cancer therapists for relief of unnecessary suffering.

## UNPROVEN TREATMENTS FOR BREAST CANCER: ARE THERE ANY REAL SUPPORTIVE METHODS?

Simon P. Hauser

Study Group on Unproven Methods in Oncology, Swiss Cancer League, Bern, Switzerland

In industrial countries breast cancer is the second frequent malignancy of women. The often metastasizing (65 to 70 %) and long-lasting illness leads patients in more than 50 % to unproven cancer treatments. Unproven treatments are defined as cancer treatments developed outside of conventional scientific medicine and there are no data available that prove a clinical benefit for patients. The Swiss Cancer League and the Swiss Society for Oncology founded in 1982 the Study Group on Unproven Methods in Oncology with the goal to collect information on these treatments. The Study Group analyzed the material and prepared reports for physicians to help them to inform the patients. In recent years the discussion about unproven drugs and treatments has increased in public and also in the scientific medicine. In addition, cancer patients can find many different promising treatments on the Internet. However, I have seen many cancer patients overwhelmed and confused by this enormous flow of information.

This paper presents an analysis of some unproven methods and remedies concerning the efficacy against breast cancer. The different methods are grouped as followed: 1. Cancer therapies based on an autonomous medical concept, such as the anthroposophic medicine and mistletoe preparations, 2. Anticancer diets, 3. Stimulation of natural and immunologic defense mechanisms by cell therapy, cytoplasmatic and thymus therapies, 4. Stimulation of oxygen respiration of cancer cells, 5. Orthomolecular treatments according to Pauling and high dose vitamin C, 6. Enzyme preparations, 7. Physical and bioelectrical methods such as electro-accupuncture and bioresonance, 8. Parapsychological therapies such as the „New Medicine“ by Hamer, 9. Pathogenic geographic zones and irradiations, 10. Carcinogenic microorganisms, 11. Cell differentiation and maturation drugs, 12. Special drugs.

Potential harms of unproven cancer treatments come from blocking or delaying an efficacious scientific treatment, losing money, and a social isolation of the patient. Patients are encouraged to apply unproven treatments mostly by relatives, friends, physicians, and the media. Today's attitude toward unproven methods mirrors a medical counterculture opposing institutionalized medicine and favoring belief in the power and the supremacy of the individual. Losing the fight against cancer becomes a personal weakness, with the patient being blamed for the relapse of the disease, especially when he did not cure himself with an holistic approach. A negative point is also that patients become very dependent on the believes and life style promoted by proponents of unproven treatments.

For patients and relatives unproven treatments may represent a temporary escape. When the logical knowledge of scientific medicine does not offer a chance for cure, unproven methods seem to open a hopeful and magic solution. A so-called holistic approach claims to purify and heal the sick person, so that the tumor has no ground or terrain to proliferate. Proponents of unproven treatments oppose a scientific evaluation very often because negative test results would disillusion patients and doctors. The routine treatment of patients with methods without efficacy as a help to care is deceit and may be harmful for patients.

The diagnosis of a cancer is still a severe event in ones live. A true care has to be based on evaluated programs. The patient should do those things for his well-being that he was accustomed to prior to his diagnosis.



## DIFFERENT PATHS TO HEALTH: EVERYBODY SHOULD CHOOSE HER OWN

prim. dr. med. Majda Kurinčič-Tomšič, spec. rehab. med., acp.

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Health and illness is manifested visibly (in physical reflection) and in the invisible or less readily recognisable mental and spiritual happening in a person. According to the energy concept of the traditional Chinese medicine, health is a balance between the energy processes in the body (microcosms) and equilibrium of these processes with the nature (macrocosms). Acupuncture (and related techniques) and macrobiotics (which includes specific nutrition and as well as lifestyle) can contribute towards the balancing of these processes. These techniques can influence the course of the illness and healing, as has been in many cases also objectively proven. In breast cancer treatment (as well as in other illnesses) it is important to take advantage of the achievements of the modern medicine and support them with the methods of the traditional, now non-conventional, healing. Which path a patient chooses in pursuit of her health, after consultation with professionals, should depend on her personality, knowledge and capacity of perception.

## THE NEEDS AND CHALLENGES FOR ACADEMIC TRANSNATIONAL CANCER CLINICAL RESEARCH

Denis LACOMBE, MD, MSc

EORTC Data Center, Brussels, Belgium

While substantial gains have been made in the early diagnosis and successful treatment of cancer, it continues to be the second most common cause of death in European Community countries. It is imperative to develop new preventive and early detection strategies, to evaluate and implement new and more effective treatments, and to disseminate the most current information as rapidly and efficiently as possible to the largest number of clinicians and patients. The most complete and reliable information about a new diagnostic test or state-of-the-art treatment advance continues to come from the progression of laboratory work to early clinical trials to appropriate large, multicentre clinical trials. In order for this process to continue, it has become necessary for research programs throughout Europe to integrate scientific disciplines, pool available resources, and establish adequate facilities to coordinate, oversee and facilitate high-quality research efforts.

Good Clinical Practice addresses public health issues in clinical research that include both pharmaceutical and non-pharmaceutical research in medicine. While clinical trials on pharmaceuticals is directed toward the development of medicinal products (drugs), there is a large and important area of "non-pharmaceutical" clinical research aimed at evaluating other key diagnostic and therapeutic strategies. This research includes the evaluation of medicinal products alone or in combination with other therapeutic methods, the evaluation of surgical technique and instruments, radiotherapy, medical instruments, and pure observational (epidemiological) studies.

The optimization of diagnostic and therapeutic strategies is needed for individual cancer patients and society. Non-pharmaceutical research often requires high patient enrollment and support of international networks of physicians working independently. Large scale trials are often best positioned to detect marginal differences in diagnostic and therapeutic interventions that are medically significant.

Public health in Europe requires that government, industry, academia, and independent researchers continue to cooperate in such high-quality clinical trials in order to define state-of-the-art treatment and identify ineffective or redundant strategies. Independent research needs to be seen as a full partner in good medical practice.

At present, independent cancer clinical research finds itself faced with an increased number of challenges: administratively burdensome and often redundant ethical review processes, a complex web of varying national regulatory requirements, and varying demands of a multicultural European environment. Key areas of biomedical and health research are currently marginalised in European policy making on public health, usually because policies are developed without taking fully into account the scientific environment and economic structure of independent research.

The economic, social, and ethical requirements of a public health policy appropriate for European citizens in the 21st Century require the complete recognition of the pivotal role played by independent clinical research. As we move toward a full European implementation of GCP and the development of stronger ethical review processes, it would be beneficial if the terms of reference were appropriately inclusive of all partners working toward the common good of European public health.

ROLE OF CANCER PATIENT ASSOCIATIONS FOR REACH TO RECOVERY  
INTERNATIONAL VOLUNTEERS

MR GRAEME BRIEN

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Reach to Recovery International Programs aim to assist women newly diagnosed with breast cancer through the support of another woman who has herself had breast cancer. Through this supportive process, the newly diagnosed woman draws on the care, concern and experience of another woman in assisting her own recovery.

A direct analogy can be made for Reach to Recovery International Programs seeking to develop and sustain themselves through association with a cancer society and/or other existing programs and services, which have skills, resources and experience to share.

