

and models developed further at a consensus meeting with professionals and the young people.

Our aim is to give a brief overview of this study and focus on the findings exclusively to encourage participants to reflect on the possibilities and challenges of service provision for adult survivors of childhood cancer. This joint presentation by a nurse and cancer survivor will enable both professional and survivor perspectives to be shared and debated.

8059

INVITED

The cure from childhood cancer: is it still a mystery?

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The use of the word "cure" in the framework of childhood cancer survivors is very controversial. The term cure from cancer should refer only to the first cancer since childhood cancers are generally speaking, highly curable. The appropriate timing for speaking about cure is not a definitive nor precise one and the interval for having a reasonable definition of cure differs from type of tumors. We recognize, however, that some late recurrences cancers may occur, but when their risk becomes negligible we all agree that the term cure from original cancer may and should be used.

In some cancers, as in many other disorders, side effects may occur. The effects may or may not affect the quality and length of life after cancer. The physician in charge should offer standardized follow-up programs which allow to determine risk factors for each former patient. Risk factors may refer either to other organs or to the possibility of second cancer. For these cases the physician in charge should determine the specific amount of advice and follow-up care important for the specific patient. In all cases the pediatric cancer unit should maintain a leading role as a memory and record of former therapy. If possible, the medical history should be made available possibly in a computer friendly format in order for the patient to carry forward throughout his life, and if necessary to other physicians. The pediatric health care team should endorse the transition to adult care. However, we understand reluctance of some long term survivors in participating in follow-up programs and we respect they right not to participate.

Pediatric oncologists are also interested in those former patients who are doing exceptionally well in their life in order for us to have a true picture of survivorship (resilience). Even if some late effects are present, the person can consider himself as cured of the original cancer. We consider side effects as a separate issue to be dealt with in specific cases. The pediatric oncologist should become aware that they former patients have learned coping strategies from their cancer history and are willing to enter in an independent adulthood beyond the pediatric clinic (let us grow up!!). In Erice, in October 2006, a statement on this topic was discussed and approved, and a final document will be published in the European Journal of Cancer. Details on this topic, following what is reported in the abstract, will be presented.

8060

INVITED

What consequences of childhood cancer do young adults consider important?

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Background: The overall aim was to explore whether, and if so in what ways, long-term survivors from childhood cancer experience that their life is influenced by having had cancer.

Material and Methods: All patients diagnosed with childhood cancer between 1985 and 1999 at Karolinska University Hospital, Stockholm, were invited to participate in the study and 253 (response rate 72%) accepted participation. Semi-structured interviews were conducted by telephone using the extended Swedish version of The Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW). Respondents were asked if anything in life was bad or good due to having had cancer. The respondent could mention as many aspects/areas as wanted and each aspect/area was subsequently rated regarding how troublesome or satisfying it was perceived on a category scale. The aspects/areas mentioned as influencing life today were analysed by content analysis.

Results: Mean age at interview was 24 years (47% female, 53% male). Seventy-four percent of the long-term survivors reported at least on negative consequence and 51% reported at least one positive consequence due to having had cancer. Only 14% did not report any consequences at all due to having had cancer. The most frequent reported negative consequences were: physical and functional impairments, psychological impact, altered body appearance, effects on interpersonal relationships,

working and educational issues and cognitive limitations. The most frequent positive consequences reported were: a more positive view and broader perspective in life, personal development, improved relationships to others, and increased empathy for others.

Conclusions: Young adults report both negative and positive consequences due to their experience of childhood cancer that may affect their quality of life. More negative than positive consequences are reported, however, the most frequently reported impairments are mentioned by a small proportion of the patients.

8061

INVITED

Post-traumatic stress symptoms in adult cancer survivors of childhood cancer – implications for care

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Previous research suggest that posttraumatic stress disorder (PTSD) is present in survivors of childhood cancer. PTSD is considered one of the anxiety disorders. It is characterised by symptoms that can be grouped into three clusters: reexperiencing, arousal and avoidance. To receive a diagnosis of PTSD, one must have been exposed to a traumatic event, defined as imminent threat to life or a serious injury. Furthermore, the person must have manifested some psychological reaction, usually fear, to this event. Subsequently, a constellation of symptoms develops, such as nightmares, intrusive memories of the event, avoidance of trauma-related stimuli, constricted affect, anger, and an exaggerated response.

