East Lancashire Prostate Cancer Support Group Newsletter

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Most men with early prostate cancer do not benefit from primary androgen deprivation therapy

Wednesday 19 March 2014 - 12am PST Medical News Today

What's Inside

"Please Note" April Meeting Now 17th April 2-4pm Mackenzie Centre

A study of more than 15,000 men with early stage prostate cancer finds that those who received androgen deprivation as their primary treatment instead of surgery or radiation did not live any longer than those who received no treatment.

The research team, led by scientists at Georgetown Lombardi Comprehensive Cancer Center, say that the risks of serious adverse events associated with the treatment - which has been linked to impaired cognition, heart disease, diabetes and other disorders - "mitigates against any clinical or policy rationale for use of primary androgen deprivation therapy in these men."

The findings, reported in the *Journal of Clinical Oncology*, draw from cancer registries linked with extensive electronic medical records in three, large integrated health plans. The men included in the study had prostate cancer that had not spread beyond the organ (localized) and did not have surgery or radiation therapy, considered curative treatment.

Androgen deprivation therapy suppresses the production of testosterone, the male hormone said to fuel growth of prostate cancer. The therapy improves survival when given with radiation for later stages of disease, and is considered the standard of care for men who have metastatic prostate cancer. Effectiveness of primary androgen deprivation therapy (PADT) has not been established.

"This study is the most comprehensive study on the effectiveness of PADT for men who forgo radiation and surgery for their localized prostate cancer, and it tells us there is no strong reason to use it in most patients," says the study's lead investigator, Arnold Potosky, PhD, a professor of oncology and director of health services research at Georgetown Lombardi. "We found only a small survival benefit for primary androgen deprivation therapy compared to no therapy in men diagnosed with higher-risk localized prostate cancer."

Use of primary androgen deprivation therapy for early stage prostate cancer is widespread. Despite the lack of randomized clinical trials to test its effectiveness, recent studies have reported it as the second most common treatment, after radiotherapy, for clinically localized prostate cancer among older men age 65 and older. The study did not compare androgen deprivation therapy

directly to either surgery or radiation therapy, the two main curative treatment options for prostate cancer. While the study did not probe the reasons why physicians prescribe the treatment in this setting, it was much more common in older men and those with higher risk of disease progression. Potosky speculates that men and their doctors may feel the treatment is a useful option to delay progression of prostate cancer for men who are not good candidates for, or who prefer to avoid, surgery or radiation due to their side-effects.

"Primary androgen deprivation therapy may be preferable to some men with early stage prostate cancer who would prefer to do something rather than watch and wait for further signs of progression to occur later and then need treatments," Potosky adds. "However, using PADT by itself immediately after diagnosis in the hopes of limiting cancer's progression does not extend survival, according to this study." The researchers are now using their database of 15,170 patients to examine rates of potential side effects from the treatment. "Given the aging American population, more men are likely to be faced with prostate cancer so its is very important to understand the whether the risks of primary androgen deprivation therapy outweigh the survival benefit," he says. "Ultimately, this is a decision for men and their doctors to make together, and we hope that our study provides some helpful information to guide these decisions."

References

Researchers from Kaiser Permanente Southern California, Kaiser Permanente Northern California, Henry Ford Hospital, Boston University School of Public Health, Harvard Medical School, Massachusetts General Hospital and the Neiman Health Policy Institute participated in the study. The authors report having no personal fi-

Risk of prostate cancer death decreased by PSA-testing and early treatment

Wednesday 12 March 2014 - 12am PST Medical News Today

Mortality in prostate cancer is lower in areas with frequent use of PSA testing compared with areas with little testing shows a study published online in *Journal of the National Cancer Institute* by researchers from Umeå University, Sweden and Memorial Sloan Kettering Cancer Center, New York, NY, USA.

The study is based on data from nation-wide, population-based registers in Sweden including the Cancer Register, The Cause of Death Register and the National Prostate Cancer Register (NPCR) of Sweden.

"Our results show that prostate cancer mortality was 20 percent lower in counties with the highest incidence of prostate cancer, indicating an early and rapid uptake of PSA testing, compared with counties with a slow and late increase in PSA testing," says Pär Stattin, lead investigator of the study.

"Since the difference in the number of men diagnosed with prostate cancer is related to how many men undergo PSA testing, we think our data shows that PSA testing and early treatment is related to a modest decrease in risk of prostate cancer death," says Håkan Jonsson statistician and senior author of the study.

"In contrast to screening in randomized studies our data is based on unorganized, real life PSA testing. We therefore used a statistical method that excludes men that were diagnosed prior to the introduction of PSA testing since these men could not benefit from the effect of PSA testing," continues Håkan Jonsson.

"The results in our study are very similar to those obtained in a large European randomized clinical study (ERSPC) thus confirming the effect of PSA testing on the risk of prostate cancer death. However, we have to bear in mind that the decrease in mortality is offset by over-treatment and side effects from early treatment. PSA testing sharply increases the risk of over-treatment, i.e. early treatment of cancers that would never have surfaced clinically. We also know that after surgery for prostate cancer most men have decreased erectile function and that a small group of men suffer from urinary incontinence. Our data pinpoints the need for refined methods for PSA testing and improved prostate cancer treatment strategies," concludes dr Stattin.