Cancer Societies develop from and within the community as a result of the desire of community members to assist people coping with cancer. This is consistent with the intentions of the Reach to Recovery International Program, only broader in focus.

Reach to Recovery International Programs that utilise the support of Cancer Societies potentially gain:

- Public association with a high profile community organisation
- Access to proven support programs on which to model other services
- Access to skills, experience and resources in volunteer selection, management and training
- Access to wide ranging oncology related expertise and resources
- Inclusion in activities of the wider "cancer community"

In addition Cancer Patient Associations themselves potentially gain from their association with a grass roots cancer peer support program.

Reach to Recovery International Programs may benefit from mutually supportive relationships with kindred organisations as a means of ensuring an ongoing and sustainable support program for women with breast cancer.

INCREASING COMMUNITY AWARENESS

Evelyn Smillie

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UK

ABSTRACT NOT ARRIVED

## BUILDING RELATIONS AND COALITIONS WITHIN YOUR COMMUNITY

Liisa Elovainio

The Association of the European Cancer Leagues (ECL) and  
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It will still take much time before children must turn to the history books in order to learn about a disease called cancer, or before cancer research has taught us how to repair immediately any DNA damages caused by carcinogens. At this stage cancer will occur increasingly. More research especially in the field of cancer prevention is needed. More cooperation is needed to achieve better prevention and much needs to be done in the field of rehabilitation and support.

Cancer Leagues are normally among the biggest public health organisations in their countries. In fact, a Cancer League is the only body equally interested in all aspects of cancer control. Cancer Leagues have formal and informal links with each other and other organisations and networks.

The Association of the European Cancer Leagues (ECL) is a good example of a fairly informal coalition of 37 cancer Leagues from 25 countries. It meets once a year in a General Assembly connected with a symposium. The Board has nine members. The Secretariat is currently in Finland.

The European Cancer Leagues have learned that cooperation between different administrative fields, education systems and health care doesn't come true by itself. In cancer issues the impact has naturally very often come from the National Cancer Leagues. Patient issues were very crucial when most of the National Cancer Leagues were born. The Cancer Leagues have by no means lost their interest and commitment to patients' well-being in spite of the fact that cancer research, prevention and earlier diagnosis including cancer screenings have emerged as important issues. In many countries there are several, even tens of voluntary cancer organisations and groups, all aiming at better cancer control and humane hospital conditions. These may cooperate but also compete with each other. The trend today is to ensure at least a minimum level of cooperation in order to not drain the scarce resources too much.

There are lots of other positive and productive coalitions in the voluntary cancer control field. The Nordic Cancer Union is one of them and the one I have known for long. It is a cooperative body for the National Cancer Societies in Denmark, Finland, Iceland, Norway and Sweden. It has joint activities in the fields of information, patient support and research. Recently the Union has carried out an extensive project: "Passive smoking and children". All the Nordic countries are small but put together their population is 22 million. With this population size it is meaningful to carry out epidemiological and clinical cancer research. The Nordic Cancer Union has initiated a new type of training for oncologists on how to listen to the patient and how to break bad news. This communication project for doctors continues now separately in the five Nordic countries according the outlines adopted during the initiation period. The Nordic Cancer Union also develops methods in order to help the patients in their new economic situation. Even in the well-fare North a patient may suffer from substantial economic losses due to the illness. The Nordic Cancer Union supports development of programmes and standards for the education of volunteers and for cooperation between these and the professionals.

In tobacco control there are tens of effective coalitions. In the spring of 1998 anti-tobacco activists from 18 countries came together in order to ensure approval of the Tobacco Advertisement Ban Directive in the European Parliament this year. An important common goal was sufficient to make all of us to do our utmost best in lobbying for a Smokefree Europe. This inspiration can be felt around other cancer issues as well, not to mention breast cancer. To my mind, breast cancer groups and tobacco control activists are the strongest and most effective collaborators on the European map.

Many extensive breast cancer coalitions exist already. One example comes from the United Kingdom, where at least 26 cancer organisations and groups have been listed in the Internet. There you gain easy access to detailed information about these organisations. The National Breast Cancer Coalition (NBCC) in the USA is another very prominent example of coalition building, so is the coalition in Canada and also Europa Donna.

DYNAMIC PLANNING TO MEET VOLUNTEER AND PATIENT NEEDS

MR JEFF DUNN

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**“To make plans and project designs brings with it many good sensations; and whoever had the strength to be nothing but a forger of plans his whole life long would be a very happy man: but he would occasionally have to take a rest from this activity by carrying out a plan – and then comes the vexation and sobering up”.**

**Friedrich Nietzsche, 1879**

Forgive the gender bias in the language; this piece by Nietzsche was written well before the advent of our “equally opportunistic” twentieth century.

Nevertheless, the sentiment conveyed is instructive. Perhaps Nietzsche foresaw our contemporary pre-occupation with all things “strategically planned” rather than “artfully ventured”!

This paper then examines a number of key planning issues associated with the development and delivery of Reach to Recovery programs.

In particular, simplifying the planning process, converting plans into action and recognising our own talents, skills and advantages, will be covered.

## HOPE FOR THE FUTURE

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With the dawning of the age of technology, we have seen a growing conviction that, with the proper application of the scientific method, a cure can be found for every disease. The thinking goes as follows: if we can diagnose it, understand it, take a picture of it, look at it under the microscope, radiate it, and use the right chemicals on it, then somehow we should be able to defeat it. Certainly, the last fifty years have seen some astonishing advances in medical science, and we all have great hopes for a major breakthrough in the treatment and even the cure for breast cancer, especially in the area of genetic research. However, in the process of focusing so intensely on the technology, the medication, the machines, and the sophisticated surgical techniques, the patients have somehow been rendered unimportant. In fact, there is nothing more important than the patients, for they are, after all, the packages that diseases are wrapped in — and each package is special, unique, and deserving of compassion.

On the horizon, we can see the beginnings of an attempt to humanize medicine — to make it, as people in the high-tech arena would say, “user friendly.” Some of the medical schools in the United States have designed curricula which include a focus on the human dimension of doctoring. Students are learning to view their patients as whole human beings rather than merely as interesting cases worthy of being reported in some medical journal. They are opening up to the range of emotions that their patients will inevitably express, and are developing the skills to deal with these emotions kindly and effectively. As this trend continues, we are hopeful that our future doctors will approach their patients more holistically, combining their expertise with respect and understanding. Students are also being introduced to alternative and complementary approaches to healing and wellness that include acupuncture, herbal medicine, nutrition, body work, meditation and guided imagery. The future of medicine will surely reflect a blending of the very best of conventional and alternative medicine, much to the benefit of the patient.

Patients, on the other hand, are finally coming to terms with the fact that they must be partners in their own health care. Thirty years ago, questioning a doctor's advice or engaging in a dialogue to find the best treatment was virtually unheard of. At that time, doctors were viewed as the ultimate experts, and their word was law. Patients were absolved of any responsibility for learning about their bodies, their diseases, and the treatments available to them. Today, I see women who have been diagnosed with breast cancer flocking to medical school libraries, learning to read and understand highly technical material, conducting searches on the Internet, and actively networking with others. As patients, we are beginning to see ourselves as important members of our own medical teams. This is a growing trend, and must be encouraged. Our voices will be heard, and they will be valued.

