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POSTER

Information needs of men with breast cancer in the United Kingdom

B. Williams¹, K. Brain¹, R. Iredale¹, J. Gray², E. France². ¹ University of Wales College of Medicine, Institute of Medical Genetics, Cardiff, United Kingdom; ² University Hospital of Wales, Institute of Medical Genetics, Cardiff, United Kingdom

Background: Approximately 300 cases of male breast cancer are diagnosed every year in the UK. There is very little research on the informational needs of men with breast cancer, and their management and care is often extrapolated from research about breast cancer in women.

Methods: Preliminary data are reported from an ongoing questionnaire survey of men with breast cancer recruited from across the UK. Data are presented regarding socio-demographic and medical characteristics, types of information received, satisfaction levels with various information, and preference for gender-specific information. Participants were recruited by their clinician or self-recruited in response to media publicity.

Results: Preliminary data are reported from 50 men aged 28 to 85 years (mean = 60.79, ± 12.357 years) who had been diagnosed with breast cancer within the last 2 to 120 months (mean = 33.87, ± 26.559 months). The majority of participants (n= 44, 88%) had received verbal information regarding their breast cancer. Patients also received written literature such as leaflets (n=33, 66%) and booklets (n=27, 54%).

Generally, participants were very satisfied with the amount of various information types received. Verbal information was described as very satisfactory by 86.7% (n=39) as were leaflets 53.1% (n=17) and booklets 47.8% (n=22) by those who had received them. The comprehension level was acceptable; verbal information 93.2% (n=41), leaflets 84.4% (n=27) and booklets 81% (n=17). However, relevance of the information to men with breast cancer varied 56.8% (n=25) said verbal information was quite relevant, while 32.3% (n=10) thought leaflets were not at all relevant and 32% (n=8) of men who had received booklets said that they were a little relevant. The majority of men said they would have preferred more gender-specific information 60% (n=30).

Conclusions: Men with breast cancer were generally satisfied with the different types of information received from various sources. However, there was a clear preference to receive information written specifically for men with breast cancer.

Data collection continues. With a larger sample, it will be possible to examine informational needs and preferences within different subgroups of male breast cancer patients.

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Characteristics and extent of unconventional therapies used by cancer patients

E. Robinson¹, H. Geva², T. Mashiach², G. Bar-Sela³, Z. Dashkowsky².

¹ The Israel Cancer Association, Haifa, Israel; ² RAMBAM Medical Center, The Quality Improvement Unit, Haifa, Israel; ³ RAMBAM Medical Center, The Oncology Institute, Haifa, Israel

The use of complementary and alternative (CAM) therapies has dramatically increased over the last decade in the western world. The study evaluates the extent and characteristics of CAM use among a large population of cancer patients.

Methods: Telephone interviews of 2,176 patients newly registered in RAMBAM Medical Center 1-3 years after their cancer diagnosis.

Results: The overall rate of CAM use was 17%. Most of them used more than one type of treatment. All used CAM in addition to conventional therapies. Less than half discussed it with their physicians. Friends and family members referred most of them to these treatments. More than two thirds of therapies used were chemical, biological and botanical pharmacological preparations. 20% used manual therapies, 13% used specific diets and lifestyles and 7% used spiritual body-mind therapies. CAM use was higher in: Israeli born Jews, women, ages 41-60, high socio-economic status, longer time since diagnosis, breast cancer and chemotherapy treatments. Among highly educated Israeli born Jews under the age of 70 who received chemotherapy 69.4% used CAM, versus 3% usage by uneducated aged patients not treated by chemotherapy. Two thirds of the patients used CAM for alleviating side effects of conventional therapies, strengthen the immune system, improve their well being, minimize emotional stress and pain relief. 62% of them reported subjective improvement. Only 27% reported on using CAM for assisting in curing the disease.

Conclusions: The phenomenon of cancer patients using unconventional treatments is very extended, varies by demographic and oncology treatment characteristics and should not be denied by the oncologists. Physicians

should learn more about complementary therapies, to be able to initiate discussions on CAM use with their patients, provide advice, inform them about possible harms, and encourage use of proven beneficial therapies.

