



EONS

eons newsletter

The Quarterly Newsletter of the European Oncology Nursing Society

Summer 2004

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The goal of the EONS Newsletter is to inform nurses about EONS and its activities and to provide a forum for cancer nurses throughout Europe to network. The information published in the EONS Newsletter is intended to inspire nurses to improve the care of the cancer patient through improved knowledge.

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Letter from the Editor

Welcome the Summer issue of the EONS Newsletter!

The theme for this issue is quality of life, a topic that was in focus for the EONS Spring convention held in Edinburgh in April of this year. Quality of life (QOL) is a well established concept within cancer care. It is an important domain in cancer nursing and an essential factor to be considered when delivering quality care to the cancer patient. In clinical trials, QOL data are useful for determining whether changes in QOL from baseline are related to a specific treatment or intervention. Most recently, ethics committees and grant giving bodies require that the area of QOL is included in research protocols. QOL is an outcome indicator that is multidimensional and theoretically incorporates all aspects of an individual's life. Most quality of life definitions are based on the World Health Organisation's definition of health as not only the absence of disease or infirmity, but also a positive state of physical, mental and social well being (WHO 1993). Quality of life is dependent upon the interpretation and perception of the individual. When defining quality of life as it applies to health care, the term "health-related" is commonly used to focus on the effects of illness or treatment on quality of life and to distinguish these from aspects beyond the realm of health care. It has been established that cancer-related symptoms correlate to a patient's QOL and, more specifically, physical symptoms as a consequence of cancer therapy clearly influence the experience of QOL. Symptoms are multiplicative in nature and may act as a catalyst for the occurrence of other symptoms. The consequences may include an impact on mood state, psychological status, disease progression, survival, functional status and quality of life. Nurses and other health-care professionals need to identify cancer patients at risk for poor adjustment during periods of illness and/or treatment due to cancer. Further, we need to learn more about how to use the concept of quality of life as an outcome parameter in clinical practice. There currently exists an increasing interest in the use of QOL assessments in daily clinical practice, yet few empirical studies have been conducted to evaluate the usefulness of such assessments. The use of QOL assessment in clinical practice may stimulate healthcare professionals to become more aware of and to inquire more deeply into specific aspects of the health and well-being of their patients. Some studies have found that incorporating standardized QOL assessments in daily clinical practice facilitates the discussion of QOL issues and can heighten the health care professional's awareness of their patients' QOL (e.g. Detmar et al 2002). This brief introduction into quality of life in cancer care was meant to stimulate your interest in the subject – learn more about the intriguing concept of quality of life in this issue of the EONS Newsletter. For those of you who want to learn even more, please have a look at the list of references for additional suggested reading. Also in this issue is an interview with our colleagues from Iceland and an update on one of the latest EONS projects, TITAN.

On behalf on the Editorial Board I would like to wish you all a wonderful summer!

Karin Ahlberg

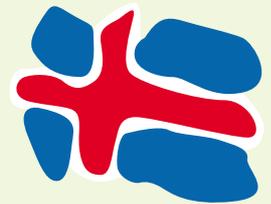
An important new step in knowledge dissemination for EONS:

Report on the 1st Novice Cancer Research Workshop

The first Novice Cancer Research Workshop was held in conjunction with the 4th EONS Spring Convention, which took place in Edinburgh, Scotland in April. The five brave participants came from Switzerland, UK, Portugal, Spain and the Check Republic. Faculty for the event consisted of five doctoral prepared nurse researchers also representing various European countries. The goal of the workshop was to promote and develop possibilities for research discussions and to exchange knowledge and experiences between European cancer nurses and researchers. Prior to the workshop, each participant submitted a draft research proposal that was reviewed by the faculty and discussed with feedback during the day. Each participant gave a short presentation of their proposal as one of the learning outcomes was to provide workshop participants with the opportunity to practice presenting papers in English. In the afternoon, two introductory lectures were given on theoretical and practical issues concerning the quantitative and qualitative approach to research. A panel discussion on how to develop research skills provided participants with practical advice. Both faculty and participants enjoyed lively discussions on creative ideas and exchange of experiences that enhanced the learning effect of the presented material. The workshop concluded with an evaluation of the experience. For all who participated this was hopefully a great experience and an important step in new ways to support knowledge exchange, development and networking for nurses involved in cancer care in Europe!



Our colleagues from... Iceland



The Icelandic Oncology Nursing Society counts about 140 members from all parts of the country, and even Icelandic cancer nurses living abroad. Our goals are to promote prevention of cancer and increase the quality of nursing care given to cancer patients. The society was founded in 1996 with the support of Kathy Redmond, former EONS president.

What are your objectives?

- To provide consultation to the board and committees of The Icelandic nurses' association on issues pertaining nursing care of cancer patients and their families.
- To influence government policies regarding prioritizing in healthcare and to guard the interests of cancer patients.
- Promote education to cancer patients and their families about spiritual, physical and social reactions to cancer and cancer treatment and the most appropriate responses to them.
- Promote cancer nursing education and encourage cancer nurses to seek further education Encourage collaboration between cancer nurses, both in Iceland and between countries.
- Promote and encourage collaboration between health care workers to ensure continuum in the care of cancer patients and their families.
- Encourage nursing research and the utilization of research findings in cancer nursing care.
- Encourage collaboration with cancer institutes and cancer foundations.

How is your society structured?

The society has a board of seven individuals, president, a president elect, a treasurer, a secretary and three other board members. The board members are elected at our general meeting, which is held in February each year. All members of the society who have paid their dues may be elected. Each board member sits for the minimum of two years, but may sit for four years. The president elect/president automatically sits for four years. We have a small fund for grants, and three members (one of whom must be a board member) of the society are in charge of going through applications and awarding the grants. Each year, right after the general meeting, we elect a committee to prepare a seminar in the fall. The committee is put together of 4-6 society members who have some interest or expertise in the subject chosen for the seminar. Each year is dedicated to a specific theme; this year's theme will be 'The oncology nurse and their work environment'. Other themes we have had are: Prevention (1997), Palliative Care (1998), Cancer Chemotherapy (1999), Building nurses' self esteem (2000), Cancer Radiotherapy (2001), Complementary therapies (2002), and Cancer Patients and their families (2003). Each year the preparation committees have tried to include views from the patients themselves.

Are you working together with other international or national organizations?