The greatest hope for the future lies in the growing awareness of the value of community. As society becomes increasingly mobile, many people move away from extended families and established friendships. So many of us find ourselves unrelated to a community of any kind, and are often too busy to devote the time to create a supportive network for ourselves. In addition, as technology demands more and more rapid and efficient problem-solving, a true understanding of the process of inner exploration and personal growth has been lost. An experience with breast cancer serves to magnify our isolation and loneliness, and invites us to connect with each other in meaningful ways. Motivated by the need to give and receive support, we will begin to build communities which will define a new kind of family — a family in which it is safe to share our pain and celebrate our triumphs.

Reach to Recovery is already there. We know about the value of community. We share ourselves, care about others, and go out of our way to be of service when other women are alone, afraid, and confused. We are doing it now, and we will continue to do it. We are the hope for the future!

Title/type in CAPITAL LETTERS	<b>"LOOKING BACK - MOVING FORWARD"</b>	
Author(s)	<p style="text-align: center;"><i>DOUBLE SPACING</i></p> <b>Mrs Elizabeth Brien (McCrum)</b> <p style="text-align: center;"><i>DOUBLE SPACING</i></p>	
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START ABSTRACT

This paper will look at past achievements of the unique Reach to Recovery Programme and consider its "Moving Forward" into and beyond the millennium.

As it is almost 40 years since the Reach to Recovery Programme began in the USA and it is the 10th Reach to Recovery International Conference, it would be prudent to just stop and take a look at what has been achieved over these many years and then in the light of such achievements - how we have been and how we can move forward with this simple, low cost, but extremely effective Service.

Much has been happening recently in the Asia Pacific region with relation to Reach to Recovery and other Cancer sites e.g., Laryngectomee and Colo-Rectal cancers. The unique, yet profound, Reach to Recovery model which we are all part of has been used in setting up these Programmes.



LOOKING BACK - MOVING FORWARD

JENNIE R. COOK

AMERICAN CANCER SOCIETY, INC.  
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USA

**"Looking Back - Moving Forward" A retrospective of the American Cancer Society's pioneering work to make Reach to Recovery truly international, coming up to the present, where we have handed it over to UICC for future development and management. It will attempt a look into the future, identifying the next challenges for the breast cancer survivor in the millennium.**

# ***Posters***

## MODELO APOVILO.

G. Zujani, H. Miles, H. Soler

APOVILO (Asociación Pacientes Oncológicos de Vicente Lopez) is a non-profit NGO dedicated to help cancer patients in their struggle against the disease, through their active participation in different activities, as well as their families, doctors, psychologists and volunteers. The high costs in treatments and research has made of cancer a social problem, in which the state is not able to cater for all the needs. We are convinced that NGOs can fulfill this role. This is the reason for our existence. Our association, founded in the Hospital Municipal Dr. Bernardo Houssay, is called **MODELO APOVILO**. It consists of 3 basic pillars:

**Patient's Support:** With the help of professionals (doctors and psychologists) patients are encouraged to take part in self-help groups, and/or receive psychological assistance; we also have self-help groups for the patients' families as well as informal meetings with doctors. The group of volunteers play a fundamental role in our organization, assisting patients and doctors while waiting at the consulting rooms, or giving their support to new patients by visiting them when they are in hospital. Many volunteers are cancer patients themselves. A great job is being done at the DAY HOSPITAL for out patients, where patients receive their chemotherapy in a lively room full of plants where they listen to music as they share sweets, cookies and tea, while the volunteers read to them, crack jokes and chat. Here, we also play cards, chess and other games.

**Social Support:** APOVILO offers a wide range of activities on its premises, a charming house that allowed the **MODELO APOVILO** to flourish by offering different workshops such as: Wood Painting, Artificial Cloth flowers, Spanish Cards, Handicrafts, Yoga, Swimming, History of Art, plus a Literary Workshop where our magazine "Challenge, APOVILO's magazine" got started and is fully run by patients and their families; we also have Tango and Salsa Classes, and Radio Soap Operas, etc. Another important achievement is the staging of four plays in a workshop where more than 30 people take an active part. APOVILO also organizes TOURS to different provinces, where patients make up a cheerful group. Other activities worth mentioning are: Dinner Parties, Dances, Fashion Shows, Music Shows. Our motto is "Enjoy and Have Fun".

**Cancer Research:** Our organization has created a "Research Unit" to complete the different aspects that APOVILO has already put forward and to increase new areas such as: Statistics, active participation in National and International Congresses. With the help of our professionals, we work on Prevention because we are convinced that cancer can be cured with information and early diagnosis. This is why we are on our way to organizing an Ethics Committee and a Tumour Committee as the scientific basis that will pave the way towards our goals.

APOVILO has taken part in the following events:

- 1997 Nursery Congress, Cuba
- 1996 9<sup>o</sup> Conference "Reach to Recovery", UICC Stockholm.
- 1995, 1996 and 1997 GETLAC International Congress, Buenos Aires
- 1996 10<sup>o</sup> National Women's Meeting, Jujuy
- 1997 11<sup>o</sup> National Women's Meeting, San Juan
- 1998 GETLAC International Congress, Buenos Aires
- We have been invited to be a part of the international web of the UICC because of the information we have submitted.

Thanks to the firm decision of the Vicente Lopez Mayor and the substantial funding of the Vicente Lopez Enterprise Foundation, APOVILO was able to build the first part of a Model Oncology Center in Vicente Lopez which consists of a Day Hospital for out patients, Consulting Rooms and an Investigation Area. We feel very proud indeed! We would like to communicate and share our experiences with other groups and institutions. These are different ways we can get in touch:

Snail-mail: Chacabuco 1880  
Florida - Buenos Aires  
ARGENTINA  
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## TREATMENT OF PAIN SYNDROME IN BREAST CANCER

**Mario Flaks, MD., and Rosa M. Bergoc<sup>(\*)</sup>, Ph.D.**

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At diagnosis, cancer patients frequently feel anxiety, lack of control and uncertainty regarding their future. During this phase, the social support is crucial. These needs can be met by family, friends, nurses, doctors and other medical staff. During terminal or metastatic phase, an important percentage of patients present primary or associate pain syndrome.

Our experience in hospital is that about an 11% of patients that show oncology-derived pain belongs to mammary cancer in stadium III or IV, and that the level of pain is in correspondence with the level I to III.

The objective of this work was to adequate the treatment of the cancerous pain with data released through patients in their responsiveness to a diagram for measuring pain. In this way, results obtained shows that: 36% of the patients with primary breast cancer shown bone metastases, 18% brain ones, 9% hepatics, and 1%, multiples metastases. Only 9% of patients with advanced mammary carcinoma (stadium III or IV) did not shown pain, whilst 45 % shown pain of level I, 27% of level II and 19% of level III. Different type of drugs were utilized in accord with the step of pain; the level I of pain was treated with analgesic and antinflammatory as salicilates, drugs derived from pirazolona and different derivatives from propionic acid. Results obtained indicate a good response to treatment in 86.7% of the cases. The level II of pain was treated with weak opium derivatives in combination with antinflammatories and under schedules proper for each case: codeine, ibuprofen, hidantoine, prednisolone, dipirona, alone or combined in different doses were employed. Pain syndrome disappear in 88.9% of treated patients. At last, pain characterized as level III was treated with stronger opium derivatives as morphine (in doses ranging from 7 to 12.5 mg each 4 - 6 hours), meperidine (75 mg each 2 - 4 hours) or nalbufine (10 mg each 4 - 6 hours), in numerous occasion combined with aminotriptilina (50 mg each 24 hours) and achieving the relieve of pain. 73.7% of patients shows response under indicated treatments.