Several authors identified a cluster of anxiety and avoidance symptoms in childhood cancer survivors. These symptoms were consistent with a trauma response and have led researchers to propose that the long-term psychosocial impact may best be understood by using the framework of posttraumatic stress. The framework of PTSD in childhood cancer survivors make sense, given the potentially traumatic nature of the cancer experience. The threat to life, intensive treatment regimens, painful invasive procedures, and dangerous complications may compound these extremely stressful experiences. In addition, long-term effects of treatment, such as growth retardation, cognitive impairment, physical changes such as amputation, and infertility can serve as life-long reminders.

It is important that health care professionals understand risk factors for PTSD because it can be related to impairment across several realms of functioning in survivors. There may also be specific implications for oncology follow-up care as survivors with PTSD may be less likely to follow-up with their health care. Reminders of the traumatic experience or extreme distress when thinking about cancer could influence behavior, making it less likely that survivors follow through with medical care and recommendations. In this presentation the current research base on PTSD in childhood cancer survivors will be reviewed. Furthermore, preventative interventions as well as the importance of screening for PTSD symptoms are discussed. Discussion will focus on what nurses and other health care professionals can do.

Teaching Lecture (Wed, 26 Sep, 09.15–10.00)

Developing clinical guidelines in IV access

8062

INVITED

Developing clinical guidelines in IV access

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Most patients with hematological disorders or cancer are in need of a venous access device in order to facilitate the intravenous administration of chemotherapy, parenteral nutrition, fluid therapy, blood products, antibiotic therapy, other medication and blood sampling. There is well known that the use of venous access devices is strongly associated with a high risk of catheter related complications during time in situ such as thrombophlebitis, infection and thrombosis. The incidence varies, for example depending on type of IV device, the patient's physical condition, the location of the catheter, hygiene and use of aseptic technique.

The high risk of complications highlights the importance of handling venous access devices in accordance with best evidence. Guidelines in IV access are available, for example the CDC Guidelines for the prevention of intravascular catheter-related infection. Guidelines are systematically developed statements to assist health care personnel about appropriate care for specific clinical circumstances. These statements generally reflect broad healthcare recommendations based on valid and up-to-date empirical evidence. However, they seldom include how to perform recommended procedures step-by-step.

This teaching lecture will focus on the process of developing clinical guidelines in IV access including step-by-step instructions. Examples will be given of how to:

1. Develop clinical guidelines in IV access.
2. Produce short film cuts on management of venous access devices in order to illustrate the text in the step-by-step instructions.
3. Evaluate compliance with clinical guidelines in IV access.

Proffered papers (Wed, 26 Sep, 13.45–15.45)

Symptom and rehabilitation

8064

ORAL

Symptom care for cancer patients at home: using technology to improve outcomes

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Effective management of symptoms resulting from cancer treatment is challenging because symptoms manifest at different time periods, in varying severity and are experienced by patients at home away from immediate attention by cancer care providers. Oncology nurses give patients instructions and written materials about potential side effects but they are given during treatment when the patient is not experiencing problems and they are not tailored to the patient's individual experience. There is no effective symptom monitoring system once patients go home and when symptom control is inadequate patients must call the clinic to gain further assistance. Many patients are reluctant to bother their providers or experience delay in providers returning their calls. Therefore the development of a systematic method for monitoring symptoms at home, providing suggestions for self-care based on the individual's specific symptom pattern and automatically notifying care providers when symptoms are unrelieved would offer an important adjunct to traditional cancer symptom management. The purpose of this presentation is to describe the development and experience to date of such a program of care called Telephone Linked Care (TLC).

TLC is a telephone-based, automatic, information-technology-enabled symptom assessment and management system with integrated patient education that was developed by an oncology nursing research team. Patients call into the system from home and report symptom patterns for the previous 24 hours. Utilizing a digitized human voice, TLC responds with evidence-based, self care strategies or other instructions based on the specific symptom pattern. TLC for example, can look back over the previous week and notice a pattern of increasing fatigue or late onset nausea and then make specific recommendations for action. In addition, symptoms not responding to treatment can trigger an automated faxed or email alert to the patient's care provider notifying them of unrelieved symptoms including a report of the daily symptom patterns since receiving treatment.

To date TLC has been tested with over 150 patients receiving cancer chemotherapy and found to be reliable and readily acceptable to patients. If used correctly, technology can provide an important assist to oncology nurses so that care can be individualized and targeted to cancer patients when they need it, allowing nursing care to be extended beyond the normal reach of ambulatory services.

