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ABSTRACT BOOK



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Concurrent Session 1; Stream 1 – Exploring the importance of supportive care

O.01 | Centers of Amelie as an comprehensive care tool

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Amelie, z.s. is a non-profit organization providing professional services to oncological patients in the Czech Republic since 2006. Amelie was found as a reaction to the personal experience of patient Pavla Tichá of the low availability of professional support care. Today, Amelie has four Centers in Prague, Olomouc, Rakovník and Liberec, and a nationwide phone line.

This article provides a look at the operation of Amelie Center services, which are linked to a unified methodology and offer comprehensive, professional, timely and targeted help for people with cancer and their loved ones so as to maintain the highest quality of life at all stages of oncology treatment, and life with a disease or a sick one.

Oncology patient or loved one can come to the Center and enjoy the individual or group services aimed at promoting facing up to the disease, acceptance of treatment and permanent changes, prevention of the negative consequences of long-term illness and direct activation of people with oncological illness.

Individual activities provided in individual meetings or interventions focusing on professional psychosocial counseling, crisis intervention and mediation of information or contacts. Group activities serve two purposes: activation aimed at managing oncological illness – reducing stress, promoting lifestyle changes (e.g. pilates, memory training), and community group activities such as tai-chi enabling the patients to meet informally.

From Amelie experience clients principally turn to Centres at the beginning of the treatment, when returning to work, and when facing up to death. The case studies will talk about these topics.

O.02 | Not just all talk: Strategies for younger women

L. Young¹

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Compared with older women, breast cancer in younger women is still relatively less common, although this is difficult to believe given the abundance of media reports and the many women we meet who are diagnosed at a young age. Although not all issues are exclusive to younger women, their reactions to them can differ significantly to older women. There is certainly no denying they face unique challenges, the list of which can be quite long. One of the most challenging is living with uncertainty and the side-effects of treatments for longer than older women. Conversely, the other challenge for younger women is facing their own mortality at a young age and the possibility of missing out on seeing their children grow up. Having breast cancer at a young age can mean an increased risk of genetic or familial cancer which consequently brings concerns for children and family members and lingering feelings of uncertainty for the future. We can keep adding to the list when we think about issues concerning early on-set menopause, sexuality, body image, and coping with society's view of youth and beauty; and what about dating, fertility, and same sex relationship issues. Younger women usually feel isolated because of these very unique issues but there's no point making a long list and not doing anything else. So, so let's begin by acknowledging and sharing but let's also try to identify solutions and coping strategies.

O.03 | Thorns in the Flesh – Lymphedema in Cancer Care

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Lymphedema emerges as the most underserved condition in cancer care. Survivors newly diagnosed with lymphedema put the onus of responsibility of prevention and management of lymphedema in the domain of oncology. As survivor, educator counsellor and massage therapist I observe the paucity of dedicated lymphedema services in the medium and low resource countries. While we wait for robust inclusion of the lymphedema protocol in the continuum of care we also work towards a meaningful patient owned and patient centred approach in addressing and management of lymphedema. This audit focuses on root causes and effects and our attempt towards 'doable' potential solutions in managing lymphedema through survivor perspectives with a workable and sustainable and replicable model.

Root causes: We identified different perspectives of lymphedema by clinicians, oncologists and affected women including human factors and ergonomics of communication; equipment and environment, finances, facilities and culture in conflict affecting lymphedema services.

Resultant effects: Late interventions with poor outcomes, psycho-social issues, pain, financial drain and poor adherence.

Launching patient survivor model of care: Based on patient survivor experiences we have launched a workable clinic based prevention and management model on pre and post-operative prevention education and rehabilitation, follow up arm care and active management. As a breast cancer advocate, I am the voice of my fellowship of survivors taking charge of our condition – *health in own hands* responsibly, until affordable and accessible institutional *inclusive protocols* fall in place with the patient survivor as the first facilitator of care.

Concurrent Session 1; Stream 2 – Body image after breast cancer

O.04 | Psycho-social Assessment of Post-Surgery Outcomes after Breast Reconstruction Surgery

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Breast Cancer (BC) surgery leads to mutilation of breast shape with negative effects on body image and self-esteem. Reconstructive and oncoplastic breast surgery can satisfy patients and improve their quality of life (QoL). It is important to assess the patient experience post-surgery using patient-reported outcome measures (PROMs) based on patient's perception of surgical care, psychosocial well-being and physical functioning.

Our objective was to identify predictors of patient satisfaction in a selective sample of women (age 26 – 75 years) who underwent breast reconstruction surgery. 120 patients underwent unilateral breast reconstruction using implant. While 38 patients underwent reconstruction with opposite breast reduction symmetrization, 27 patients underwent therapeutic mammoplasty. All patients were asked to complete the standardized BREAST-Q questionnaire 1 year after surgery. The response rate for BREAST-Q questionnaire completion was 98 % with 147 out of 150 study participants completed the questionnaire. PROMs could be distributed into 4 distinct groups based on the reconstruction outcomes namely (a) very much satisfied (93 %) (b) definitely and mostly satisfied (94 %) (c) satisfied with the outcome (88 %) (d) definitely agree on having reconstruction rather than the alternative of having no breast (91 %). Significant improvement was observed in post-surgery satisfaction about breast appearance, psychosocial, sexual and physical well-being. Reconstruction surgery had an overall positive impact on quality of life. In patients that did not undergo breast reconstruction, psychological issues related to sexuality were observed.

We propose that BC Management protocols should also include additional counseling support to explore benefits of breast oncoplasty surgery.

O.05 | Walk with pride: a guide to restoring body image after breast cancer

R. Prasad¹

¹ Indian Cancer Society, Main Office, New Delhi, India

Struggling with body image is an age-old tradition for women. Too fat, too skinny, bad skin, bad hair... Each woman finds one aspect of herself that she wishes she could change. Add breast cancer and these insecurities get amplified. Breasts are the epitome of womanhood. They represent femininity, sexuality, beauty and motherhood. Thus, it's no wonder that practically every woman with breast cancer struggles with body image after mastectomy. Mastectomy – the life saving yet cruelly disfiguring surgery many women undergo – leaves a woman feeling less of a woman. One study describes the different personal meanings of mastectomy as ranging from 'No big deal' to 'Losing oneself completely'. The inevitable changes in the body image after mastectomy affect her physically, psychologically & socially. Physically, it's the loss of a visible body part, Psychologically; she's a mental wreck coming to terms as her confidence and self-esteem are affected. Studies have shown that immediate breast reconstruction can help a woman adjust to the changes to her body but every woman in India can't afford it & not every woman's experience is positive after using it. Thus the silicon prosthesis with proper fitting helps restoring the body image best. Its weight, the same as the other breast helps maintain equilibrium. Tucked into a prosthetic bra, no onlooker is any wiser! Easy accessibility is crucial in making the difference. Cancer policymakers must take action on recommendations to make assessing and addressing altered body image, intimacy and sexual concerns an integrated part of breast cancer treatment/care.

O.06 | My body, Myself. Altered Body Image

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¹ Reach for Recovery Kenya, Management, Nairobi, Kenya

Dear Body,

I wasn't always happy with you. I wanted longer legs, a flatter tummy, firmer arms. But 14 years back, we went through alot. You and I.

We faced Cancer together.

We lost our right breast, had chemotherapy, our hair fell off. Had radiotherapy and now only use deo on the left hand since we don't sweat on the right hand anymore, but you know what, we got through it and now I've learned to love and accept you for what you are.

