

ESMO gave me a chance to help make a difference: a personal reflection on the occasion of receiving the 2015 ESMO Award

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ABSTRACT

On the occasion of receiving the ESMO 2015, Prof Nathan Cherny reflects on the potential of the individual clinician to address issues of consequence on a wider scale through the auspices of a professional medical society. He describes his 20 year relationship with ESMO illustrating the potential of harnessing the power of ESMO to influence care, professional behaviours and distributional justice in the provision of care. He urges oncologists to be inspired by the credos that he was nurtured on emphasising professional and personal integrity and the audacity to push boundaries.

I wish to dedicate this award to the promotion of care, the pursuit of peace and understanding between people, and the on-going challenge for making the best possible care available and affordable to all.

Nathan Cherny

It has been 37 years since I was first introduced to the world of medical oncology as a 20-year-old second-year medical student diagnosed with a metastatic non-seminomatous germ cell tumour. That today I am an oncologist and palliative medicine specialist, and a recipient of the European Society for Medical Oncology (ESMO) Award, is only by virtue of the development of effective anticancer therapies and the dedication of skilled oncology clinicians applying the best of contemporaneous care. The path from my bed in the oncology ward of the [Peter MacCallum Cancer Centre](#) in Melbourne, Australia, to my current situation, has been a most extraordinary journey, giving me the opportunity to reflect on where we have been, where we are going, and to emphasise the themes of integrity and audacity in the field of oncology.

In his seminal paper on the ethics of professional medical societies,¹ Pellegrino, the great American bioethicist and physician,

emphasised the centrality of the moral mission of medicine and the critical importance of integrity, as the basis of authority and trust.

Professional organisations have the potential to influence policy care and practice far beyond the capacity of any single member. Medical development is a form of social change, and professional organisations based on solid ethical principles and moral integrity, such as ESMO, give us the power to make a difference. This potential to make a difference has been the basis of my 18-year relationship with ESMO, and has certainly changed my life.

My key professional mission with ESMO has been to promote medical oncology as a field committed to both, the best of science and the highest standards of care, and to support ESMO, its representative body in Europe, as a professional organisation committed to promoting those core elements of our professional ethos.

This I have sought to do through:

1. Improving the provision of palliative care (PC) for patients with cancer by oncologists and cancer centres;
2. Improving access to care for all patients with cancer;
3. Promoting honest and clear communication regarding the capacities and limitations of the anticancer therapeutic repertoire.

IMPROVING THE PROVISION OF PC FOR PATIENTS WITH CANCER BY ONCOLOGISTS AND CANCER CENTRES

The importance of PC for patients with cancer, even at an early stage of their disease, is undeniable. Not only do patients benefit from an improved quality of life, through reduction of symptom burden, and the

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associated physical and psychological distress, but studies have also shown that early implementation of PC may improve survival.^{2,3} In addition, in an era of increasingly expensive cancer therapeutics, it should also be noted that patients who receive early PC tend to spend less time in intensive care units and are less likely to be readmitted to hospital after returning home, leading to an overall reduction in the cost of care.^{4,5}

In 1998, my colleague Rafi Catane and I drafted a plan for the establishment of a Palliative Care Working Group (PCWG) in ESMO. Recognising the barriers to diffusion that were impeding the uptake of PC by clinicians and cancer centres, we sought to develop a programme to target these specific issues. This has been a team effort that could not have been achieved without the participation of a wonderful collection of oncologists from around Europe, dedicated to this project.

In 2003, PCWG published three policy statements,⁶ which remain relevant to this day:

1. The role of the oncologist
 2. Minimal standards for PC in cancer centres
 3. Core elements of PC education for oncology trainees
- Simultaneously, the PCWG established two incentive programmes:
1. [Trainee grants in palliative care](#)
 2. [The ESMO Designated Centre of Integrated Oncology and Palliative Care programme](#)

The [criteria for the designated centre programme](#) were derived from the WHO guidelines published in 1990⁷ and the experience that Professor Catane and I had gained during the development of the integrated oncology and palliative medicine service at Shaare Zedek Medical Center in Jerusalem. The underlying philosophy was to create incentives and a structured model that could provide a template for development of integrated oncology and PC programmes in other locations.

