East Lancashire Prostate Cancer Support Group Newsletter

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What's Inside

Guardian Newspaper's story about choline shortage affecting prostate cancer patients awaiting PET CT scans

Please note: I'm sending this email to all prostate cancer support groups I found on the Prostate Cancer UK website. I've spoken with Karen Stalbow of Prostate Cancer UK and she's aware I'm doing this. I'm not suggesting she's authorised it, as no one has. I'm sending it off my own bat, as I believe my recent experience that made the news about PET CT choline scans/PSMA scans is worth sharing.

Hello

My name's Richard. I was briefly mentioned in a story published in Monday's Guardian Newspaper about prostate cancer and a shortage of a cancer scan tracer called choline.

I'm going through prostate cancer diagnosis for a third time. I'm with UCLH in London.

Because of a lengthy wait for a PET CT choline scan with UCLH in March/April, when I rang hospitals around the UK to check the cause of the hold-up, one of them said "… *there's a national choline shortage.*"

As I know the Guardian Newspaper's journalist Haroon Siddique, I let him know. He did some research which confirmed there was, or had been a shortage, and wrote the story in the link above.

The key things to note in the story:
PET CT choline scans are only given to guys with recur-

rent prostate cancer, so it only affects some of us. And, in the article, UCLH confirm the NHS has made funding available to reduce the lengthy waits for PET CT choline scans by making the more sensitive and better PSMA scans accessible *"for a limited period"*. In theory, this should apply across the UK, as Haroon received confirmation there had been a national shortage. It's amazing the way the government's magic money tree suddenly bears fruit when cancer stories make the news.

Clearly, there's no need for panic. But as a friend of mine who had prostate cancer 16 years ago is also slightly sceptical of the NHS's sudden promise to deal with scan delays now Haroon's story's hit the newsstands, I thought I'd make your group aware of the delays and lame excuses I initially received that made no sense.

The chances are you've seen the story but, if not, the above might give your some of your group's members awaiting PET CT choline scans the opportunity to politely press for a PSMA scan "*for a limited period*". I hope this helps.

With best wishes

Richard,

London.

Article available on the Link below.

https://www.theguardian.com/society/2019/apr/07/nhs-patients-have-prostate-cancer-scans-cancelled-after-supplier-problems-england

Prostate cancer incidence and mortality have declined in most Countries

April 2, 2019

American Association for Cancer Research

Prostate cancer incidence and mortality rates are decreasing or stabilizing in most parts of the world, with the United States recording the biggest drop in incidence, according to results presented at the AACR Annual Meeting 2019, March 29-April 3.

Despite the trend toward declining or stabilizing rates, prostate cancer remains the second most commonly diagnosed cancer and the sixth leading cause of cancer death among men worldwide, said the study's lead author, MaryBeth Freeman, MPH, senior associate scientist, Surveillance Research, at the American Cancer Society in Atlanta.

"Previous studies have indicated significant variation in prostate cancer rates, due to factors including detection practices, availability of treatment, and genetic factors," Freeman said. "By comparing rates from different countries, we can assess differences in detection practices and improvements in treatment."

Researchers examined prostate cancer incidence and mortality patterns across five continents using the most recent cancer incidence data from the International Agency for Research on Cancer and mortality data from the World Health Organization. They examined long-term trends, from 1980 through 2012, for 38 countries that provided "high-quality" data (information assessed as accurate, timely, and complete) and short-term trends for 44 countries with available incidence data and 71 countries with available mortality data. The short-term data encompassed a five-year period that varied slightly among nations, but most often reflected 2008-2012.

Of the 44 countries examined for incidence data, prostate cancer rates during the most recent five-year period increased in four countries, with Bulgaria showing the largest increase. Rates decreased in seven countries, with the United States showing the largest decrease. Rates stabilized in the remaining 33 countries.

Among the 71 countries analyzed for mortality rates, rates decreased in 14 countries, increased in three countries, and remained stable in 54 countries.

Globally, as of 2012, prostate cancer was the most commonly diagnosed cancer among men in 96 countries and the leading cause of death in 51 countries.

Other findings: -- The highest incidence rates in the most recent five-year period were found in Brazil, Lithuania, and Australia. -- The lowest incidence rates in the most recent five-year period were found in India, Thailand, and Bahrain. -- The highest mortality rates in the most recent five-year period were found in the Caribbean, specifically Barbados, Trinidad and Tobago, and Cuba; South Africa; Lithuania; Estonia; and Latvia. -- The lowest mortality rates in the most recent five-year period were found in Thailand and Turkmenistan.

Freeman said she and colleagues were surprised and pleased to see that so many nations have achieved stability in prostate cancer rates, meaning that rates have not increased during the period examined. In coming years, she said, global health experts would hope for more nations to move from stability toward decreasing incidence and mortality rates.

