Mapping the unmet needs of colorectal patients

Despite 471,000 people being diagnosed with colorectal cancer in Europe every year, no research has been published on the needs of these patients. At EONS-9, Geoffrey Henning, EuropaColon’s Director of Policy, held a session with nurses to tease out some key issues. Here he reports on the findings.

Report by: Geoffrey Henning

The chance to address a session at the EONS conference offered a welcome opportunity to talk to nurses about EuropaColon, which is the only organisation dedicated to colorectal cancer in Europe. I was able to report on what we have achieved in our 10-year history, on the outcome of our two patients’ conferences, the products developed by our expert patients’ advisory group, the newly developed patients’ diary and the use of the health check barometer, as well as the range of resources the colorectal community now uses as lobbying tools.

I explained about the White Paper we published to set the boundaries for the treatment and care of colorectal cancer patients across Europe, and about the importance of the declaration on the fight against colorectal cancer adopted by the European Parliament in 2010.

However, with no studies about the needs of patients with colorectal cancer, I was keen to start developing ideas that can be put in a questionnaire addressed to our patients’ organisations. The intention would be to collate them into a paper that would provide a detailed list of these needs.

It was not clear at the beginning how much would be achieved at the session. However, they all revealed some knowledge of the disease, which came out as the interactive session developed and ultimately became highly productive.

The session agreed on some broad headings – Physical, Emotional and Social – under which the details of patients’ needs could be gathered, but there was not much time available to dig deeper into these needs. There were also very differing approaches between countries, with levels of intervention and support being considerably more sophisticated in some countries than in others.

DETAILED INFORMATION

Under the ‘physical’ heading, a clear picture was formed of patients needing quite detailed levels of information and advice about their treatments and side-effects and about how these would affect their functioning both during and after treatment. Information about managing pain, physical changes and changes in bodily functions, along with fatigue, were all seen as important to cancer patients.

Body weight and other physical changes are issues that also need to be managed. Overweight patients need support to reduce their weight and get enough exercise to keep it under control; anorexic patients need support to ‘bulk up’ to assist the body’s recovery. Referral to a qualified gym instructor is an option in some countries. In others, however, no advice is given about exercise, despite the proven benefit of regular exercise, particularly for patients diagnosed with colorectal cancer, during and particularly after treatment.

Social needs were seen as an important area. Relations with family and partners was high on the agenda; sexual function and desire; dealing with disclosure; stigma associated with colorectal cancer amongst friends, colleagues and family;
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Geoffrey Henning received useful input during his session on colorectal cancer at EONS-9.

Financial issues are often of concern to cancer patients, many of whom have to take leave from work for extended periods or are even unable to return. This affects them in so many ways, including their ability to eat suitable and healthy food during and after treatment.

A diagnosis of cancer affects all patients to the core of their being, leading to a wide range of emotional reactions. Nurses are at the centre of any patient’s treatment and the active listening they offer is often sufficient. However, some patients might need dedicated counseling. In some countries, nurses reported that referral to a range of social services is possible, in other countries not. The importance of a contact telephone number was highlighted; and it was felt that the recently launched EuropaColon Patient Diary could be a useful resource.

Finally, no one in the audience mentioned the spiritual needs of patients. This is a need that tends to be felt most acutely by patients nearing the end of their lives, and the omission reinforced our initial concerns, when preparing for this session, that more work is urgently needed to identify the needs of patients with metastatic colorectal cancer. Funding will be needed to make this possible.

The next steps will be to develop a range of questions for patients to answer and rate, so all the needs identified at this session can be properly evaluated. The findings will be published shortly.

Further information at www.europacolon.com

EuropaColon – facts and figures

- Launched 10 years ago, EuropaColon is committed to preventing deaths from colorectal cancer and improving the quality of life and support for those affected by the disease, which is the third most common cancer amongst men and second most common among women worldwide, and accounts for the highest estimated rate of cancer deaths in Central and Eastern Europe.

- EuropaColon now has 35 partner groups in 30 countries. It brings them together to raise awareness of the disease, to lobby governments to extend screening coverage, as colorectal cancer is highly treatable if diagnosed early, and to promote greater access to the best treatment and care.

- Since its inception, EuropaColon has launched the European Colorectal Cancer Awareness Month in March, organised two major conferences and a series of country meetings, published a White Paper “A Framework for Improving Outcomes for Patients” and set up an Expert Patient Advisory Group.

and the importance of peer support were all recognised. Interestingly, none of the nurses reported that dedicated meet-up groups were organised in their hospitals to help patients meet other patients. I mentioned a new social networking tool for patients being constructed by EuropaColon, which should be available by March 2015, and requested that any nurse wishing to start a ‘meet-up group’ in their hospital to get in touch.