National Cancer Patient Experience Programme 2012/13

Presented at the March Meeting by Deborah Dobson

At a very well attended March meeting it was delightful to be informed and entertained by one of our founder members Deborah Dobson (Urology Nurse Specialist).

The subject was the recent NHS National Survey on Patient Experiences whilst undergoing treatment within the System. Ranging through all aspects of Patient Care.

Deborah's focus, being a Urology Nurse Specialist and part of our group was on the Treatment of Cancers (Page21 of the report below) which made comparisons %wise to three questions that were asked about access to their GP. The final report is available to view at the link at the bottom of the page (Each area of the country has published it's own report, the link below is for the East Lancashire Hospitals NHS Trust just click or enter the link then enter your post code etc to find your hospital and Department for the results).

National Cancer Patient Experience Survey 2012/13
East Lancashire Hospitals NHS Trust

Comparisons by tumour group for this Trust

The following tables show the Trust and the national percentage scores for each question broke
tumour group. Where a cell in the table is blank this indicates that the number of patients in that
below 20 and too small to display.

Seeing your GP

	Q1. Saw GP once/twice before being told had to go to hospital		Q2. Patient thought they were seen as soon as necessary		Q4. Patient's health got better or remained about the same while waiting	
Cancer type	**This Trust**	**National**	**This Trust**	**National**	**This Trust**	**National**
Breast	95%	92%	90%	90%	93%	94%
Colorectal / Lower Gastro	64%	69%	78%	81%	80%	76%
Lung	65%	68%	80%	84%	77%	75%
Prostate	87%	76%	89%	87%	90%	89%
Brain / CNS						
Gynaecological	76%	72%	81%	80%	74%	73%
Haematological	74%	63%	80%	81%	80%	68%
Head & Neck						
Sarcoma						
Skin						
Upper Gastro	85%	68%	97%	78%	50%	68%
Urological	86%	78%	89%	85%	85%	87%
Other Cancers	63%	65%	79%	77%	71%	72%
All cancers	80%	74%	85%	84%	82%	80%

From Left to Right Hazel Goulding (Treasurer) Leon D Wright (IT Admin) Stuart Marshall (Secretary) Steve Laird (Vice Chairman) Dave Riley (Chairman)

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We are a group of local people who know about prostate cancer. We are a friendly organisation dedicated to offering support to men who have had or who are experiencing the effects of this potentially life threatening disease.

The East Lanc's Prostate Cancer Support Group offers a place for free exchange of information and help for local men and their supporters (family and friends) who may be affected by this increasingly common form of male cancer.

At each meeting we strive to be a happy, supportive and upbeat group of people; encouraging open discussion on what can be a very difficult and perhaps for some an embarrassing subject. We have lively, informative, interactive, sharing and above all supportive meetings.

CIVITAS Healthcare Systems France: Sécurité Sociale

A Talk Given By

Colin Ormston

Anyone resident in France for more than three months must register at their local CPAM (see below) for national health insurance coverage. Having done this, an individual is issued with a 'carte vitale,' similar to a credit card that indicates national insurance rights in electronic form. The carte vitale is not a means of payment, but it does enable the government to credit patients with the correct level of reimbursement immediately (see below) and removes the need for the large amounts of form filling required under the old *carte d'assure sociale* system.[16] The carte vitale also enables a rapid exchange of information between health professionals and the CPAM. The French like their privacy and were concerned about the confidentiality of the personal information stored on the card. However, security is ensured by the need for a second doctors'

card—the *Carte Professionnel de Santé* (CPS), which identifies the doctor and must be entered into a machine along with the patient's carte vitale in order to access patient records.[17] The information subsequently transmitted can only be read by the CPAM and all personal details are guarded by the *Commission Nationale de l'Information et des Libertés*.

Organisation

The NHI system is administered in schemes according to occupation. The general

scheme, dominated by the *Caisse Nationale d'Assurance Maladie des Travailleurs Salariés* (CNAMTS: the public fund for salaried employees), covers approximately 87 per cent of the population, including CMU beneficiaries (see below).[18] The CNAMTS operates through a system of 16 regional and 105 local funds, each with a management board composed of an equal number of representatives of employers and trade unions.[19]

Other basic funds cover specific occupational groups: for example, the agricultural scheme (Mutualité sociale agricole, MSA) covers around 6 per cent of the population, comprising farmers, agricultural employees and their families.[20] There is also a large and recently improved scheme for the self-employed (Régime social des independents, RSI) which now provides the same benefits as the CNAMTS.[21] The three main schemes (CNAMTS, MSA and RSI) were federated by the 2004 reform act into a National Union of Health Insurance Funds that also has structures at regional level. This new federation has become the sole representative of the insured in negotiations with health care providers.[22]

CPAMs, also known as the sécu of the CNAMTS, are responsible for the reimbursement of claims and benefits. They also manage preventive services and general sanitary and social care in their area.[23] The *Caisses Régionale d'Assurance Maladie* (*CRAM*), which now fall under their respective ARS, assume responsibility for the CPAMs in their area.[24]

NHI Coverage

Although the French health care system is predominantly publicly financed, treatment is not free at the point of use; instead, patients will usually pay an up-front cost which is partially reimbursed by the government. The carte vitale system means that this reimbursement is usually immediate: a laudable innovation as it prevents patients from being greatly out-of-pocket until reimbursement is received.