As well as being members of EONS, the society is also a member of ISNCC and both newsletters are sent to all society members. We keep contact with the other Scandinavian oncology nursing societies and two of our board members will be attending a conference in Stockholm later this April. A few of our members are individual members in ONS and EBMT, but no formal contact is between our society and those.

What are the benefits for your members?

Of course all members receive the EONS newsletter, as well as the ISNCC newsletters and we try to write two newsletters a year, one in the spring and one after the seminar in fall. Members have the option of a reduced fee to our seminars and to ECCO and the EONS conference.



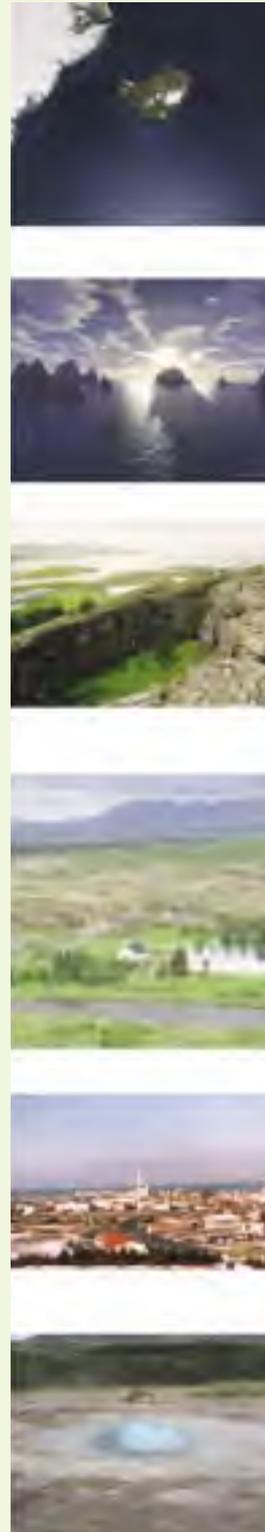
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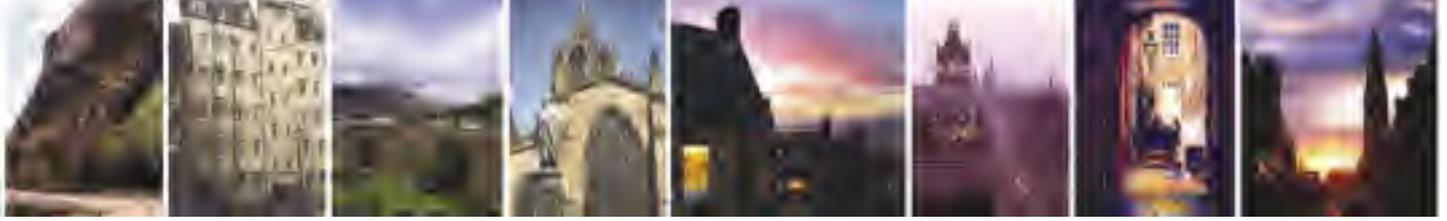
Your relationship with EONS?

A member of our board sits on the advisory counsel of EONS, and we try to take active part in any meetings of EONS. The society pays for the advisory council member to attend EONS meetings, and we took part in the strategy meeting last March in Brussels. We feel that it is important for such a small society to be part of the overall European Oncology Nursing Society, to receive news of what is happening elsewhere in Europe and hopefully EONS will consider having their conference in Iceland one year.

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Highlights from the 4th EONS Spring Convention:

With the wavering steps of toddler hood behind us, and using the knowledge and experiences (sometimes painfully) gained through adolescence, EONS has successfully reached early adulthood. This developmental achievement was evident by the sophistication and excellent quality of the 4th EONS Spring Convention held in Edinburgh from 15-17 April. Starting with an inspiring welcome lecture by Malcolm Chisholm, Scottish Minister of Health, and ending with a panel discussion highlighting the nursing contribution to quality cancer care as viewed by EONS Past-presidents, the conference content reflected state-of-the-art information on quality of life presented by lecturers who demonstrated not only expert knowledge, but expert presentation skills as well.

Seldom does a politician exhibit knowledge and support of nursing practice as did Minister Chisholm in his presentation. After relaying good news on decreasing cancer death rates in Scotland, he went on to describe the results of studies focused on aspects of living with cancer from the perspective of patients and care-givers conducted in Scotland. Among other recommendations, the study indicates a need to increase the number of specialists in cancer care. Mr. Chisholm is a strong supporter of specialisation in cancer nursing and to underline his support he approved the establishment of a cancer nursing framework aimed at shaping and defining nursing services delivered to cancer patients. As further evidence of the Minister's interest in and support of cancer nursing, Prof. Nora Kearney of the University of Stirling has received 2.7 million Euro to conduct a national study exploring cancer patient experience and trends in morbidity as a basis for planning the nursing workforce. This is the largest grant sum ever awarded to a nurse researcher in Scotland.

An introduction to defining analysing and interpreting aspects of quality of life was provided by two experts Kristin Bjordal (a medical oncologist from Norway) and Andrew Bottomley (EORTC Data Centre, Quality of Life Unit, Belgium). Both researchers compared and contrasted the benefits and usefulness of measuring quality of life (QL) in cancer patients. Dr. Bjordal advised using existing proven tools in their entirety (rather than abbreviated versions to decrease time required for completion) and to be alert to culture sensitive items when translating questionnaires. The EORTC QLQ-C30, the



Malcolm Chisholm, Scottish Minister of Health

FACT-G and the Rotterdam Symptom Checklist were cited as good examples of instruments which can be used to evaluate quality of life specific to cancer patients.

Both speakers were critical in their discussion on how, when and why QL should be measured in cancer patients. While Dr. Bjordal provided several reasons why health-related quality of life (HRQL) should be measured in cancer patients, Dr. Bottomley noted that the dramatic rise in the number of published studies (400 in 1990 as compared to 1600 in 2002) has not, in his opinion, significantly impacted on clinical practice. It is important to remember when reading and utilising HRQL study results, that questionnaires measure a particular person's (e.g.- patient's) quality of life at a particular point in time during a particular research study. Study results can and should be used to alert clinicians to actual and potential patient problems and are therefore of benefit for other patients. Future research directed at tool design, methodology, and appropriate timing for measuring QL will yield more applicable results.



