

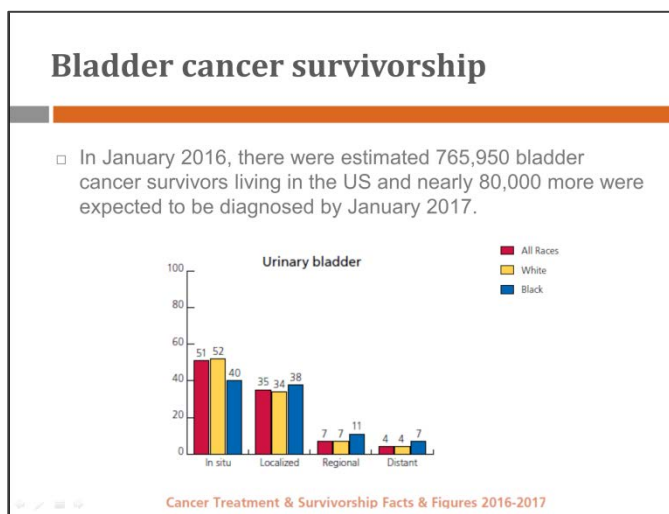
Presented by:



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Dr. Wittmann: Now, I want to talk about the normal and very unique experience of loss and grief in living with a cancer diagnosis. I'm going to talk about what happens at diagnosis and then what happens during survivorship, how people experience grief during a recurrence or progression of disease, and then also, in the advanced stages of bladder cancer. This is of course applicable to other cancers as well.

At diagnosis, people often describe feeling that they lost innocence in the sense of invulnerability because we always hear about other people being diagnosed with chronic conditions or life-threatening conditions, but when it happens to us, it's a different experience. All of a sudden, the reality that a life-threatening illness has come along is very, very real. With it comes the anticipation of what the treatment is going to do and how one's body is going to change and what functional changes might occur.



At diagnosis, it's easy to experience both the loss of innocence and that's just normal grief and the anticipatory grief, not knowing how one's going to be affected and how well one's going to do with treatment. There are often mitigating feelings, hope of recovery, hope that the treatment will work, faith in the treatment team and the advice that one is getting, and the support that usually comes with cancer if the diagnosis can be very, very positive and helpful.

Many, many people live in bladder cancer survivorship, and that's really the longest

period of time of living with bladder cancer. As you can see in this statistics and in this figure, almost a million people in the United States live with bladder cancer. We don't have information on other ethnic groups but here, you can see that whites and African Americans experience this in pretty similar proportions. We know that men experience bladder cancer more often than women.

There are various losses that a person with bladder cancer can experience and many of you are of course experts on this. There can be a loss of organs and therefore, function. If there is muscle-invasive bladder cancer, then the bladder is usually removed. With it for women, the uterus and ovaries are often removed. For the men, the prostate, which results in the change in urinary function because now, the urine is sent to the outside world in a new and different way. The loss of the ovaries and prostate leads to sexual dysfunction, and that has an impact on the relationship.

The impact of losses during survivorship

- **Loss of organs and therefore function**
 - Loss of bladder, uterus and ovaries, prostate
 - Change in urinary function
 - Sexual dysfunction and its impact on relationship
- **Usual role, includes work and finances**
 - May not be able to do heavy tasks around the house
 - Unemployment, disability income, insurance issues, financial security
- **Developing other conditions**
 - Heart disease, UTIs
- **Fear of recurrence, coping with the deaths of other survivors**



There is a chance that bladder cancer treatment can have an impact on one's usual role, like not being able to work or not being able to do heavy duties around the house. It also can have an impact on employment, disability income, insurance, and in general, financial security.

During the course of survivorship, it's possible to develop other conditions, and then they would have to be addressed as well. Then most of men and women who experience any kind of cancer live with a fear of recurrence and coping with the death of other survivors, which of course, bring about the fear of recurrence as well.

Losses during survivorship – body and function

- **Coping with loss and grief**
- **Loss of organs and therefore function**
 - Engage actively in rehabilitation, maximizing functionality
 - Talk to a sexual health counselor about maintaining sex life
 - Talk to a counselor/social worker about your grief and how to work on these problems



How do people cope? What do we know about that? Let's start with the losses that had to do with the body and function. For many aspects of the changes that come with the removal of the bladder or with being on chemotherapy. Various rehabilitations that's available or that should be made available and it's important for people to realize that and that they can discuss with their healthcare providers what's available. Certainly, nutrition counseling and nutrition support, there's a management of diversion, for example, understanding very well

how chemotherapy works and what it affects and doesn't affect.

For sexual issues, there are sexuality counselors who can help with sexual rehabilitation and with learning how to maintain a satisfying sex life. For mental health issues, for example, if the person gets depressed or can't get past certain feelings about what happened to their bodies, it's important to realize that mental health counsels, often these will be social workers, can be helpful in sorting through those feelings, not just for the person with bladder cancer but also for family members, family caregivers, partners, children, those kinds of services can also be accessed.

