

Optimal comprehensive symptom control: an overall strategy

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Introduction

Despite remarkable progress in the curative treatment approaches of several types of neoplastic diseases — even in initial or subsequent disseminated stages — the prognostic outcome of the great majority of adult cancer patients, once the disease has developed metastatic spread, is very limited. More than 500,000 people in the United States of America and even more in Europe and in Asia die each year of progressive, incurable cancer [1]. This is remarkably different in childhood and adolescent neoplastic disease, where today the majority of patients become long-term survivors, although to some variable extent with pronounced qualitative somatic and psychological sequelae in their future [2,3].

The cancer types prevailing in adults after 50 years are mostly slow-growing solid tumours, especially adeno-carcinomas such as gastrointestinal, lung or kidney cancer, that are biologically disinclined to respond easily to the present armamentarium of mostly cell cycle-dependent antineoplastic agents. In addition, a large proportion of these adult cancer patients report to physicians too late in their disease evolution and are already in an advanced stage at diagnosis, as we do not yet have an effective means for either primary or effective secondary prevention of most malignant visceral tumour types. Most treatment approaches in adult cancer patients with progressive incurable cancer types are therefore ‘palliative’, directed to prevent and treat unnecessary suffering of these patients on their way to a premature death [4].

The paradigm shift from cure to care

When cure is no longer possible, the goals for treatment outcome and the tools to optimally meet them, have to be clearly reset — which is not always the easiest task to accomplish with advanced cancer patients, suddenly realising the limitations of their remaining lifespan and the potential extent of suffer-

ing until death. According to various studies in the field, patients tend to interpret their prognostic outlook more optimistically than their direct care-givers, especially the medical staff: doctors and nurses [5]. It can take some time and considerable painful discussions, to convince a patient — especially if he experienced a prior happy period of sustained tumour remission — of his relapsing and progressive disease, and also of the inevitable and premature termination of his life. Despite all potential progress in experimental, translational and clinical cancer research, end-of-life (EOL)-care will always be required. Furthermore, the need for this type of care will increase in the future, in view of the progressive prolongation of our lifespan that has occurred due to increased medical and social possibilities and resources. Thus, supportive and palliative care aimed at ameliorating the patient’s overall suffering by trying to alleviate disease and treatment symptoms using treatment to slow down disease progression and/or prevent the side-effects of the drugs is going to be needed increasingly in the future. Supportive care (which is the somatic, physical and spiritual support of the patient during all stages of his evolving disease) and palliative care (which is mainly directed at maintaining the best possible quality of life in EOL-situations) are becoming increasingly important topics in education and the practice of supportive and palliative care in adult oncology [6].

The term ‘palliative’ needs to be clarified here, at least at the European level: for a physician, also an oncologist (usually engaged in ‘curative’ medicine), any treatment approach less than curative (radical surgery, curative radiotherapy, curative leukaemia/lymphoma treatment) is ‘palliative’ in nature: for this reason, the cytostatic and endocrine treatment of metastatic breast cancer — although very successful over several years — is generally considered palliative treatment, since most patients will finally succumb to their metastatic disease. However, for nurses, politicians and the lay-public, ‘palliative’ clearly means EOL-care, concerned with maintenance of quality of life

(QOL) in terminal stages and not at all with chemo-endocrine treatment of metastatic neoplastic disease: "no tubes — no needles". It is for this reason, why we have coined the more neutral term 'supportive care' and founded a respective society and even an international journal with the same name more than 15 years ago, in order to get away from this semantic interprofessional confusion, surrounding 'palliative' care [6].