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Long-term quality of life (QoL) following prostate irradiation: relationship to anorectal symptoms employing a proctitis-specific QoL instrument

S. Turner¹, A. Kneebone², T. Bolin³, N. Spry⁴, V. Gebiski⁵. ¹ Westmead Hospital, Radiation Oncology, Sydney, Australia; ² Liverpool Hospital, Cancer Therapy Centre, Sydney, Australia; ³ Prince of Wales Hospital, Gastrointestinal and Liver Unit, Sydney, Australia; ⁴ Charles Gairdner Hospital, Radiation Oncology, Perth, Australia; ⁵ Sydney University, Clinical Trials Centre, Sydney, Australia

Introduction: Rectal injury is the major cause of late symptomatology in men receiving definitive radiotherapy (RT) for prostate cancer with potential for significant, though poorly understood, effect on long term quality of life (QoL). This study evaluates the impact of anorectal morbidity on long-term QoL and to define the relationships between patient-reported symptoms, late Radiation Therapy Oncology Group (RTOG) rectal scoring and QoL.

Materials and Methods: 201 patients who had participated in a double-blind Phase III trial testing the value of oral sucralfate taken during radical RT for prostate cancer completed a cross-sectional survey at a median time of 75 months (range: 58- 92 months) following treatment. The survey comprised a departmental anorectal symptom questionnaire, the EORTC QLQ30 and a comprehensive proctitis-focused QoL module currently under development with the EORTC. All had undergone at least one sigmoidoscopy at a minimum of 12 months following RT. QoL instrument results were examined in relation to anorectal symptoms (frequency of motions, rectal bleeding, mucus or faecal leakage) and objective measures of rectal injury including endoscopic changes and late RTOG scores.

Results: The QLQ30 instrument detected a significant QoL deficit in the domain of cognitive functioning only for men reporting faecal leakage, although global health status and other dimensions did not demonstrate QoL detriment in any subgroup of patients. Factor analysis of the proctitis module identified a cluster of questions relating to the effect of rectal symptoms on social and emotional functioning (we termed this the s/e domain) that showed strong association. Incontinence of mucus (reported by 31% of patients) or faeces (37%) of any degree had a strongly significant negative impact in the s/e domain ($p=0.008$ and $p<0.001$ respectively; Wilcoxon rank sum test). Long-term bowel frequency and bleeding did not appear to influence scoring in the s/e domain in the proctitis module. Similarly, late RTOG score was a poor discriminator between men scoring poorly on the specific proctitis instrument and others. Sigmoidoscopy score did correlate significantly with worst late RTOG grade ($p<0.001$; Chi squared test) and severe sigmoidoscopic changes were more commonly linked to poorer long term QoL in the s/e domain.

Conclusions: More global measures of QoL may well not detect the subtleties of problems specific to RT-induced anorectal morbidity. This study demonstrated that incontinence of mucus or faeces has a major negative long-term impact on social and emotional functioning a situation partly reflected by sigmoidoscopic changes but not by RTOG toxicity reporting. The EORTC proctitis module requires further testing and formal validation.

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Terminal cancer care: the "Home-Care" model as an efficient and cost-effective treatment.

M. Ranuzzi¹, G. Palmeri¹, D. Manzo¹, R. Scirocchi¹, A. Taddei¹, S. Brunetti¹, P. Ranaldi¹, A. Sabbi¹, S. Gentile¹, R. Vercelloni¹. Gruppo Ricerca Assistenza Domiciliare Oncologica, Home-Care, Rome, Italy

Background: The G.R.A.D.O. Association (Gruppo Ricerca Assistenza Domiciliare Oncologica) providing home-care for cancer patients was begun in June 1998. Our aims are: aid, research, study, promote, organize, carry out the home-care for these patients, prevalently by voluntary service. Moreover, we aid the public and social structures involved in cancer care. The drawing thought of our work is that, in the advanced phase of cancer, the best place of treatment should be the patients' home, considering that house is the natural container of persons' life which, with a convenient help, would prefer to spend the terminal phase of their life at home rather than in hospital.

Patients and methods: This service is provided upon request from the family doctor or directly from the patients who are unable to travel or whose condition need a palliative treatment. Patients are visited at home by an oncologist with the aid of a professional nurse with oncologic experience;