The favorable results obtained with the appiled treatments indicate that: a) The employed diagram for measure of pain was adequate; b) The employed treatments were appropriated. We believe that there is yet much work to be performed in this field so related with the life quality of the oncology patient.

BREAST CANCER COUNSELLING.

MRS. KUHELI MUSTAFA.

WACC. DHAKA, BANGLADESH.

The name of my organisation is Womens Association for Cancer Counselling Bangladesh (WACC). As the incidence of breast cancer is increasing day by day and I being a breast cancer patient myself I have set up this organisation with the objectives of creating awareness and help counselling the cancer patients in the National Research Institute of Cancer Hospital, Dhaka, Bangladesh. My organisation has been recognised by the Bangladesh Cancer Society.

I have gone through the training of 'International Reach to Recovery Forum' held in Tata Memorial Hospital, Bombay, India, in December 1996 and till now I am the only participant and pioneer in my country.

WOMEN'S AWARENESS OF BREAST CANCER IN THE CITY  
OF SÃO PAULO

Paulo Iakowski Cyrillo, Nassif Alexandre Galeb Jr.,  
Luiz Claudio Figueiredo, Edison Mantovani, Gerson  
Botacini das Dores, João Sampaio Goes Jr.

CLÍNICA PSICOLÓGICA OBJETIVO DA UNIVERSIDADE PAULISTA  
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This study was conducted to investigate the causes of delayed treatment of breast cancer in women who lives in the City of São Paulo. After interviewing 1.509 women, distributed by age, educational and socioeconomic status, the authors found that women are not aware of early detection and do not practice any sort of preventive measures. Also they feel insecure over the disease and most of them hardly believe in the possibility of an effective cure. For these women, the physician is the major source of information and the best person to emphasize the great importance of early detection to improve chances of cure. The authors concluded that the concept of cure and awareness of cancer incidence must be the objects of largescale campaigns and programmes, specially through mass communication.

**RECOVERY PERIOD: ITS FUTURE PROSPECTS  
CROATIAN MODEL OF REACH TO RECOVERY PROGRAM**

Borosa Vjekoslava, Strnad Marija and Sabol Ruza

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In Croatia, like in many other countries, female breast cancer is the most common cancer in women. Every fifth cancer-affected woman here has a breast cancer. The number of new cases and deaths from this cancer site have been on a steady rise. Annually, over 1,400 (58/100,000) new cases are diagnosed, with more than 750 (31/100,000) women dying. Noting the size and importance of the problem, the first 8 Croatian lady volunteers have completed a course, receiving their certificates from the International "Reach to Recovery" Program. On the model of other countries, the Branch of Croatian Women Volunteers was founded within the Croatian League against Cancer. Our Reach to Recovery Program was started in 1994 at the University Clinic for Tumors, Zagreb. Because of the then war, under the Reach to Recovery Program concept the volunteers were taking on duty turns twice a week, which included answering phone calls, in the afternoon hours at the University Clinic for Tumors on the League against Cancer premises. Through conversing with and advising female patients, the Program was also run in another larger university clinic in their hairdresser's parlor which supplied the female patients with cancer, breast cancer and other carcinomas with wigs. Group support to the women undergoing a breast operation is given by the breast operated women's clubs. In Zagreb, they were established already in 1982. In 1996 and 1997 they were founded in Osijek, Rijeka, Požega, Split, Pula and Metković. A professional team made up of social workers, physiatrists, psychiatrists, psychologists and surgeons does the program planning, follow-up, and evaluation. On average, the professional team and volunteers have monthly joint meetings conducted by program coordinator, Mrs. Vjekoslava Borosa. The volunteers undergo regular annual supplementary courses. For program promotion, TV, press and radio are used, particularly so in the month of the fight against cancer. Locally and internationally, the program is also promoted at technical and scientific gatherings, as well as through popular science lectures for the public. It also had leaflets printed. Currently, a popular brochure for female breast cancer patients is prepared. The chief obstacles still encountered by the Program are insufficient female patient awareness, uninterested medical staff, absence of continuous financial support, lack of adequate rooms, as also the undersynchronization and insufficient work intensity of the professional team. It is planned to achieve full national coverage with the network of female volunteers carrying out the Program. Also, a National Center to Help Breast Cancer Patients is to be set up: beside coordinating the current Program it would provide services such as, education programs, psychological aid, counselling and similar. It would collaborate with corresponding domestic and foreign institutions. This clearly requires permanent sources of finance and adequate resources translated into premises, equipment, employees etc. Through continuous activities the thus organized Center would raise patient awareness, provide them and their families with larger aid, improve the patients' quality of life and reduce female breast cancer patient mortality.

INTRATUMORAL THERAPY WITH VRCTC-310 FOR REFRACTORY SKIN METASTATIC BREAST CANCER.  
PRELIMINARY REPORT.

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Ventech Res.; APOVILO, Hosp. B. Houssay, Bs. Aires; Cantabria Inc., Madrid.

A natural product VRCTC-310, is derived from purified snake venom fractions. It is composed by crotoxin and cardiotoxin. It has shown activity against human tumors either by intramuscular route or by intratumoral route. Four patients (pts) with relapsed and refractory skin metastatic breast cancer were treated from May 1996 to November 1996, with VRCTC-310, 0.33 mg/m<sup>2</sup> by intratumoral route every week. All pts had confirmed histologic diagnosis of disease. As prior treatment all pts underwent a surgical procedure, radiation therapy, no less than three lines of chemotherapy and hormonotherapy. A big thoracic tumoral mass was the main site for therapy. All pts gave informed written consent before treatment. Peritumoral multiple disseminated nodular lesions served as control. The VRCTC-310 dose was diluted with 1 ml of lidocaine and it was injected into the skin tumoral mass in four different quadrant every 7 days. Objective response was registered in tow pts (CR 1, PR 1).

Local pain at the injection site, spontaneously reversible, was the only side effect. Most of nodular satellite lesions reduced in size or disappeared during treatment. Because of the lack of limiting toxicities, VRCTC-310 appears as an useful contribution for the treatment of refractory skin metastatic breast cancer. These results, make the regimen feasible for out-patient treatment and further studies using the above-mentioned approach are warranted.



REACH TO RECOVERY IRELAND – A CELTIC EXPERIENCE

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REACH TO RECOVERY IRELAND WAS FOUNDED IN 1979.

THIS POSTER WILL LOOK AT THE DEVELOPMENT OF REACH THE RECOVERY OVER  
THE PAST 20 YEARS WITH PARTICULAR EMPHASIS ON THE WORK CURRENTLY  
BEING UNDERTAKEN BY VOLUNTEERS. THESE INCLUDE:

SELECTION AND TRAINING METHODS

RETRAINING

EDUCATION IN SCHOOLS OF NURSING, GENERAL PRACTITIONER TRAINING  
SCHEMES, PUBLIC EDUCATION, WONKA 98 (WORLD CONGRESS OF GENERAL  
PRACTITIONERS), DEVELOPMENT OF A NATIONAL BREAST SCREENING PROGRAMME  
FOR REPUBLIC OF IRELAND.