Freeman said the study confirmed the impact of prostate-specific antigen (PSA) screening. She explained that in the United States, prostate cancer incidence rates increased from the 1980s to the early 1990s, then declined from the mid-2000s through 2015, largely due to increased use of PSA screening. This type of screening is less available in lower-income nations, contributing to diagnosis at later stages and higher mortality rates, Freeman said.

Freeman pointed out that some nations plan to scale back recommendations for PSA screening, as it is believed to lead to diagnosis and possible overtreatment of prostate cancer cases

that would never become symptomatic.

"Overall, patients should be having an informed discussion with their providers about the benefits and harms of PSA testing for detection of prostate cancer," she said. "Future studies should monitor trends in mortality rates and late-stage disease to assess the impact of reduction in PSA testing in several countries."

Freeman said one limitation of the study is the variability in data among different countries. For example, some countries may have only collected data from certain geographic areas, whereas others may have collected data from the whole nation. However, she added that the breadth of data in this study allowed researchers to draw a comprehensive portrait of prostate cancer incidence and mortality around the world.

Story Source:

Materials provided by **American Association for Cancer Research**. *Note: Content may be edited for style and length.*

PROSTATE CANCER UK

YouTube, 8th hole dedication and funding research: golfers club together to stop prostate cancer

All over the UK, golf lovers are rallying together against prostate cancer, raising over £700,000 in the last year alone. Here we meet just a few of our supporters doing what they can to beat a disease that kills 1 man every 45 minutes – the time it takes to play 3 holes of golf.

15 Apr 2019 In - Our supporters Golf Comments (0)

Rick's #YTGolfDay

Rick Shiels, PGA pro and iconic name in the YouTube golfing community, is using social media to open up his fundraising to the world. Next month, Rick (pictured above) will generously donate all proceeds from the world's first YouTube golf day at Formby Hall to Prostate Cancer UK. With over 40 of the biggest golfing online content creators set to take to the green on 6 May, it promises to be an iconic, action-packed day. Why not put the date in your diary and tune in?

Andrew Murray – our golf championship host

Former European tour golfer Andrew Murray has been supporting us for over five years and will host our golf championships this September in Belfast, Birmingham, Glasgow, Cheshire and Middlesex. Want to come? Raise money this summer and we'll invite you to say thanks.

Andrew helps us drive home the message in support of his golfing mentor Brian Nield who is living with prostate cancer by hosting his own charity golf day and by hosting ours. He's one of a growing number of PGA professionals joining the fight. See you in September Andrew!

Josh Muncie and the 8th hole initiative

Josh Muncie at Sanquhar Golf Club in Dumfries, Galloway, is joining in with our 8th hole initiative. He asked his club if they could dedicate their 8th hole to raise awareness of the disease affecting one in eight men.

"Sanquhar Golf Club is proud to be signed up to the 8th hole initiative. The club will do as much as they can in any way to help raise money and awareness to stop prostate cancer. If any golfer lands a ball in any of the three bunkers they'll give a donation to the cause," said Josh, who lost two grandfathers to the disease.

Alison Levy and Abridge Golf Club

Alison Levy, Chairman of the Charity Committee at Abridge Golf Club, has hit a hole in one and raised an incredible £13,000 from golf days at her club in memory of her dad who sadly died from prostate cancer.

Alison will be putting the funds raised towards vital research being carried out by Professor of Nanotechnology Paula Mendes (pictured above). Paula and her team at the University of Birmingham are developing a highly accurate PSA test to better identify high-risk cancers while at the same time reducing unnecessary interventions for those that are low risk. The £13,000 raised by Alison and the

ladies at Abridge will enable Professor Mendes' lab team to buy a microplate reader – a vital piece of equipment.

Simon de Castella and the Vestis Golf Tour

Simon de Castella has a novel way to raise money with the Vestis Golf Tour. We'll let Simon tell you more:

"We run Vestis Golf Tour like a professional tour to allow players to experience what it's like. Entrants receive welcome packs, get announced on the first tee and can win lots of amazing prizes. Money is raised through challenges, pro clinics, sponsored outfits, friendly betting between the players, and selling branded merchandise on event days."

"I support Prostate Cancer UK for Dad and the memory he's left behind. Within the two and a half years since his death, the progress in research and understanding of the disease has come on a staggering amount. That wouldn't be possible without donations to Prostate Cancer UK."

Thank you

Thank you to thousands of golfers, PGA professionals, our partners in golf (the PGA, European Senior Tour, HowDidiDo and Golfshake) and clubs across the UK for rallying together and raising awareness to help stop prostate cancer being a killer.