The complexity of supportive and palliative care needs a global view

Due to the complex nature and presentation of symptoms and the notorious polymorbidity of our mostly advanced cancer patients, as well as the mainly, but not exclusively, medico-pharmacological treatment approaches in the palliative setting, medical oncologists and their specially trained nursing oncology colleagues play a key role in the recognition and execution of EOL-care in advanced cancer patients. Looking at the literature, there is a clear preponderance of publications about the characterisation and treatment of certain isolated symptoms, which are usually those where medical progress is tangible and those, probably more than others, interesting to the pharmaceutical industry and their successful drug development. Here, clearly 'pain', 'nausea/emesis' and 'infections' are the three great front-runners. In the Journal of Supportive Care in Cancer, more than 40% of the roughly 300 annual manuscript submissions are about the prevention and treatment of (late) nausea and emesis by new anti-emetics and drug combinations (Senn, unpublished 2001).

However, the nature of suffering in advanced cancer, not only in the terminal phase, is complex and a global approach is badly needed so that the patient's predominant needs and problems are not neglected. What are these problems? Table 1 shows the prevalent symptoms of advanced cancer patients in a terminal palliative care unit in Cleveland/USA, where pain (84%), fatigue and weakness (69 and 66%), as well as anorexia (66%) and lack of energy (61%), are

Table 1
Prevalent symptoms of advanced cancer

Pain	84%	Constipation	52%
Easy fatigue	69%	Early satiety	51%
Weakness	66%	Dyspnoea	50%
Anorexia	66%	Weight loss	50%
Lack of energy	61%	Cough	49%
Dry mouth	57%	Anxiety	48%

From D. Walsh et al., J Supp Care Cancer [7].

Table 2
Prevalent side-effects/symptoms in patients on cancer chemotherapy

Substantial hair loss (wig)	74%
Nausea + emesis	73%
Unusual fatigue	67%
Increased urination	49%
Dry skin	48%
Loss of appetite	48%
Sleeping difficulties	47%
Stomatitis, taste alterations	43%

From Griffin AM et al., Ann Oncol [8].

the most prevalent problems in their patient group [7]. This list and prevalence looks different, if generated in an oncology outpatient department with actively treated chemotherapy patients (Table 2) or again different in home care, depending on the institution, the questionnaire and the distribution of cases [8]. Incidence and intensity of symptoms, as well as patient mix and performance status are clearly interrelated and superficial generalisations are not helpful.

We have taken a somewhat different approach in St. Gallen, and have asked our (medical-oncology) cancer patients, what their prevalent problems were, rated independently at the 'physico-somatic' and at the 'psychological' level (Table 3). Here, with physical problems, excessive fatigue was clearly the number one concern of the majority of patients, followed by nausea and emesis, sleeping disorders, nutritional problems and pain. With psychological problems, the knowledge of having cancer, uncertainty about the disease course, lack of information, isolation from relatives and fear of dependence on others were the most prevalent concerns of the patients [6]. This has prompted us, several years ago, to select 'fatigue in cancer' as one of our foremost nursing oncology research topics [9] and to immediately take action educating our medical house staff regarding the patient information policy and the development of the relevant professional skills. It is extremely important,

Table 3
Prevalent physical and psychological problems in medical oncology patients ($n > 100$)

Physical problems:	Psychological problems:
1. Excessive fatigue	1. Knowing they have cancer
2. Nausea + emesis	2. Uncertainty about the disease course
3. Sleeping disorders	3. Lack of information
4. Nutritional problems	4. Isolation from relatives
5. Pain	5. Fear of dependence on others

Senn HJ, Glaus A, J Supp Care Cancer, 2001, in press [6].

that caregivers realise, what the real and prevalent problems of their patients are: it may be not the certainly dreadful, therapy-induced hair-loss or the apparently intractable pain in their lumbar spine that the patient fears the most, but other fears such as losing their dignity or becoming dependent on those whom the patient has cared for all of his/her life! The integration of psychosocial aspects and care elements into the daily medical and nursing oncology practice is essential and needs assessment on a professional level, provided we want to offer our patients really optimal and global symptom control. In this context, we should also pay attention to the family carers and their environment by constant re-assessment of the stability of the home-care setting in order to avoid early or late collapse of this home-care, resulting usually in unnecessarily premature or late-terminal hospital readmissions [10,11].