During the afternoon session which focused on the value and usefulness of measuring HRQL, Alex Molassiotis pointed out that compliance is high among patients completing QL questionnaires and patients who participate in studies feel otherwise overlooked problems are being given attention. Despite progress in developing tools sensitive to measuring QL, numerous issues remain unresolved. For example, most QL questionnaires are generic and don't take gender differences into account, stated Sara Faithfull. Factors contributing to an individuals' definition of QL are different for men than women; this is especially evident in information-seeking behaviours where females actively seek help and health-related information and males tend to rely on information provided by family and peers. This argument was supported by results of a study conducted by McCaughan that investigated information seeking behaviour of newly diagnosed males. In her study, Ms. McCaughan found that the care and needs of men with cancer seems to be misunderstood and neglected and although they have unmet needs, men are reluctant to seek information on their disease or treatment.

Tone Rustøen provided a presentation on the relationship between hope and quality of life. She noted that although numerous studies have identified the positive aspects that a strong sense of hope provides patients in times of crisis and loss, it is unclear how feelings of hope contribute to quality of life. One assumption to explain the relationship may be that a positive outlook focusing on future possibilities contributes to a general feeling of well-being. She recommended that health care professionals increase hope in patients by taking the time to talk with them and by providing honest and truthful information.

Workshop sessions at the 4th Spring Convention were clinically-focused and targeted to meet the learning needs of the novice or advanced practitioner. In general, the workshop coordinators did an



Celebrating the 20th Anniversary of EONS

extraordinary job in preparing the content for their sessions. The number of attendees at the various workshops sometimes exceeded the seating capacity of the room. Space does not permit a summary of all 8 workshops presented over the two-day conference.

The recognition of outstanding achievements in cancer nursing was again a part of this year's convention. K. Petsios, et al, (Greece) received an award for their outstanding poster entitled "How children with cancer view their relationship with their nurses: a pilot study". Karin Bergkvist (Sweden), Theresa Wiseman (UK), and Alexander Molassiotis (UK) were presented with EONS-Roche Research Awards at a ceremony sponsored by Roche on Thursday evening. Pentelis Perdikaris (Greece) was the recipient of this year's EONS Young Researchers Award. A summary of the content of his research study, entitled "Cancer related fatigue in children and adolescents with cancer", will be published in a future issue of the Newsletter.

A highlight of conference was the concluding session which celebrated EONS' 20th anniversary. A chronology of the events leading to the establishment of EONS (presented by Past-president Liz Holter) and a history of the development of the now well-recognised EONS Core Curriculum (presented by Past-president Hansruedi Stoll) provided newcomers to EONS with a historical background of the Society and its most important activities. Past-presidents Kathy Redmond and Nora Kearney used their knowledge of politics and health care systems to emphasize the impact cancer

has on each of these areas and to encourage nurses to become more involved in the larger cancer picture. It is of little doubt that members of EONS can be proud of the achievements the Society has attained in the short span of 20 years. Past-president Agnes Glaus highlighted some of these achievements and both she and Past-president Giel Vaessen provided insight on how individual involvement can be of benefit in advancing cancer nursing at all levels.

The 4th Spring Convention was successful in furthering knowledge of cancer care. There is little doubt that measuring quality of life provides valuable and useful information on the cancer experience. Although the interpretation of past study results into practical interventions is of benefit to current patients, there is work to be done in further refining measurement tools to improve validity and reliability which in turn will increase acceptance into practice. A review of the accomplishments EONS has achieved in 20 short years is rather astonishing. The idea put forward by a handful of people to create an organisation representing cancer nurses in Europe has grown into a professional society with a healthy working budget, aspiring goals and an ever-broadening base of actively contributing members. Hopefully, inspired by the successes of EONS, nurses in the individual Member States of the EU will strive to achieve their goals in moving cancer nursing care forward. The future of cancer nursing looks bright. What will we achieve in the next 20 years?

Quality of Life at the web

Surfing the internet I visited Shawn Griffith's Web Site at <http://www.a1networks.com/shawn/> While reading through the personal report by Shawns' parents I looked for examples of QoL and also found humour!

March 15th 2003: Shawn's spirits and energy are great. He stayed up late the last two nights with his nurses. He has been asking for an exercise bike but somebody must've rode off with it! He's been playing soccer for a couple hours a day - on his laptop! As you can see by the picture soccer is a physical sport and they started Gatorade by IV (just kidding)! The chemo and orange Gatorade are close enough in colour I could make this place go ballistic by pouring some Gatorade on the floor beneath his chemo bag! The Hazardous Material Team and the evacuated patients wouldn't think it was very funny!



The thought of a practical joke

QoL:

Being able to enjoy



A fast food meal at your friends' anniversary



A good sleep when tired



Watching the super bowl with your family



Playing computer games while admitted to the hospital

TITAN launches with pilot programmes in Ireland

Why develop a major new education initiative?

A little more than one year ago now, an EONS expert nursing panel met with Amgen (Europe) GmbH to discuss the impact of haematological toxicities on cancer care. It was clear that a priority should be given to raising the awareness of haematological toxicities such as thrombocytopenia, anaemia and neutropenia, through education, and to explore the availability of risk assessment tools to help in their prevention and early detection. These priorities matched well with EONS' vision of quality cancer care and excellence in cancer nursing practice.

EONS was aware that the US Oncology Nursing Society (ONS) had developed and implemented a programme dedicated to haematological toxicities called ATAQ (Appropriate Treatment Assures Quality), and in May 2003, we met with leaders of the ATAQ initiative at the ONS Congress in Denver. The aim was to learn more about the ATAQ programme and to investigate its suitability for European audiences. As a result of this initial meeting, the Training Initiative in Thrombocytopenia, Anaemia and Neutropenia (TITAN) was born and a Working Group was established to oversee the project's implementation. Nursing practice varies between the US and Europe, and so the Working Group decided to base the development of the TITAN programme on a study of nurses' learning needs in relation to haematological toxicities, as well as an expert evaluation of elements of the ATAQ programme. The Working Group commissioned a learning needs assessment of European oncology nurses, which sought to identify current knowledge about haematological toxicities, and those specific aspects of these toxicities about which nurses were interested in learning more. In parallel, ten European oncology nursing experts participated in the ONS national conference on haematological toxicities in Dallas (October 2003) with the aim of assessing the different components of the ATAQ programme. By November 2003, the Working Group had a clearer understanding of the learning needs for European nursing audiences, which provided guidance for the development of our TITAN education programme, based on an agreed core curriculum and programme structure. In March 2004, EONS, in collaboration with IANO (Irish Association for Nurses in Oncology), ran the first pilot TITAN course in Ireland, and one month later, at the EONS 4th Spring Convention in Edinburgh, I was pleased to launch TITAN with friends and colleagues from Europe, Australia and the US. The launch event generated a great deal of interest and several requests to run TITAN in different countries have already been received.

