1288 POSTER

Ethnic language information films - considering cultural, political and religious issues

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Introduction: Health professionals now have a strong agenda to improve the information patients receive about their cancer treatment[1], particularly amongst ethnic minority patients who have reported higher dissatisfaction rates[2]. Research shows that a high satisfaction rate (81%) is achieved when videos are used to prepare patients for cancer therapies[3], especially when used to support good verbal and written communication.

Method: A New Opportunities Fund Lottery grant was awarded to translate the video 'Chemotherapy & Radiotherapy' into Urdu, Hindi, Gujarati and Bengali. A questionnaire was developed to ascertain the cultural, religious and political sensitivity of each ethnic group before translation. 95 questionnaires and copies of the video were sent to 18 hospital oncology units & 13 community centres in areas of high Asian population, and temples, mosques and Gudwaras, together with 21 charities and organisations involved with Asian health, and ad hoc to Asian priests, doctors, nurses, patients, support workers, friends and relatives.

Results: 61 questionnaires were returned. The largest response was from Asian related charities & organisations (86%) and interested individuals (75%): 29% Urdu, 23% Bengali, 23% Gugarati, 10% Hindi, 15% other. Faiths represented were Hindu 40%, Islam 42%, Sikh 11% and other 7%. 58% of respondents felt there should be major changes to the film within several categories, the 5 most pertinent being (1) use Asian patients (2) use well known Asian presenters (3) emphasis of the text should be on factual information regarding treatment & side effects rather than to cancer (4) music (5) dress. Filming took place in a number of hospitals throughout the UK over a year, with particular help from Coping With Cancer, Leicester.

Conclusion: Converting English information strategies into ethnic languages requires considerable market research for them to be accepted by the target audience, particularly in terms of cultural, political and religious sensitivities. These films are being distributed by CancerBACUP on 0808 8001234. Further information from cancernet.co.uk/asia. Reference: 1. NICE Committee. Supportive and Palliative Care Clinical Guidelines. 2002. 2. Thomas, R, et al. Patients preferences for video directed information. Effects of age, sex and ethnic group. EJCC 1999, 8, 81-86. 3. Thomas R, et al. Forewarned is forearmed - Randomised evaluation of a preparatory information film for cancer patients. EJC 2000, 36, 1536-1543.

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The Sun Awareness/Melanoma-Prone Lifestyle Enquiry (SAMPLE) questionnaire: a new tool for epidemiological melanoma research.

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The development of SAMPLE will be described, its derivation from validated sources, its foundation in health behaviour theory and its use in a pilot-scale study.

Background: Sun exposure is a risk factor for malignant melanoma. The UK government's cancer A new questionnaire is described that assesses both sun exposure, sun protection and awareness of reduction strategy aims to increase awareness of risk factors, change behaviour and improve sun-protection in those at high risk. The implication is that a higher level of awareness of the link between sun exposure and melanoma leads to behaviour modification and a reduction in melanoma incidence. SAMPLE was developed specifically to study both knowledge and behaviour in study populations

Materials and Methods: The SAMPLE questionnaire has 4 sections:

1. demographic details;
2. 9 questions adapted from Jerkegren et al 1 capturing the individual's sun-related behaviour and titled Exposure;
3. 5 questions about Protection, covering respondents use of sunscreen, wearing of hats, covering of arms and legs, and avoidance of strong sunlight; as used by Campbell and Birdsell 2;
4. 18 questions focusing on Knowledge about moles, malignant melanoma and the biological effects of the sun.

A complete version of the SAMPLE questionnaire will form part of the presentation.

Results: The use of SAMPLE in a study (publication pending) of sun exposure amongst healthcare professionals will be described. Results obtained using SAMPLE will be compared with results from studies using other research tools.

Conclusions: Prevention and control programmes have been successful in increasing knowledge and awareness of skin cancer, but major changes in attitude and behaviour have not occurred 3. A study using SAMPLE as its research tool has shown that healthcare professionals (including oncologists and cancer nurses) continue to expose themselves intentionally to undesirable amounts of UV radiation, despite their universally high awareness of risk factors for malignant melanoma. This is consistent with studies in other populations 1,4,5. Assumptions by public health bodies that improving awareness of the risks of sun exposure will reduce the incidence of melanoma are probably incorrect.

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1290 POSTER

Longitudinal assessment of fatigue in Greek women with breast cancer undergoing radiotherapy.

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Background: Fatigue is one of the most common symptoms reported by cancer patients. Radiotherapy induces fatigue in up to 80% of cancer patients. Only few studies have investigated the pattern of fatigue over time in women with breast cancer undergoing radiation therapy, providing conflicting results. The purpose of this study was to describe and evaluate the phenomenon of fatigue in breast cancer patients during their radiotherapy.

Materials and methods: The convenience sample in this study was 106 women (I and II stage of breast cancer) between 29 and 78 years old (mean 55,34 ± 12,35) undergoing adjuvant radiation therapy as outpatients for a 5-7 week period. All of them had already undergone breast cancer surgery (83% breast conserving and 17% mastectomy). Moreover 57,5% of the women had undergone chemotherapy too. The instrument used for fatigue assessment was the Piper Fatigue Scale. Data collection was obtained by interviews prospectively over three points in time: in the first two days of therapy in the middle and during the last week of therapy. For statistical analysis non parametric statistics (Friedman test and Wilcoxon test) were used.