In dealing with complex symptoms in polymorbid, advanced cancer patients, it is not only essential to recognise and to assess, but also to document these problems, and to make use of them in daily practice and in clinical research. For these purposes, the creation of practical in-house flow-sheets or diaries to record prevalent symptoms and problems, for example with a daily repetitive single- or multi-dimensional VAS (visual analogue scale) may be helpful in routine practice, as well as for educational purposes [12]. It is essential to integrate the patient himself into such an approach because he will be the person who finally benefits from our endeavours to optimise symptom control, as well as his and also our QOL. It is not the task of oncology nurses nor doctors to judge the extent and quality of their patient's symptom control and problems in a paternalistic way, but to act on the basis of the (well-informed) patient's *own* perception of their disease and his/her problems [13,14]. Certainly, much is still needed to be done in medical as well as nursing education, regarding the growing awareness of EOL care, especially in Western societies and medical systems [15,16].

The orphan topics of supportive and palliative care

As stated above, during the last 10–15 years, some aspects of supportive and palliative cancer care have made remarkable progress, not only promoted by academia, but mostly by clinical research investments from industry [6]. This is especially true for 'infections' (antibiotics), pain (opioids, pumps) and nausea + emesis (modern antiemetics, especially the expensive 'setrons'). While the well documented

Table 4

Orphan topics of supportive and palliative care in cancer patients

Mucositis/dysphagia
Anorexia/weight loss
Dyspnoea/cough
Diarrhoea (disease- and drug-induced)
Obstipation (disease- and drug-induced)
Rehabilitation and psychological disorders

Senn HJ, Glaus A, J Supp Care in Cancer, in press [6].

progress in these fields has not yet spread all over the globe and many (technical, psychological and financial) limitations of the optimal use of these modern supportive and palliative care medications prevail, there are still other areas of severe problems, where virtually no progress at all has taken place. We have called these 'orphan topics of supportive care', listed in Table 4, mainly characterised by the fact that there has been no direct interest to stimulate investment in these fields due to the lack of a clearcut research and economical basis in the recent past [6,17].

Some of these 'orphan topics' however, with the generous and helpful support of industry, have been promoted in recent years to the stage of 'fashionable topics in supportive care', such as 'fatigue' and 'anaemia' (erythropoietin), vascular access problems (implantable venous port systems) and bone pain (bisphosphonates). Let's hope, that other remaining topics will follow, especially those with a large negative impact on QOL in advanced and terminal disease, such as 'anorexia', 'mucositis/dysphagia' and 'dyspnoea/cough', as well as spontaneous and drug-induced 'diarrhoea' and 'constipation', for all of which the literature is scanty and the evidence-based treatment recommendations are few [18]. Most cancer patients with severe dyspnoea do not even get a proper work-up to classify the causes of their problem, a situation, which greatly impairs clinical research and treatment effectiveness. The situation with 'dyspnoea' is very similar to that of 'pain' in cancer patients some 20 years ago and 'nausea + emesis' some 12–15 years ago, when it was widely accepted that cancer patients generally suffered from pain and one was inevitably vomiting when treated with cytostatic drugs!

The same holds true for psychiatric complications in advanced cancer, a domain in which the Journal of Supportive Care in Cancer has presently taken the lead by publishing a whole series of well-founded papers in the field, drawing more attention on the part of oncologists and oncology nurses to the needs of their patients and to their own role of professional support in this context [19,20]. It is neither necessary,

nor practical, to refer every advanced or terminal cancer patient to an experienced psycho-oncologist; but the experienced psycho-oncologists of our countries and centres have to prepare us, the experienced medical and radio-oncologists and oncology nurses, to become a psychologically more skilful partner for our patient's and their respective needs.