What does TITAN aim to do?

The overall goal of TITAN is to improve the prevention, detection and management of haematological toxicities in patients with cancer, thereby helping to reduce the incidence of these serious complications, minimise their negative impact on quality of life and maximise beneficial outcomes for the patient.

TITAN programme objectives are to:

- provide an update on the impact of haematological toxicities on clinical outcomes and quality of life in patients with cancer
- help to characterise those cancer patients at risk of haematological toxicities
- review the evidence underpinning the assessment, management and evaluation of haematological toxicities
- update participants on innovative and evidence-based methods for educating patients, their families and other nurses about complications associated with cancer treatments
- encourage participants to actively disseminate the knowledge gained.

What are the needs and desires of European oncology nurses?

The learning needs assessment consisted of a 73-item (multiple-choice and true/false) questionnaire completed by participants at ECCO 12 and members of some national nursing societies between September and December 2003. In all, 455 respondents were involved from 22 countries, with varying experience in a range of oncology settings. The results suggested that there is a good baseline understanding of haematological toxicities amongst European nurses, although knowledge of more specific areas appears to differ by country, and to be somewhat lacking in parts. However, nurses are willing to develop their knowledge and would welcome more responsibility for the education of patients. At present, most nurses are involved in neutropenia and anaemia patient education, with a smaller number also being involved in their detection, risk-assessment and management. Although nurses throughout Europe suffer from a lack of funding for continuing professional education (CPE), and in some cases, a lack of support in terms of paid study leave, it is clear that those who undertake more CPE make a greater contribution in their workplace. These results confirmed our opinion that European nurses would greatly benefit from, and be motivated to undertake, a comprehensive haematological toxicities training programme. However, it was interesting to note that on a country-by-country basis there is considerable inconsistency in the approaches to patient education and management – as such, we appreciate that TITAN needs to be aware of these variations to ensure that the course is relevant and informative to all countries wishing to implement the programme.

How are we piloting TITAN?

The programme has been developed to meet the agreed core curriculum and comprises:

- a pre-course revision pack
- an attended course
- a dissemination project.

The pre-course revision booklet aims to ensure that all participants have at least the basic level of background knowledge on haematological toxicities to fully contribute to, and gain from, the attended course. The main learning element of TITAN is the short course that is delivered through a mixture of presentations,

case studies, discussion sessions and an element of informal testing to reinforce learning. Patient and family education is integral to successful management of haematological toxicities, and the course includes a dedicated session that explores the principles, strategies and innovative resource materials that can be employed to optimise the educational process.

Perhaps a key element that sets this programme apart from others is the requirement for all participants to undertake a dissemination project in the six-month period following the course. The project can be undertaken individually or in groups. This is a very valuable asset, as it allows the programme to extend its reach by encouraging the participants to impart some element of the TITAN curriculum to colleagues (for example via a lunchtime presentation or study day), or patients (for example by developing patient education leaflets) in a format of the participants' choice. In addition, the project will serve to consolidate the participants' own knowledge.



Figure 1: Participants at the Dublin pilot course



The Irish pilot

TITAN's first pilot was held in Dublin in March of this year. It was a great success, which is in no small part due to the excellent organisational efforts of the Irish Association for Nurses in Oncology (IANO), to whom we are very grateful. The majority of the 32 participants were experienced oncology nurses. Such experience equipped them well to critically appraise the course structure and content, which provided us with an excellent insight into what was required from TITAN.

The course was met with great enthusiasm – nurses acknowledged a need for such an initiative, and demonstrated both interest and clear motivation to learn more and share their experiences with others. Participant evaluation forms revealed largely very positive feedback. It was regarded as well organised, well structured and relevant and it was felt to meet its objectives to a large degree. The materials associated with the programme (pre-course revision, course materials and audio-visual aids) were exclusively rated as good or very good. However, some participants felt that the day was too intensive, and that more time could be allocated for group discussion and case studies.

Irish pilot – feedback

- “Overall TITAN was a very valuable, well-structured programme.”
- “The quality of the presentations was excellent.”
- “The information provided was mainly very relevant.”
- “The presentations were pitched at the right level, although possibly a little basic for more experienced participants.”
- “The attended course was too intensive for one day.”
- “More time should be allocated for asking questions, general discussion, practical exercises and case studies.”

Participants identified a number of potential dissemination projects during the course, including projects targeted at family doctors and community nurses to help them to recognise chemotherapy-related symptoms, as well as developing patient materials. The dissemination plan forms were submitted as anticipated, and dissemination projects are currently underway. The best dissemination projects from the pilot schemes will be showcased at the ECCO 13 conference in Paris in 2005.

The French pilot

A second pilot was carried out in Paris, in June, in liaison with the Association Française des Infirmier(e)s de Cancérologie (AFIC). It followed the same structure as that described above, using translated pilot materials modified according to the Irish feedback, and in line with French nursing practice and culture. Forty oncology nurses attended the French pilot, which, this time, was run over two half-days. As with the Irish pilot, there was a high level of interest in the course and initial feedback about the content and overall structure has again been very positive.



Figure 2: Participants at the Paris pilot course

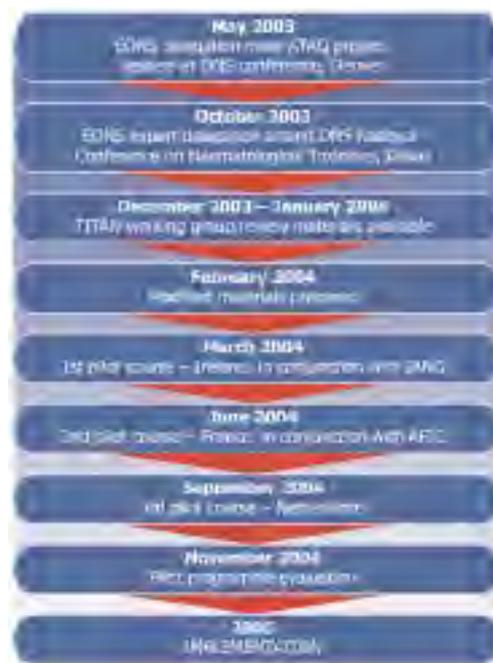


Figure 3: TITAN implementation timetable.

When will TITAN be implemented?