Not perfect, but beautifully imperfect. You are my body and I'm proud of you!:)

For many women, negative changes in body image become part of the long-term side effects of treatment, this is especially true in women whose body image centers around their femininity. Some have surgeries that they come to see as a form of disfigurement. Others may have their breasts intact but they still experience swelling associated with lymphedema, or weight gain after chemotherapy, or early menopause. For those who already had low self-esteem, the effects of treatment can make it worse.

"Body image is not only about appearance; it is also about feeling and sometimes loss of sensation or sexuality," In some women, negative impacts on body image are mediated by other factors like social support and having a good relationship with a spouse and family. Culture also matters in the way women think about and talk about their bodies.

Cancer has an impact on intimate relationships, can cause sexual dysfunction, and affects how people perceive their sexual identity.

Concurrent Session 1; Stream 3 – Breast cancer in younger women

O.07 | Pregnancy and breast cancer supporting joy and anguish

J. Lovelock¹, K. Campbell²

¹ Mc Grath Foundation, Breast Care Nurse, Mount Martha, Australia

² Mc Grath Foundation, Breast Care Nurse, Murray Bridge, Australia

As a midwife, supporting women through pregnancy childbirth, has been mostly a joyous occasion. As a breast care nurse supporting women with a cancer diagnosis can present emotional challenges, for both the families experiencing breast cancer and the health team caring for them. Combining these roles provides joy and anguish for all involved. The joy of a new life combined with the threat of extinguishing another. Pregnancy associated breast cancer (PABC) is often diagnosed late, with breast changes being masked by the pregnancy.

Balancing the health of the mother and foetus together with appropriate cancer care presents its own unique challenges, and as a PABC diagnosis is uncommon, it may also provide the health care team caring for the mother increased stress.

This presentation will discuss treatment options for PABC and ways to support the woman, her family and the caregivers during this time.

O.08 | Quality of life and influence factors in young breast cancer

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¹ The Fifth Center of PLA General Hospital, Oncology department, Beijing, China

Traditionally, a young age at diagnosis of breast cancer in women has been considered an independent adverse prognostic factor associated with a higher risk of relapse and death. To investigate the quality of life (QLF) in Chinese young breast cancer patients, and analyze the influence factors, we investigated 218 women breast cancers less than 40 years old with EORTC QLQ-C30(V3) and EORTC-BR23. Fatigue, insomnia, shortness of breath, pain and constipation were the main symptoms reported in 218 young women (average 35.6±4.3) with breast cancer. The trouble caused by hair loss is obviously higher than other systemic adverse reactions. In the functional dimension, the scores of body shape, sexual pleasure and outlook on the future were significantly lower than those recommended by EORTC. The social, cognitive or emotional function, and fatigue, pain, insomnia, loss of appetite, body shape, sexual function and outlook on the future of the cured patients were significantly better than those of the survivors with tumor (P<0.05). The young breast cancer patients in China had higher score of financial difficulty than the recommended scale reference value (P<0.05). Clinicians should strengthen the control ability of these symptoms during follow-up. More attention should be paid to body shape changes and hair loss. Doctors, family members and society should care patients and help them with a positive attitude. In addition, strengthening social medical security is conducive to relieving the economic burden of patients and improving the quality of life of patients.

O.09 | Czech project Bellis supports young women with breast cancer

N. Samková¹

¹ Nad Ryšánkou, Krč, Praha, Czech Republic

“A shared fear is half the fear, a shared joy is twice the joy” This is the motto of the project launched in 2012 by the Alliance of Women with Breast Cancer. The project is targeted at young women under 45. It addresses issues as pregnancy and maternity, relationships and partnership issues, and self-consciousness. Young patients are economically active women with high financial commitments. Patients registered with Bellis are mostly women who have recently been diagnosed or who have recently completed their course of treatment. Remission is a long-awaited period for patients, and great hopes can often be dashed. Patients face the necessity of confronting the permanent consequences of treatment, leading to periods of deep self-reflection and rediscovery while figuring out a way to adapt and live life again after treatment. They often experience anxiety and a feeling of a lack of control over their own health as the frequency of doctor's visits and check-ups declines after their treatment is concluded. Here's where Bellis steps in. Bellis offers mutual support, professional help, psychological courses, professional courses and group meetings with the specialists. Twice a year Bellis organizes regular therapeutic gatherings, offering physical activities under the heading “Back in shape”. Some of the most popular events Bellis organizes are those that promote self-confidence, such as charity fashion shows, photo projects and the publication of charity calendars. The essential part of Bellis' activities is holding events for the public with a focus on prevention including self-examination education lectures.

O.10 | Life is worth fighting for

P. Svobodová¹

¹ Aliance žen s rakovinou prsu, Bellis, Hradec Králové, Czech Republic

I was 29 when I was diagnosed with breast cancer. I went through chemotherapy, radiation, and had a double mastectomy as I am BRCA 1 positive. When I faced these blows of fate I thought that I would end up stuck away somewhere in a corner and that I would completely fall apart. Gradually, my thoughts settled down. You have to get right back up when something knocks you down. I wanted to live. So I tried to and I came to realize that the reward – life – is worth the fight. Today I think a little differently. I try to think positively and I enjoy every day. I have set my priorities in life. I have the best boyfriend I could hope for, a family that supports me, friends who will always be here for me. And though it might sound like a cliché, I feel stronger today than I have ever before. Two years ago I became a project coordinator for the Alliance of Women with Breast Cancer project called Bellis – Young Women with Breast Cancer. We are focused on supporting breast cancer patients and survivors under 45 who are coping with the disease. Young survivors have a higher prevalence of psychological issues, including anxiety and depression. Therefore the need for intensive online communication requires lots of personal emotional involvement. I am happy that I can use my own experience to help others.

Concurrent Session 2; Stream 1 – The importance of education and advocacy

O.11 | Life after cancer treatment, Quality of life with late effects

E.H. Utne¹

¹ *Brystkreftforeningen, Chair of the board, Oslo, Norway*

Life after Cancer treatment. How to get on with your life.

The treatment of today for breast cancer leaves a lot of cancer survivors with serious late effects. Most of us will not be able to return to the life we had before.

The life expectancy is higher and higher because of good research and that is great, but because we now live longer after treatment the quality of life varies from person to person. It is important to make awareness about these issues. We have to educate the general public, it is important that the GP get the knowledge so that they can recognise the signs of all the late effects. We experience today in Norway that this knowledge is limited which results in the signs not being taken seriously and in worse case the patient can develop serious psychological issues because of the lack of understanding from a doctor who can't find anything wrong with you.

Another issue here is that we have to educate the employers. It is sometime the most difficult task to come back to work full time. A cancer survivor needs to ease into working life again. Working life is one of the normalities of life, if you can manage 10, 20 or 50 % work it makes us feel like some part of us is back to a normal life a few hours a week. To be part of every day life, and the social aspect of having a job to go to is very underrated.

O.12 | Breast cancer awareness in workplace programmes in Greece

I.E. Argyri¹, M. Chrysanthou¹, E. Leka², D. Liva²

¹ *Hellenic Association of Women with Breast Cancer "Alma Zois", Board of Directors, Athens, Greece*

² *Hellenic Association of Women with Breast Cancer "Alma Zois", Social worker, Athens, Greece*

As of 2005, the breast cancer awareness campaign in workplaces is a standard programme of the Hellenic Association of Women with Breast Cancer "Alma Zois", running consistently every year, covering both urban and rural areas in Greece. Upon request, the programme provides valid information on breast cancer prevention and early detection, to employees in the Private and Public sector, Ministries, Industries and other Institutions. The participants are predominantly female employees and the event is held in their workplace. Information is presented comprehensively and according to Engel's Biopsychosocial Health Model. A skilled team, composed of a specialist doctor, a social worker and a volunteer breast cancer survivor, trained by "Alma Zois", present three different aspects of the breast cancer experience. The programme is successful, in raising awareness on breast cancer prevention and the impact of the disease on the workforce. It targets a 'closed' but at the same time a dynamic system. It helps to break taboos in the working environment and through valid oral and printed information it disseminates healthcare messages to the broader family circle of employees. Human Resources Departments usually organize the event, in the context of personnel health and safety or corporate social responsibility, as well as breast cancer incidence among their personnel. Management, peers and colleagues, obtain a clearer insight into the psychosocial issues of a breast cancer woman survivor and her difficulties in adjusting to her family and work responsibilities during the rehabilitation period.

