Proffered papers
Patient's perspectives

1580 ORAL

The troubles with communication 'a patient's story'

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Background: Dumfries and Galloway is a rural region situated in the south-western corner of Scotland. It covers an area of approximately 2500 square miles with population of 147,000 based in three major towns and the rest in smaller towns and villages spread across the area. The current population profile is markedly different from the Scottish population profile in that we have a larger proportion of elderly and a smaller proportion of younger citizens a trend, which is set to continue. The average age is of 41.9 compared to the average in Scotland of 39.2. The health board has service contracts for various parts of the cancer journey with several providers throughout southern Scotland and northern England, although for most of it's cancer services it sits within the South East Scotland Cancer (SCAN), network based some 75 miles to the east. Therefore patients may travel significant distances to have investigations and treatments in other areas. As a nursing profession we were aware that good communication was a key component to delivering a smooth and well planned treatment pathway for our patients. However we were also cognisant that difficulties occurred that could mar the experience for patients. It was decided that the best method of identifying problem areas was to draw on the experiences of patients. Once an area had been highlighted it was then possible to devise an action plan to either eradicate or minimise them. This would mean that service changes were being driven directly by patients and constructive efforts could be made to bring about change.

Materials and Methodology: Using the Cancer information Centre, within the district hospital in Dumfries as a base the following methods were used to identify problem areas in communication. Informed consent was attained from all those involved and the reasons behind the study explained to them. Unstructured interviews were conducted with 6 cancer patients and recorded on video camera. It was the patients' choice whether this occurred as part of a group or as an individual. The Cancer Information Manager who was known to all the patients and the Lead cancer nurse who was known to some of the interviewees conducted interviews. Interviewees: 4 female; 2 male. All had different experiences of various site-specific cancer journeys.

All had previously identified areas where communication had been highlighted as a problem area in their cancer journey. In fact it transpired that their experiences were not unique and they reflected the experiences of a wider patient group. The interviews were typed to produce transcripts that contained the salient information needed. The patients, to ensure that they were in agreement with the content then read the transcripts.

Results: Communication issues highlighted involved

- Lack of information around where patients had to stay and the facilities available to them when having radiotherapy treatment.
- Incorrect information being given by an outside service provider to a patient.
- Patient refusing specialist nurse input due to poor explanation of service and subsequent difficulties in accessing the service when required.
- Patients moving to the area unable to rely upon local medical knowledge when support services requested.
- Patients who had surgical treatment elsewhere did not have a connection to local information services.
- Misunderstanding of the use of medical terminology and lack of clarification.
- Difficulties in accessing information concerning rare cancers.
- Lack of professionals knowledge about cancer diagnosis.

Conclusions: Patients could see the value of relating their stories to have a positive influence on changing service provision for the better. In the main all the areas that were highlighted by using the patients stories of their cancer journey would not have been apparent to nursing staff. All the experiences had been responsible for adding to the stress and loss of control so often experienced by cancer patients. In each case there were positive actions that could be taken to try to ensure that a repeat of the situation did not occur. Tools were developed to fill information gaps, information packages containing details that patients wished to know. Networking with other organisations was commenced to increase understanding and provide contact numbers for professionals based within our locality. Support groups were advertised in local GP surgeries and a planned programme of updating the information arranged. An education programme open to all professionals was developed to include patient pathways and clarification of roles. Cancer services information booklet was devised and distributed to all areas that had any input to cancer service provision both in and out with our area. Patients felt empowered to be able to videoconference their stories to national meetings so that others could learn from their experiences. Nurses changed their practice to ensure that information given to patients included the types highlighted as needed in this study. It is proposed that both the Cancer Information & Support Manager and the Lead Cancer Nurse attend the ECCO 13 conference. To be available to talk through the initiatives with all who have an interest. The video interviews could be shown Posters with various problem areas and their solutions displayed. Tools that have been developed will be available for attendees to examine and take away with them to be adapted for their own use or information.

1581 ORAL

Patient perspectives on communicating with health care professionals about sexual concerns

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Background: Cancer has an impact that is felt in more than physical ways. There are often emotional, social, psychological, spiritual and practical changes as well. Patients frequently face challenges in coping with the needs which arise during the course of their treatment. In particular, patients have reported challenges in communicating with health care practitioners about their needs and in obtaining the help or assistance they would like to have. Busy clinical settings and heavy caseloads can present barriers to patients receiving timely and appropriate help for unmet needs. These challenges escalate when the needs are related to sensitive psychosocial needs such as those related to sexuality. This study was undertaken to describe patients' perspectives about communication with cancer care professionals regarding sexual concerns.

