

coping. During the last months of the treatment, the expectations change over to questions about the future.

Table 1. Cognitive expectations under chemotherapy treatment

Time	Cognitive expectations identified	Reference
Start to 1 month	All possible information	McCaughan & Thompson 2000
	Treatment procedure and drug administration	Lock et al 2002
	Diagnosis, prognosis, treatment, support services, examination, aftercare and impact of illness	Vogel et al 2000
	Side-effect prevention, how chemotherapy works, how chemotherapy affects body	Knowles et al 1999
1 month to 5 months	Side-effect prevention, how chemotherapy works and how it affects body	Knowles et al 1999
	How treatment influence daily living, how other patients experienced and coped	Friis et al 2003
	How to deal with emergency, diagnosis, aftermath of chemotherapy, duration of treatment	Iconomou et al 2002
	Illness, recovery, treatments, side-effects and trajectory of illness	Piredda et al 2008
Last course	Information of examination and medical tests	Vogel et al 2000
	Treatment completion, success of treatment, symptom recurrence and follow up arrangements	Skalla et al 2004
	Structured and detailed plans for palliative treatment and supportive care plans	Friis et al 2003

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POSTER

The impact of cytoreductive surgery and hyperthermic intraperitoneal chemotherapy on the experienced Quality of Life during the first two months after procedure

P. Bottenberg¹, Y. Heddes-te Winkel¹, V. Verwaal¹, E. van Werkhoven¹.

¹NKI – AVL, Surgery, Amsterdam, The Netherlands

Background: Since 1995 cytoreductive surgery and hyperthermic intraperitoneal chemotherapy (HIPEC) is performed in the Dutch Cancer Institute – Antoni Van Leeuwenhoek Hospital (NKI – AVL). During this period nurses have observed an impact of the HIPEC on the experienced Quality of Life (QoL) of the patients. Therefore was the objective of this study to investigate the impact and the effect of surgery induced factors on QoL in the first 2 months after surgery.

Patients and Methods: In the period July 2006 – August 2008 29 patients with peritonitis carcinomatosa of colorectal origin were asked to fill in QoL questionnaires. 17 patients completed all forms. The drop out of 12 patients was due to re-admission ICU (2), transfer to another hospital (1), delirium on ICU (1), death (1) and forgetfulness (7). Of the 17 patients 8 are male and 9 are female. The average age is 54.4 year (range 34–73 years).

The QoL was measured with the EORTC QLQ-C30 questionnaire in a time span of 2 months: 1 day before, 2 weeks and 2 months after surgery.

The surgery induced factors were divided in length of admission (long term ≥16 days, 8 patients and short term <16 days, 9 patients) and in complications after surgery (relaparotomy, fistulas and disturbed wound healing; uncomplicated 10 and complicated 7 patients).

Results: The overall experienced QoL of all 17 patients showed a decline 2 weeks after surgery but increased to 68% of the baseline measurement 2 months after procedure.

The effect of the length of admission was not significant different in both groups. Also there was no significant difference when measuring the effect of complications on the experienced QoL.

Discussion: In this study we did not find a significant difference in QoL between complicated/not complicated patients and short/long term hospital admission. There are a number of draw backs in this study. The most important is the inability of sick patients to fill in forms; this is most clear in ICU patients. Because of the lack of validated tests of QoL for ICU patients, no answers could be given for this first period after treatment. Subsequently a critical reconsideration of assessment time is necessary. The small number of patients is also an important draw back.

Conclusions: Though patients experience a decrease in quality of life after surgery, this recovers during time. This empiric knowledge can be used in the information that patients receive (e.g. of nurses) before and during hospital admission.

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POSTER

Difficulties of access of an holistic care program for oncology patients in the Milan territory, Italy, a non profit association experience: Guida ONLUS

D. Anelli¹, M. Bottoni², R. Di Credico³, D. Lichosik⁴. ¹L'IPERBOLE/GUIDA ONLUS, Roma, Italy; ²L'IPERBOLE/GUIDA ONLUS, Roma, Italy; ³GUIDA ONLUS, Milano, Italy; ⁴AIAO, Milano, Italy

Background: The Milan, Lombardy, Italy area has been shown important difficulties for a family with one of its members suffering from an oncological disease to orientate and find information about social and sanitary services either public or private available in the territory.

Material and Methods: Retrospective analysis of the activity of a non profit association Guida ONLUS, that shares information and attend to the orientation of the sick person and their family towards social and sanitary services public and private existing in the territory of the Milan area in the past five years. Analysis of the requests presented by the families and by the patients to face the oncological pathologies.

Results: The data we have demonstrates that the families cannot find an unique interlocutor that can guide them towards the most suitable services for their needs this situation requires from the families huge commitment in terms of physical and mental energy as well as economical resources to locate, understand and access the care services available than can better satisfy their eminent and future needs. The accessibility of the information does not use telematic channels and has temporary limited windows of access that reduce the knowledge and accessibility of the service itself and as a consequence does not satisfy the needs of the family.