## IMPACT OF PSYCHOSOCIAL INTERVENTION ON THE QUALITY OF LIFE OF ELDERLY CANCER PATIENTS

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The aim of this study was to assess the impact of three different psychological interventions on the quality of life (QL) of elderly cancer patients with symptoms of anxiety and/or depression. Seventy-four patients were enrolled in the study. All were aged over 65 and had solid tumours or haematological malignancies, generally in advanced stages (III-IV). The cancer treatment was administered for a mean duration of 5 months and the mean number of chemotherapy cycles was 4. After stratification for the main prognostic factors, patients were randomly assigned to one of three groups: *Group A*, psychopharmacological treatment; *Group B*, treatment A plus social support carried out by volunteers and *Group C*, treatment as Group B plus structured psychotherapy. The planned duration of intervention was the same as that of the medical treatment. Patients who did not complete the planned chemotherapy nevertheless received all the planned psychological intervention. The evaluation of patients' QL was assessed using either uni- or multi-dimensional instruments to explore functional status and physical symptoms as well as psychological status at subsequent times during treatment (i.e., pre-treatment, mid-treatment and at the end of treatment). The present study shows that the combination of psychopharmacological treatment with either social support for patients and their relatives carried out by volunteers (SSV), or SSV plus structured psychotherapy (SSV.+ SP), yielded the best results in terms of QL in the long-term treatment of elderly patients with advanced cancer. According to the analysis these two 'integrated' approaches proved to be almost equally effective.

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## ABSTRACT

### INTENSIVE RESIDENTIAL WORKSHOPS

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Our organization - besides several and various other activities - holds annually INTENSIVE RESIDENTIAL WORKSHOPS in pleasant Italian towns.

They are specifically ment to study in depth the reaching and maintaining of psycho-physical health, combining technics of relaxation and individual insight with group analysis and discussion.

They are especially thought for women who have esperienced the breast cancer, but family members, medical staff and social operators in general are welcome.

They are the result of our belief in the need of developing new kinds of learning to guide people to reach their set goals, enabling them to focus on the "dark sides" of their paths to recovery and clarify them.

Since we verified that these workshops are very useful and have a positive effect on participants, we have decided to continue this experience.

The intensive residential workshops last 4-5 days and are held every year in a different town, they are managed by a psicologist operating in our organization, and are opened to 20 participants.

After several workshops held in our hometown we chose the residential formula, because we realized that being at home is an obstacle to freely relax (thoughts about work, family, and so on, are difficult to remove).

Title/type in CAPITAL LETTERS	BARRIERS THAT COME IN THE WAY OF HELPING OTHER MASTECTOMEES IN NEPAL.
	<i>DOUBLE SPACING</i>
	MRS. NITA POKHAREL
Author (s)	<i>DOUBLE SPACING</i>
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Institution Town Country	
START ABSTRACT	

Cancer breast is second most common cancer of women in Nepal. In order to help other mastectomees in Nepal, certain psychological, social and economic barriers need to be resolved. People in general have various myth regarding cancer. These myth causes sadness, depression, helplessness denial and hinders seeking medical help in early stage. These myth are cancer is incurable, it is communicable, death due to cancer is inevitable, its treatment is waste of money. Cancer victim has done a great sin in this life or past life and is getting the punishment of it by nature. People usually do not accept the children of cancer patient for marriage partner. Therefore, most women hide it if her children are to be married. There is scarcity of oncologist, cancer surgeon, oncology histopathologist. There is no cancer hospital. Cancer patients are treated in general hospital and nurshing home by general doctors who use trial and error methods, spoil the treatable case, do not refer the patient to onchologist. There are case who are getting cancer treatment but are not cancer case. Educated and those who can afford go to another country (India, Thailand) for confirmation and treatment. The spoil case also go to other country even if they could not afford. They sell their land or house or take loan for treatment. Some patient who should not died are dead due to wrong treatment or has gone to advanced stage. It is difficult to council the would be mastectomees in such condition. Our known mastectomees are middle class working ladies who are working full time in their office in order to earn their living,. They need to travel by public transport that is more time consuming and involving cost also. Therefore, visiting other mastectomy is a problem unless some incentives or remuneration could be provided to volunteers. At present, the volunteers are not trained and there is no infrastructure in society like man power, secretarial support, equipments like computer, fax, typewriter, breast prosthesis and the literature. Being a developing country, most people are illiterate. Female literacy is only 24%. Those who are literate also cannot understand english well.

THE PSYCHIC SUPPORT OF WOMEN AFTER MASTECTOMY  
IN THE POLISH MOVEMENT OF SELF-HELP.

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The important element of rehabilitation and post-operative adaptation of women with breast cancer after mastectomy is psychic support.

Incidence of breast cancer in Poland is about 9000 new cases a year. In Poland radical mastectomy modo Patey remains the main treatment method. Good psychic rehabilitation is lacking in most hospitals curing the women with breast cancer.

The movement of self-help within women after mastectomy organize psychophysical rehabilitation in the "Amazons clubs" and develop the activity of volunteers.

The women may obtain both non-professional and professional support in their clubs. The volunteers after adequate group training provide emotional support in the hospitals and in the clubs. The trainers of volunteers are two psychologists-consultants of The Federation of Polish Clubs of Women after Mastectomy (Małgorzata Amamczak and Teresa Turuk-Nowak, the author of this poster).

Professional psychic support is given through the groups of psychologists-cooperators in the clubs. Individual and group meetings of women after mastectomy with psychologists are possible in each club. Psychologists are trained in psycho-oncology and hold the meetings devoting more time to the exchange of their own professional experiences.

## POLISH "AMAZONS" THE "BABY" OF "REACH TO RECOVERY INTERNATIONAL"

Wiesława Dąbrowska-Kiełek, Krystyna Kostro

### The Federation of Polish Clubs of Post-Mastectomy Women "Amazons"

The first "Amazons" Club was established in 1987 by the inspiration of "Reach to Recovery" movement to bring help to breast cancer survivors. Next, the clubs joined into The Federation of Polish Clubs of Post-Mastectomy Women "Amazons". The Federation consists of 65 clubs all over Poland. They have about 10.000 members with 500 trained volunteers. It is an independent, registered organization seated in Warsaw.

It has become a member of the "Reach to Recovery" since the visit of Mrs Francine Timothy, Former President, "Reach to Recovery International" Committee. At that time special training of volunteers was organized and sponsored by the Reach to Recovery. Since that moment our organization has followed the patterns of similar Western European and American movements. It develops systematically and is scientifically based. It is a significant organization in the combat against breast cancer and support to breast cancer survivors.

We are proud that such celebrities like Madame Nancy Kisinger met with "Amazons" Club members in June 1997.

During the training programme for "Amazons" Club, members our delegation were honoured by the invitation of Madame Hilary Clinton, the wife of the US President.

Mrs Betty McCrum, President of the Reach to Recovery International paid us a visit during the celebrations of the X Anniversary of the Federation in 1997.

All the anniversaries and significant events are attended by the celebrities of the world of politics, culture and medicine such as:

- the Wife of the Polish President (Jolanta Kwaśniewska was a honorary patron of "Amazons" Clubs events)
- Wives of Ambassadors (American, Canadian),
- Senators,
- Actors, artists, painters, etc.

