

ORIGINAL ARTICLE

Prostate cancer from the horizon of the patient

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Abstract

The democratization of civil society and the development of modern medicine changed the sacrosanct doctor-patient relationship to a doctor-partner dialogue. Values and respect were lost in the process where common courtesy and empathy in trust were replaced by patient rights. *Launch of Europa Uomo*. Europa Uomo, the European prostate cancer coalition, represents 22 national, autonomous patient support groups. Its aim includes increasing the awareness of prostate diseases, support individualized treatment as a balance between optimal medical treatment and personalized care delivered by a multiprofessional team. We expect our information/education from dedicated professional societies while in return we share care for properly informed members as well as a fast, unbiased and cheap distribution of information/innovation across the European continent. *The role of a patient group*. Our advocacy role is focused on quality of life, tailored treatment, knowledge of risk factors, support for research and last but not least active partnerships. We believe that we can play a modest but basic role in common actions to overcome inequalities in treatment and care in Europe. Our responsibilities range from defining patient obligations to facilitating translational research and saving scarce health resources. *The horizon of the patient*. Our hope is to plead for a treatment policy on the man first and then on his cancer and to improve treatment outcomes by multiprofessional collaboration and the development of expert Prostate Units. *Future expectations*. A transparent, open communication line between the multiprofessional team and the patient is mandatory. The existing uncertainties should be discussed with common sense but always leave a factor of hope in survival or quality of life.

In the ascent of mankind disease and its consequences was a calamity for the individual and the population. This resulted in a deep respect towards the healers of the times as it was accepted that the Gods used disease to punish populations and individuals alike for their committed sins. The patient could only hope for divine support to survive and recover sometimes despite the treatments received.

We all honor the great Hippocrates of Kos as the father of modern, human health care especially for his golden rule “do not harm”. Still each one of us knows that we do have to harm the patient with cancer to restore his health and end up with a new post treatment quality of life. For most of the history of civilization the patient had to submit to the Latin roots of the word. He had to have patience and endure his misery.

The actual reality is not so much different as we blame the environment as the major cause of cancer and reproach the lifestyle of the patient in smoking, alcohol consumption, lack of exercise resulting in

obesity as causes of cancer. Major changes as secularization and democratization coupled to the development of the information technology and relative, widespread wealth in our Western societies created a social health care where the major income of most health care professionals comes out of the collected taxes from the population [1].

The net result is a development towards the mantra of the French population: “Liberté, égalité, fraternité”. We are still recovering from the 1968 wave where titles and expertise were brought down to the lowest possible denominator. Our elected politicians contributed so much to the process that they receive in population polls the lowest figures of trust while fortunately physicians and firefighters still enjoy the trust of the great majority of the population.

It is clear that this trust is based on the merits of the previous generation and that this generation has to earn their own credit in trust.

All these changes opened the chance for the patients to claim rights in the organization and practice in

Table I. Health care stakeholders.

Health authorities	
Insurance agencies	Public
	Private
Professionals	Clinical
	Research
Industry	Pharma
	Technology
Cancer leagues	
Consumers	
Patients	

social health care. It is of course true that they are at the bottom of the hierarchy of established stakeholders in health care and that the overall atmosphere of doctor – patient relation and communication could and still can be improved (Table I) [2].

This was effectively achieved in the USA with women's groups as the National Women's Health Network exercising pressure in civil society to defend their viewpoints on a number of public health issues quickly followed by many.

The launch of Europa Uomo

The Europa Donna association was launched in 1995 to improve breast cancer management in Europe and they lobbied successfully into the European Parliament. As this movement was supported by the European School of Oncology (ESO) it was predictable that a patient coalition against prostate cancer was to follow. In effect at the end of 2002 the concept of Europa Uomo was discussed in the Italian government at the time that the prime minister Berlusconi was diagnosed and treated for prostate cancer. After a number of preparatory meetings, Europa Uomo

Table II. Manifesto Europa Uomo.