With the Irish and French pilots successfully completed, another will take place in The Netherlands. We hope to fit in at least one other pilot but certainly expect Europe-wide implementation in 2005. The extremely positive feedback from the pilot courses reinforces the position that TITAN will have in helping to improve the quality/quantity of life for the patient and strengthening the role that oncology nurses have to play in that.

Feedback from all the pilot courses will be integral to the final TITAN curriculum and core TITAN materials. We will then be able to liaise with those who have already expressed an interest in TITAN – of which there are already several parties – and follow up with national oncology societies to initiate the local roll-out of TITAN in 2005. We will also provide guidelines to facilitate the organisation of TITAN courses, to ensure a level of consistency between them, while still allowing for country-specific tailoring. Initially courses will be available in English, French, Dutch, German, Italian and Spanish. It is clear that nurses have the potential to play a vital role in the care of patients with cancer-related haematological toxicities. TITAN aims to harness this potential and maximise nurses' contributions to such healthcare issues by providing an innovative educational programme that has been made possible by an unrestricted educational grant from Amgen (Europe) GmbH.

Useful links to education resources available via the web:

1. http://www.oesweb.com/print_all.asp
Provides access to a range of publications on haematological toxicities, including:
 - Oncology Supportive Care Quarterly, focused on nursing issues in the care of oncology patients
 - Rethinking Platelet Growth Factors
 - Discovering the Options: Hematopoietic Growth Factors and the Oncology Patient
 - Totally New...Totally Clinical: Interactive Case Studies on Nursing Management of Cancer-related Anemia and Neutropenia.
2. <http://www.cancersource.com/tsl>
Are oncology nurses the strongest link?
3. <http://cancersourcern.com/nursing/ce>
Provides access to a range of continuing education courses on haematologic toxicities.
4. <http://www.pfizerhealthliteracy.com>
Provides information on health literacy and preparing materials that comply with health literacy guidelines.

The Cancer Patient and Quality of Life

Andrew Bottomley

European Organisation for Research and Treatment of Cancer (EORTC) Data Center, Brussels, Belgium

(The following is a synopsis of an article which was published in *The Oncologist* 2002; 7:120-125. Gratitude is extended to the Editor of *The Oncologist* and Andrew Bottomley for permission to use parts of the original article for publication in the EONS Newsletter.)

Increasingly, researchers are faced with situations where patients may not gain benefits in terms of traditional end points, such as survival or disease-free survival. It may, however, be possible to see significant changes in health-related quality of life (HRQOL). HRQOL, a multidimensional construct and an important concept, has proven difficult to define.

Generally, HRQOL covers the subjective perceptions of the positive and negative aspects of cancer patients' symptoms, including physical, emotional, social, and cognitive functions and, importantly, disease symptoms and side effects of treatments. As recently as 20 years ago, there was little available literature on quality-of-life benefits; increasingly more randomized cancer clinical trials include HRQOL as the main end point.

Measuring HRQOL is a difficult task. HRQOL is subjective and many of the components, such as social functioning and spirituality, cannot be directly observed. When measuring quality of life, it is important to focus very clearly on specific domains important to cancer patients. Additionally, using single unidimensional measures, such as the Karnofsky Performance Status (KPS) measure, may not be sensitive enough to detect subtle changes in patient HRQOL improvement. Using a combination of instruments that measure various HRQOL domains may provide more information on how quality of life is influenced by disease and treatment.

Collecting HRQOL data in a clinical trial can be challenging. It requires resources and a survey in the patients' own language. Important data may be difficult to obtain if the patient's performance status declines. Approaches used to increase compliance in completing HRQOL assessments have been the development of comprehensive education programs prior to and during clinical trials and the inclusion of baseline questionnaires as part of the eligibility checklist. Pre-trial workshops aimed at training nurses and data managers in collecting HRQOL may also yield more valuable results.

In summary, increasing numbers of studies with quality-of-life outcome assessment as either a secondary or a primary end point are appearing. It is becoming clear that HRQOL information may lead to improvements in the status of the individual cancer patient. While many challenges exist in this field, it is hoped that the future will provide more acceptance of HRQOL and a more universal understanding of the concepts of HRQOL.

Although regulatory agencies now recognise the benefits of HRQOL as a basis for approval of anticancer drugs, and international research groups include HRQOL in their studies, introducing HRQOL into oncology has been difficult. Two reasons for this are the subjective nature of the results of HRQOL studies and the barriers to acceptance by clinicians.

When questioned about HRQOL, 80% of 260 senior oncologists responded that HRQOL should be collected from patients; in practice, only 50% managed to do this citing limited time and



resources as barriers to collecting information. In another survey, 88% of 60 Canadian and U.S. oncologists noted that it was important to examine HRQOL although 33% felt that the current measurement tools were inadequate.

Common Definitions of Quality of Life

While quality of life is not easy to define, several authors have made attempts to define this subjective term.

The state of well being that is a composite of two components: the ability to perform everyday activities that reflect physical, psychological, and social well-being; and patient satisfaction with levels of functioning and control of the disease (Gotay CC, Korn EL, McCabe MS et al).

The subjective evaluation of the good and satisfactory character of life as a whole (van Knippenberg FC, de Haes JC).

The gap between the patient's expectations and achievements; the smaller the gap, the higher the quality of life (Calman KC).

Quality of life represents the functional effect of an illness and its consequent therapy upon the patient as perceived by the patient (Schipper H, Clinch J).

An individual's overall satisfaction with life and general sense of personal well-being (Schumacher M, Olschewski M, Schulgen G).

A patient's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (WHOQOL Group).

Quality of Life in Cancer Patients

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Introduction

In a study examining research priorities of Norwegian nurses who are members in the Norwegian Society of Nurses in Cancer Care, quality of life (QOL) was given the highest research priority 1. This finding is in line with similar international research findings. For example, a perusal of the research priorities of nurses in other countries revealed that QOL also is given high priority in Canadian, Dutch and American samples of nurses 2,3. This shows that nurses in cancer care value QOL, and its significance for cancer patients. At the same time, there is claimed to be a gap between an ever-increasing interest in research into QOL and the lack of impact this research has had into actual care 4. A recent survey from Norway, for example, showed that women with breast cancer still face the same problems and that more than 60% of the patients and their family reported that they had no access to support outside their circle of family and friends⁵. As one woman phrased the experience; "It was like being left alone in a black hole" Implementing meaningful QOL study results into practice is a challenge for the future. It is of great importance that the results of existing research be disseminated to health care workers. Another important issue is that future research is of clinical value, capturing what is of greatest significance for the cancer patient. This short presentation will focus on some areas emphasized by patients with cancer as being of relevance for their QOL. Definitions of some commonly used terms will be provided to help the reader better understand the topic.