O.13 | M Shakti- awareness of breast cancer: Turning the devil's eye inward

R. Prasad¹

¹ *Indian Cancer Society, Main Office, New Delhi, India*

Incidence of breast cancer is on the rise being the no 1 killer of women in urban cities of India. Keeping this in mind Indian cancer society has worked towards providing Health promotive communication comprising of awareness and all resources related to breast cancer in the form of a mobile based app which is audio-visual, interactive and informative. This is aimed at being information sharing and relationship building. Since it is awareness generation in nature, it has been employed strategically with the aim to bring about behavior change in women, which will be measurable in the long run. It will help an Indian woman report suspicious lumps early rather than late presentation so that the conquest of cancer is by choice not chance. This abstract highlights the value of mobile technology being used in health communication with the aim to provide rights and opportunity for women to participate in decision-making processes, which affect their health. The mobile health tool has created opportunities for sharing knowledge and skills ensuring that the women have access to communication tools so that they can themselves communicate within their communities at their level and with the people making the decisions that affect them. Its designed to be scalable in nature, economical in the long run, having a wide audience base with an interactive and participatory form of communication contextualized within Indian culture with inbuilt monitoring mechanisms in place for follow ups. Devi, the Goddess associated with strength looks inward to ignite the woman's inner strength.

O.14 | The importance of education and advocacy

E. Takawira¹

¹ *Reach For Recovery Zimbabwe, volunteer/secretary, Harare, Zimbabwe*

In my country Zimbabwe where literacy stands at over 80 % its disturbing to note that almost half the population is not well educated about cancer disease. It was only when I was diagnosed with breast cancer that I went on a journey to know more about this disease. Many believe that it's caused by witchcraft hence opt for traditional medicines only to present late at the health facilities. In November 2010, 2 years after my cancer treatment I attended a volunteer training facilitated by Anne Steyn and in 2013 I attended the Cape Town Conference. I came back armed and determined to reach out and raise awareness about Breast cancer and advocate for affordable medications. Knowledge is very important and can reduce deaths. In order to educate my people and raise awareness on breast cancer we have partnered with various organisations to do awareness campaigns

in community gatherings. I have also appeared on television programmes and local newspapers talking about cancer. My desire is that the whole nation gets as much information about early detection and treatment. Awareness will encourage people to change lifestyles especially eating habits, stress and visiting healthcare facilities when one feels there is something wrong in their bodies. The disease is caught early and treated cheaply instead of the latter stages. Education and advocacy go hand in hand and as breast cancer survivors we are advocating and lobbying for cheaper cancer treatment and decentralised oncology centres as there are only a few centres in our country.

Concurrent Session 2; Stream 2 – Myth-busting: Dispelling the myths about breast cancer

O.15 | Let's give breast cancer a break: Distinguish myths from facts

D.I. Sethi¹

¹ Indian Cancer Society- Delhi, ICS - JAGRITI Awareness And Screening, New Delhi, India

Breast cancer is one of the most commonly diagnosed cancers in women in urban as well as in rural areas. While there are certain risk factors which are inherited and are not changeable, lifestyle changes are known to prevent this cancer. Any new thought regarding breast cancer is circulated in the media and spreads fast by the word of mouth and electronic media. So much so, that it becomes difficult to recognize myth from reality. Some of the myths prevalent around are: diagnosis of breast cancer means death, it brings bad luck, it is contagious, it cannot affect younger women, men cannot get breast cancer, if there is no family history you are safe, biopsy/FNAC will spread cancer, mammogram is unnecessary exposure to radiations and pain, if there is no pain in a lump it need not be treated, an injury on the breast will lead to cancer, life is not normal after cancer. The more recent ones being circulated are, chest exercise will prevent/increase cancer, underwired bras, tight clothes, black clothes, breast augmentation, using antiperspirant/deodorants, eating sugar and dairy products can cause cancer, so on and so forth. During our awareness talks in the wider sections of the society with women groups, both in urban and slum areas, we come across such misconceptions. Question answer component in the awareness sessions helps to dispel the myths and strengthen people with facts so that they can make informed choices about their treatment options and live a healthy life.

O.16 | How Storytelling saves the lives of women with breast cancer

S. Jacobs¹

¹ Reach for Recovery SA, Board of Management, PRETORIA, South Africa

Through many centuries people have shared riveting experiences through stories. Stories though unassuming and innocent allow us to digest information and make important decisions more easily. In South Africa, where we face major challenges to treating and supporting women with breast cancer, we have found that personal stories are a powerful key for dispelling myths and misconceptions about breast cancer. A number of stories can attest to this. Moema believed her illness was a communication from her ancestors, and did not want her family or church to know. When she finally saw a doctor, it was too late and sadly she passed away. When Sara, a school teacher, found she had breast cancer, her family told her to go to a traditional healer. She sought mainstream medical treatment rather and for that decision, her family abandoned her. Lonely and confused, she took her own life. Busiswe's family-in-law told her she would not be welcome in their home if she opted for surgery. She did. Her husband left her. Fortunately there are also stories of victory. There is Mpho's husband who insisted she visit the doctor, and supported her through treatment and recovery. There is Minah who turned to Reach for Recovery and found hope and strength in our community. She's now been a volunteer for 17 years. These stories, and many others, illustrate the importance of support groups and acting on correct information as early as possible. A story has the power to change and save lives.

O.17 | Shear the Beliefs and Irradiate the Myths

R. Sivaram¹, D.S. Rebecca¹

¹ NAG Foundation, NGO, Pune, India

Diagnosis of breast cancer affects women in many ways. Loss of breast, hair and presumed sexuality are major concerns of survivors. While getting cancer out is the primary concern, collateral damages receive no redressal. This paper deals with challenges of dealing with Sexuality, Body Image and Personhood further aggravated by accrued myths and beliefs about disease, self and the micro environment a woman lives in. Allowing her time to grieve it is in this transformation phase of acceptance that women exhausted of all their emotions begin to relook at themselves, their illness and their significant others. It is at this juncture that we begin facilitating healthy and proactive self appraisal and a reflective independent thinking model combining informal conversations and health education. Facilitation towards a complete being addresses the multiple dimensions of health and a 7th dimension the healed new self.

This paper looks at accrued experiences as counselor and health educator accrued experience which reflects the processes involved overcoming the barriers of beliefs and myths, the family, social and cultural baggage we carry that delay or prevent optimal healing. Practicing these processes help women to:

- Connect more with logic than emotion, without denying the emotion
- Pin down inconsistencies and mistakes in reasoning process
- Overcome problems methodically, objectively and find alternate solutions
- Identify and work on thoughts and ideas that are important and matter
- Reflect on relevance and justification of their thoughts, values and beliefs

Self belief is the key to a satisfied relationship with the self and significant others.