Conclusion: We think that is necessary to create a unique reference centre that is able to guide every single family towards the most suitable social or sanitary service available in order to deal, in an holistic way, with the needs of care during all of the oncological illness phases of one of its members.

References

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Poster presentations

Managing cancer services

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POSTER

Involving people of diverse ethnicities in cancer research: an exploration of experiences, attitudes and barriers

I. Okamoto¹, D. Wright², Y. Gunaratnam³, P. Cotterell¹, C. Foster¹.

¹University of Southampton, School of Health Sciences, Southampton – Hants, United Kingdom; ²Macmillan Cancer Support, Research Manager, London, United Kingdom; ³Goldsmiths College University of London, Department of Sociology, London, United Kingdom

Background: Patients from minority ethnic groups are under-represented in cancer research, resulting in services and therapies that may be inappropriate or unable to meet their needs. This UK study aims to identify research experiences of cancer patients from minority ethnic groups; barriers to their involvement in research; and experiences and strategies of research nurses seeking to involve minority ethnic groups.

Material and Methods: Semi-structured and narrative interviews were conducted with 22 adult cancer patients and 8 research nurses. Patients were purposively sampled by ethnicities (South Asian, Chinese, Black African/Black Caribbean), languages (Hindi, Gujarati, Urdu, Punjabi, Cantonese, Mandarin, English), research experience and gender. The data were analysed using thematic analysis.

Results: Patients who had participated in cancer research in the past generally showed positive attitudes towards their experiences. They were also happy to take part in future research due principally to access to treatment and altruism. For those who had decided not to take part in research previously, the timing of recruitment, the risk of participating in research, and the type of research were factors which affected their decision-making. Patients and nurses identified the following potential barriers to involving minority ethnic patients in cancer research.

1. General concerns about participating in research
2. Demands of participation
3. Language and communication
4. Patients' different understanding of cancer and research
5. Influence of family and community

6. Nurses' limited understanding of different cultures
7. Recruitment system and lack of facilities to accommodate minority ethnic patients.

Patients' and nurses' suggestions for strategies to improve recruitment of minority ethnic groups to cancer research were grouped into four themes:

1. Improve communication between patients and nurses
2. Improve patients' understanding of cancer and research
3. Improve nurses' understanding of different cultures
4. Improve recruitment system and facilities.

Conclusion: Factors related to patients, nurses, and services were identified as barriers to research participation and recruitment. Recommendations include providing cultural awareness training for nurses, and more time and space for nurses to establish trust with patients and their families, more effective interpreter services, translated materials, patients' education, and support for patients to share cancer experience with others.

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POSTER

Developing information for patients – working together

B. Zoppi¹, C. Annoni¹, L. Orlando², S. Liptrott², E. Cocorocchio², F. Gigli², G. Magon³. ¹Istituto Europeo di Oncologia, Out-Patient Department, Milan, Italy; ²Istituto Europeo di Oncologia, Division of Clinical Haemato-Oncology, Milan, Italy; ³Istituto Europeo di Oncologia, Department, Milan, Italy

Background: Bone marrow (BM) biopsy and aspiration are invasive procedures often performed in haematology patients (pts). Our outpatient team was aware of the complexity of the pathway for pts undergoing the procedure, in terms of administration, personal preparation, what to expect, potential complications and support available. The team wanted to know pts views of the information received about the procedure and ways it could be improved.

Material and Methods: A questionnaire was given to 20 pts either undergoing or having undergone the procedure. It looked at verbal information currently provided regarding the procedures. Results were analyzed; a thorough literature and peer review was undertaken and an information booklet was produced. This was evaluated by another group of 20 pts assessing its utility and suggestions for further improvements.

Results: In the initial questionnaire assessing information needs, 60% pts didn't feel adequately informed about risks/complications of the procedure. Over half (55%) said they were informed about the consequences of not undergoing the procedure and its use in the future management of their condition (65%). 13 pts weren't adequately informed about alternative options. 11 pts said they were aware of the general nature of the procedure, and 10 pts were aware of the technical detail of the procedure. 11 pts (69%) said they preferred written information to complement the verbal information provided. On this basis, an 8-page booklet was devised to cover the procedure and the aspects highlighted in the initial questionnaire. We evaluated perceptions of 20 pts of the booklet. All 20 respondents had read the booklet. Overall feedback was positive. All respondents reported that the booklet was the correct length, easy to read, and the majority said the print size was correct (95%, n = 19). 90% (n = 18) said they felt all arguments had been covered. 2 pts suggested that hematoma and bleeding should have been covered and it was unclear whether they would be 'unwell'.