Tumour Humour

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Abstract

An anecdote from a radiation-oncology setting is the underpinning of this recommendation that physicians consider introducing humor into the doctor-patient relationship.

A 64-year-old man was referred to me to discuss therapeutic options for his recently diagnosed prostate cancer. His wife told me that “John was paralyzed by the choices.” Because the urologist sent a detailed note along with magnificent MR images, the patient expressed reluctance when I gestured that the time had come to perform a digital rectal examination of his gland. Then, just as my gloved finger anticipated palpation of the nodule, he thunderously farted. “Is this what they mean by being in the cloud?” I asked. Rather than retorting with an I-told-you-so, he craned his neck backward and cheerfully reciprocated: “It just goes to show you that physicians aren't the only ones who offer sound advice these days.” Approximately 90 minutes later, at the end of the visit, the patient consented to receive a course of external beam irradiation and hormonal therapy under my direction.

Although admittedly low-brow, the anecdote illustrates how both patients with cancer and their oncologists might resort to humor even at the outset of their relationship. “Humor” and “cancer” are words that rarely exist in the same sentence. Yet though it is risky to conjoin the two, there are moments when nothing could be more appropriate.

According to Martin and Lefcourt [1], the “humor-health hypothesis” suggests a beneficial link between humor and health that may occur by direct or indirect processes. Proponents of the direct variant assert that humor brings positive physiologic changes that may manifest in altered pain thresholds, immunopotentiation, and even extension of survival for patients with certain diseases. In contrast, the indirect humor-health hypothesis implies that humor may moderate feelings of misery or be socially beneficial. Although humor has been studied in numerous clinical settings, very little literature exists to guide cancer physicians on how best to use humor in practice.

Neither giggles nor belly laughs are likely, on their own, to vanquish the malignant cells lurking within our patients, but humor can make its contribution toward combating malignancy. Humor can soothe a patient's tension, unmask hidden sentiments, or reveal subconscious beliefs, providing important information for physicians. Even in the absence of rigorously proven health benefits, humor can improve the patient-doctor relationship and enable both partners to proceed more effectively together through decision making and treatment.

Oncologists have only recently contemplated how to integrate humor into their workflow. Penson et al. [2] contended that humor may be an indispensable clinical tool because it can lighten the mood of a difficult consultation, soften feelings of isolation, and unite patient, caregiver, and family. The authors share tips for inserting humor into medical practice. They suggest using "safe" one-liners—for example, ridiculing popular targets, including lawyers and politicians—or encouraging lighthearted behavior—for instance, allowing a child to paste disposable tattoos on the patient's bald scalp to soften the starkness of alopecia.

Many of us can similarly draw from our own basket of playful gimmicks. One that works for me, particularly during a first encounter in my radiotherapy practice, is to sketch the anatomical regions through which x-ray beams will travel. Typically, a puzzled look accompanies my patient's effort to decipher my drawing ("Is that a heart or a pancreas?"), whereupon I reassure, "I'm a much better physician than I am an artist." Next, as I illegibly label my primitive diagram, I ask the squinting viewer, "What do you call someone who can read a doctor's handwriting?" then I quickly provide the answer, "A pharmacist!" Admittedly, in our era of electronic medical records, the relevance of that quip is diminishing, but even when the response is a wince rather than a smile, most patients recognize that I am trying to put them at ease and will generously contribute to the building of bonds between us.

In a survey of women treated for ovarian cancer at the University of Wisconsin, Rose et al. [3] noted a willingness of patients to hear traditional jokes and amusing stories from their gynecologic oncologists. More than 75% of respondents remark that humor helped them to cope with their diagnosis and alleviated anxiety. The investigators caution, however, that rapport with the physician appears necessary before humor can be invoked. The authors deem humor to be appropriate only after a climate of trust, a critical component of the therapeutic relationship [4], has been established. But I wonder. In order for humor to be effective, must trust pre-exist, or can humor effectively build trust?

I vote in favor of the latter. Unfortunately and too frequently, tall barriers (e.g., fears of transference) and deep moats (e.g., indifference) separate patients and doctors. Along with eye contact and attentiveness, humor serves as one of the most useful wall-scaling and moat-leaping devices that we tote in our amorphous black bag. Humor, provided it makes space for subjective tastes and cultural diversity, can be used to gently probe the convictions of those who seek our expertise. There is much to be learned about another human being when we delicately sprinkle the discourse with subtle sarcasm or occasionally resort to wryness and even eccentricity. Sometimes, we welcome humor by just recognizing another person's efforts to be funny and their willingness to be vulnerable. Such moments are precious and fragile. When I notice someone giving humor a try, I cannot help but discard my pretenses and become engaged. In almost any relationship, when one player is willing to lighten up, the other is able to open up.