The success of this programme surpassed all expectations. ESMO can now boast of having almost [200 accredited centres](#) for the provision of integrated oncology and PC around the world. Indeed, recent international surveys have highlighted the unique prevalence and strength of this large cohort of centres. This has defined a new standard of care for oncology, not only in Europe but around the world, with The American Society for Clinical Oncology following suit only years later.

In 2001, we launched a survey of the Oncologists Role in Palliative Care in Oncology in Europe. Published in 2003,⁸ the survey highlighted that, although most oncologists have very positive attitudes towards the importance of PC, there was a profound gulf between belief and practice, and indeed only a small proportion of oncologists at that time devoted significant energies to this task ([box 1](#)). These findings augmented ESMO's resolve to address issues relating to knowledge deficits, the culture of care and the need for structured programme development to better integrate PC into oncological care.

A second ESMO survey was undertaken to evaluate the communication disclosure practices among oncologists in Europe, particularly addressing the factors that influenced the willingness of oncologists to discuss issues related to diagnosis and prognosis with their patients. This study, published in 2010,⁹ highlighted the importance of education and the institutional culture of care within individual hospitals as major factors influencing oncologist's practices of disclosure and communication ([box 2](#)).

Over the past 10 years, the PCWG has championed multiple educational initiatives, including the publication of an [ESMO Handbook of Advanced Cancer Care](#), to help with the management of patients with advanced cancer, and a range of ESMO clinical guidelines addressing vital supportive and PC activities¹⁰⁻¹⁴

Supported by the then president David Kerr, in an effort to help patients with advanced cancer and as an indirect tool to influence physician behaviours by raising patient expectations, the PCWG developed the '[ESMO guide for patients with advanced cancer](#)' and subsequently a [physician's handbook for using the ESMO guide for patients with advanced cancer](#). The patient guide has now been translated into 12 languages.

IMPROVING ACCESS TO CARE

Access to affordable and effective analgesics for the management of strong cancer pain and affordable access to anticancer medications are both critical to the delivery of quality oncological care and, in particular, care to patients with advanced and incurable disease.

In 2006, Paris Kosmedis, the then president of ESMO, joined in launching an ESMO programme to address the major problems of accessibility to opioids for the management of cancer pain in Europe.¹⁵

In 2007, along with the European Association for Palliative Medicine, ESMO launched a survey to map the formulary availability, out-of-pocket cost and accessibility of opioids in the management of acute cancer pain, as well as the regulatory barriers that often impeded patients' access to these medicines.

The [report](#), published in 2009,¹⁶ highlighted major discrepancies in access to opioids, particularly between Western and Eastern Europe. It highlighted the problem of over-regulation as a major barrier that was impeding the effective management of cancer pain for large numbers of patients in Europe.

These data were so dramatic and profound that we felt that it was important to expand the project to look at the extent of the problem in [Africa](#), [Asia](#), [Latin America](#), the [Indian subcontinent](#) and the [Middle East](#). This massive project was undertaken in collaboration with the WHO, the International Union for Cancer Care, the Pain and Policy Studies Group of the University of Wisconsin, and with the participation of another group of 19 international oncology and palliative medicine organisations. The data collected were relevant to more

Box 1 Key findings of the ESMO survey of oncologists' knowledge and attitudes towards palliative care⁸

The survey of the ESMO membership demonstrated a high level of consensus regarding the importance of the oncologist's role in the provision of supportive and palliative care to patients with advanced cancer and dying patients. Most medical oncologists believe that oncologists should coordinate the care of patients with advanced cancer and dying patients, that initiate supportive and palliative care should be initiated during the active treatment phase, that medical oncologists should be expert in the management of the physical and psychological symptoms of advanced cancer and that cancer centres should provide supportive and palliative care as part of the basic basket of services.

