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POSTER

The information and support needs of people living with cancer in South West London

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Introduction: Patient information and support services have expanded rapidly over recent years, however, many people living with cancer feel that their needs are still not adequately met. A study was undertaken to identify existing local information and support resources, to highlight examples of good practice and areas where improvements could be made.

Methods: Semi-structured interviews and discussion groups were held with 39 health professionals in both primary and secondary care, and 82 cancer service users.

Results: In addition to information about cancer itself, patients want information about living with cancer to help them cope more effectively with the illness. The existing knowledge base and normal coping strategies, all determine what individuals want regarding the type of information, in how much detail and at what stage of their cancer journey. Patients perceived that the provision of information and support services was often fragmented. Most patients received their information from hospital-based cancer professionals and did not readily identify their family doctors as a resource. Patients often felt particularly vulnerable once treatment had finished. Many people wanted to pursue self-help strategies and sought more information about available internal and community-based support services.

Conclusions: There was no consensus regarding the optimal provision of information and support. The development of a local patient information strategy will ensure continuity in the provision of patient information across the different services. The provision of reliable and timely information to people with cancer and their families could be achieved through information resource centres in cancer centres and units, and the primary care sector.

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POSTER

Mapping the symptoms of pelvic radiotherapy: nursing assessment of risk and supportive care

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Purpose: This study aimed to map in detail the effects of radiotherapy treatment on a cohort of men with prostate and bladder cancer, and through regression analysis, identify risk factors for symptom occurrence and severity. The success of radiotherapy depends on eradicating tumour cells. However normal tissues caught in the treatment field inevitably become damaged at the same time, resulting in sometimes complex and distressing side effects, which have negative consequences for quality of life. Clinically it is hard to predict which patients are likely to experience treatment reactions and to plan future health care needs.

Methods: 115 men were assessed during and following radical pelvic radiotherapy for urological cancer. Assessment of symptoms was through RTOG observer rated toxicity scores and self assessment of symptoms. This self assessment covered major bladder and bowel toxicity, general fatigue, as well as impact on activity and feelings of being unwell. Assessments were completed longitudinally over the course of treatment at 2 weekly intervals.

Results: The results showed a pattern of rising acute symptoms that diminished gradually, once therapy was completed. Nocturia and fatigue were identified for all men as symptoms causing most distress, those with bladder cancer experienced greater severity of symptoms. The extent of symptoms at start of radiotherapy was not predictive of severity of side effect occurrence, but a rise in symptoms and occurrence of problems at week three was predictive ($p < 0.001$) of later severity of acute side effects. Those who were older had significantly ($p < 0.006$) greater fatigue scores.

Conclusion: Self assessment of symptoms by patients could be a useful tool in identifying those most likely to suffer from greater severity of side effects. More detailed and focused patient assessment at week 3 of treatment warrants further evaluation as a means of predicting those at risk of developing symptoms. Treatment modification and introduction of targeted supportive care strategies could then be introduced to minimise the distress associated with the multidimensional impact of radiotherapy.

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POSTER

From cure to care. An ethical dilemma in cancer survivorship

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Every years about ten million of people develop cancer, world wide. About 30% of these have a favourable prognosis and 60% will die. "Medical" treatment carried out without the participation of the patient, which tends to focus on pathology, risks neglecting the psychosocial and spiritual needs of someone who is gravely ill from cancer. According to Crawford et al, 1998, the fundamental aim of nursing is to communicate "care". It is clear that any decision-making guidelines must be sufficiently flexible to adapt to the requirements of both person receiving care and care-giver. It is well recognized that patients have unrealistic expectation of cure fostered by extended treatment schedules and repeated hospitalization, even when the clinicians know that the objective is palliative rather than therapeutic. When and how patient should be made aware of the change in focus of care is as important as diagnosis and treatment. The autonomy of the patient is a central component in making life worth living. This means a process of care in which nurses have the moral, ethical and legal right to involve the patients. Towle et al, 1999 hold that informed consent must take account not only of risks and benefits of the treatment options but also of the attitude and values of patients. From a technical point of view the patient is seen as more as a physical condition than as a person. A part of the art of treatment is knowing when to refuse/stop aggressive treatment and how to justify this decision to colleagues, patient and relatives in the face of unrealistic expectation. In our institute in Milano we had 5000 new admission in the year 2000. Of these 20% were transferred to palliative care, when curative therapy failed. The survival rate for these patients was 60-70% at 3 months, 30-40% at 6 months and 20% at 12 months. The prospect of a lingering, painful and undignified death has reawakened fear in the mind of the patient and reopened the debate in Italy on legalization of euthanasia. Two different approaches to confronting unbearable pain is discussed nowadays: either legalize euthanasia or improve palliative care. Both are founded on the desire to relieve suffering. If we, as nurses, are to improve this situation, there is need to: promote the legitimacy of prescribing analgesic instead of over-treatment, set standards of quality of life below which therapy should be considered pointless, educate people on the limits of medical technology and on concept of a peaceful death.

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POSTER

ARC support services in cancer care in Ireland

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Psychosocial factors have a role to play in understanding cancer in terms of the psychological consequences, the treatment of symptoms, improving the quality of life and longevity. Patients react to a cancer diagnosis with a variety of emotions including despair, shock, fear, anger, guilt, denial, anxiety, depression, hostility or acceptance. The type of support required by patients depends on a number of factors, including the type of cancer and the family situation. Wright et al (2001) describes social support as access to relationships that meet basic interpersonal emotional needs, validation of personal identity, help with tasks and support in controlling and handling emotions. ARC Cancer Support Centre was established in Dublin in 1995 to offer support to people affected by cancer and those who care about them. The professional support is holistic and complements the primary medical care with education and psychosocial care. ARC Cancer Support Centre offers emotional support, informational support and appraisal. Supportive interventions currently cover a wide range of services including stress management techniques and relaxation, psychological interventions including psychotherapy, cognitive therapy and family therapy, support groups and workshops, psychoeducative groups and research based complementary therapies.

Information is a basic form of support. Having correct and adequate information is essential to helping the patient and family adapt to a cancer diagnosis. Many studies suggest that patients with good information are more satisfied with their care and demonstrate lowered levels of anxiety and depression. The role of support groups has also been well documented in cancer support care.

Studies have shown that complementary therapies have been considered helpful in enhancing well-being, creating symptomatic relief and promoting well-being when used as an adjuvant to traditional medical care.

The function of ARC Cancer Support Centre has been and continues to be a source of support to all Irish people affected by a cancer diagnosis. This support will enable the newly diagnosed patient to view their cancer diagnosis, not as a death sentence, but as a reprieve and a chance to change their lives and the lives of those who care for them.