All the visit not only honour our organization but strengthen our importance on national and international seale.

In order to fulfill our goals we cooperate with the following organizations: Europa Donna, Association of Pink Ribbon, National Coaliton to Combat Cancer, Wifes of Voivodes.

The Federation of Amazons` Clubs constitutes a consolidated group of women full of faith, hope and love and therefore it is strong. A tribute should be paid to Dr Krystyna Mika, Coordinator and animator of the Federation for her hard work and devotion.

LOOKING BACK - MOVING FORWARD: THE RESULTS OF  
A 10-YEAR EXISTENCE OF REACH TO RECOVERY IN RUSSIA

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It is a great honour and pleasure to represent the Russian Reach to Recovery Association Hope/Nadezhda here in Ljubljana. Ten Reach to Recovery International Conferences is a wonderful jubilee and a significant history of this extraordinary Volunteer Breast Cancer Support Program. For almost fifty years since its initiation by Terese Lasser such kind of non-medical service to today's affected women has already proved benefit of a person-to-person contacts to improve the quality of their life. A wide dissemination throughout the world brought this program to Russia and by the end of 1998 we will be celebrating our 10th anniversary. This event makes us look back and estimate what has done and how. We have an international recognition: in 1992, in Trieste our Association became an affiliated member of Reach to Recovery International Forum and two of its founders were honoured by receiving the Reach to Recovery International Medal. We took part in last four Reach to Recovery Conferences and are very proud with a received high reputation. We were invited for participation at different National Congresses and attended the First World Conference for Cancer Organisations (Australia, 1996) and the First World Conference on Breast Cancer (Canada, 1997). Following accepted Reach to Recovery standards we meanwhile develop our responsibility for the local program and promote it in accordance with own socio-cultural peculiarities. Ten years ago we started to open a new stage of public relations and to show that it was possible to stay cooperative not thinking of fee or another kind of compensation. We began to turn charity in oncology from a declaration to a real action. It was not an easy task to be adjusted to this position both for those who accepted a support and for those who shared it. At first it was necessary to admit the support needs of breast cancer patients and to get rid of egoism. The former breast cancer survivors, selected and trained, understood the whole situation best of all. They have caught the main meaning of the Reach to Recovery Program - public awareness in breast cancer. Up to now our volunteers are sure that their noble activities are required by healthy women not less than by patients because knowledge is a power. Each woman should hope on her skill to listen to her body and to see a doctor as soon as she finds something wrong. Exactly because of this purpose our volunteers hold annual city meetings and a lot of people learn more and more about their ability to prevent advanced disease in a case of its rise at the early stage. Visits, information, practical and emotional advice are not the complete list of our volunteers' fair work as well. Nevertheless they need to overcome some essential problems that are in doctors' approach to their patients and in mentality of former sufferers who could be recruited as volunteers or are at present included in this activity. Indeed professionals often do not initiate patient's talk to a volunteer and are not quite supportive of the Reach to Recovery Program strategy. As for new volunteers some potential candidates are frequently afraid (or are strictly rejected) to be involved while they have own unsolved psychological difficulties or not each individual is able to serve free of charge. There are still some barriers to convince any of our activists to advance their training in expertise to communicate. It really impedes the process of cooperation and makes us be persistent in observance of chief Reach to Recovery principles. We maintain a position that volunteers should see themselves that without their own responsibility it is impossible to expect particularly good results. Management of our Association shows that volunteers should be assessed by those who had been in the sphere of their interaction. Therefore wishing to sum up our Reach to Recovery we have studied opinions of 50 breast cancer patients who had received our supportive program. The questionnaire concerned patients' attitude to a Reach to Recovery conception and a capacity of our volunteers' aid. All women-respondents were satisfied with our support. Nobody leveled criticism at our volunteers because they positively changed the quality of patients' life assisting them to cope with difficulties of adjustment to current vital circumstances. It is obvious that today's sufferers may follow optimism of today's survivors. Everybody is able to watch that physical, emotional and cosmetic consequences of cancer can be reduced if both medical treatment and non-medical care will be provided. The assessment of a 10-year existence of Reach to Recovery in Russia gives us a satisfaction that it has a big value especially in the areas of coping skills and knowledge. Doctors' involvement might offer strength to the Program in patients' eyes. Nearly 80% of patients testify that their beloved surgeons should stay in more open contact with them and be more flexible in choice of a type of a convenient support. The benefit of the Reach to Recovery Program appears to be that it enables today's breast cancer patients to occur less affected by the fact that they have a malignant disease. Volunteers are granted with a generous feeling of their advantage for others. It is right to look back systematically in order to move forward and forward.

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## BALANCE BETWEEN HEALTH CONDITION AND QUALITY OF LIFE IN PATIENTS WITH INFLAMMATORY BREAST CANCER

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When evaluating cancer therapy, not only its effect on the course of disease but also its impact on the quality of patient's life (QL) during and after therapy should be considered. This is all the more important in view of newly introduced treatment modalities, as every novelty does not necessarily imply a better QL. It is difficult to set some uniform criteria for the evaluation of QL, as this normally reflects a totally subjective impression of every individual patient, which is influenced to a greater or lesser extent by various physical, mental, social, occupational and spiritual factors.

Our analysis was concerned with inflammatory breast cancer patients and their subjective assessment of their global health condition (HC) and QL during and after therapy, as well as with possible discrepancy between the two.

The analysis included 13 patients with inflammatory breast cancer at an average age of 54 years (range 28-65 years), primarily treated by ChT (6 cycles) which was followed by surgery and irradiation. The treatment was carried out within the framework of EORTC trial 10921 and lasted 7 months on average. Complete response was achieved in all patients. After completed ChT, the patients were treated by tamoxifen. General HC and QL were assessed by means of EORTC QLQ-C30 questionnaire (version 2.0), questions 29 and 30. The patients were asked to evaluate their general HC and QL with grades from 1 to 7. In one year period they filled in 7 questionnaires, i.e. before the beginning of therapy, and one-, two-, three-, six-, nine- and twelve months after it. Average score for each of the two questions was calculated in the seven time periods. All the patients were informed about the diagnosis of breast cancer before filling in the first questionnaire.

We found that at the beginning of treatment the patients' assessment of HC was slightly better than that of QL (5 vs. 4.7). The scores in both parameters were decreasing by duration of treatment, reaching the lowest values in the 2nd month (3.4 vs. 3.6). From that point on, both scores were on the increase until the end of treatment (5.3 vs. 4.9). On the repeated evaluation 3 months later, the subjective grade of HC dropped slightly (to 4.7) while the subjective grade of QL was still on the slight increase (5.1). In the next trimester, however, the opposite picture could be observed: while the scores for HC showed an increasing trend, those for QL were decreasing all until both parameters reached practically the same values (4.9) one year after the beginning of treatment.

During the 6 month treatment period, subjective scores of HC and QL were parallel. It is interesting to note that in the first few months of therapy, when the extent of the disease was decreasing, the subjective score for HC was decreasing as well, and that three months after treatment-related side effects were still present, the subjective score for QL was increasing. This indicates that patients' subjective assessment of their HC and QL is different from that shown by objective criteria. After completed therapy, the subjective scores for HC and QL reach the same levels as at the beginning of therapy, which is consistent with the actual situation and patients' improved health status.