Conclusions

In summary, realistic supportive and palliative care and optimal symptom control in advanced cancer patients needs a comprehensive, global approach and cannot be viewed as a fractional problem of single, isolated treatment steps and possibly contradictory decisions. First, the patient's needs and problems have to be critically assessed and taken seriously. Second, diagnostic steps should be taken (also in advanced cancer) to correctly classify the nature and origin of the problem in order to select the necessary treatment, if available. Third, the patient's psychosocial status should also be analysed and this should be integrated into an effective global patient management strategy. Fourth, optimal comprehensive symptom control can only be obtained when it is organised and performed in a truly inter-professional manner, where the most experienced medical, nursing and psychosocial experts join forces in the best interests of their patients.

References

- 1 American Cancer Society. Facts and figures. ACS, Atlanta, GA, USA, 2000.
- 2 Cella DF, Tulsky DS, Gray G et al. The functional assessment of cancer therapy scale: Development and validation of the general measure. *J Clin Oncol* 1993, 11: 570–579.
- 3 Wolfe J, Grier HE, Klar N. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000, 342: 326–348.
- 4 American Society of Clinical Oncology. Cancer care during the last phase of life. *J Clin Oncol* 1998, 16: 1986–1996.
- 5 Vachon M. Psychosocial needs of patients and families. *J Palliat Care* 1998, 14: 49–56.
- 6 Senn HJ, Glaus A. Supportive Care in Cancer — 15 years thereafter. *Supp Care in Cancer* 2002, in press.
- 7 Walsh D, Donelli S, Rybicki L. The symptoms of advanced cancer. Relationship to age, gender and performance status in 1000 patients. *Supp Care Cancer* 2000, 8: 175–179.
- 8 Griffin AM. Prevalent side effects/symptoms in patients on cancer chemotherapy. *Ann Oncol* 1996, 7: 189–195.
- 9 Glaus A. Fatigue in patients with cancer: Analysis and assessment. *Recent Results Cancer Res* 1998, 145 Springer, Heidelberg.
- 10 Sherman DW. Reciprocal suffering: the need to improve family caregivers' quality of life through palliative care. *J of Palliat Med* 1998, 1: 357–366.
- 11 Peruselli C, di Giulio P, Toscani F et al. Home palliative care for terminal cancer patients: a survey on the final week of life. *Palliat Med* 1999, 13: 233–241.
- 12 Bruera E, Kuehn N, Miller MJ et al. The Edmonton Symptom Assessment System (ESAS): a simple method of assessment of palliative care patients. *J Palliat Care* 1991, 7: 6–9.
- 13 Morasso D. Psychological and symptom distress in terminal cancer patients with met and unmet needs. *J Pain Symptom Manage* 1999, 17: 402–409.
- 14 Singer PA, Martin DK, Keiner M. Quality end-of-life care: patient's perspectives. *JAMA* 1999, 281: 163–168.
- 15 Rabow MW, Hadie GE, Fair JM et al. End-of-life care content in 50 textbooks from multiple specialties. *JAMA* 2000, 283: 771–778.
- 16 Ferrell BR, Grant M, Virani R. Strengthening nursing education to improve end-of-life care. *Nurs Outlook* 1999, 47: 252–256.
- 17 Peterson DE. Oral problems of supportive care: no longer an orphan topic? *Supp Care Cancer* 2000, 8: 347–348.
- 18 Ripamonti C, Twycross R, Baines M et al. Clinical-practical recommendations for the management of bowel obstruction in patients with end-stage-cancer. *Supp Care Cancer* 2001, 9: 223–233.
- 19 Stiefel F, Berney A, Mazzocato C. Psychopharmacology in supportive care in cancer: a review for the clinician. I. Benzodiazepines. *Supp Care Cancer* 1999, 7: 379–385.
- 20 Berney A, Stiefel F, Mazzocato C. Psychopharmacology in supportive care in cancer: a review for the clinician. III. Antidepressants. *Supp Care Cancer* 2001, 8: 278–286.