1. To find ways and means to promote quality of life for prostate cancer patients and their families;
2. To promote the dissemination and exchange of evidence-based as well as factual and up-to-date information on prostate cancer;
3. To promote prostate awareness and appropriate diagnosis and prognosis;
4. To emphasize the need for appropriate early detection;
5. To campaign for provision of and access to optimum treatment;
6. To ensure quality, supportive care throughout and after treatment;
7. To promote multiprofessional quality care and appropriate medical infrastructure;
8. To acknowledge good clinical practice and promote its development;
9. To ensure that all men fully understand any proposed treatment options, including entry into clinical trials and their right to a second opinion;
10. To promote the advancement of prostate cancer research.

Table III. Europa Uomo's view on cancer management.

1. Optimal medical treatment
Evidence/conscious based
Multiprofessional
2. Patient-centered care
Shared care with broad support
Holistic/reciprocal respect

was formally established in 2004 in Milan as its legal site with the support of ESO and the Oncologic Center Antwerp (OCA). The original confederation formed with 12 autonomous national organizations expanded rapidly to 23 groups representing their respective countries in 2010. It represents and supports patient groups focused on prostate diseases in general and prostate cancer in particular. The aims include increasing the awareness of prostate diseases, the support of individualized treatment based on optimal medical treatment and personalized care as well as patients' advocacy as a priority focused on quality of life, based on solidarity and mutual respect.

These goals are clearly expressed in our 2004 Manifesto (Table II). The ten objectives speak for themselves where one should note the emphasis on quality of life as well as the promotion of prostate cancer research [3].

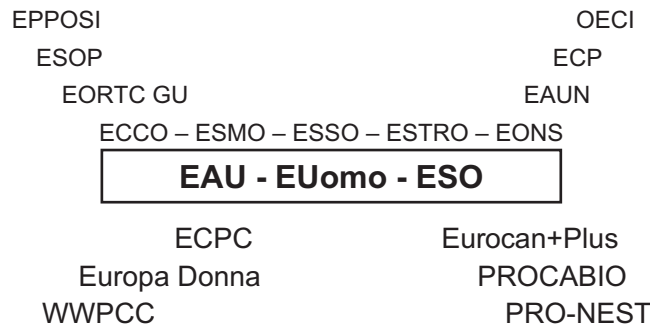
Our trust in optimal medical treatment which we consider the responsibility of the treating multiprofessional group brought us the sympathy and genuine support of the professional groups. Our updated and evidence based information/education standards are exclusively from top of the bill professional support. For Europe we have received first quality instructions from our multiprofessional scientific committee and the executive board of the European Association of Urology (EAU). Please note that in the European health care organization based on national health care systems our national membership groups have their own scientific committee to implement the updated European guidelines adapted to their culture and standards.

On the other hand we want to be involved in patient-centered care that we like to share with a broad support on all aspects of care including psycho-social,

Table IV. Proactive prostate cancer call out.

- Governments to be aware of prostate diseases
- Governments to support research biomarkers
- Remember the risk factors of prostate cancer
- Tailored treatment to the individual patient through appropriate use of PSA test
- Partnership building to reduce burden of disease, identify common actions and overcome inequalities in medical treatment and holistic care

Partnerships Europa Uomo



Europa Uomo 2010

- Europa Uomo (EUomo)
- European Association of Urology (EAU)
- European School of Oncology (ESO)
- European CanCer Organization (ECCO)
- European Society for Medical Oncology (ESMO)
- European Society of Surgical Oncology (ESSO)
- European Society for Therapeutic Radiology and Oncology (ESTRO)
- European Oncology Nursing Society (EONS)
- Genito-Urinary group of the European Organization for Research and Treatment of Cancer (EORTC GU)
- European Society of Oncology Pharmacy (ESOP)
- European Platform for Patients' Organizations, Science and Industry (EPPOSI)
- European Association of Urology Nurses (EAUN)
- European Cancer Prevention organization (ECP)
- Organisation of European Cancer Institutes (OECI)
- European Cancer Patient Coalition (ECPC)
- Europa Donna
- WorldWide Prostate Cancer Coalition (WWPCC)
- Eurocan+Plus
- European initiative to develop tailored treatment of PROstate CANcer by BIOMarkers (PROCABIO)
- Prostate Research Organizations-Network of Early Stage Training (PRO-NEST)

Figure 1. Partnerships Europa Uomo.

emotional, spiritual and financial problems related to disease (Table III).