O.18 | Patient Perspectives about Spirituality and Spiritual Care

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Objective: This study was undertaken to explore the perspectives regarding spirituality and spiritual care held by individuals with advanced disease. The aim was to gain a deeper understanding about their viewpoints surrounding spiritual care and the role of health-care professionals in providing such care.

Methods: Sixteen individuals with advanced disease and a prognosis of <12 months underwent an in-depth interview. Transcripts were subjected to a qualitative descriptive analysis to identify salient content and themes.

Results: Four overall themes were identified: spirituality is personal, spiritual distress is about separation, spiritual care is about connecting, and conversations about spirituality must align with the patient's beliefs. Sub-themes emphasized the individuality of spiritual expression, the potential for illness impacting spiritual beliefs, and the value of connections to one's spiritual community. Participants thought healthcare providers needed to be able to identify individuals who were experiencing a spiritual struggle, acknowledge the reality of that struggle, and connect the individual with the appropriate resource or person.

Conclusions: Patients with advanced disease are likely to express their spirituality in unique ways. Being able to talk about their spiritual beliefs and doubts during illness without judgment was seen as a benefit.

Concurrent Session 2; Stream 3 – Catching it early

O.19 | Breast cancer community screening in Pune, India

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Breast cancer (BC) incidence is on the rise in India. Early detection is limited due to lack of awareness in women about disease symptoms, screening modalities, breast self-examination and/or routine mammographic screening leading to negligence and costly delay in diagnosis and treatment.

Our team has established a 3-tiered community BC screening project in Pune, India. Paramedical professionals conduct awareness talks in local languages for sensitization of women about BC related facts and myths. Thereafter, BC screening is performed using a mobile mammography van fully equipped with an analog mammogram. Women under 40 are screened by clinical breast examination (CBE), while women above 40 years undergo mammographic screening. CBE or Mammography screen positive cases are referred to our tertiary care center for appropriate diagnosis, work-up and clinical management.

In the period between February 01, 2016 – July 31, 2017, we were able to sensitize approximately 58,000 women in 250 awareness talks. 217 screening camps were conducted in which 6477 women participated. 4070 women underwent CBE-based and while 2257 women under mammography screening, respectively. 759 women (12 %) were found to be CBE-positive while 416 women (18.5 %) were mammography positive. Of the screen-positive cases, 11 suspicious cases underwent biopsy. 6 cases of BCs and 5 cases of benign breast diseases were identified and underwent complete treatment.

Our 3-tier model for community BC screening was found to be effective in early detection of BCs in Pune city. Further evaluations on cost-effectiveness and scale-up feasibility are required for implementation in other low resource settings.

O.20 | Introduction of MRI for early breast cancer detection in China

A. Shi¹, O. Ho Cheng²

¹ China Cancer Rehabilitation, Heqiaolijing, Chaoyangqu, Beijing

² Aurora Healthcare US Corp, Skyview Terrace, North Andover

Nearly half of all breast cancer diagnoses in China occur in women under the age of 50. Younger women, especially in Asia, tend to have denser breasts making diagnosis by mammogram more difficult. These cases therefore are often diagnosed at a later stage with poorer prognosis. In 2013, Aurora Healthcare donated a mobile MRI trailer to a hospital in Taiwan, which proved to significantly improve the rate of earlier detection of breast cancers in younger women. After learning of the positive results obtained in Taiwan, Professor Anli Shi began working with Aurora to bring the improved breast cancer screening through MRI to younger women in the People's Republic of China as well. In this presentation, the authors will discuss the steps they are taking to make the screening available throughout the country.

O.21 | Fiji and Australia: a sisterhood project raising awareness and education

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¹ 105 Park Road, Nowra, Nowra, Australia

The Fijian Women's Breast Cancer Project is an ongoing collection of bras and pre-loved breast prosthesis donated by generous Australians to help women in Fiji. I became involved in this project nearly from its inception, but only in September 2016 the possibility to accompany Lily was made a reality. We traveled together in June 2017. My short and eventful time in Fiji was an emotional, educational and life changing experience. This is the story of how and why it began and how has evolved into a campaign with the hope of raising awareness for many women overseas through generous donations from Australia. Donated breast prosthesis and bras are fitted for free to women that have undergone a mastectomy. We work closely with

the Fiji Cancer Society and the Fijian Ministry of Health. The Fiji Cancer Society covers the costs of the shipping charge and manages the donated stock to make it available to the nurses for breast cancer patients and volunteers. Surplus bras are used as a free gift to encourage women to attend cancer awareness education events. This is called the "Awareness with a Gift" program. Educational visits to various locations by cancer survivors encourage women to seek medical attention as soon as they notice changes in their breast. Many women do not seek medical help until their cancer has reached more advanced stages. Public education is needed to raise awareness about the importance of early detection to reduce the high mortality rate from breast cancer in Fiji.

Concurrent Session 3; Stream 1 – Psychological aspects of breast cancer

O.22 | The Needs of the Patient: A Model for Caring

A. Steyn¹

¹ Reach to Recovery International / Reach to Recovery South Africa, Mowbray, Cape Town, South Africa

A diagnosis of cancer marks the beginning of a journey full of emotional, psychological, physical and practical challenges. Improving the Quality of Life of the patient is the most important aspect of a model of caring. This presentation will deal with these issues and show that emotional care is just as important as the physical treatment of breast cancer.

O.23 | From chaos to calm supporting families experiencing breast cancer

J. Lovelock¹

¹ Mc Grath Foundation, Breast Care Nurse, Mount Martha, Australia

According to the World Health Organization breast cancer is the most commonly occurring cancer in women. In 1998 and 2004 Breast Cancer Network Australia (BCNA) held national conferences for women with breast cancer and it was identified that having access to breast care nurses (BCN) was a priority for all Australian women, regardless of where they lived.

A BCN is a registered nurse who has undertaken further education-; they are specialist nurses who understand all aspects of breast cancer treatment. They work as part of a multidisciplinary team, to assist individuals diagnosed with breast cancer and their families, by providing physical, psychological and emotional support from diagnosis throughout their treatment and recovery. BCN assist by being patient advocates, clarifying information for them and by being the principal liaison between the patient and their medical team. Women and men with metastatic disease are also supported.

The McGrath Foundation is a unique mix of government, corporate and charity funding which places specialist BCNs wherever they are needed- their vision is for every Australian family undergoing breast cancer treatment to have access to a BCN, no matter where they live. No referral is needed and there is no cost to the families. A Mc Grath Foundation BCN also promotes good breast health understanding, by educating people about the importance of breast health, being confident in detecting changes in their bodies and being knowledgeable about the risk factors for breast cancer.

O.24 | Dealing with depression after a breast cancer diagnosis

C. Hirsch¹

¹ Reach to Recovery International, President, Towson, USA

Breast cancer is a life-changing experience, and most patients – as well as their loved ones and caregivers – face some degree of anxiety or depression. It's estimated that 1 in 4 cancer patients are clinically depressed. Anxiety or depression may arise at any point along the cancer continuum, from waiting for confirmation of a diagnosis to long-term survivorship. It may occur regardless of stage at diagnosis. In this concurrent session, we will identify various factors that may trigger anxiety or depression, such as fear of suffering or dying, changing body image, changing family roles, employment issues, inability to live life as usual, and financial issues. We will discuss symptoms of anxiety and depression and will suggest solutions that those affected may try on their own, such as: seeking peer support from other breast cancer patients or survivors; meditating or practicing relaxation techniques; gathering factual medical information in order to take control of treatment decisions; and exercising or engaging in physical activity if able. Further, we will discuss the importance of talking openly about the breast cancer experience and will describe "red flags" that suggest that professional help may be needed in order to overcome severe depression or anxiety.