Quality of life

There is no consensual definition of quality of life, but there is consensus that quality of life is a subjective phenomenon 6. QOL is and must be handled as a subjective phenomenon; the patient's own perspective is of great value. We know today that objective phenomena such as pain, nausea and vomiting influence quality of life in a negative way, but to what degree it affects QOL is individual 6. It is also a consensus that quality of life is a multidimensional phenomenon. Disagreement exists as to what domains should be emphasized in definitions of QOL. The domains specified vary to some degree from definition to definition.

One often cited definition of QOL in the nursing field is the one developed by Carol Ferrans and Marjorie Powers, first published in 1985 7. Ferrans' 6 defines QOL as:

«a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her». The authors state that QOL is comprised of four underlying domains: a health/functioning domain, a socio-economic domain, a psychological/spiritual domain and a family domain. Thus, quality of life is defined as a multidimensional construct covering all aspects of life.

Research has shown, and Ferrans and Powers also claim, that cancer can affect all of these domains.

Quality of life and cancer

Ferrans and Powers developed a questionnaire to measure QOL based on their definition 7. It consists of two different sections. One section measures satisfaction with the various domains. The other section measures the importance of each domain for the subject. Both the satisfaction and the importance sections contain 34 items. The items are scored on a six point Likert scale ranging from "very satisfied" to "very dissatisfied" for the satisfaction items, and from "very important" to "very unimportant" for the importance items. The QOL scores are the products of the satisfaction responses and the

importance responses. In this way, the QOL score reflect not only satisfaction with each domain, but also how much value or importance an individual places on this domain. This corrects for the influence of individual values. In a sample of 194 Norwegian cancer patients, the majority were women with breast cancer and living with someone, their QOL was highest in the family domain (mean score 20.93 SD 5.4) and in the socio-demographic domain (19.57 SD 4.6) and lowest in the psychological and spiritual domain (17.87 SD 5.40) and in the health and functioning domain (17.72 SD 4.79).

We also evaluated what was of greatest importance to the patients based on the importance section in the Ferrans and Powers Quality of Life Index. We found that family related matters were rated as of greatest importance: children highest, followed by family happiness and health. The emphasis and significance of family-related domains in quality of life must be considered seriously. Knowing that family is of such great importance to the patients underlines the significance of including them in the care of the patients. Looking at what was of least importance; faith in God was rated as being of least importance. Sample characteristics and culture can perhaps explain this. Having a reasonable amount of stress and worries was also reported to be of less importance. This may mean that some emotional distress was to be expected. Other items considered less important were sex life, personal appearance and neighborhood. Halldorsdottir and Hamrin⁸ performed a phenomenological study to explore the lived experience of having cancer, as perceived by people who have been diagnosed and treated for cancer. Data were collected through in-depth interviews with nine people who were in the remission or recovery phases of cancer. The overriding theme of the lived experience of having cancer was "experiencing existential changes." Five basic sub themes were identified in the participants accounts, all of which are part of the existential changes involved in the lived experience of having cancer. These sub themes were: uncertainty, vulnerability, isolation, discomfort, and redefinition.

Landmark and Wahl⁹ interviewed 10 women to find out how they experienced living with newly diagnosed breast cancer. Open-ended interviews were used. The analyses of the interviews showed that existential issues arose as an important aspect of living with newly diagnosed breast cancer. Results further indicated that when women's total existence is threatened, a tenacious attitude in the form of a willingness to live becomes mobilized. The 'will to live' emerged as the central theme. All energy was channeled into a tenacious fight for life. A common factor among the women in this study was that they appeared to activate unknown strength in their fight as supported by the following quotes from different interviews: "There is more between heaven and earth, something that is pulling the strings, so maybe that's why I keep holding on", "Something has happened to my concept of goodness and nearness, life has got new perspectives" and "You get unknown strength, you just decide to stand and face it". Landmark and Wahl 9 conclude that an understanding of how women experience their new and changed life situation is important to the support nurses give in the process of healing. Nurses need this knowledge to be better able to assist women and their families in their development of coping strategies.

Conclusion

From this short presentation of QOL research in the cancer field, family matters were identified as being of greatest importance and the patients had the highest QOL in this domain. The existential changes were stressed by the patients and their QOL was lower in this domain. The study results show that it is reasonable to emphasize the psychosocial and existential domains in QOL for cancer patients. The results of this QOL study have clinical implications for nurses.

Treatment of Cancer Treatment Induced Bone Loss: Results of a European Survey

Jan Foubert, President, EONS

The knowledge and training of nursing staff is essential to ensure the safety and comfort of patients receiving therapies. The use of biphosphonates as an adjunct to standard antineoplastic therapies in patients with advanced cancer is becoming more extensive. In addition to treating hypercalcemia and malignancy, biphosphonates are approved for treating patients with bone metastases from a wide range of solid tumours or osteolytic bone lesions from multiple myeloma.

Nurses can play a vital role in toxicity prevention, detection and management, and patient education in regards to biphosphonates. Continuing Professional Education (CPE) is an important tool in maximising nurses' contributions to such healthcare issues, enabling nurses to maintain awareness of recent research, refresh knowledge, and facilitate consistency of best practice.

Methodology

The European Oncology Nursing Society (EONS) conducted a survey on the treatment of Cancer Treatment Induced Bone Loss (CTIBL) amongst its members to evaluate eventual interest in continuing education in this area.

The survey was conducted in the form of a 15-minute self-administered questionnaire carried out between October and December 2003. The questionnaire was distributed to representatives of national nursing societies and to associate members. In all, 21 countries completed the questionnaire (a 75% response rate). The following countries participated in the survey: Belgium, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Lithuania, Norway, Portugal, Slovenia, Spain, Sweden, Switzerland, Turkey and UK.

