I. The Trust Equation: The Patient's Point of View

3------Mr. Darryl Mitteldorf

I will give the patient's point of view on communication and the trust equation. To the many patients here, I will try to leave you with some take-homes. Most of you know me from the Male Care Group. I am also an oncology social worker in private practice for the last 12 years. I have seen about 1300 patients, most all of whom were presenting initially with prostate cancer and associated anxiety. I have seen the dark side of the patient-doctor relationship, so forgive me if my presentation is morbid and depressing, but I will try and not let that happen. Also, don't let me forget to mention doughnuts; doughnuts are very important for this.

There are several things that patients present with when meeting with their doctors which end up being the source of disappointment, and that is an assumption that their doctor will instantly and perhaps magically understand what their lives are about, what is going on for them, and who they are as men. Patients assume that doctors know who they are, but in the 10-15 minutes you spend with a doctor, they cannot completely grasp who you are as a man; they will not know your concerns regarding prostate cancer diagnosis, treatment, or how you want your life to ensue for the rest of your natural life.

No one is going to know who you are unless you tell them. As Dr. Litwin mentioned, it is better to be able to tell, the opposite of don't ask, don't tell. That said, there are many patients who do not want to come out to a doctor as a gay man and a number of other different issues, and that is okay. Simply feeling comfortable that it is possible to tell your doctor who you are, can allow you to have a better experience with your doctor. Yet, there are limits to what a doctor can really understand about you. Not every doctor is gay; in fact, very few doctors are, and those who are not may not be entirely out. Each man must understand that there are limits to what a doctor can do for them. It is not incumbent upon a patient to have to teach their doctor what their lives are about, but it is good to have some sort of feeling of comfort that it is possible to do so. Every patient should try and find a way to find comfort within their doctor, in part by knowing his own body as well as you possibly can.

Every time you go to your doctor's office, get copies of everything; take it home, spend a few minutes relaxing in front of it, then attempt to digest what is written in front of you. The goal is for you to feel confident and somewhat more in charge of your treatment and of the understanding of what that treatment means to you and your life and your body. If you have questions, ask your doctor, even call him as soon as possible to get an answer.

Not every doctor can control the hospital experience. You want your doctor, especially if you are a gay man, to have preparation around visitation rights. As a gay man, you know there are circumstances where people are going to behave in ways that simply do not feel good to you; you want to work with your doctor to mitigate any related issues. It is incumbent upon our shoulders as patients or patient advocates to speak to our doctor and clearly enunciate what our needs are.

Regarding doughnuts: every nurse on Planet Earth that I have ever met likes a doughnut. Most patients that have gone into hospital stays with a 12-pack of Dunkin' Donuts and

have left them on the nursing station has reported to having a wonderful experience in the hospital. Bribe your nursing staff. Bribe every shift of nursing staff with doughnuts. The underlying aspect of that is to know that people are people; just because somebody has an LCSW or an MD or an RN after their name does not imply that they are born with compassion; it simply means that they are adult human being who has gone through a degree of training and has passed tests and is respected enough by their hiring facility that they have a degree of expertise and of caring for patients, that they are hired and working with you. As humans, people will behave appropriately to you if you behave appropriately to them.

Lastly, in my practice, when we have men who present as straight, as saying they are married and in heterosexual relationships, there is a small percentage of men that have sex on what is called the down-low, or have affairs with men even though they are in married relationships. At least in Manhattan, there are many more men in straight-appearing relationships who are enjoying sex with men. If you are one of them, that is okay; you do not have to come out as gay or bisexual to your doctor. But speak to your doctor alone one-on-one without your wife or significant other and tell him or her that you may come to them with concerns that I am not talking about now; most doctors will understand that.

The take-home for today is doughnuts; know your body as best as you can; and however you can, carve out time with your doctor alone. Please take advantage of that. Thank you.

Female Participant

Could you address the clinic experience that many doctors face with the adversarial patient or the adversarial family? We all know the skills of dealing with communication, but every now and then, your wonderful long-term relationship with the patient suddenly includes the family targeting you.

Dr. Litwin

My personal experience with a harsh-sounding patient's family member is emblematic of the fact that people with cancer, or any disease but particularly with cancer, feel typically out of control because this control has been wrested away from them through the process they have been through. Our job as health care providers is to try to reinstill them with a sense of that control. Also, there must have been some negative experience which triggers someone to have an adversarial approach with a doctor. I believe it is about just standing there and letting the venting come, then stepping aside and letting it go on past, and then engaging the patient at a very personal direct level to get to where I need to be with them. But it definitely can be challenging. I would advise patients to try to avoid being adversarial; you want to be collaborative with your physician.

Male Participant

With respect to visiting the doctor, because prostate cancer affects sexual function, I think it is important always for whoever the partner is, whether gay or heterosexual, to be there at the patient's appointment with the doctor. It is important for doctors to get the patient to bring a partner. Also, I think we need to stress particularly the need to look at

the efficacy of treatment and the way treatment is provided in other countries. The evidence shows that we are slipping behind.

Mr. Mitteldorf

You make a very good point about sexual partners presenting with their partners in the doctor's office. Within the gay community, gay men are twice as likely to have prostate cancer in the context of their family as for straight men. Usually, the responsibility of identifying as being gay falls on the patient.

Dr. Litwin

One reason why the U.S. health care system is ranked 37th is not that the quality of care available is not number one, but rather that we do not get health care to everybody who needs it. The way we ration care is based on ability to pay: poor people do not get good access to health care, wealthier people do.

Male Participant

Are many doctors reaching out to contribute time to make presentations, referring patients to patient support groups? Where is the trend there in terms of patient education and empowering patients, getting them to take control and be in control of their disease, doing something about it?