This policy worked so well that we organized a proactive prostate cancer call out in 2009 with our European Association of Urology (EAU) and ESO partners [4]. The call out is presented in Table IV. This call proved to be an instant hit and was immediately endorsed by the main oncological and patient organizations (Figure 1).

This European network contains all the expertise represented by surgeons, radiation and medical oncologists, nursing, technicians and all health and social personnel needed for its ultimate goal to provide optimal treatment and holistic patient care

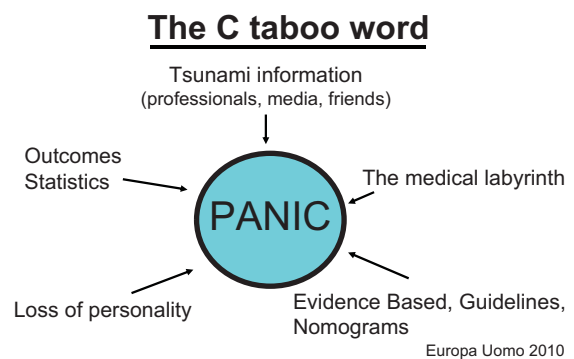


Figure 2. The C taboo word. The word cancer is a taboo word for patients in the diagnostic process causing a vision of death by cancer and acute panic in many instances.

Table V. Typical patient complaints.

Improper, incorrect information
The doctor has no time
No choice in their own treatment
Lack of respect

covering psychological, emotional and social needs of the patient.

The decision of the European Commission to invite patient support groups to participate in the European Partnership Action Against Cancer (EPAAC) program is a milestone in the integration of the patient as a partner in cancer clinical research in Europe.

The role of a patient group

And yet despite of all this hard work and dedication by many we still face the sad problem that a newly diagnosed unprepared cancer patients faces the spell of the great C taboo word that his life is at stake and his quality of life gone for the rest of his remaining days (Figure 2) [5].

We call it the “lost” patient syndrome. A state of mind that stays for a number of days or weeks despite concerted efforts of the general practitioner, the nursing or data manager. A well known moment in the disease history where the patient has an endless list of questions and the doctor has never time to answer them. Here starts the supporting role of the patient support groups united in a shared mission, to mobilize the solidarity of the survivors to provide correct, updated, clear and validated information in a stepwise manner on the medical pathway from diagnosis to beyond primary treatment [6]. Ideally public awareness on the history of the disease has been available for the general public before the diagnosis. Further education, a sympathetic ear and understanding psychological and emotional distress can be improved by the shared experience of being treated for cancer [7].

The pitfalls next to the need for the “perfect” information/education are the number of experts to be encountered in a less than smooth circuit, the inflexible guidelines or nomograms representing cohorts but

Table VI. Role of prostate cancer patient support groups.

1. Involve in all aspects of holistic care;
2. Establish fast and cheap networks of reliable, updated information/education;
3. Support optimal medical treatment for all as well as research be it translational or basic;
4. Sharing best practice and aim for expert prostate centers;
5. Save health resources by avoiding duplication or unreliable diagnostic procedures.

Table VII. Partnership with patient groups.

1. Strength in numbers (votes) can be influential in political (Health Authorities) policies;
2. A plus factor in negotiations with government bodies (Landmark 2010);
3. Enables an independent flow/exchange of medical information and best practice (Watch the source);
4. Partnerships reinforce recognition.

never individuals and unfortunately the incomparable, uncontrollable outcomes in the world of medical practice. Here we hope to see the development of reference expert centers in the near future with breast cancer as a good example.

A special attention should be given to the loss of personality in the hospital environment when one becomes a room number or worse a disease number. In our modern society where good manners and etiquette seem to be fading for the egocentric approach patients resent that they are improperly informed, the lack of time from the doctor for their needs, the exclusion of choice in their own treatment and, yes a lack of respect from the doctor. Typical examples are a number of phone calls during the medical anamnesis, a decision chat with a naked or undressing patient and ridicule any alternative treatment that the patient has chosen (Table V).

It is less of a problem in private practice but it should be avoided as a general rule in any hospital or hospice. An atmosphere of relaxed respect and proper communication solves many misunderstandings in the daily routine where an informed, prepared patient makes the chores of the nursing and medical staff much easier.