# THE INFLUENCE OF THE EARLY CHILDHOOD FAMILY CLIMATE ON LATER BREAST CANCER MORBIDITY

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## INTRODUCTION

Some biological and clinical factors are well known to promote cancer. The role of psychological factors has not been fully explained yet.

The quality of first relations, especially in early childhood families' climate, has an important role in personality shaping and its response to stress. Numerous psychosomatic studies have been investigating the influence of relations between personality, family climate in childhood and later stress situations on cancer morbidity. The results were controversial. Although some authors have found out that cancer patients comparing to the normal population, have had evidence of cold childhood emotional climate(Le Shan 66, Thomas- Duszynski 74, Thomas 79, Bahnson 80, Fox 83, Greer 83, Baltrusch 86, Grassi 86, Graves 91). The other authors have not confirmed those findings (Giraldi 97, Duszynski 81).Therefore ,we try to elucidate the role of above mentioned factors in the initiation and development of breast cancer.

## PURPOSE

Our study was aimed to investigate the influence of family climate in early childhood on later cancer morbidity by using FAQ (Family Attitude Questionnaire), developed by Caroline Bedell Thomas. In the case of significant results, the FAQ might be used for the screening of risk groups or for early cancer screening.

## MATERIALS AND METHODS

The study, which was carried out on the entire territory of Slovenia, included 363 consecutively diagnosed breast cancer patients. The control group was matched by number, sex, age, education and area.

All breast cancer patients and the controls were filling in the FAQ. The questions were related to the following areas: relationship with the father, relationship with the mother, relationships between parents and subjective family evaluation.

The answers were scored according to a special schedule using +1 or-1, and grouped by the following parameters: closeness to the parents (CTP), emotional demonstrativity (D) and matriarchal dominance (MD). For every parameter the average(AVG) and standard deviation (STD) were expressed.

Student t-test was used for statistical analysis. The P values were given.

## RESULTS

The average (AVG), standard deviation (STD) and P-values for patients(pts) and controls (con), regarding the closeness to the parents (CTP) , emotional demonstrativity (D) and matriarchal dominance (MD) score are given in Table 1.

	CTP	D	MD
<b>AVG pts.</b>	4.931	2.033	-1.455
<b>STD pts.</b>	4.341	1.388	2.351
<b>AVG con.</b>	4.756	1.900	-1.232
<b>STD con.</b>	4.585	1.410	2.475
<b>P value</b>	0.278	0.112	0.101

Table 1. Average (AVG), standard deviation (STD) and P-values in relation to closeness to the parents (CTP) , emotional demonstrativity (D) and matriarchal dominance (MD), in group of the breast cancer patients compared to the control group. There were no significant differences found between groups. The characteristics of family in childhood are given in Table 2.

	Breast cancer patients	Control group
Complete family	263 - 72.45%	254 - 69.88%
Single parent family	40 - 11.01%	37 - 10.22%
Up to 17 yrs of age: divorce or death of one parent	52 - 14.32%	58 - 16.02%
Living elsewhere (not in the family)	8 - 2.22%	14 - 3.88%
<b>Total</b>	<b>363 - 100%</b>	<b>363 - 100%</b>

**Table 2.** Family in childhood

#### CONCLUSION

The results of our survey on a series of 363 consecutively diagnosed breast cancer patients and the same number of controls all over Slovenia were not consistent with the results reported by many other authors confirming the influence of family climate in early childhood on later cancer morbidity. The family climate score in both groups was lower than in those referred by other authors. The causes could be attributed to different role of the family in our country. Our results have not confirmed the usefulness of FAQ for the purpose of the early breast cancer or risk group screening. We believe that psychical factors play a decisive role in the initiation and treatment of cancer. The whole personality in interaction with the surroundings should be taken into account. For such an evaluation the FAQ is not sufficient.

# THE MEANING OF LIFE WITH WOMEN AFTER BREAST CANCER TREATMENT

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## INTRODUCTION

Breast cancer is an illness having deep effect on the life of every woman. Though it is a dangerous illness and heavy life experience it is also a challenge for the woman to direct all her energy into positive values and into new quality of life. The patient needs encouragement that in spite of all she can hope to continue a full life. For this purpose the help of a volunteer is very welcome. The volunteer visits the patient already during her stay in the hospital. Later on the support groups represent an appropriate form of help. In our country the programme of Breast Cancer Support Service called Reach to Recovery (Pot k okrevanju) is carried out within the Cancer Patients Association of Slovenia.

Very frequent topics of conversation in the support group are the questions about the meaning of life and about the meaning of suffering. Logotherapy gives an answer to these questions. We wanted to evaluate the purpose of life of breast cancer patients; therefore a logo-test research has been carried out in all groups.

### Logotherapy and the meaning of life

Logotherapy is the third Viennese psychology school coming after Freud's psychoanalysis and Adler's individual psychotherapy. The author of logotherapy, Viktor E. Frankl (1977), denominates his logotherapy a complementary psychotherapy since it is based on biophysical and psychological dimension and is especially dedicated to specifically human, i.e. spiritual dimension. Its consideration of human is complex, from the viewpoint of all three dimensions. Frankl calls spiritual dimension also noogenic dimension after a Greek word *noos* – spirit. It encompasses all that is specifically human: will to meaning, ideas and ideals, imagination, responsibility, transcendence, in short, the complete field of human freedom.

The meaning of life is always concrete and applies to a specific person in specific life circumstances. We can speak about the life mission every human has. Every human is unique and lives in a unique historical context therefore he has special possibilities and requirements intended specially for him. The possibility to make something of a situation is unique too. If we do not take a chance, it is lost forever. The meaning is not achieved forever either, it constantly changes depending on the situation. It cannot be applied to things by choice, it can only be found. Frankl says that one is successful only when he discovers his own life tasks, and fails if he sets his goals arbitrarily and apart from complete reality.

Speaking of the realisation of the meaning of life in logotherapy, we think of three value categories through which our life gets its purpose. These values are creative values, experiential values and attitudinal values.

Creative values are realised by our work, experiential values by experiencing and attitudinal values by accepting something unchangeable and fatal as a fact. In how an individual faces such fatal states open a lot of possibilities. This means that human life finds fulfilment not only in creation and happiness but also in suffering.

Attitudinal values apply to meeting with unchanged destiny and to human attitude towards it. There is a question how one accepts one's destiny – furiously or with composure, generously or pedantically, heroically or cowardly, in a way that is appropriate for others or awe-inspiringly.

No suffering can break one who is prepared to find the meaning of his suffering; it is impossible to imagine a loss where some slight possibility of meaning could not be found. Logotherapy teaches us to say "yes" to life in spite of all.

Hence the essence of the attitudinal value is in how one faces the unchangeable fact. It may sound as tautology when we say that the illness gives one the opportunity to suffer. The intention of logotherapy is to make one fit also for

suffering while the psychoanalysis wants to make one fit only for pleasure and individual psychology only for success. Namely, there are situations when one can be fulfilled only in real suffering and solely in suffering. But “an opportunity for something” can be missed even in case of an opportunity for real suffering, accordingly even in case of the possibility to realise attitudinal values. Now we can understand why Dostojevski said that he feared only one thing – not to be worthy of his own suffering.