O.25 | Life Beyond Cancer: Sexuality, Intimacy, Self Esteem

L. Young¹

¹ The Wesley Hospital Choices Cancer Support Centre, Choices Cancer Support Centre, Auchenflower, Australia

Women whose lives have been affected by breast cancer have to deal with many unexpected side-effects of treatments and whilst well documented, issues concerning self esteem, intimacy, and sexuality remain taboo topics. People who have been affected by cancer often approach the subject of survivorship slightly differently to others so by acknowledging these issues and offering some practical solutions that may improve this part of their lives, these discussions are in a sense investing in the hopeful side of survivorship. The emotions of grief and loss are often only attributed to death and dying but the same feelings of anger, loss of innocence, frustration, and disbelief also impacts significantly on the lives of those it touches in relation to sexuality and intimacy. Women report they not only want to find solutions for themselves but also for their partners for whom they often experience enormous guilt about the impact this has on them. Leonie Young is a long-term breast cancer survivor who was diagnosed as a young woman. She works in a nurse led support service, where sexuality and intimacy are regularly addressed in private conversations and in workshops jointly facilitated with the Clinical Nurse Manager who is also a specialist breast care nurse. To break down barriers, this sensitive topic is addressed with the use of humour and compassion.

Leonie's experience in supporting women along with her anecdotes and survivor understanding add a perspective to help the audience gain insight and find solutions.

Concurrent Session 3; Stream 2 – Strategies for living well during and after breast cancer

O.26 | Nurturing my other half survivorship through holistic healing

R. Sivaram¹, A. Kotwal¹

¹ NAG Foundation, Ngo, Pune, India

The descent from a routine normal to a vulnerable patient after a breast cancer diagnosis puts every woman in different coping zones depending on her personality, situation and circumstance. Kubler-Ross' *acceptance* as a coping mechanism in this paper is redefined as both the last stage in the progression of her emotional state as well as the first stage in her transformation leading to a new normal. My experience in counseling and educating women with breast cancer from diagnosis to survivorship highlights issues bothering a woman's head and heart- fear of recurrence and survival, sexuality, personhood and survivorship (SPS) in the same order. Beliefs and perceptions nurtured about these issues affects long term outcomes in quality of life and healthy survivorship. The *holistic healing approach* is a strategy for living well and long-term survival facilitating proactive actions for quality of life, expanding the definition of new normal to include *adjusted new normal*. The roadmap to this healing process begins at the moment of acceptance and transformation and strategies are structured in phases from a preparatory phase during treatment to survivorship. In conjunction with clinical and follow up care, holistic healing approaches like Reike, Yoga, meditation, other complementary art and therapies are found to enable healthy survivorship and an *adjusted new normal*. The universality of feelings of hope and despair are the same for every woman afflicted, however coping mechanisms differ. Holistic healing approaches transcend barriers to reach out and energizes. This paper looks at allowing ourselves to be healed holistically.

O.27 | When breast cancer and art walk hand in hand

S. Bianca¹

¹ ZEBRA Breast Cancer Counselling Centre, Patient Advocacy, Koeln, Germany

Only one day and a few words were sufficient to realize that my life would change overnight.

In the year 2000 I heard the shocking words: "You have Breast Cancer".

I was diagnosed with a triple-negative collision tumour.

After breast conserving surgery with immediate partial reconstruction, I went through chemotherapy and radiation.

THIS TRACK WAS A MARATHON AND NOT A SPRINT!

Exactly 5 years later I had a second cancer, again triple-negative.

This year 2018 unexpectedly I had to undergo surgery because of a renewed diagnosed triple-negative tumour.

Honestly, I am a 3-time Breast Cancer Survivor... and I LOVE LIFE!

And because of the reason that I survived, I wanted to give something back.

I had never painted before, so one day I decided to start experimenting with colours and shapes on the canvas.

I began to enjoy the freedom of painting and to bloom my life with bright colours.

Sending my phantasy on a journey and unlock my creative potential without explanations and without words.

After some time I discovered images that visibly originated in my subconscious... my feelings... my healing emotions.

I picked 22 paintings and made a story out of it and gave it the title "Message of Hope".

Since many years I have been disseminating my powerful survivorship story.

I let Breast Cancer and Art "walk hand in hand" around the world.

Encourage and motivate breast cancer patients to develop their creativity and use art therapy to express their hidden emotions and feelings during and after treatment, which can heal both soul and body.

The Power of Hope keeps us going when times are tough!

O.28 | Introduction to the Hand-Painting Pink Ribbon Talent Workshop

L. Su¹

¹ Pink Ribbon Care Fund and Shenzhen Pink Ribbon Breast Care Center, Beijing, China

The Hand-Painting Pink Ribbon Talent Workshop rehabilitates women who have suffered from breast cancer by helping them build confidence, develop artistic skills, and live happier and more fulfilling lives. Workshop participants are trained to hand-paint floral designs onto practical items such as scarves, backpacks, clothing, and shoes. This helps them maintain calmness and find peace and fulfillment, all of which help with their physical recoveries. The participants share a sisterly bond with other workshop participants. The message of the Pink Ribbon Care Public Welfare network is that breast care must be practiced 365 days a year. For that reason, the floral designs painted in the workshop represent each of the four seasons: the spring orchid, the summer lotus, the autumn chrysanthemum and the winter plum represent the flowers of the four seasons. Breast cancer survivors from both sides of the Taiwan Strait demonstrated the Pink Ribbon Caring for Four Seasons Flowers" on the stage of the 7th Global Conference of Chinese Breast Cancer Organizations.

Concurrent Session 3; Stream 3 – Success stories from local groups

O.29 | The Ditto Project: A unique story of Ubuntu in action

S. Jacobs¹

¹ Reach for Recovery SA, Board of Management, PRETORIA, South Africa

In South Africa the word “Ubuntu” denotes the inter-connectedness of all humans. It embraces reaching out with kindness and compassion. The Ditto Project offers comfort and dignity to women who cannot afford silicone breast prosthesis. It came into being through people working together to share diverse resources and talents. The services offered by Reach for Recovery SA have always included a prosthesis service. In 2011 the initiative received a boost when the South African Mushroom Farmers’ Association came on board as sponsors. This partnership was the result of research indicating that fresh mushrooms could play a role in the fight against breast cancer. Every October pink punnets of mushrooms are sold at Pick n Pay stores. The Power of Pink campaign has raised funds to provide a total of 5857 silicone prostheses (costing more than R3.7 million) to patients from low income groups. In 2014 we introduced the name “Ditto” (meaning the same again), thanks to the creativity of a design student who felt a woman receiving a prosthesis would like to have one as close to the real thing as possible. The final link in the chain of support is made up of our volunteers who help patients regain confidence after the trauma of breast cancer surgery by encouraging them to have a prosthesis fitted, at little or no cost. The Ditto Project is a beautiful illustration of the concept of Ubuntu – people giving to others along life’s journey, and in the process healing themselves.