Conclusion: We worked with patients to identify their information needs regarding an invasive procedure. From the analysis of the questionnaires in the first stage, we developed a booklet that was successfully implemented and we observed a very positive feedback. Further areas such as pain and detail regarding potential for bleeding need to be developed. This method of developing patient information could be applied to other clinical areas and procedures.

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POSTER

Development and daily use of a nurses electronic diary form, for hospitalized patients

M. Campregher¹, S. Lazzeri¹, E. Modena¹, F. Valduga¹, E. Galligioni¹. ¹Santa Chiara Hospital, Medical Oncology, Trento, Italy

Background: Since June 2000 we have developed and adopted in our Department an Electronic Oncological Patient Record (EOPR), for the total management of cancer patients (Ann. Oncol; 20, 2, 2009). The electronic management of hospitalized patients however, represents a great informatics challenge, because of the multiple hospital days, the number of laboratory and instrumental test, the management of evolving clinical conditions and corresponding therapies, the various professionals involved, who even change on duties.

Material and Methods: We have developed a specific nurses diary form for hospitalized patients, based on a users centred design. Once developed,

the prototype was long refined by a small task group, through a continuous interactive-iterative feedback process, to optimize the system architecture and users interface. An educational session was then provided to all users, to clarify structure and functions, followed by a training of new activities in small groups.

Results: The nurses diary form was strictly integrated with the doctors diaries and the unified therapy form, where any single patient prescription and timing of drug administration are reported, and the name of prescribing doctors and administering nurses are traced. Moreover, a synthetic and updated summary of the patient course was provided, with significant clinical events, relevant tests, decisions and therapies, automatically extracted from the detailed forms. This summary resulted particularly useful for the équipe duty reports and for home prescriptions and recommendations, at patient discharge. After 2 months of daily use, a specific questionnaire administered to the majority of nurses, revealed high levels of nurses satisfaction (10/15) and the new informatics tool was considered complete (14/15), facilitating data retrieval (13/15) and well integrated in the EOPR (13/15), but at the cost of additional work 13/15.

Conclusions: An electronic nurses diary form, may be successfully developed for hospitalized patients and integrated in an EOPR. Its acceptance by the équipe however, largely depends by the users-centred design, the proper education and the training provided.

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POSTER

Caregivers' needs in oncology: information, information, information!

R. Berardi¹, W. Bacelli², M. Scarozzi³, R.R. Silva⁴, E.T. Menichetti⁵, G. Rossi⁶, M. Marcellini⁵, M. Duca¹, K. Marilungo², S. Cascinu⁷.

¹Università Politecnica Marche-Ospedali Riuniti An, Clinica di Oncologia Medica, Ancona, Italy; ²Ancona, Ancona, Ancona, Italy; ³Ospedali Riuniti, Clinica di Oncologia Medica, Ancona, Italy; ⁴Ospedale Profili, Oncologia Medica, Fabriano, Italy; ⁵Ospedale Civile, Oncologia Medica, Senigallia, Italy; ⁶Ospedale Civile, Oncologia Medica, Jesi, Italy; ⁷Università Politecnica delle Marche, Clinica di Oncologia Medica, Ancona, Italy

Background: Cancer is not only an individual problem, but it affects the entire family, in particular the patient's caregivers. Involvement of family caregivers is essential for optimal treatment of cancer patients in ensuring treatment compliance, continuity of care, and social support.

Based upon scientific research, the present study is aimed at focusing attention to caregivers trying to provide an understanding their unmet needs, in order to plan interventions for providing them support.

Patients and Methods: In the first step of the study a survey focusing on the main needs was designed.

Among the others, the explored needs were: medical and nursing information, psychological support, social welfare. The items also investigated the details of the caregiver (age, sex, degree of kinship, knowledge of the type and stage of cancer of the patient...). The surveys were distributed to the caregivers of all the consecutive cancer patients coming in one specified week to the Day Hospital of all the four Dept of Oncology (Ancona, Fabriano, Jesi, Senigallia) in our Province. At the same time, the medical oncologist completed a questionnaire reporting the personal and clinical information of the patient.

Results: 137 caregivers answered to the survey. Median age of the patients was 65 years (range 30–87), while median age of the caregivers was 59 years (range 21–78), M/F ratio was 71/66 for the patients and 46/91 for the caregivers. In 64% of cases, the partner was the accompanying person.

Among the medical needs, the most reported was having a medical and nursing assistance during the nights and the weekends. The need of having any one referential medical oncologist was also reported as important.

Among all the explored needs, the most reported was receiving a human, correct, simple and full information regarding the disease, the therapeutic options (in particular in the place of residence) and prognosis.

Conclusions: The present study showed that the need of an exhaustive and simple information is still unmet in the internet age. On the basis of this results, we decided to improve the information given to the patients with an ongoing project which includes a web site as well as booklets dedicated to the patients living in our region and periodical meetings with the patients and their caregivers.