Results: In this study fatigue was increasing during radiotherapy. The level of fatigue in the middle of the therapy was found significantly higher than the initial levels ($p<0,001$). Moreover, the fatigue measurement in the last week was found significantly higher than the measurement in the middle of the therapy ($p=0,002$), as well as than the measurement of first two days ($p=0,001$). The results will be discussed in relation to their stage of cancer and their previous therapy (surgery or chemotherapy).

Conclusions: This study shows that fatigue increases during radiotherapy in women with breast cancer, which is in accordance with the results of some studies. The exacerbation of fatigue during therapy suggests that this common and debilitating symptom should receive appropriate recognition from nurses and other health professionals.

1291 POSTER

The study registration project - Danish studies of people with cancer from a nursing perspective

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Background: The Special Interest Group (SIG) for Nursing Research, Development, and Information Dissemination has been set up as a part of the Danish activities for cancer nurses. Soon after the group started working it became obvious that studies related to cancer nursing often had an element of duplication and that already existing information was not disseminated to a sufficient extend to nursing practice. The Study Registration Project was set up as a response to this situation.

Purpose: All type of Studies (e.g. pedagogical, clinical, management oriented) with relevance for nursing to people with cancer conducted in Denmark from 1989 and onwards has been incorporated in a database. The aim was to support colleagues to use this database, find, and use studies with relevance to their practice and avoid duplication of studies.

Material and Method: Studies were defined both as research-studies and as quality-developments-studies - and were divided into three main groups: planned, ongoing, and finished. The SIG group designed a questionnaire consisting of items e.g. about type of study, the aim, methods, how the study was published, where the study was done, who participated in the study etc. The questionnaires were distributed to all Public Cancer Centers in Denmark, hospices, and Hospital Department for Palliative Medicine and Centers Training Specialist in Cancer. About 80 questionnaires were distributed and announced in two different Danish nursing magazines. The registration has been ongoing since 1999 and is continuous. It is now also possible to register on-line (www.fs13.dk) .

Result and Conclusion: The poster presentation will consist of an overview of the studies registered in the database. Presently 42 studies are registered. They are primarily from the multi centers, and primarily quality-developments-studies. All the studies were categorized into 10 different groups as ex. Palliation, Rehabilitation, Children and Young People, and Relatives etc. Both quantitative and qualitative approaches have been applied. There will be a summary of results from the questionnaire and an on-line demonstration of the database.

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Do patients benefit from nursing research? An overview of a service user/patient need identified from our research, how it is being addressed and the impact and benefit to the individual

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Aims: To address the key issues related to nursing research and their benefits to patients. To emphasize how scientific knowledge can be implemented and how this can be of importance to each individual.

What is research? Research is defined as "an attempt to extend knowledge through systematic, scientific enquiry" (Hockey 1986) It is about finding answers to questions and solutions to problems.

One of the problems identified by many information charities is the difficulty in reaching ethnic minority communities. People seek information in a variety of ways and people from other communities may find it difficult to access culturally sensitive, appropriate information in other relevant languages.

Nursing research has already had a great impact in the field of communication and support for people with cancer. It has been highlighted in recent years the need to communicate openly with people and not use avoidance strategies. The result of this evidence being that there is greater openness in communicating with people affected by cancer and a positive change is occurring.

The view of CancerBacup. Britain's leading cancer information and support charity. is that in line with the NHS National Cancer Plan everyone has the right to relevant information that is culturally sensitive and appropriate to their individual language and needs. In response to CancerBacup's research and evidence that the needs of people in black and ethnic communities were not being adequately met, an interpreting service has been implemented to address these needs and give many more people the opportunity to access cancer information.

This paper will address the needs that were identified for an interpreting service through our statistical information and user feedback, as well as discuss how the service was set up and examine the implications of providing information to a far bigger overall population.

CancerBacup recognises through outreach work and research implemented by the ethnic minorities' Cancer Information Specialist, that the need to develop information services for a wider more diverse population is increasing and therefore the interpreting service will need to be evaluated effectively to measure the impact. Further statistical data from CancerBacup will be able to demonstrate this impact.

Nursing research has the ability to impact patient care on a global scale. The developments in recent years of how research is conducted and results implemented, means that nurses have the knowledge and tools to evaluate their practice effectively, implement their research results accordingly, and plan their care appropriately to meet the many and diverse needs of their cancer patients.

1293 POSTER

Ethical dilemmas in patients with breast cancer in clinical research

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Background: Medical ethics estimates behaviour of individual or a group in medical profession, defines certain moral obligations and requires self control, and above all, love for human beings.

Aim: To analyze, within existing ethical standards and principles, more precisely and in detalis specificities at obtaining informed consents for participating in clinical trials, according to attitudes of the Institute.

Method: Methods of obtaining informed consents of the patients for inclusion into clinical trials depends on national regulations. Oral consent is sufficient in our country. We have considered special and specific circumstances of giving consent of patients with breast cancer, for inclusion into adjuvant programmes. Specificity consists of the following:

- We are used not to tell complete truth to a patient in relation to diagnosis (generally);
- On the other hand, such a group of patients should be told about necessity for adjuvant therapy;
- Informed consent means detailed explanation of the course of disease, without treatment, and within therapeutic protocols as well, of reason by randomization, and that brings to certain dilemmas concerning obtaining consent of the patients.

Results: Our experience shows that the patients, most frequently are familiar with nature of their disease, although word cancer is neither used by the patients, not by the team of professionals. So, nurses meet new requirements as members of professional team in clinical research.

Conclusion: It comes from all above stated that a nurse, participating in medical research, should highly balance its professional competencies and follow attitude of her collaborators in professinal team.