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Poster

The usefulness of a multidisciplinary educational programme after breast cancer surgery: A prospective and comparative study

L. Koinberg¹, A. Langius-Eklöf², L. Holmberg³, B. Fridlund⁴. ¹University, Medicin and care nursing, Linköping, Sweden; ²University, Karolinska institutet nursing, Stockholm, Sweden; ³Department of surgical Sciences, Division of surgery, Uppsala, Sweden; ⁴University, Nursing science, Växjö, Sweden

Aim of the study was to compare and evaluate a multidisciplinary educational programme with traditional follow-up visits to a physician after breast cancer surgery in terms of well-being, aspects of self-care and coping ability one year after diagnosis.

A reduction in the intensity of follow-up after breast cancer surgery is recommended. New follow-up models are being debated and could be of interest.

Methods: The study design was non-randomised and comparative. Ninety-six consecutively selected women with newly diagnosed breast cancer classified as stage I or stage II, participated in either a multidisciplinary educational programme MP (n = 50), or traditional follow-up by a physician PP (n = 46). Three questionnaires were used: Functional Assessment of Cancer Therapy General (FACT-G), a study specific questionnaire regarding self-care aspects (SCA) and Sense of Coherence (SOC).

With the exception of physical well-being at baseline there was no significant difference between the groups. The women in the multidisciplinary educational programme increased their physical and functional well-being (p < 0.01). The women in traditional follow-up by a physician increased their functional well-being while social/family well-being (p < 0.01) decreased over time. There was a statistically significant difference in sense of coherence (p < 0.001) in the traditional follow-up by a physician between baseline (mean 74.4, SD 12.4) and the one-year follow up (mean = 67.7, SD = 11.4). Thus, women in the traditional follow-up by a physician scored lower in the area of sense of coherence one year after diagnosis.

Conclusion: A multidisciplinary educational programme may be an alternative to traditional follow-up by a physician after breast cancer surgery, but more research is needed about the financial benefits and effectiveness of such a programme.

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Creativity and assertiveness in advancing the fight against breast cancer

M. Ziv. Israel Cancer Association, Givatayim, Israel

Background: We will describe the ways in which we as a voluntary organization have succeeded in initiating and implementing a National Mammography Screening Program.

We will also discuss the creative means and ways that were adopted to break the "code of silence" and to put this issue on the women self-awareness agenda, and contemporaneously on the public health agenda.

Results: The results of this program after 7 years of operation and control will be presented.

The means of bridging gaps in mammography screening compliance rates in various sectors of the population will be discussed.

Conclusions: Through lobbying and advocacy activity, a National Mammography Screening program could be implemented and by using quality control we could improve compliance rates in unique sectors and increase early diagnosis rates.

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Europa Donna Cyprus Experience 2002-2005

M. Diona. Europa Donna Cyprus, Nicosia, Cyprus

The subject of the poster is as indicated to present the Cyprus Forum experience from its establishment until the present. The poster will illustrate in pictures and words the course and the results of the Forum during this period. It also includes the demographic facts of Cyprus.

The presentation aims to show that Advocacy executed in a well organized way, by well informed and passionate advocates can bring results.

2002 was a landmark year for the Cyprus Forum.

In January the Constitutional Assembly established Europa Donna Cyprus as an independent association. A 15-Member Board was elected, and by February the group had new offices and a full time secretary. This important event, covered by the media, also included the launch of the Europa Donna Cyprus website, www.europadonna.com.cy, which aims at giving reliable information to Greek-speaking women. A specially held press conference briefed the media on Europa Donna and EBCC-3.

In March the Europa Donna position on screening for breast cancer was presented to the Health Parliamentary committee, and our Forum now participates with the Ministry of Health team working on this programme. In addition, a panel discussion on genetics testing and breast cancer was held in which about 200 people attended. As part of the Cyprus advocacy programme, we met in May and June in order to lobby doctors and parliamentarians as well as with other breast cancer survivors in order to involve them in the Forum.

In 2003 we strengthened our advocacy activities, we continued to lobby Parliament on the necessity of screening. We organized a Breast Cancer awareness week, translated and issued over 8000 copies of the Europa Donna Passport to Breast Health and issued a new leaflet on Lymphoedema.

We have held ongoing training and educational activities including a lecture on breast surgery by Prof. W. Audretsch to the public and to the Cyprus Surgical Society and a two-day training workshop for breast care nurses and physiotherapists run by the team headed by Miri Ziv. In order to finance a mammography unit, Fashion Targets Breast Cancer was launched in the Presidential Gardens in Cyprus in October 2002.

Our second newsletter has gone to 40,000 homes, supplementing a Sunday newspaper. On Women's Day over 300 pink ribbon "Awareness" pens were given to women employees. And in January 2003 we celebrated our birthday with a street party in Nicosia!! We continued again to lobby Parliament on the necessity of screening and advocate with the media.

SUCCESS!! In June 2003 the launch of the screening program was announced. By August the piloting program started at a specially designed women friendly section of the outpatients department of a hospital in Nicosia.