Materials and Methods: In-depth interviews were conducted with 30 cancer patients (breast, gynecological, prostate, colorectal, and head and neck) to explore this issue. Interviews were audiotaped, transcribed verbatim, and subjected to content and thematic analysis.

Results and Conclusions: Patients confirmed they had experienced concerns about sexuality because of their cancer diagnosis and treatment. They also experienced barriers when they raised their concerns with health care providers and wanted to discuss these matters. Many felt they did not want to raise their concerns with providers who were "very busy". The findings have clear implications for education of staff members and practice in cancer settings concerning the sexual concerns experienced by cancer patients, talking about these topics in a sensitive manner, and linking patients with the services they may required.

1582 ORAL

Needs evaluation among patients with advanced colon cancer who receive chemotherapy at home

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Background: Cancer patients suffer from physical and emotional distress, suffering from the treatment and feel isolated even within their own family system. Colon patients, in addition, suffer from physical problems that cause embarrassment, and discomfort (like lost of control over secretion) they also suffer from low self esteem, exhaustion, pain, no appetite and lower sexual drive. Knowing all of that and in order to improve the quality of life for these patients, we found in researches showed that chemotherapy at home can improve the patients' quality of life. Patients reported that they feel fear and distress when they have to receive treatments in the hospital. They feel anxious, under lot of stress. They also feel as they become a burden on their family that have to accompany them to the treatment.

Method: We conducted twenty home visits, within six months, to twenty colon cancer patients who received chemotherapy at home. The home visit included conversation with the patients (about an hour and half) and they were asked to complete two questioners and to return them to the staff during their next clinic visit. The questioners included three areas:

1. Their medical condition, physical functioning and emotional state;
2. Sources of support within the family system and within the community;
3. Level of satisfaction regarding getting the treatment at home.

Results: In the questioner regarding adjustment to current state and level of emotional distress 91.7% answered that their emotional distress is high. The method of home visits was proven to be official because we were able to check if the patient is in a supportive environment that suites his needs. 90% of the patients reported that although they were in close and supportive relationships with their family members, they feel isolated. 80% of the patients were unaware of their legal rights and of community supportive services. Some of the patients expressed a wish to have a volunteer visiting them at the home. 100% of the patients noted on the advantages of receiving chemotherapy at home and stated that their emotional distress would have been probably higher if they were treated at the hospital.

Conclusions: According to our evaluation, patients who can receive treatment at home, improves their quality of life, strengthens the coping skills and increasing their level of satisfaction since. Furthermore there is a need to involve community social and nursing services in order to build a supportive system that can reduce the feeling of loneliness and isolation

1583 POSTER

Helping children to understand . . . (a guide for parents with cancer)

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Summary: Cancer has an unquestionable emotional impact on patients and family and this impact seems to *be more visible* in families with small children. Families have to go through an **adaptation** process when faced with the problems of the disease. This process must be planned so that family members can adjust to the new situation. Children realise that something is "going on", though they may wrongly interiorise their doubts and fears as the representation of the disease has different meanings depending on the stage in the child's development. According to VICENTE "representations of words are the essential element of the association of ideas. Representations of words have their origin in children's perception of the language of others....but as their individual development progresses its quality changes, acquiring more elaborate meanings and making room for symbolic representation" *(*1994: 72). Healthcare professionals can help define strategies that will minimise the suffering of these families and help them get through this difficult period of their lives. Based on the above quotation, and combining daily health care experience, we can safely say how important it is to know **what to say, how to say it and when to say it** when telling a child what is happening to his or her family member and to know how to help the family **deal with** this new situation. It is also important for them to **share** emotions, concerns and fears and thus strengthen family ties. We have drafted a **GUIDE** dealing with these aspects to complement the education of these families.

1584 ORAL

Complementary and alternative therapy use among people undergoing cancer treatment

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Aim: This study was funded by the Department of Health to generate new understanding about the ways in which patients with cancer use Complementary and Alternative Medicines (CAM) as an adjunct to their conventional cancer treatment, and to identify the perceived value or otherwise of using CAM.

Method: A survey of 304 recently diagnosed patients attending two cancer centres was conducted over a 3-month period to determine CAM use before and since diagnosis. Quota sampling was used to reflect national cancer incidence. A sub-sample of 40 patients participated in semi-structured interviews.