Dr. Litwin

This goes to the issue of empowering or re-empowering patients. Assist is on my list of five A's: assist patients however you can to empower themselves and to get educated. I tell people to be reticent about what you read on the internet; one must consider the source of the information. In general, doctors are way behind the curve in terms of what I call the inter-web: we are scared of the patient that is going to come with a stack of printouts and going to be adversarial, but to be able to guide patients towards the many resources that are available I think has great value, and we should do better.

Mr. Mitteldorf

There is the question of patient motivation and quality of resources. Us-Two [phonetic] has an email list number of just under 30,000. Male Care with its three niches, gay men, advanced disease men, and men diagnosed under the age of 40, and under the age of 50 now, has an email list twice that size. Looking at niche motivation, where do men feel most desperate to reach out and find information? There are men reaching out; it is a question of how much need they feel that they have to reach out.

Male Participant

Do you find in patient communities that patients understand that for there to be a constructive dialogue, which is presumably the purpose of all of this, that they have obligations, too, to such things as civility, transparency, lack of censorship, and those things, or do you find that it is just as fragmented and problematic on the patient side as presumably on the doctor side, online specifically?

Mr. Mitteldorf

We have 300 million people in the United States and three billion men around the world; you could argue anything for any large number of people. The short answer is yes, there can be improvements among patient population and among physicians and their relationships and understanding not just how people empirically designate what their medical experience is like, but how they express it and understand it emotionally and psychologically, and within the context of their day-to-day life. Around pain, we have all had in our offices the pain scale with the little smiley face thing; a patient will write that I have had four, five, or six, but they will go home begging for double doses of Percocet, or not being able to sleep. Why is that? Everyone wants to be a good patient; everyone wants their doctor to feel they are the special patient worth taking care of. Within the gay context, it is being the good boy. Reporting from a patient point of view is not always accurate and representative of their experience of your care, or of Dr. Litwin's care, or of anyone else's care; it is everybody's responsibility.

Female Participant

There are psychologists and social workers in every hospital in the United States. People should make more use of the kinds of services that are available right there in your hospital. They can be very helpful. It is not just the physician who needs to hear the patient, but it is everybody who sees the person to be welcoming, to be calm, to get the information in a way that is respectful and supportive, and if you do not get it, patients, advocates, spouses and partners, and siblings and whoever all you are, ask for it. Ask to see the social worker; Darryl is a great example of an oncology social worker. Also, what resources the doctor may be unable to get, may be obtained by the social services department, social work department, or psychology or psychiatry departments. There should be more coordination.

Please ask, please tell (ALPHA)

By Darryl Mitteldorf, LCSW

Many doctors say, "I treat all patients the same." But not all patients are the same. Married and single patients have different treatment goals and expectations. Younger and older prostate cancer patients have different ways to digest their diagnosis. And, men who have sex with men have different concerns, too.

Hearing a prostate cancer diagnosis revisits the coming out experience.

Coming out as a gay man is often an isolating experience, and is echoed by hearing that he is diagnosed with cancer.

It is hard for a man to come out as a gay or bisexual man, now he is faced with coming out as a cancer survivor….even harder when your social community is so deeply invested in supporting other issues such as HIV/aids and Don't Ask, Don't Tell.

Many gay men start have expereiced their early lives in heterosexual relationships and marriages. They have tried hard not to be gay, and struggled to get past the fears and

risks associated with being out. Now, they are trying hard to not be the person diagnosed with cancer, not the person whose life is once again at risk.

Patient needs assurance that his doctor respects him as a gay man. Simply by asking a man if he enjoys sex with men, women or both, sets a calm and understanding clinical relationship. The patient needs to hear his doctor ask questions to understand the patients concerns about treatment outcomes, such as sexual performance, and will take steps to protect him from all of his practical concerns, such as visitation rights.

Doctors should be prepared to respond to gay focused questions as well as clearly communicate a sense of comfort around sexuality. Being Gay is not the same as being short, tall or Russian. Learn basic "gay science," such as what being a bottom versus top is all about, how some men enjoy prostate massage or play with ejaculate. Gay couples can present as mundane or inflamed as heterosexual couples; accept the idea that a gay marriage is dynamic and love filled. Children are important. Many gay couples have sons and daughters. Include them in consults in the same way you might discuss any other family members. Ask if your patient's husband is also diagnosed or is concerned about prostate cancer. And sperm banking should always be discussed. Never assume that Gay men lack interest in fathering children. Take a few minutes to google Gay history. Understand that ADT echoes in history as a punishment for gay men. Gay men sometimes struggle with externally induced self-blamefor the problems of their own health. Assure men that their behavior is not responsible for their prostate cancer. Men diagnosed with HIV/aids as young men, are now aging into the realm of prostate cancer diagnosis.

Get your nursing and office staff on board. And, offer your patient the opportunity to speak with you, alone…even if he presents with his wife and declares him in a heterosexual marriage. Many men do not consider themselves gay, but they do enjoy sex with other men, often in secret. We all want our patients to feel comfortable reporting their symptoms from their own person context and set of goals. In 2010, in just about every part of the Earth, our gay patients face a special challenges in reporting their goals and symptoms. With very little preparation, we all can make our gay patients feel safe, listened to and well treated.

If you don't think you have gay patients, you simply haven't asked.

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The following resources are appropriate for clinicians and patients:

Malecare

Gay men's cancer survivor national nonprofit

http://www.malecare.org

Out With Cancer

Gay online cancer survivor support groups

http://www.outwithcancer.org

The National LGBT Cancer Project

http://www.lgbtcancer.org