O.30 | Let’s care, be aware

D.I. Sethi¹

¹ Indian Cancer Society- Delhi, ICS - Jagriti Awareness and Screening, New Delhi, India

Breast cancer, a global disease, is the most common cancer in majority of the cities in India, and 2nd most common in the rural areas. According to our health service providers, the rising incidence of breast cancer, especially in younger age group patients is a cause of great concern. Most Indian women, aged 20 – 40, single or married, tend to neglect their bodies and avoid active discussion about it. Awareness makes them guilt free and bold. It helps in early detection, timely medical attention and effective cure so that they can win over cancer and live a meaningful life. This is where I, a retired Professor from Delhi University and a volunteer of ICS, step in and educate the people at various locations, schools, colleges, offices, factories, women groups, villages, and urban slums. Our awareness group of trained volunteers, ICS Jagriti, delivers awareness talks through slide shows, video films, literature, mobile app, and media. The aim is to make every young woman aware of possible symptoms, allay fears and myths, explain about Self Breast Examination, answer queries and have our survivors share real-life experiences. This helps empower the women to make their own critical decisions and take care of their health. In schools, cancer education concentrates on training the teachers and students to understand the importance of healthy eating habits, physical exercise, risk factors for cancers, and personal hygiene. We feel the choices made in youth go a long way in keeping them disease free.

O.31 | An overview of the China Cancer Rehabilitation Society

A. Shi¹

¹ China Cancer Rehabilitation, Heqiaolijing, Chaoyangqu, Beijing

Since the 18th RRI Breast Cancer Support Conference was held in Beijing, China in 2015, The China Cancer Rehabilitation Society (CCRS) launched numerous initiatives to raise awareness about female breast cancer and the importance of screening, early detection, and effective treatment. These include the Run For Her (Run For Her Family), which took participants from the Great Wall of Beijing to the Bird’s Nest in Olympic Village. 63 cities across the country carried out similar walking activities. Hundreds of thousands of patients and their families, social volunteers, doctors and experts participated, increasing public awareness of prevention and treatment of female breast cancer. In 2017, more than 7 million people clicked on an online campaign that featured personal stories of cancer patients and survivors. In addition, a large conference was held in Beijing at which anti-cancer “stars” and their families, patient organizations, and medical professionals were honored. More than 1,000 patient education sessions are conducted online and offline each year. Experts are invited to give special lectures and answer questions interactively. Popular science articles are published weekly on websites and public numbers. Popular science pamphlets and quarterly journals are written and distributed to patients’ organizations throughout the country. In addition, training sessions are held on topics such as psychology, marriage, childbearing, employment, and skills for young breast cancer patients. Activities involving literary and artistic performances, talent competitions, drama, and music are also included.

O.32 | Patient-reported outcomes for telephone-based cancer peer support services

M. Fitch¹

¹ University of Toronto, Faculty of Nursing, Toronto, Canada

This project was designed to identify the most relevant patient reported outcomes for a telephone peer support service and identify indicators that would be feasible to measure on a routine basis. Interest in measuring patient reported outcomes has been growing within cancer agencies. In particular, community-based support agencies want to identify appropriate patient reported outcomes for use in evaluating their programs.

In-depth interviews were held with staff members (n=6), volunteer peer support counselors (n=4), and individuals who called the service (n=20). Verbatim transcripts were subjected to a descriptive qualitative analysis wherein the participant experiences provided a foundation to identify relevant outcome indicators.

Structure, process, and outcome variables were identified as important for measurement. Structure indicators need to be identified by staff or volunteers while callers can report on process and outcome indicators. Process indicators are relevant because the approach used during a call by the peer

counselor is critically important for achieving the intended service outcomes. Process indicators cited by patient callers included feelings of comfort, being listened to, and not judged. The patient reported outcome indicators identified included: reduction in anxiety, heightened insight regarding their situation, increase in information, and feeling connected and supported.

A range of indicators were identified as relevant for evaluation of a telephone peer support service. Some indicators could be captured at the point of service while others would require follow-up inquiry. This work could serve as a model for similar organizations to evaluate their own services.

Concurrent Session 4; Stream 1 – Patient navigation and the role of volunteers

O.33 | Meeting the support needs of women with advanced breast cancer

L. Young¹

¹ The Wesley Hospital Choices Cancer Support Centre, Choices Cancer Support Centre, Auchenflower, Australia

The values and beliefs of the Wesley Hospital Choices Cancer Support Centre (Choices) are to provide appropriate support and information to all people affected by cancer. Choices' services are based on and reflect the philosophy of providing a therapeutic environment respecting the needs of patients and their supporters. Evidence suggests women diagnosed with advanced cancer often do not receive the same information and support as those with an early stage diagnosis since it is perceived they "know the ropes" because of their earlier diagnosis. Treatment regimes and often general poor health also prohibit them from frequently attending support programs. Choices offers two monthly support groups for women living with advanced cancer, one for all ages, and the other for younger women. The sessions vary with opportunities to access information on matters relating to decision making concerning treatment, life management, treatment side-effects, and community services. The ability to connect with others in similar circumstances cannot be under-estimated and these sessions enable crucial connections along with encouragement to meet and connect outside of regulated sessions. Importantly, they are encouraged to join any session offered rather than be restricted to those with a diagnosis of advanced cancer. Whilst the value of modern communication models such as blogs and video-conferencing is not disputed, feedback supports the desire for personal connection. The sessions provide a safe environment to openly share and discuss concerns and learn strategies to assist them to live well with their disease.

O.34 | Moving Forward: Supporting people to live well beyond breast cancer

M. McCoy¹, J. Finnegan-John², A. Harris¹

¹ Breast Cancer Care, National and Regional Development- Regional Services, Sheffield, United Kingdom

² Breast Cancer Care, Evidence and Impact, London, United Kingdom

Background: Breast cancer is the most common cancer in the UK. Though earlier detection and advancements in treatment may have improved survival rates, the need for support doesn't stop when hospital based treatment ends. Research shows that one in four women find the end of treatment the hardest part of primary breast cancer.

Breast Cancer Care is a UK wide support charity, working in collaboration with healthcare professionals to provide a supportive self-management intervention called Moving Forward for people at the end of treatment. An evaluation was conducted to measure the impact of Moving Forward.

Method: Self-reported outcomes measures included EQ-5D (quality of life measure) and the Patient Activation Measure (a self-efficacy measure). Economic proxies based on breast cancer specific concerns underpinned Moving Forward's Social Return on Investment (SROI). 873 baseline surveys and 552 follow-up surveys were completed between November 2016 and March 2017.

Key findings:

- Significant improvement in quality of life and effective self-management
- A reduction in the number and severity of breast cancer specific concerns
- SROI of £1:£4.50

Discussion: Moving Forward improves the quality of life of breast cancer patients and could provide economic value to the NHS, providing clear evidence of the importance of post-treatment support.

O.35 | Recruiting Volunteers

A. Steyn¹

¹ Reach to Recovery International/ Reach to Recovery South Africa, Mowbray, Cape Town, South Africa

This presentation will look at what volunteerism means and how volunteers can be used in an organisation. Peer support volunteers have a credibility that paid staff never have. A recruitment plan is essential to recruit motivated volunteers. Suggestions for recruitment will be discussed as well as how to work with volunteers. Volunteers gain from their experience in many ways and increasing their skills level can enable them to offer better supportive care, and allow them to play an important role in community education and advocacy. Successful recruitment of volunteers and a successful volunteer programme will enhance an organisations profile and benefit patients as well as the volunteer.

Concurrent Session 4; Stream 2 – Metastatic breast cancer

O.36 | Conversations in mBC

R.K. Pritam Singh¹

¹ Breast Cancer Welfare Association Malaysia, Management, Petaling Jaya, Malaysia

A group of women living with metastatic breast cancer offer mutual support and friendship to each other using WhatsApp as a channel of communication. Messages exchanged cover providing psychosocial support to each other, sharing information regarding access to life-extending treatment, and trading practical tips on complementary therapies as well as managing side effects of treatment.