Results: CAM use before diagnosis was reported by 33% of patients. Following diagnosis, CAM use was reported by 28% of patients. Of the 100 CAM users before cancer diagnosis, 57 had also used CAM since their diagnosis. Twenty nine CAM users since diagnosis had not used CAM before. Patients who used CAM were more likely to be younger ($p < 0.001$ for trend) and female ($p < 0.001$), with a higher educational level ($p < 0.003$ for trend). Forty five percent of CAM users since diagnosis had breast cancer, compared with only 17% of non-CAM users. Almost all CAM users since diagnosis found CAM helpful and no-one reported that they were unhelpful. There were no apparent differences in CAM use according to socio-demographic characteristics, or recruitment clinic. The pattern of CAM use reported by patients varied considerably. Data indicate that there may be important factors over and above individual beliefs and motivations, influencing CAM use.

Conclusion: This study is the first to reveal how CAM use may alter following a diagnosis of cancer. Factors such the clinical team, the availability of CAM within cancer treatment settings, information about CAM and safety considerations, may be important influences on CAM use among patients undergoing cancer treatment.

1585 ORAL

Exercise during cytostatic treatment: group cohesion and quality of life

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Background: A series of studies have shown that physical activity improves cancer patients' functional capacity and Quality of Life (QOL). Few of these studies have included exercise carried out in a group setting, and the patient's experience with the in-group processes remains unexplored. This study selected for investigation an intervention that combined exercise and group organisation.

Intervention: The intervention consisted of a group-based intervention that combined physical activity (warm-up: ball games and aerobics, heavy resistance training and cycling on stationary bicycles) with three additional components: body awareness exercises, relaxation, and massage. The objective of this study was to examine patients' experiences with group cohesion during the intervention and changes in social and emotional aspects of QOL outcomes.

Material and Methods: The study used a method triangulation component design. Seven qualitative semi-structured group interviews were conducted post-intervention. Quantitative assessments ($n = 55$) of selected QOL dimensions (EORTC QLQ-C30, SF-36) were made at baseline (test 1) and repeated after six weeks (test 2). Group interviewing was selected to ensure detailed and precise characterizations of group cohesion, while the questionnaires assisted in gaining a quantitative pre-/post-test evaluation of the intervention on standardized and well-validated cancer and health specific outcomes in the individual patient.

Results: The interviews revealed that the group setting motivated the individuals to pursue personal endeavours beyond their physical limitations. Training was carried out in an atmosphere characterized by a special "esprit de corps", and reciprocal upward comparison. Patients agreed that their mandate was primarily about abstraction of and distraction from their illness, and reported that they felt like sport teams. Questionnaire data showed significant improvements in relation to emotional functioning ($t(54) = -2.055$, $P < 0.05$), social function ($t(54) = -3.042$, $P < 0.01$); and mental health ($t(54) = -2.418$, $P < 0.05$).

Conclusion: The focus on the qualitative aspects of group exercise is a contribution to the understanding of the mechanisms behind cancer patients' motivation to stay active during and after treatment. This study identified a conceptualization of group cohesion that forms a valuable basis for a larger randomized controlled trial to conclude whether the observed changes hide a causal link.

1586 ORAL

Hospital follow-up for breast cancer: the search for recurrent disease

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Background: Following completion of breast cancer treatment, patients are traditionally asked to return to hospital outpatient clinics for 'follow-up'. Recent policy documents question the value of this traditional approach and the impact of routine surveillance procedures on survival and quality of life. As a result, reductions in duration of follow-up have been proposed. However, there is little research into the nature and content of follow-up care. What happens during follow-up consultations? This presentation reports on a study that examined the nature and content of hospital follow-up for women treated for breast cancer in a UK hospital.

Methods: This study primarily took an ethnographic approach that involved observation, recording and timing of 104 consultations between patients and health professionals. In addition, in-depth interviews were conducted with medical and nursing staff involved in the provision of follow-up care for women with breast cancer ($n = 14$). Patients who had been observed were asked to complete a questionnaire about their clinic visit.

Results: Hospital follow-up was focused on searching for recurrent disease (through clinical examination and routine mammograms) and providing reassurance that cancer had not returned. However, no recurrences were detected during the 104 consultations observed in this study. Health professionals did not expect to find recurrences on clinical examination but patients perceived that the clinical examination was the primary means of detecting recurrent disease. Consultations were brief (mean 6 mins), although patients over-estimated duration. There was little opportunity for patients to discuss information needs or psycho-social concerns as clinics were heavily focused on medical signs and symptoms of recurrence.

Conclusion: The traditional approach to follow-up care for women with breast cancer is historically based and does not empower patients to take