Results

90% of respondents indicated that they have a role in the management of administering biphosphonates; the Czech Republic, Finland, Lithuania and Turkey all indicated that nurses do not have a role in the management. 80% of respondents indicated that nurses in their country have a role in the administration of biphosphonates, observe patients during drug administration, and perform assessment for eventual side effects. In terms of educating patients about the use of biphosphonates, 75% indicated that they were currently involved in patient education. In contrast, 85% of all respondents indicated that there is a need for further education in this area. The Scandinavian countries (Denmark, Sweden and Norway) and France felt there is no need for further education. Areas of interest identified were safety profiles, infusion time, indications for use, pharmacology, monitoring side effects and renal function impairment. Compliance strategies and patient choice in regard to the type and route of administration were the most frequently requested topics. Respondents also indicated that they would like to receive evidence-based literature, patient education materials and patient videos. 60% of the respondents indicated that they were involved in giving the information provided to patients receiving biphosphonates. Information on time of infusion, use of the drug and side-effects, indications, common routes of drug administration and safety aspects were most mentioned by the respondents. Respondents were asked to rank their knowledge of biphosphonates in the areas of administration, indications for use, safety and infusion time (see Table 1).

Table 1. Knowledge about biphosphonates

	Good	Sufficient	Poor
Administration	57%	38%	5%
Indications	37%	53%	10%
Safety profile	47%	38%	15%
Infusion time	63%	30%	7%

Knowledge about safety profile and indications was rated as poor by the countries Lithuania, Iceland, Belgium, Cyprus, Spain, Israel and Turkey. Only 17,5% of respondents indicated that their society or institution provided information on administering biphosphonates or treating patients with bone metastasis at a recent conference or through educational materials. In countries where a training course was conducted, it was organised by a pharmaceutical company (Finland, France, Sweden, Belgium and Norway) or by a foundation (Myeloma Foundation in the UK).

42,5% of the respondents indicated they were using guidelines or standards for the intravenous administration of biphosphonates. In addition, the majority of respondents were referred to perfusion schedules, blood parameters, guidelines for the preparation and standards for the control of parameters during drug administration. In most countries, drug information and guidelines for administration were developed by the pharmaceutical company delivering the drug. 50% didn't use guidelines or standards and 7,5% didn't know about the existence of such guidelines or standards.

In response to the question "would you consider that patients receive sufficient and qualitative information about biphosphonates from physicians, nurses, patient information groups and pharmaceutical companies, the responses were varied (see Table 2).

Table 2: Patient sources of information on biphosphonates

	yes	no	don't know
Physicians	45%	20%	35%
Nurses	45%	45%	10%
Patient Groups	15%	52%	33%
Industry	18%	50%	32%

Many countries indicated that they were unaware if their patients received information from any of the groups mentioned above. Portugal, Greece, Iceland and Spain answered with 'don't know', while others such as Turkey, Germany, Cyprus, Belgium, Lithuania, France and Switzerland answered that patients didn't receive enough information from any of the groups. The majority of countries answered that they were unsure if patients received information from patient groups.

Conclusion

The results of this study show that the involvement of nurses in patient management varies greatly among European countries and probably reflects differences in nursing practice. Even in countries where several organisations participated in the study, the responses were very different (UK, Spain, Sweden and Switzerland for example).

The majority of respondents indicated an involvement and an interest in education. Collaboration with the pharmaceutical industry in educating nurses on various types of biphosphonates and their use would be useful as they have already developed educational materials and several have indicated interest in collaboration with EONS.

In terms of developing patient educational materials, a joint collaboration with patient representatives, physicians, industry and nurses would provide the best option to develop educational materials that meet patient needs and to strengthen the collaboration between all involved parties.

Report on Visit to the 29th Annual ONS Conference: “The ride of your life”

Jan Foubert,
EONS President

The 29th annual congress of the Oncology Nursing Society took place from 29 April until 2 May in Anaheim, California, the home of Disneyland. The city, located near Los Angeles, reminded me of the French Côte d’Azur with palm trees and other exotic plants except here they are surrounded by huge buildings and hotels.

Approximately 5000 participants from 23 different countries were represented. The conference officially started with the opening ceremony, appropriately accompanied by the famous Beach Boy song “California”. During the Award Ceremony, Aliza Yaffa (former EONS Board Member) was presented the ONS International Award in recognition of her outstanding contributions to the improvement of cancer care in the State of Israel.

On my first congress day, I attended a session entitled ‘Oral chemotherapy – is it really safe?’. I was a bit disappointed as the lecture was more about oral chemotherapy agents in general and safety aspects were not directly addressed. However, it was made clear that patient education in this new way of administering chemotherapy is vital for the success of the treatments. During lunch, I visited the Amgen sponsored Mystery Theatre ‘Unlocking the Clinical Mysteries of Supportive Care’. An outstanding lecture on improving clinical outcomes in patients with mucositis was presented by June G. Eilers. The session provided me with an overview of the state of the science concerning mucositis in cancer treatment. Economic and health related burdens associated with mucositis and the identification of nursing implications for care of patients receiving therapies that cause mucosal toxicity were discussed.

The EONS/ONS lecture was about ‘Infection-Control Issues: managing new and emerging organisms with an update on SARS, West Nile Virus, Monkey Pox, Crutchfield Jakob, MRSA’. David Tucker, from Guy and St Thomas Hospital NHS Trust, represented EONS with a lecture on TBC [NOTE: please provide full name]: a global problem from an UK perspective. A word of thanks is extended to David for his interesting lecture on behalf of EONS.

In the evening, the “famous” attendee reception took place with lots of food, drinks, good conversation, and a super live band. The atmosphere was fabulous, the music was great, and everybody was out on the dance floor.

The Friday session started with a lecture on ‘Novel Imaging Technologies: Opportunities in Cancer Research, Diagnosis and Treatment’ during which molecular imaging and optical agents were reviewed. An overview of how imaging will be used in the future and also the current clinical use of PET and SPECT with their clinical limitations provided the participants with state of the art information.

I was pleased to be invited to the ONS/Shering Clinical Lectureship at lunchtime during which Esther Muscari presented her award lecture on ‘Lymphoedema: responding to our patients’ needs’. After describing her own practise in Charlottesville, the award recipient urged the audience to include a routine assessment for the misunderstood problem lymphoedema in their practice. She emphasised the importance of providing patients with knowledge on lymphoedema. In the afternoon, I visited the podium presentation on “Following Fatigue in Cancer Care”. The session made me realise that despite the fact that fatigue has been rigorously discussed

during the last decade, issues related to the clinical implications of assessment and treatment have only reached 20% of the nursing population.

In the evening, I was invited to attend the President’s Reception in a brewery museum, a beautiful location. During the reception, I was able to catch up with old friends and representatives from other associations and the ONS Headquarters in Pittsburgh.