Next Landmark for the Cyprus Forum was the hosting of the Sixth Europa Donna Pan European Conference the theme of which was *Uniting for Standards – Equality for all*. It brought together breast cancer advocates from 27 European countries to compare and discuss strategies on how to implement the European Parliament Breast Cancer resolutions. Experience from established regional or national programmes was used as a model to help apply the resolution in each country. Hosting the conference reinforced the bonding of our members and local support and action.

In November a group of radiologists and radiographers was sent to Ormelia, Greece for a 2 day training on screening. Also Europa Donna Cyprus board members attended the EUROPA DONNA advocacy training course in Milan.

In 2004 Europa Donna Cyprus second birthday was celebrated by honoring the media people who are by our side. In January also a second group of radiologists and radiographers was sponsored for a training course in Ormelia.

In March a lecture by Prof. Alberto Costa on "Breast Surgery" was attended by over 300 people.

In May an awareness talk by Europa Donna Cyprus in Ayia Napa on "Breast Surgery" with a breast surgeon and a plastic surgeon as guest speakers was well attended. Europa Donna Vice President was invited to Cairo at the Cairo University to present the Europa Donna Cyprus advocacy work.

An awareness talk followed in Paphos and the now established now afternoon gathering of women with breast cancer from all over Cyprus in Nicosia.

June brought with it a pleasant surprise and a great present to the women of Cyprus: The donation of a large sum of money to Europa Donna Cyprus for the purchase of a mobile mammography unit to cover the rural areas of the island as part of the screening program.

In September followed a visit by Dr. Lawrence von Karsa of E.B.C.N. who was asked by Europa Donna Cyprus to advice the Cyprus Ministry of Health on the screening program.

The October 11-18 awareness week started with a press conference, followed by an awareness talk by Dr. Pariboo and Mrs Gloria Frielich on "Breast Cancer Quality of Life" which was well attended by over 200 people. The next day the same guest speakers, a pathologist and an oncologist from Cyprus gave a talk for the members of the Surgical Society.

Over 60,000 copies of the passport to Health were circulated in magazines and stories of women with breast cancer experience were hosted in women's magazines.

In December another awareness talk followed in Geroskypou, Paphos.

2005. In January the inauguration of the first mammography mobile unit which was donated to Cyprus Ministry of Health by Europa Donna Cyprus, coincided with our third birthday.

In February followed another awareness talk in Limassol, and TV channels presented the "bag" a first present to women who are operated on with all necessary information and gadgets.

In March a talk by Prof. Alberto Costa and Cathy Redmond on "what every woman should know" was presented in Limassol. Different awareness talks followed, to the diplomatic corps wives, to members of CYTA, to residents of Lakatamia and a reception was organized at Geroskypou where the mobile unit was welcomed.

Women's day was celebrated and over 3000 pink ribbon "Awareness" pins were given to women employees.

Board members of Europa Donna Cyprus attended the 4th European Cancer Conference in Hamburg where we participated actively in the proceedings.

April included the General Assembly, a seminar by Willie Fourie to physiotherapists on "Late Complications after Mastectomy". At the same time a signature collection was being gathered for the necessity of assuring and ensuring trained nursing staff. Also another awareness talk was organized at Polis, a distant small town of the island.

In *May* we were invited to talk in Ayios Athanasios in Limassol.

In *June* a great event marked our advocacy work – the adoption of the pink silhouettes of Australian Breast Cancer Coalition with a guest speaker the President of the Australian Breast Cancer Network Mrs Lyn Swinburne. The site chosen was by the Presidential Palace.

July followed with the second part of the seminar "Late Complications after Mastectomy" for physiotherapists by Willie Fourie from South Africa.

In *October* awareness week saw our first leaflet on "How to deal with friends and colleagues with Breast Cancer", the illumination in pink of Nicosia Municipality, and the distribution of 200,000 leaflets on general advice on breast cancer through a chain of bakeries. The highlight of the week was the Europa Donna Cyprus first one-day Seminar on "Breast Cancer" by local experts which was attended by over 200 women.

Also in our effort to reach young people we distributed over 50,000 coasters to clubs and cafes.

In *November* a large delegation of the Cyprus Forum attended the Pan European Conference in Rome.

- We now have 1500 members.
- We are preparing 2 new leaflets:
 - 1st – on how to communicate with Children, the facts of breast cancer and
 - 2nd – on advice regarding insurance policies.
- We are organizing meetings with women with breast cancer experience from all over Cyprus.
- We are invited to attend and speak to women all over the island by all sorts of groups.
- We are partners with the Ministry of Health on the best implementation of the screening program.
- We are passionately involved to achieve and offer to women in Cyprus the "BEST POSSIBLE"

The above wording will illustrate along with photos and a map of Cyprus with demographic facts on the work of Europa Donna Cyprus.

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Providing information and support on all aspects of breast health and breast cancer in Ireland

N. Fitzgibbon, T. Droog, A. Langtry. *Irish Cancer Society, Action Breast Cancer, Dublin, Ireland*

In 2001 the Irish Cancer Society launched Action Breast Cancer (ABC) to provide breast cancer information and support. ABC's services are free and include a national helpline, patient education, one-to-one support, health promotion, research, advocacy, and professional support.