The survey results demonstrated discrepancies relating to practice and skill levels of the respondents.

1. Whereas, 88.4% of respondents agreed that medical oncologists should coordinate the care of patients with cancer at all stages of disease including end of life care, actual practice was found to be much less: only 43% commonly coordinate the care of patients with cancer at all stages of disease including end of life care, less than 50% collaborate commonly with any supportive/palliative care clinician (including social workers), only 39% commonly coordinate meetings with the family of dying patients and only 11.8% commonly manage delirium (despite the high prevalence of this problem among patients with far advanced cancer).
2. Whereas 60.4% of respondents reported that they were expert in the management of the physical and psychological symptoms of advanced cancer, only 37.0% said most oncologists they knew were expert in the management of the physical and psychological symptoms of advanced cancer.
3. Whereas 70.4% responded that they have a close working relationship with the palliative care (or hospice) services in their region, reported levels of collaboration with palliative care and hospice services was relatively low: only 37.8% often collaborated with a home hospice (palliative care) team, and only 35.1% and 33.3% often collaborated with a palliative care medical specialist and nursing specialist, respectively.

Those issues in which there was a polarisation of attitudes are worthy of specific attention:

1. A substantial 42% of respondents reported that they had not received adequate training in palliative care during their residency training.
2. In response to the statement, "most medical oncologists I know are expert in the management of the physical and psychological symptoms of advanced cancer", more respondents disagreed (41.8%) than agreed (37.5%). It seems, therefore, that most oncologists have a low assessment of their colleagues' readiness to manage the physical and psychological symptoms of advanced cancer. This is consistent with the findings regarding training.
3. Just over a third of respondents reported that they feel emotionally burnt out by having to deal with too many deaths. In this survey, this predilection to burnout was associated closely with negative attitudes to involvement in supportive and palliative care, and low levels of actual involvement or referral to specialist colleagues. Burnout, therefore, was not so much associated with over-exposure but, rather, with poor attitudinal preparedness and aberrant role definition. On the other hand, physicians with a positive attitude toward end-of-life care and their role in it, expressed a much lower tendency to burn out and much more personal satisfaction from end-of-life care despite the fact that they were much more personally involved with dying patients.
4. Respondents were divided as to who should coordinate the palliative care of patients with advanced cancer. Although 74.5% of respondents agreed that the medical oncologist is the best person to coordinate the palliative care of patients with advanced cancer, when asked about the role of the palliative care specialist, 36.3% of respondents agreed that they are the best professionals to manage the palliative care of the same patient population. This ambivalence was evidence of the relatively low proportion of oncologists who frequently consult with a palliative medicine physician and of the relatively high prevalence of respondents (35.2%) who felt that palliative care (or Hospice) physicians do not have enough understanding of oncology to counsel patients with advanced cancer regarding their treatment options.

than 5.7 billion people around the world. This project also represented the first substantial collaboration in what would go on to become a profound relationship between ESMO and the WHO.

This massive collaborative project, known as the [Global Opioid Pain Initiative \(GOPI\)](#), and the data derived from it,^{17–24} set an international agenda to address problems of access, cost and regulatory barriers around the world, and placed ESMO squarely as a central participant in this critical global endeavour.

In light of substantial concerns regarding the availability, out-of-pocket costs and accessibility of anticancer drugs, particularly in the economically less well-developed parts of Europe, ESMO in partnership with the WHO, Union for International Cancer Control and Institute of Cancer Policy, King's College, London, launched the first of two sequential projects to address the availability and accessibility of anticancer drugs, [first in Europe](#) and subsequently in the [rest of the world](#).

These projects piggybacked on the methodology and experience that we accrued during the opioid studies and are now providing critically important new data to address the problems of equity in access to cancer care, which is a pandemic problem in all but the wealthiest countries in the world.