I was awake early on Saturday for a breakfast meeting with the ATAQ representatives to discuss developments in the TITAN project. Afterwards, I visited the poster and exhibition areas. The international symposium, ‘Complementary Therapies: An international perspective’ was very interesting. Alexander Molasiotis (EONS Board Member and EJON Editor) presented a lecture on the use of complementary and alternative therapies in cancer care obtained from a European survey. His lecture was followed by presentations on complementary and alternative therapies in Turkey and China. This session showed that the use of complimentary and alternative therapies is steadily increasing in Europe. Herbal medicines, homeopathy, spiritual healing, high dose vitamins/minerals and relaxation techniques are the 5 most common therapies in use. A large number of unproven therapies are used, but most of these are lacking scientific evidence of efficacy and issues of public health safety may arise. At lunchtime I attended a symposium from the Leukemia and Lymphoma Society on treating the older patient with leukemia, lymphoma and myeloma. Cancer is increasingly a disease of the elderly and elderly patients with cancer are a special sub-population. These patients are at greater risk for developing chemotherapy-induced myelosuppression. There is reluctance to administer standard chemotherapy to these patients often resulting in under treatment. In place of long-term therapy, elderly patients prefer short cycles of treatment. Providing optimal and equal treatment can result in equal outcomes in otherwise healthy elderly patients. As is now well-known, despite the fact that the elderly are a large population, they are rarely included in clinical trials due to co-morbidity factors.

In the afternoon, the lecture on nutrition during cancer treatment and recovery while living with advanced cancer included a presentation on promising pharmaceuticals and nutritional aides. A presentation on physical activity during and after cancer treatment highlighted a growing interest in the role of exercise for cancer survivors. Preliminary evidence from research studies shows that moderate exercise is a safe, feasible and beneficial intervention.

In the evening, I had the opportunity to present the TITAN program to the audience. They were very enthusiastic about this EONS initiative and impressed by the work completed to date and the ambitious time schedule we have proposed. TITAN will probably be presented on a larger scale at the next ONS conference in Orlando in April 2005.

The experience of attending the ONS conference was very interesting. Like ECCO, participants must make a choice between numerous sessions and excellent speakers. A comparison of the presented topics at ONS with ECCO showed me that EONS is on the right track. Due to the scope and breadth of the ONS conferences, they will surely continue to serve as a benchmark for other international cancer nursing conferences. The conference illustrates that we can learn from each other; clear communication and good collaboration will prevent reinventing the wheel.

Reducing the impact of nausea and vomiting on quality of life

Nausea and vomiting are commonly experienced following chemotherapy and radiotherapy, and have a substantial negative impact on patients' quality of life. With effective antiemetic regimens available, total control of post-treatment nausea and vomiting is a realistic goal for most patients, but is not always achieved. A workshop session at the recent EONS 2004 meeting (Edinburgh, UK) identified contexts where nurses felt that supportive care could be improved, including control of nausea and vomiting.

The effect of nausea and vomiting on quality of life

Prior to treatment, patients are commonly very anxious about the prospect of nausea and vomiting. Those who do experience these symptoms have a significantly greater impairment of quality of life than those who do not ($p < 0.05$), in terms of physical, cognitive and social functioning, global quality of life, fatigue, anorexia, insomnia and dyspnea.¹

As reported at this year's EONS meeting, post-chemotherapy nausea is more prevalent and less well tolerated than vomiting, thus having a greater impact on quality of life.² With a patient's experience of nausea being subjective and historically difficult to treat, this symptom has often been neglected.

Closing the gap between patient and carer perception

Nausea and vomiting are still underestimated by healthcare professionals, particularly in the delayed post-treatment phase (Figure 1).³ This mismatch may result in patients suffering unnecessarily if their symptoms are not being recognised.

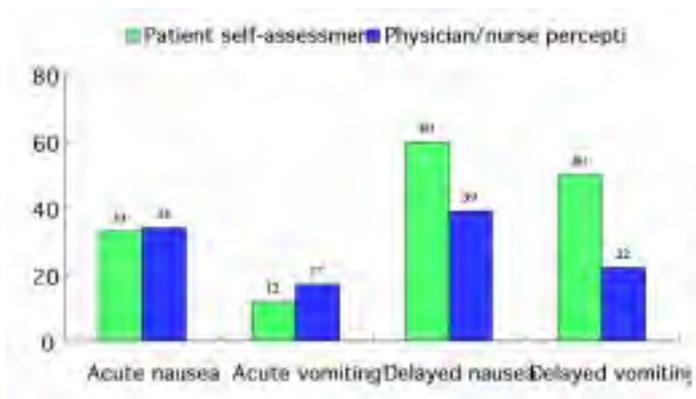


Figure 1 Physician/nurse perception of nausea and vomiting following highly emetogenic chemotherapy, compared with patient reality.³ *Cancer*, Vol. 100, No. 10, 2004, 2261–8. Copyright © 2004 American Cancer Society. Reprinted by permission of Wiley-Liss Inc., a subsidiary of John Wiley & Sons, Inc.

Aim for prevention, not management, of symptoms

It is important to focus on total prevention of nausea and vomiting from the outset:

- delayed nausea and vomiting are significantly less likely if acute (first 24 hours after treatment) control is achieved⁴
- patients who experience nausea and vomiting are more likely to experience anticipatory symptoms with further cancer treatment than those who do not.⁵

Current antiemetic guidelines recommend the prophylactic use of a 5-HT₃-receptor antagonist and dexamethasone for adults or children receiving highly emetogenic chemotherapy.⁶ A 5-HT₃-receptor antagonist is appropriate for highly or moderately emetogenic radiotherapy.⁶

A broader approach to patient assessment

Discussions at the supportive care workshop at EONS 2004 highlighted that quality of life assessment tools are used extensively in clinical trials, but are under-used in daily practice. Regular nurse–patient dialogue can be supplemented by more structured information gathering, using tools such as:

- the Functional Living Index-Emesis (FLIE) scale
- visual analogue scales
- patient diaries.

Appraise and reappraise the level of antiemetic control

Nurses are well placed to identify any need for rescue therapy, and may also advise on the need to modify a patient's antiemetic regimen on subsequent treatment cycles. In patients who do suffer from nausea or vomiting while taking standard therapy, switching to another agent from the same class may improve control or the addition of an anti-anxiety agent may be beneficial. Patients should not expect to feel or be sick as an inevitable part of their cancer therapy – this is one aspect of their quality of life that we should be able to preserve.