This group, known as the Pink InspirerS, create a social support network among themselves. While they maintain contact with their respective clinicians, family and friends, the Pink InspirerS connect and engage in frequent communication with their peers. Newly diagnosed individuals are introduced to the group, where she is welcomed with a round of introductions, and a string of questions and answers. This form of asynchronous communication among peers is of value in terms of establishing a readily available source of support and advice from those journeying on the same path.

With the majority of the Pink InspirerS receiving continuous life-extending treatment, they often share ways to juggle their time with work, family responsibilities and “me time”.

Despite the constant reminder of their fragile mortality, their conversations are seldom short of jokes and laughter.

The ladies of Pink InspirerS feel better equipped to face the challenges of their daily life, knowing their support group is close at hand.

You may wonder, does the death or sudden progression of disease in one of the group members affect the others badly? Most agree that these friendships are worth forging, even when memories are the only mementos that remain.

O.37 | Unmet needs of women with metastatic breast cancer in Australia

J. Lovelock¹, K. Pilatti¹, D. Spence¹

¹ Breast Cancr Network Australia, Camberwell, Australia

Introduction: Although metastatic breast cancer is incurable, many people are now living longer due to advances in treatment. BCNA synthesised the results of two recent research projects to determine the unmet needs of people with metastatic breast cancer. Description/Methodology: Data was extracted from BCNA's online member survey (2017) and Financial Impact of Breast Cancer survey (2016). 527 people with a diagnosis of metastatic breast cancer participated in the member survey. The financial survey examined out-of-pocket costs of breast cancer for a wide variety of treatments and supportive care services, and was completed by 153 people with metastatic disease. Results/Outcomes: 76 % of people with metastatic disease had at least some unmet information and support needs in the 12 months prior to the survey, compared with 51 % of women with early breast cancer. Unique unmet needs included wanting information on relevant clinical trials (34 %) and palliative care services that can help from time of diagnosis (42 %). Other significant information needs included managing fatigue (50 %), physical activity and healthy eating (45 %), anxiety and depression (37 %) and managing financial costs of breast cancer (33 %). Young women (<40 years) had higher needs for information and support. Conclusions: People with metastatic breast cancer have more unmet needs than those with early breast cancer. Attention to the unmet needs of this population will help to reduce inequities in care that exist for people with metastatic breast cancer in Australia. BCNA has increased its focus on supporting people with metastatic disease.

O.38 | Beyond bc – living with mbc in nowadays

A. Stefanaki¹

¹ Achaia Association of Women with Breast Cancer “ALMA ZOIS”, Patras - Western Greece, Patras, Greece

Metastasis in nowadays. How is living with it? What are the feelings? Above all, what are the needs?

Being a mbc patient, myself, I'll try, through my story, to report about the great influence and impact that metastasis, had on someone's personal and family life focusing especially on professional life. I'll stress about the difficulties a mbc patient meets in reintegrating into the working environment and I'm going to describe the important differences in life, body, appearance, and mental status of a mbc one, compared to one with primary disease. I'm going to outline the general perspective of a mbc patient about himself, about the disease, thoughts, emotions, fears, hopes and about all the environment around, but also the view of the society towards a mbc patient. I'll extensively refer also to the special and different needs, that mbc patients certainly have and the special policies and legislation, needed, as well as the impact of the serious lack of accurate metastatic cancer registry data in many European countries, which blocks the adoption of relative initiatives. As Octobers getting more and more pink, the metastasis remains screaming silent. Metastasis is a completely another story. It is not a story for winners, but one for just warriors, concerns millions of women worldwide, (the rate increases rapidly), who continue their everyday fight against the disease.

O.39 | I am living with, not dying from, advanced breast cancer

D. Parr^{1,2}

¹ Breast Cancer Support Inc., Support Group Co-ordinator, Auckland, New Zealand

² Freelance researcher and writer, Self-employed, Auckland, New Zealand

In August 2018 I was diagnosed with advanced (stage 4) breast cancer (ABC). Because of my history of loco-regional recurrence, my surgeon ordered a PET (positron emission tomography) scan, which identified three oligometastases. I have no symptoms and have been told that I could have “lived with this a long time with knowing about it”. Instead, I now live with the knowledge that I have incurable breast cancer.

As the technology for diagnosing ABC becomes more advanced and out-paces the ability to treat the disease, it will become increasingly common for people like me to be diagnosed before they present with symptoms. This poses challenges, both for the New Zealand medical system (treatment options

and access to drugs), and for the women and men affected. Advanced breast cancer is widely perceived as a death sentence, but those of us who fall into this category must learn to live with it as a chronic disease.

The challenges we face include societal perceptions of cancer, uncertainty about the future, fear of disease progression, and concern about the availability of treatment options, among others. The one certainty in life is death, but how do we live well with the reality of our mortality?

Concurrent Session 4; Stream 3 – Far-reaching effects of breast cancer on patients and their families

O.40 | Evaluation of the physical and mental health of the caregiver

K. Bergstrom¹

¹ Netcare Breast Care Centre of Excellence, Research, Parktown, South Africa

A large percent of geriatric patients require assistance with instrumental activities of daily living (IADLs). These activities can include transportation, housework, shopping etc. These types of activities are generally performed by family caregivers. Vulnerable caregivers can have their own mental and physical health issues and feel that taking care of the patient is causing them further stress. Studies have shown that depression is common in family caregivers. Daughter caregivers are at a higher risk for caregiver strain and were found to have increased anxiety and depression.

Geriatric patients often feel that they present as a burden to their families. Specialized geriatric patient navigation is needed to pay attention to potential distress of the patient. Navigation can help promote caregiver participation resulting in better treatment compliance in the geriatric patient. Support groups can be provided to the caregiver to address their needs while caring for the geriatric patient as well as support systems to assist with the different treatments for the patient e.g wound care. Communication is encouraged between the healthcare team and the caregiver, to give better understanding of the treatments side-effects, potential risks and benefits. The geriatric patient should be encouraged to ask the questions they need to without feeling that they are being a nuisance. Paying close attention to the caregiver's mental and emotional state during consultations will also help recognise any potential issues that may rise in the future. Navigation of the caregiver will result in better treatment compliance in the geriatric patient.

O.41 | Couples face breast cancer during economic crisis in Greece

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The present work constitutes a qualitative research based on the experience of the couple facing primary breast cancer during the period of economic crisis in Greece. More specifically, it is investigated that the person as a biopsychosocial system, who participates in the wider family and environmental system, experiences the disease experience with her partner.. The main findings of the research show that before cancer diagnoses difficult situations occurred in woman's life, like loss of loved ones that led to psychological pressure and self-collapse. It turns out that breast cancer experience affects woman, her partner and the children of the family. It turns out that wife and husband are trying to understand and interpret the appearance of breast cancer in their lives. Couples experience similar feelings when woman is being diagnosed with breast cancer, they face illness together while the whole family system tries to face the needs of everyday life. The economic crisis has an impact on family income and on the national health system and social benefits.

O.42 | Emotional burden caused by weight gain

M. Velling¹, C. Richel¹

¹ Dutch Breastcancer Association, Quality of life, Utrecht, Netherlands

Background: There is a strong focus on weight loss during (of: caused by) treatment of breast cancer. On the contrary the subject of weight gain, which has a major impact on quality of life, receives insufficient attention.

Methods: The Dutch Breastcancer Association surveyed a panel of 930 (former) breastcancer patients regarding their experience on information and support with weight changes caused by their treatment. For this survey an online questionnaire was developed that included seven close-ended and three open-ended questions regarding: weight changes, experienced burden, received information and support. Quantitative data were analysed using descriptive statistics.