## **METHOD**

### **Definition of problem**

The goal of our research was to find out to what degree was the life of women after breast cancer treatment fulfilled with the meaning of life. The meaning of life represents a good basis for mental health, positive attitude to life and meaningful orientation assuring existential safety. Or on the other side, was the mental health endangered leading to existential frustration, existential vacuum and all the way to the purposeless life and noogenic neuroses.

### **Instruments**

Logo-test measuring the sensations of the meaning of life was used in the research. Logo-test was developed in a dissertation in the years 1969 –1971 at the Institute for Experimental and Applicable Psychology of Vienna University under the tutelage of Giselher Gutmann. The purpose of the research was the recognition of logotherapy with the contribution of scientific evidence of the validity of its main statement saying that good fulfilment of inner meaning ran parallel with good mental health and vice versa.

Already in 1972 logo-test and its scientific side products (verification of 49 logotherapeutic theses on the whole) were published in the book *Der Wille zum Sinn (Will to Meaning)* by V. E. Frankl and a contribution by E. S. Lukas (1986, Huber Verlag, Bern).

### **Construction of logo-test**

Logo-test consists of three parts. The first part are “meaning factors” of human life which have been divided into nine major substance groups by V. E. Lukas:

1. One's own wellbeing (possessions, prestige, comfortable life)
2. Self-realisation (acquiring of identity, appearance, success)
3. Family (partnership, children, home, existential foundations)
4. Main employment (education, study, profession, work)
5. Sociability (love, contacts, social duties, friends)
6. Interests (knowledge, hobby, sports, travelling, side activities)
7. Experiencing (experiencing of nature and art, mood, harmony)
8. Service to belief (religion, politics, reform)
9. Life distress (conquering of illness, self-preservation, acceptance)

The second part of logo-test is trying to understand psychometrically the phenomena of “existential frustration” which are: aggression, regression, super-compensation, reaction to run, rational acceptance, neurosis, depression, whereat only one of these seven frustration effects is equal to positive overcoming or being prepared to come to terms with the situation or to repair the situation as much as possible.

The third part of logo-test in the first place states the difference between the “awareness of success” and “fulfilment of inner meaning”, the two variables which according to logotherapeutic comprehension are not congruent; there can be a considerable gap between them in a human life. Then it states “positive approaches” to bad or good life attitudes.

## **RESULTS AND DISCUSSION**

The results have been treated on a personal computer by means of statistic package SPSS. The research included 129 women from 9 support groups operating in different places in Slovenia.

## 1. Measuring of sensations of the meaning of life

During the logo-test the women of average age 54,56 years achieved  $x_{sr} = 11,89$  (arithmetic mean of final results) and  $s = 3,65$  (standard deviation) ranging them into good life purpose.

With the logo-test we wanted to find out whether it was true that one's life can have the purpose in spite of hard life experience such as breast cancer. We wanted to state two things:

- whether and through what substance one could ascribe the purpose to one's own life; or on the contrary
- whether one suffered because of alleged purposelessness of one's life.

The "fulfilment of inner meaning" is herewith relatively independent of external life situation of an individual. It can succeed even under hard life conditions such as for example in case of our women who had breast cancer; while the functions like standard and success can mean even an obstacle in the search of life purpose.

In the third part of logo-test the women had to describe their life comparing what they had wanted and what they had longed for before with what they had really achieved in life and what was their attitude to it like.

Hereunder are quoted some of their thoughts which clearly show human aspiration for the purpose of life:

"I try to do the things that give me joy. I am happy that by means of my illness I could become what I am today. I am capable of giving so much more now, to my husband and to my children as well as to my friends and relatives. The sole fact that I am alive makes me happy. I think that my life is a gift. I give and obtain so much love. Never have the violets had such beautiful colour, never have they smelled so sweet as that spring when after the initial shock I began to fight for my life."

"I think that many a deprivation has a lot of meaning in one's life. I found that out during my illness. Everything I have ever given up for my family and my home has been repaid hundred times during my hard trial when my nearest and dearest stood beside me."

"In spite of financial problems in my family I succeeded in getting a profession I had always wanted, I studied on and was successful; I set up a family and my own home. I have never set up high and unreachable aims. I tried to walk with small steps, from one aim to another and overcome the obstacles on the way. My success makes me happy as well as the success and happiness of others."

"I think that one can never achieve everything or very rarely. One makes do with small lucks and looks for new values, positive values and happiness with a happy family – here I think more of my son and his family than of myself."

"With cancer diagnosis all my world collapsed. To tell you the truth, I only got the will to become well and live on when I saw that my family; my husband and the kids really missed me and loved me. My life motto was WHO IS WILLING IS ABLE. I applied by this motto in my illness and I won."

"My illness came and woke me from apathy when I was 42. I began to live a fuller life. I learned to drive the car. I succeeded in creating good relations with my children. Today almost everything around me brings me joy, from nature to children and my grandchild. I think that I reached my aims in life."

"Although I haven't achieved everything in my life I ever wanted, I am very happy. I am happy for every day, week, month and year that I live with my family. I have an understanding husband, two daughters and a granddaughter who is the sunshine and a new meaning of my life. I never insisted in something that I could not get. I am happy with what is given to me. I try to make the best of everything. That is why there are many happy moments in my life even now."

"My husband and my children stood by me during my illness. I tried hard not to burden them with my illness. With this experience we have all become stronger."

## 1. Correlation between individual sub-tests and age

Correlations are used for an insight between individual sub-tests of the logo-test and age of test persons. Correlation between the age and logo-test sub-tests is important with logo 25 and is approaching to the importance of logo 15 and logo 17.

Logo 25: "The hope that in spite of all a failed intention or an accident can be turned into a positive event if you make every effort" means that older women tended to low scored answers. That means that they are more aware of the fact that the worst event can be turned into something positive, in short, that they should not despair.

Equally the next two sub-tests

Logo 15: "I have relations and commitments to one or more persons and I find joy in fulfilling them", or  
Logo 17: "I enjoy certain experiences (enjoyment of art, observation of nature,...) and I would hate missing them"

show that older patients are more aware of their obligations to others, of importance of nature and beautiful experiences.

## 2. Logo-test structure

Logo-test structure was verified by factor analysis. Factor analysis is used to ascertain latent variables explaining the correlations between manifested variables.

Factor analysis excluded five factors having eigenvalues higher than 1 (according to Kaiser criterion). All five factors explain 46% of variance.

Factor 1 was denominated "life nonfulfilment". It most satiates the statements of the second part of logo 2 while logo 1 is negatively satiated with F1, which is in accordance with the structure of the test part of logo 1. Namely, the statements of this part are orientated in meaningful factors, viz. in the factors of "life fulfilment".

Factor 1 confirms the fundamental structure of the second part of logo-test, which determined the effects of "existential frustration" in this part.

Factor 2 was denominated "life fulfilment". It most satiated the third part of logo-test, which is again in accordance with the orientation of inner meaning fulfilment and with discovery of good or poor life conditions.

Other factors too, confirm the fundamental structure of logo-test.

## CONCLUSION

Women after breast cancer treatment are experiencing their life as being meaningful, which confirms the basic thesis of logotherapy, that even in fatal conditions such as breast cancer they do not despair, but they demonstrate high "defiant power of spirit".

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