We have identified that the prohibitive cost of new medications is generating major inequities of care in treating certain cancers [in Europe](#), such as EGFR-mutated non-small cell lung cancer, RAS and RAF wild type metastatic colon cancer, metastatic melanoma, Her-2 overexpressing metastatic breast cancer, renal cell cancer and castrate-resistant prostate cancer.

[Data derived from the rest of the world](#) have shown that even anticancer medications on the WHO essential drug list are often available only at full cost in many of the poorest countries in the world, and that accessibility is commonly impaired by problems of distribution and manufacturing. As in Europe, we again found that

Box 2 Major findings from the ESMO communication survey⁴

Based on responses from 298 oncologists across all regions of Europe, the study indicated that individual clinicians generally display a range of behaviours, including non-disclosive as well as disclosive behaviours, depending on the dynamics of individual interactions between oncologist and specific patient. Although regional cultural norms influence oncologists' attitudes towards disclosure and, indirectly, their self reported behaviours, the impact is influenced by other factors: in particular, perceived institutional professional norms, the degree of training in breaking bad news and the frequency of exposure to requests by family members to withhold information from the patient.

The impact of local professional norms and education is particularly salient since these issues are amenable to change. The impact of the respondents' perception of local professional norms regarding disclosure on their attitudes and behaviours was substantially highly significant ($p < 0.0001$) and, importantly, it was independent of local culture. Irrespective as to where they worked, in Western or non-Western countries, physicians who reported a strong institutional culture of disclosure tended to have both attitudes and behaviours conducive of disclosive communication and shared decision-making. In non-Western countries, almost 50% of respondents either disagreed (38.6%) or disagreed strongly (10.8%) with the assertion, "In my work setting, I am expected to discuss matters first with the family and only later with the patient", and these norms powerfully influenced their attitudes and behaviours as compared with respondents who agreed (32.3%) or agreed strongly (10.8%). The impact of perceived professional norms had not previously been studied in this way.

The impact of professional norms is augmented by education. The data also suggest that younger physicians as well as physicians whose work involves a large proportion of patients with advanced incurable cancer are more likely to have positive attitudes and behaviours regarding disclosure and shared decision-making.

Another important finding of this survey relates to the prevalence of requests by family members to have information regarding either diagnosis or prognosis withheld from the patient. The responding physicians from non-Western countries reported this phenomenon either often (64.6%, 53.8%) or always (10.1%, 23.4%) regarding the issues of the diagnosis and prognosis, respectively. Responding physicians from Western countries also reported this phenomena, but with far lower frequencies; often (13.9%, 23.0%), always (0%, 1.6%). Universally, requests by patients to have information withheld from family members were distinctly uncommon. The frequency with which physicians were requested to withhold information was an important factor that impacted on both attitudes and practices regarding disclosure.

These findings support the importance of regional culture as a factor that influences the attitudes and behaviours of individual oncologists. Among the responding physicians from non-Western countries, 20–25% were extremely non-disclosive and this phenomenon was not observed among the respondents from Western Europe, Australia and the USA. Indeed, the combination of working in a non-Western country, frequent exposure to requests from a family members to withhold diagnostic and prognostic information from patients, a lack of training in communication issues regarding breaking bad news and local professional norms that supported non-disclosure practices, often went hand-in-hand.

prohibitive cost of new medications is generating major inequities of care in all but the wealthiest countries.

These findings highlight the major public health challenges in the delivery of cancer care in impoverished and developing economies worldwide. They also highlight the human consequences of the savagely aggressive pricing policies associated with new medications over the past 15 years. These findings now challenge us as an organisation and as a profession to vigorously address the problems of affordability and sustainability, and the need for a pricing structure for medications that reflects patient outcomes, while still providing adequate reward and incentives for research, development and marketing.