Results: 66 % of women who responded, indicated that they gained weight. There was a positive correlation between emotional burden and weight gain. In addition these women received often less information and support whereas the demand for these was higher in this group. It was remarkable that the majority of the women that experienced an increase in weight did not report changes in diet or exercise. Weight gain is most frequently reported after a combination treatment of chemotherapy and anti hormonal therapy.

Conclusions: This study shows that women with breast cancer experience physical and emotional burden of unwanted weight gain, resulting in a decreased quality of life. Additionally they encounter a lack of support from health care professionals on this issue. The Dutch Breastcancer Association advocates for better and earlier information and support on weight gain in hospitals. Moreover because weight gain is a known risk factor for both the development and recurrence of breast cancer.

O.43 | Turning a threat into an opportunity

C. Parkyn¹

¹ ESCA Cancer Support, Bosom Pals Coordinator, Chavannes Des Bois, Switzerland

I would like to talk about how cancer made me and my family healthier and about how after a very tough physical challenge I experienced an incredible change of mindset which has helped me to live my life differently and with more courage! I know now that I am capable of many things that I would have previously thought impossible, Including speaking in public! This is turning a threat into an opportunity.

I will start by showing a 2 minute "teaser" from a 20 minute film which was filmed by renowned cameraman Keith Partridge <https://adventurecamera.co.uk> and directed by Tania Cotton <http://www.movementwise.org>. The full length film is 20 minutes long and features several renowned experts, Dr Magdalena Kohlik. Specialist in Breast Cancer Diseases and Dr Finn Mahler and Dr Boris Gojanovic of the Swiss Olympic Medical Centre in Geneva. It documents my journey from non road cyclist to completing a 100 mile (160 km) charity bike ride for Breast Cancer Research 2 months after having a full hysterectomy.

My presentation also features the lifestyle and dietary changes that my whole family have made since my diagnosis and the ways in which our lives have changed for the better. I have sometimes wondered why I waited for a cancer diagnosis to make these positive changes, so my advice is to not wait to live and love your life. There are clearly no guarantees but why on earth wouldn't you try and stack the deck in your favour?

Poster Guided Tour

P.01 | Intimacy and sexuality after breast cancer: professional guidance needed

M. Velling¹, M.E.M. Ouden den², M.N. Pelgrum-Keurhorst³, M.J. Uitdehaag³, H.M. Vocht de³

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³ Saxion University of Applied Sciences, Research Center of Nursing, Deventer/Enschede, Netherlands

Approximately 60–70 % of breast cancer survivors experience sexuality problems resulting from treatment. This study investigated information and communication preferences with professionals on the topic intimacy and sexuality of women diagnosed with breast cancer.

Members of the Dutch Breast Cancer Patient Association were surveyed regarding their experiences and preferences about information on intimacy and sexuality. An online questionnaire was developed that included five close-ended and one open-ended question regarding: information received; type of professional preferred; method and timing of communication on the topics of intimacy and sexuality. Quantitative data were analysed using descriptive statistics. A deductive framework analysis was performed on the open-ended answers to enrich the data of the close-ended questions.

In total, 667 female breast cancer (ex-)patients participated. In 46 % of the women the information received matched their needs. Most women preferred to receive information about the impact on intimacy and sexuality from a nurse (66.4 %) or primary doctor (27.9 %). The preferred method of communication was a conversation with a professional together with their partner (51.6 %) or a personal conversation with a professional. Respondents emphasized the importance of appropriate timing of information, preferably at least shortly after the treatment course (45.1 %).

This study shows that intimacy and sexuality should be repeatedly included in consultations, at every stage of the disease but especially shortly after treatment. Women with breast cancer expect that professionals (preferably nurse or primary doctor) initiate this subject via a personal conversation (alone or with their partner).

P.02 | The burden of informal caregiving for breast cancer patients

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As a result of the ageing population, changing opportunities and governmental healthcare cutbacks, inpatient care is shifting to outpatient care for many illnesses, including breast cancer. This increases responsibilities for families and friends of ill patients, which may impact on the caregivers' abilities to work and financial situation. The aim of this study is to quantify and analyze the burden of informal caregivers for breast cancer patients in the Netherlands.

The iMTA Valuation of Informal Care Questionnaire was used to evaluate the economic and health-related burden of informal caregiving for breast cancer patients. The survey was available online for responders during 6 months. Multiple regression analysis was performed to quantify correlations between informal caregiver and patient characteristics, as well as the amount of informal care given.

The survey yielded 44 complete responses. On average, informal caregivers of breast cancer patients spent 63 hours on informal care per month although 80 % had a job (58 % fulltime). 26 % reported to experience financial burden caused by informal caregiving. A significant correlation was found between the caregivers personal health and the health from the person they provided care for ($P=0.002$). No correlation was found between cancer stage and the amount of informal care provided. The majority of caregivers valued an hour of informal care with €21 – 25 (29 %).

Breast cancer puts a significant burden on informal caregivers and should therefore be considered when evaluating novel treatments. Estimations on the amount of informal care provided by caregivers could be utilized in health economic evaluations.

P.03 | A cross-sectional study among hospital volunteers in México

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³ Hospital Civil de Guadalajara

⁴ University of Madrid

⁵ AFFU ST. Olavs Hospital and The Norwegian University of Science and Technology

The Voluntary work has become a very important complementary staffing solution in hospital wards. However, several studies have shown that volunteers are doing an important job in hospitals. These studies have also shown a relationship between hospital volunteering and burnout; few studies have focused on the relationships between volunteer burnout, work engagement, and their own mental health, well-being or quality of life. In this cross-sectional study, we aimed to investigate the relationship between burnout, work engagement, mental health, well-being and quality of life among hospital volunteers working in Mexico. Through six questionnaires that were used to assess the volunteer's experience with burnout, work engagement, psychological factors and quality of life.

Preliminary Results: Forty volunteers operating in two different hospitals were asked to fill the self-report questionnaires. Preliminary results indicated that well-being and quality of life are factors that are related to burnout among volunteers.

Discussion And Conclusions: This study targets the possible associations between well-being, as well as other psychological factors, and burnout among volunteers in hospital wards. The preliminary results might provide the possibility to understand how to prevent burnout, as well as recommend interventions in the volunteer context, in order to improve well-being and mental health.

P.04 | To save lives of women from cancer on time

R. Santhanakrishnan¹

¹ Sri Dhanvantri Trust, Board of Trustees, Chennai, India

PENN NALAM (Women Wellness – Translation) – A Unit of Sri Dhanvantri Trust, Women for Women Wellness Centre was born (24.08.2009) nine years ago after my Diagnosis for Cancer.

I had the opportunity to interact with people from different walks of life through my treatment period. I realized that;

- There is lack of awareness about breast cancer and there is very little research done in India.
- Medical fraternity needs to move from treating advanced cancers, and to invest on early detection.
- The cost of breast cancer is prohibitive in our country.
- The psycho social support that is required during the treatment period and afterwards is sourly lacking.
- Woman is the backbone of family. But unfortunately, in India she does not take care of herself.

The Vision of PENN NALAM is to “Save lives of Women from Cancer on time.”

Hence PENN NALAM has dedicated itself to Educate, Care, Screen, Diagnose, and Treat and to take care of Women’s health by doing Screening and all other related services at a very affordable cost. So far we have conducted 798 awareness camps, sensitized above 200,000 women and conducted 429 screening camps, screened 17570 Women. We have two mobile screening buses which offers doorstep screening services to the women. Now we are in the journey of establishing a Centre of Excellence called Chennai Breast Cancer Research Foundation (CBCRF) for Breast Cancer treatment in Chennai, Tamil Nadu, India. It is the First of it’s kind in South East Asia.