Let it be known that Europa Uomo in this era of legal patient rights and charters equivocally sees a number of recommendations/obligations of patients and their relatives and friends to the multiprofessional treating team. These obligations involve respecting the standing rules in the different areas

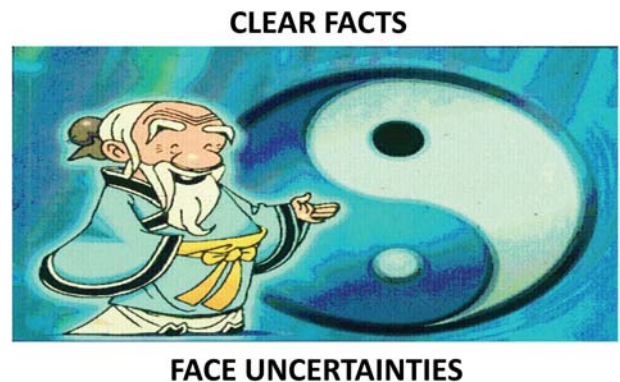


Figure 3. A ying and yang balance is advocated in information, and treatment of cancer.

Table VIII. Phases in the treated history of prostate cancer.

1. Suspicion:
 - Serendipity according to age
 - Risk factors
 - Positive marker(s) (PSA)
2. Confirmation:
 - Biopsies
3. No diagnosis without prognosis
4. Primary treatment:
 - Overdiagnosis (AS)
 - Underdiagnosis
5. Secondary treatment (WW)
6. Castration Resistant Prostate Cancer (CRPC)

of treatment, understanding the communication failures that can happen in busy centers, see the staff as trained individuals and above all inform them on any kind of other treatment or advice that one receives.

The fact that many cancer diseases especially breast and prostate become long time chronic diseases by the disease or by the treatment should encourage both doctors and patients to engage in a mutual congenial partnership [8].

As a conclusion one sees the constructive role of the patient support organizations as effective to reach holistic care, organize cheap and efficient grass roots information, support basic and clinical research and by being partner save money for unnecessary examinations in follow-up, chronic care (Table VI) [9]. These efforts and outcome results in improving health care can be easily multiplied by expanding the network. Basic requirements are shared interests, similar objectives and a good transparency of the positive but different goals of the participating partners including all possible stakeholders. Each association or project has its own broad or targeted agenda. The last thing one needs is an hidden agenda as a successful partnership is based on win-win situations where the expertise and/or the means of the different partners are utilized to reach a common goal (Table VII).

The horizon of the patient

Coming back to the individual prostate cancer patient still his horizon is the treating urologist. It is understandable as the track record of the urological specialty involves the mortality reduction of benign prostatic

Table IX. Active surveillance vs. watchful waiting.

Active Surveillance	Watchful Waiting
Fit patient	Co-morbidity/age
Low risk cancer	High risk cancer
PSA dynamics define treatment (+ biopsies)	Symptoms define treatment
Option: cure	Option: palliation

Table X. In a nutshell.

1. Prostate cancer is a heterogeneous disease with a long, natural history.
2. This chronicity is specific for the disease but includes treatment related illnesses.
3. Age is the most important risk factor increasing the burden in an ageing society.

hyperplasia (BPH) to zero following an orderly transition from surgery to medical treatment of lower urinary tract symptoms (LUTS) and still looking for less invasive treatments.

The track record of managing prostate cancer has been less spectacular and has been uneven in the balance of facts and remaining open questions. In a way we watched the importance of two Noble prizes to reward progress in the clinical treatment of prostate cancer. The first one bestowed on Charley Huggins 25 years after his fundamental studies on the physiology of the prostate resulting in the surgical castration as primary treatment of prostate cancer. The second one bestowed on Andrew Schally for his isolation and analysis of the natural LHRH decapeptide leading to a tsunami of medical castration.

All patients with prostate cancer have been treated or threatened with some endocrine manipulation and most have enjoyed the palliative power of primary endocrine treatment in a far advanced, metastatic prostate cancer. It is only in the last decades and after the outcomes of randomized, clinical trials that it became clear that managing prostate cancer involves more than endocrine treatment [10].