Last week, I made a self-deprecating remark concerning my hospital's cuisine. This prompted a patient to free-associate about how all food repulsed her lately. We smiled—and sighed with relief. Because even though she had been diagnosed with gastric cancer, she was reluctant to reveal details about her daily eating habits. As trust began to build, we could

come to a decision regarding which adjuvant therapy to select. Specifically, we chose the regimen that was less dependent on her caloric intake. Humor need not be laugh-out-loud funny to have value.

When I inform colleagues that I consciously attempt to engraft humor into my medical practice, I am sometimes greeted with startled looks. I realize that there is something about the admixture of humor and illness that the human sensibility strains to assimilate. And of course, there are hazards in using humor. Some patients may feel that I am not earnestly relating to their ordeal. Others might conclude that I have crossed an invisible line of propriety or judge me to be less competent and therefore incapable of helping them. I hate to generalize, but physicians are by nature perfectionistic and proper. We cringe when humor—womp-womp—falls flat. Several years ago, a patient did not like one of my quips. “Why does everyone have to be a comedian?” she exclaimed. I apologized, yet the experience still stings. But what to do? To use humor is to assume risk.

I am encouraged when I observe patients lead the way by displaying iconic bumper stickers (“I had chemo today—What's your excuse?”), by wearing provocative T-shirts (“DO NOT DISTURB—Busy kicking cancer in the butt”), and by attending the one-woman shows of Tig Notaro and Julia Sweeney (God Said Ha!). I vividly remember, during my internship, an engineer I treated for a glioblastoma that had replaced much of his cerebral cortex. He dangled the waiver that the hospital made him sign, consenting not to use mobile phones while admitted…because they may cause brain tumors. He is no longer alive, but the ironic interlude that we shared lingers.

During an interview on a late-night talk show, comedian Jerry Seinfeld remarked that the hardest thing to do in life is to make someone laugh. I doubt that we will ever be able to measure whether a comedian’s work is more arduous than that of a neurosurgeon, coal miner, or Middle East diplomat, but Seinfeld's point, I think, is that the challenge of eliciting laughter demands getting to know another individual and his or her circumstances. Therefore, humor, I believe, can be a deeply human device.

When we strive to introduce humor into the patient-doctor relationship, we are acknowledging the “personhood” of those we hope to heal [5]. We are suddenly seeing people in terms of who they are rather than exclusively in terms of whatever ailment they have. At a time when modern medicine is accused of being sterile and routinized, the respectful pursuit of humor announces that we are not prepared to be detached. When we endeavor to ascertain what a patient deems humorous, we are taking an interest in another person: what matters to them and who they are.

Humor, including the black humor that so many of us exchange behind the scenes, need not be an adaptive response to mediate career-related stress or a prophylaxis against burnout. Humor must not arise from the power differential that separates physicians from patients but, ideally, emerge from the points of vulnerability that both harbor [6]. As such, humor is an emotional connector, and I believe that patients who are the recipients of such quests for humor feel cared for and find renewed belief in their doctors.

The vignette presented at the start of this article could have dissolved into shame or alienation. Instead, mutual willingness to consider humor helped bring a happy end. I am still not sure of how best to harness and apply humor, an intricate, context-dependent phenomenon. But that prostate cancer case, and so many others like it, have convinced me that clinicians who sincerely advocate humor are truly committed to celebrating the personhood of others and not just tooting their own horns.

Go to:

Disclosures

The author indicated no financial relationships.

Go to:

References

1. Martin RA, Lefcourt HM. Sense of humor and physical health: Theoretical issues, recent findings and future directions. Humor. 2004;17:1–19. doi:10.1515/humr.2004.005. [Google Scholar]

2. Penson RT, Partridge RA, Rudd P, et al. Laughter: The best medicine? The Oncologist. 2005;10:651–660. [PubMed] [Google Scholar]

3. Rose SL, Spencer RJ, Rausch MM. The use of humor in patients with recurrent ovarian cancer: A phenomenological study. Int J Gynecol Cancer. 2013;23:775–779. [PubMed] [Google Scholar]

4. Lee TH. Eugene Braunwald and the Rise of Modern Medicine. Cambridge, MA: Harvard University Press; 2013. doi:10.4159/harvard.9780674726567. [Google Scholar]

5. Chochinov HM, McClement S, Hack T, et al. Eliciting personhood within clinical practice: Effects on patients, families and health care providers. J Pain Symptom Manage. 2015 [Epub ahead of print] [PubMed] [Google Scholar]

6. Levinas E. Humanism of the Other. Champaign, IL: University of Illinois Press; 2003. [Google Scholar]

Abstract

Disclosures

References

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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.