8065

ORAL

Survey of joint aches, pains and stiffness in women with primary breast cancer

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Background: As the detection and treatment of breast cancer is improving, more women are living with the long-term sequelae of breast cancer treatment. Joint aches, pains and stiffness are some of the most commonly described problems amongst these women, and the limited research evidence suggests these may be experienced by three quarters of women following primary breast cancer treatment (Carpenter and Andrykowski 1999). While these symptoms can be caused by ageing and/or the menopause (Franco et al 2005), there is some evidence to suggest that they are specific to or exacerbated by primary breast cancer treatment (Felson and Cummings 2005). Although they are reported as common problems, very little research has focused specifically on them and detailed information about their prevalence, causes and impact on women is not available.

Aims: To determine the prevalence of joint aches, pains and stiffness in women after treatment for primary breast cancer and to explore possible causes in this population, with particular emphasis on the role of different anti-cancer therapies.

Methods: This is a cross-sectional survey comparing 260 women who have completed treatment for primary breast cancer with an age-matched group of 260 women without breast cancer attending for mammographic screening. Measures used are the Nordic questionnaire for analysis of musculoskeletal pain [16], the Brief Pain Inventory [17] and the SF-36 general health questionnaire. A further short questionnaire collects information on conditions which could cause joint pain and stiffness, such as rheumatoid arthritis, fibromyalgia etc. and other factors which may have a bearing on these pains such as: menopausal status, lymphoedema and weight.

Results: The survey is in progress at the time of writing the abstract and results will be presented at the conference.

Conclusions: This research will for the first time provide robust evidence of the prevalence of joint aches, pains and stiffness in women after breast cancer treatment. It will establish whether they are a significant problem requiring further research and intervention. If so, hypotheses will be generated about the aetiology of these symptoms, which will provide a basis for the development of interventions for their management as well as informing further research. Future research will focus on uncovering the impact of these symptoms on women's lives, and identify and test potential interventions.

8066

ORAL

Development of an integrated psychosexual clinical assessment strategy for women receiving pelvic radiotherapy

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Background: Pelvic radiotherapy creates a number of physical effects and psychological responses that impact negatively on the sexual well-being of women and their partners. The aim of this study was to develop an assessment methodology to improve the clinical evaluation of sexual morbidity following radiotherapy in women with pelvic malignancy.

Methodology: This focused ethnography used participant observation of gynaecological and colorectal oncology follow-up clinics (50 gynaecological, 19 colorectal consultations) plus in-depth interviews with women (n=24), partners (n=5) and health professionals (n=20) to explore the context and content of sexual morbidity assessment after treatment completion. Women with gynaecological (cervical, endometrial) and non-gynaecological (rectal, anal, bladder) cancer who had completed pelvic radiotherapy 3, 6, 12 and 24 months previously were included. Doctors, nurses and therapy radiographers were interviewed for professional perspectives on assessment.

This paper presents analysis (using SPSS v.14 and NVivo v.2) of observation and interview data.

Findings: Consultations focused on disease surveillance, specific aspects of toxicity monitoring and managing active symptoms. Psychosocial issues were raised in only 42% (n=29) of consultations. Sexual concerns were not routinely assessed in gynaecological clinics (11/50) while in colorectal clinics sexual morbidity was predominantly assessed via standardised clinical trial toxicity monitoring (6/19).

Thematic analysis of patient and partner interviews revealed substantial unmet need in relation to the assessment and management of women and couple's sexual recovery. This included failure to manage radiotherapy induced menopause, inadequate knowledge of advice sources regarding sexual difficulties and distress caused by unresolved difficulties including loss of sexual desire, dyspareunia and reduced sexual satisfaction.

Health professionals felt inhibited discussing sexual concerns with older women and those with later stage disease and were unlikely to do so unless they had defined referral pathways.

Conclusions: The current model of medical follow-up may not be an appropriate clinical context for the optimal assessment and management of sexual concerns associated with pelvic radiotherapy. These findings are important for the development of supportive care services and the training of health professionals engaged in post-treatment toxicity assessment, patient information and support.

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ORAL

Sleep-wake disturbances: preliminary results from a study among cancer patients during active-phase chemotherapy

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Background: Sleep-wake disturbances have been recently recognized as a first priority symptom for nursing assessment and intervention in oncology patients. Although they may have an impact on functioning, mood, symptom