As simple observers of clinical progress and translational/basic research in cancer we are sometimes surprised by the professional groups ignoring clean facts and unanswered questions alike in proposing clinical decisions to their patients. We prefer to balance facts and uncertainties according to old wisdom before we try to come to a shared decision on important crossroads in the treated history of dealing with one's prostate cancer (Figure 3).

A patient diagnosed with prostate cancer goes through different phases of the disease (Table VIII).

Table XI. Incontinentince/erectile dysfunction by treatment or age.

Treated	vs.	Normgroep
Incontinence urine 23-48%	vs.	4%
Incontinence bowel 5-14%	vs.	2%
Erectile Dysfunction 40-74%	vs.	18%

Thesis F. Mols, 2007

Table XII. Existing uncertainties in the management of prostate cancer.

1. PSA figures, biopsies, Gleason grading
2. Imaging TRUS, MRI
3. Improvements in surgery, radiation
4. The biology of man and his cancer(s)

First of course the serendipity of the cancer and an increased PSA number. Second confirmation of the suspicion and then going for a reliable prognosis. Once established it is time to discuss primary treatment among the available procedures including active surveillance.

The next phase, many times disappointing, is the outcome result of the primary treatment and its side-effects. Again another shared decision in secondary treatment is important and the outcome of this treatment and its side-effects.

Last of course is the recognition that our prostate cancer is progressive and ultimately lethal. Here the treatments look more invasive as they don't carry the promise of cure. The choice should include watchful waiting. The latter is very different from active surveillance as here there is no chance to return to primary, curable treatment (Table IX) [11].

By this time the need for a multiprofessional team is so obvious that the urge to establish expert prostate units in our health system becomes more attractive to the patient and professional alike.

Despite the label of incurable cancer many people can and do enjoy good quality lives. It is usually in the last year of their lives that prostate cancer suffer from the disease progress expressed in back pain, bone fractures, anemia, fatigue and lower urinary tract obstruction.

Prostate cancer is a chronic, heterogeneous disease with high incidences in the seventh and eighth decade of life with a specific mortality in the ninth decade. The low mortality, meaning death by prostate cancer, is relative (2–4%) as the number of patients is so high and most patients still die by their concomitant lethal diseases (Table X).

Future expectations

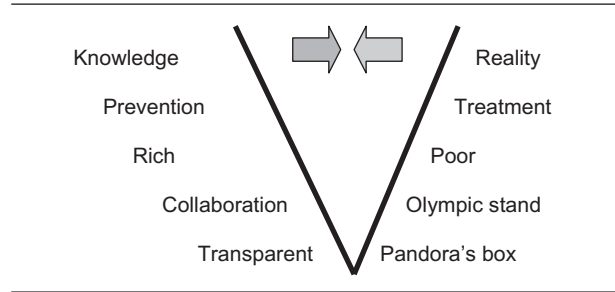
What do patients and their respective groups expect in future, optimal treatment?

First and above all a good communication line between the different members of the multiprofessional team with a transparent, open information to the

Table XIII. A plea from Europa Uomo.

Focus on the man first and then on his cancer.
 Improve outcome by multiprofessional action and expert Prostate Units.

Table XIV. Priorities to improve management of cancer.



patient. It would start in choosing treatment, now based on nomograms and guidelines [12,13], with objective, reliable treatment results and side-effects. The side-effects of curative treatment are sometimes underestimated for the individual patient. The figures related to primary treatment are important (Table XI).

Treat the available diagnostic uncertainties with common sense to keep the confidence of the patient. These uncertainties include the PSA numbers, the biopsies, the nomograms, the Gleason score and the imaging procedures. Improvements are possible and expected in all domains. For screening, prevention and primary treatment results we wait for the ongoing clinical trials (Table XII) [14].

Last we have seen improvement in treatment results of castration resistant prostate cancer (CRPC). Here the patients expect access to these clinical trials or new treatments. If one looks for a bottom line we should advise to treat the man and his co-morbidities first and then his cancer (Table XIII).

All these factors are condensed in Table XIV where we express hope that the existing gap between the available knowledge and the practiced reality may close in the near or distant future.

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