The rate of NHI coverage (reimbursement) varies across goods and services but there are several reasons for which patients are exempt from co-insurance. For example, those with chronic conditions such as diabetes and AIDS are exempt from co-payments, as are pregnant women after the fifth month, handicapped children and war pensioners too.25

Below are some examples of NHI reimbursement rates:26

- Hospital treatment: typically 80 per cent of the cost will be reimbursed to the patient, although there is a daily charge of €18 for stays over 24 hours.

- GP visit: 50-75 per cent depending on compliance with recently introduced gatekeeping system (see below)

- Vaccinations: 65-100 per cent

- Prescriptions: 35-100 per cent depending on their medical necessity and effectiveness.

- Dentist treatment: 70 per cent

- Other expenses, including transport costs: 30 per cent

The remaining costs not covered by NHI, known as the 'ticket moderateur', can be reimbursed if the patient is a member of a voluntary private health insurance plan. However, some recently introduced co-payments are not reimbursable by either NHI or VHI and are intended to improve patient cost-consciousness without causing great financial strain. These co-payments are limited to an annual ceiling of €50 and include: €1 per doctor visit, €0.50 per prescription drug and €18 for hospital treatment above €120. In a further attempt to control costs, NHI will reimburse a greater proportion of health care costs if a patient registers with one doctor (their 'médecin traitant'). This doctor is considered to be the first step in a coordinated care pathway and therefore the system follows a form of gatekeeping. If a patient does not declare which doctor they are registered with, they cannot follow a coordinated care pathway and are therefore liable to pay higher co-payments that cannot be covered by VHI.[27] This provides a strong incentive for French citizens to register with a doctor, who becomes their first port of call for health care needs that cannot be solved by the pharmacy.

Medical goods and services covered

Medical goods and services

qualifying for coverage by NHI include:28

- Hospital care and treatment in public or private institutions providing health care, rehabilitation or physiotherapy;

- Outpatient care provided by GPs, specialists, dentists and midwives;

- Diagnostic services and care prescribed by doctors and carried out by laboratories and paramedical professionals (nurses, physiotherapists, speech therapists, etc.);

- Pharmaceutical products, medical appliances and prostheses prescribed and included in the positive lists of products eligible for reimbursement;

- Prescribed health care-related transport.

In order to be eligible for coverage, diagnostic services, treatment, drugs and prostheses should have been provided or prescribed by a doctor, a dentist or a midwife and distributed by health care professionals or institutions registered by NHI.

Initially, NHI was supposed to focus on the coverage of curative care in the case of illness or accident. In practice, however, more and more preventive care is covered, particularly for preventive treatment provided in a doctor's practice, such as mammography, cervical smear tests and recommended immunisations. Since 2007, a fixed budget of €50 per year has also been allocated to smokers for covering smoking cessation goods.[29] NHI does not cover cosmetic

Real Enough to be Honest

Readers Shared Stories Prostate Cancer Survivors Recount Tales of Incontinence and Other Side Effects. (Low Blow on NBC News)

Many of the guys in my Malecare prostate cancer support group deal with pee. Some for a year, as your surgeon told you, and a few, probably forever. What all tend to say after a few months passes from surgery is they have no regrets. They are alive and hope to die from something other than prostate cancer. So, do know, you are not alone, and guys you do not know are thinking of you.
Anonymous

It takes a real man to admit he struggles with incontinence, impotence and some of the other side effects that can accompany prostate cancer treatment

And a lot of you are real men, confident enough in yourselves, your manliness and your bodies to recount for others the paths you've traveled.

In response to the last "Low Blow" installment, where MSNBC.com reporter Mike Stuckey revealed that he "pees his pants" following surgery, many readers wrote to tell him he's not alone — and not to be ashamed. The brotherhood understands, even if others don't always, one man wrote.

Some offered practical tips on dealing with incontinence and while others wrote about how its changed how they feel about themselves.

Read on for more reader comments:

Except for a few details, the story could have been about me. Only it took over three years for me to go without a diaper. Even now I have an occasional squirt or drip, mostly when I do heavy lifting. Too much coffee seems to affect the frequency and amount of pee. On the plus side, I'm retired and can easily stop what I'm doing to go change. But more than anything I now feel confident that I can control it. I even took a three-hour flight a few weeks ago and my "precautionary" diaper was dry as a bone when I arrived. With my PSAs showing "No measurable amount," I'm