PROMOTING HONEST AND CLEAR COMMUNICATION REGARDING THE CAPACITIES AND LIMITATIONS OF THE ANTICANCER THERAPEUTIC REPERTOIRE

Experiences in Israel and the USA taught me that overstating or estimating the benefits of new treatments by oncologists or oncology organisations not only compromises their credibility and integrity but also has the capacity to have significant harmful consequences. This can involve public policy decision-making, in particular with regard to the misallocation of limited financial resources, and it can undermine the credibility of

oncology research reporting. It can harm patients who choose to undertake treatments based on exaggerated expectations that may subject them to risk of adverse effects, inconvenience and substantial personal cost. In the public domain, such claims may fuel inappropriate hype or disproportionate expectations about new treatments and the need to allocate public resources or personal funds to provide them.

When I first pitched the idea of developing a scale for the magnitude of clinical benefit, it was based on an appeal to the promotion of professional and organisational integrity, and an important public health need.

The ESMO leadership, under the tutelage of Martine Picard and subsequently Rolf Stahl, endorsed these concerns and this led to the formation of a [wonderful task force](#), under the leadership of Elizabeth De Vries and Martine Picard, faced with the challenging task of designing a standardised, generic, validated approach to stratify the magnitude of clinical benefit that could be applied across a broad range of different anticancer therapies.

The team assembled to perform this task included Richard Sullivan, Urani Dafni, Martin Kerst, Alberto Sobrero and Christoph Zielinski. This has been a challenging project on many levels: intellectually, scientifically and even philosophically. It has involved multiple incarnations, extensive and rigorous field testing and

numerous peer reviews from experts across different disciplines.

The scale was published in 2015²⁵ and is a first version of a dynamic work in progress. Further experience in the months since the paper was published has already produced new insights, which have led to further discussion, and will undoubtedly lead to future refinements of the scale and an expansion of the types of studies that can be evaluated with it.

Building a justified consensus as to how clinical benefit ought to be evaluated is part of the organisational discipline that is necessary to maintain and promote the professional integrity of oncology and ESMO as a representative professional organisation.

It is been an enormous privilege to participate in this project.

CONCLUDING REMARKS

More than an acknowledgement of my contributions (which would have been far more marginal if not for ESMO and the support it has given me), the importance of this ESMO award to me was that it acknowledged that ESMO prioritises the promotion of care, the relief of suffering and distress as a central part of the oncological endeavour, the importance of healthy scepticism and scientific curiosity, and the critical importance of professionalism and professional integrity.

That ESMO and the oncology community values these things as much as I do is truly and deeply gratifying.

ESMO gave me a chance to help make a difference, and together I think that we have made an impact on the culture of cancer care, and the manner in which it is delivered in Europe and beyond. For that opportunity and support, I am overwhelmingly and forever grateful.

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Figure 1 Holding the 'Flower of Hope' with my father Dr Jack Cherny, and my youngest brother David Cherny.

spiritual care psychological care, and other services and volunteers who I am blessed to work with. The department of Bioethics at the NIH in Bethesda who inspired me to broaden my horizons. My patients and their families, from whom I learn every day. The wonderful membership of the ESMO executive and the ESMO staff (particularly Nicola Latino and Gracemarie Bricalli) who have given me so much encouragement and support. The membership of the ESMO Palliative and Supportive Care Working Group and the Magnitude of Clinical Benefit task force. Finally, my extraordinary wife (and love of my life) Nancy and our four children Calanit, Noa, Eitan and Gil (Figure 2), my brothers Mark (Figure 3) and David (Figure 1), and my extended circles of family and friends who keep my life balanced between work, social engagement, nature, and an appreciation of all life gives us including, and above all, love and connectedness.



Figure 2 My family: Gil (19), Noa (11), Eitan (16), Calanit (7), Me (57), Nancy (XX).



Figure 3 My late mother, Berta (Betty) Cherny, with myself and my brother Mark Cherny.

A FINAL THOUGHT

My late mother Betty Cherny (Figure 3) was an inspirational woman who we lost at a relatively young age. She left me inspired by a modification of the serenity prayer that I would like to share with you: God grant us the wisdom to accept the things we cannot change, the courage to change the things we can, the wisdom to know the difference and the chutzpa (audacity) to push the boundaries.

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