Over the last five years, we have been continually developing our services for the public, at the heart of which is the Freephone Helpline. The Helpline is staffed by specialist cancer nurses who offer information, support, and appropriate referral for women who are concerned about breast health, women who have been diagnosed with breast cancer, their families and carers, and healthcare professionals.

In order to meet the need for clear, concise information, we are continually producing and updating literature and supporting materials. This includes a series of factsheets on every aspect of a breast cancer diagnosis including the different aspects of living with the disease.

The Helpline also offers a support programme called Reach to Recovery, which works on the principle of personal contact between the patient and a specially trained volunteer who has had breast cancer.

In January 2005, we launched a programme to address the unique needs of younger women with breast cancer. Services include biannual conferences for younger women, a specialist nurse, and the selection and training of younger Reach to Recovery volunteers.

Professional support is also a key element of ABC's service. Most recently we have developed a workshop for nurses working in oncology to improve communication with breast cancer patients around sexuality.

ABC's annual Breast Cancer Awareness Month campaign takes place in October. A high profile advertising campaign and a nationwide roadshow are just two of the many mediums used to target Irish women in order to make them breast aware for life. Throughout the year, ABC is constantly seeking to raise awareness in communities and workplaces across the country by organising presentations about breast awareness, screening and early detection.

Now that we have firmly established ourselves as the leading provider of breast cancer information and support, we have started to significantly develop our advocacy programme, and we are currently working on ensuring that the national breast screening programme will be fully rolled out by the end of 2007. We are also undertaking major nationwide research into the provision, supply and fitting of breast prostheses.

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Poster

Need for development of guidelines and outcome measures for the management of learning disability patients with breast cancer

S. Govindarajulu, S. Narreddy, L. Willoughby, J. Barker, M. Shere, S. Cawthorn, A. Sahu. *Frenchay hospital, Breast care, Bristol, United Kingdom*

Aim: In England there are 1.2 million people with mild to moderate learning disability (LD) and 210,000 with severe LD (25,000 old people). Women with LD are living longer and are prone to age related diseases such as breast cancer. The likelihood of encountering the learning disabled (LD) with breast cancer is high. Guidelines exist for breast and cervical screening for the LD (1999). Specialized breast units have a need to develop guidelines to manage symptomatic breast cancer patients.

Method: We present our experience in the management of 5 patients with varying degrees of LD diagnosed in 2004–2005. 3 had mild to moderate LD and 2 had severe LD. LD patients were involved in the decision making process and allowed to express their needs and preferences. In the severe LD patient consent to diagnosis and treatment were in the best interests of the patient with consideration into the women's wishes, views from persons who know the patient well. The patient, carer, family, social worker and general practitioner were all involved. Patients were discussed in the multidisciplinary meetings. 2 had mastectomy with axillary clearance + adjuvant hormonal treatment. 1 had mastectomy + axillary clearance and contra lateral breast reduction + chemo and hormonal therapy. 1 had wide local excision + axillary sampling + radiotherapy and adjuvant hormonal therapy. 1 had inflammatory cancer, a course of chemotherapy and refused any further treatment. Patients had support from the breast care nurse in the hospital and at home as and when required. Complementary therapies were also offered to patients.

Discussion: LD patients should be encouraged to utilize the screening programme and seek help when they have a symptom. Health service should be easily accessible and extra support provided. They should be given adequate time. There should be information leaflets specifically designed for the LD for every stage of the management process. Family/carers of the LD should also have access to information and support. There should be required support when LD patients are admitted into hospitals for surgery. Patient centered care must be provided.

Conclusion: The health care needs of LD people must be met and be delivered to a high standard. Health professionals involved in the management of LD patients should have training in dealing with these patients. Outcome measure of the health status of the LD should be comparable to that of the general population. Hence guidelines and outcome measures for management of LD patients with breast cancer need to be developed.

Wednesday, 22 March 2006

16:00–16:45

POSTER SESSION

Psychosocial aspects

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5-year follow-up of sexual functioning and sexual enjoyment after radiotherapy for early stage breast cancer in the START trial

J. Mills¹, G. Sumo¹, J. Bliss¹, P. Hopwood². *On behalf of the START Trial Management Group. ¹The Institute of Cancer Research, Clinical Trials and Statistics Unit, Sutton, United Kingdom; ²Christie Hospital NHS Trust, Psycho-oncology Service, Manchester, United Kingdom*

Introduction: Long-term QL for women with early breast cancer is being systematically investigated in the START trial. This analysis examines self-reported sexual functioning (SEF) and sexual enjoyment (SEE) following surgery +/- chemotherapy, and after radiotherapy (RT), over 5 years follow-up, irrespective of the radiotherapy schedule received.

Methods: QL was evaluated in 2180 patients (mean age 56.5, range 26–86) using EORTC BR23, 10-item Body Image Scale (BIS) and 14-item HADS prior to and 6, 12, and 24 and 60 months after RT. Three BR23 items assessed SEF/SEE. Spearman correlation coefficients were evaluated