Losses during survivorship – usual roles, finances

- 13% of non-elderly cancer patients spend at least 20% of their income on out-of-pocket cancer care costs
- 50% of Medicare beneficiaries spend 10% of their income on cancer care costs
- Cancer patients are 2.65 times more likely to file for bankruptcy
- Patients who declare bankruptcy have a 79% greater mortality risk than those who do not



Zafar, JNCI, 2016, Bernard et al., J Clin Onc, 2011, Davidoff et al., Cancer, 2012

Let's talk about usual roles and finances. Families need to renegotiate their roles if there's a need for other people to assume responsibilities. This is best done by serious sit-down in conversation and planning because if people do it automatically, it's easy for family caregivers to get burnt out, resentful, and unhappy and for bladder cancer survivors to feel guilty and uncomfortable. If this is understood and supported, provided or found for the person who needs to assume more

responsibility then I think the family can get along very, very well and again, you can probably access a social worker who can help with that.

I did want to bring you some statistics about the financial impact because somebody actually asked about that in the questions that they sent along ahead of time and I think that's a really important issue in cancer.

As you can see here, for younger people with cancer, at least 13% spent 20% of their income for out-of-pocket cancer care cost. This is probably not a big deal for people who can continue working and who have very substantial income, but for people and families that have lower or middle income, this is a huge hit and then what becomes important is what kind of insurance one has, what kind of scope is there, what kind of resources there are to supplement does disability cover this. That becomes very challenging because you don't want people to be rationing between getting their treatment and having food on the table.

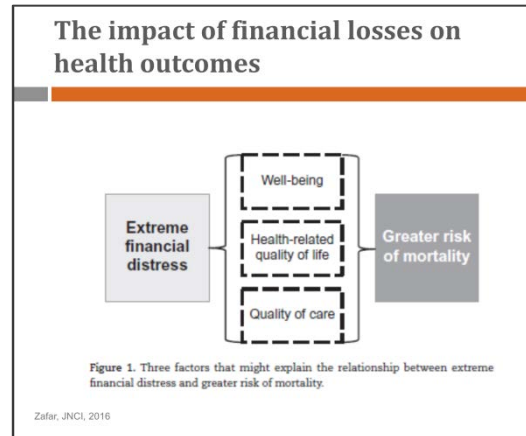
Also, for older patients on Medicare, they might spend 10% of their income on cancer care costs and most people on Medicare live on fixed income. Spending 10% of cancer care can be quite a lot and these

are averages. You can imagine that there are some who spend less and someone who actually spends more and so that is a significant burden.

As the studies have shown, cancer patients are almost three times as much as people who don't have cancer to file for bankruptcy, and then patients in the bankruptcy have almost 80% greater risk of mortality. These are very, very big impact.

I want to show you a representation of this in a graphical form. You can see here that extreme financial distress can lead to lesser wellbeing, decreased health-related quality of life and poor quality of care, all of which with a person at greater risk of mortality. I'm sure that some of you who are listening could be getting this lecture right here.

How to cope with this? As I said, it's always important to find resources. For these kinds of financial and work-related issues, there are many things that impact them. It's what kind of insurance that person has, what kind of income that person has, what kind of arrangement an employee is willing to offer for somebody who has to take leave to get cancer treatment.



The people who can help with that are social workers who usually in many treatment centers where cancer is treated, and they can if they don't know the resource, if they can't help themselves through their own knowledge, they can really contact the resources.

Losses during survivorship – usual roles, finances

- Coping with loss and grief
- Find a resource and advocate – social workers in your treatment centers can help
- Useful resources
 - Cancer care
www.cancer.org/diagnosis/bladder_cancer
 - American Cancer Society
www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-financial-and-legal-matters.html
 - Legal Cancer Resources Center
www.cancerlegalresources.org/

The Cancer Care Organization has information about financial issues for bladder cancer patients. The American Cancer Society does as well. The Legal Cancer Resources Center has volunteer lawyers who can also help with things like disability or advocating for cancer patient's rights.


It's very important to know what the resources are and find a way to access them, and as I've said, don't do it alone or you can do it alone but you can also find an advocate or a social worker.

Earlier on, I mentioned also the idea that one might develop other conditions during bladder cancer survivorship and in that case, if there are then more conditions that are being managed, it's really

important to organize the healthcare team to communicate very well. A primary healthcare provider can perhaps organize the team or sometimes the oncologist will do that, make sure that there is coordination of care. There may be various specialists that have to be surrounding the bladder cancer patient.

Losses during survivorship

- **Coping with loss and grief**
- **Developing other conditions**
 - Engage in organizing health team
 - Exercise – has been shown to reduce inflammation and possibly reduce relapse/disease progression as well as improve mental health and cognitive function
- **Fear of recurrence, coping with the deaths of other survivors**
 - Follow up with regular surveillance appointments
 - Recognize Short Upsurges of Grief and allow those to happen
 - Seek support



© Duncan et al., BMJ, 2017, Winter-Stone et al., Cancer Epid Biom Prev, 2017

There could be somebody dealing with financial issues, then somebody dealing with physical therapy for physical issues, an endocrinologist for diabetes, a heart specialist and so on. Somebody needs to organize this group so that the group coordinates care very, very well.

One of the things that I wanted to be sure to mention is that exercise is tremendously useful in managing one's health which means bladder cancer and other conditions. There is now research that shows cancer entails tissue

reformation and that exercise reduces it and I'm just giving you a very simplified form but there is some evidence that exercise can reduce the risk of cancer progression. It also can improve mental health and cognitive function.

Now, depending on how well a person's feeling, one might need to get a health coach and again, find resources to help pay for that if that's necessary but exercises are very, very beneficial.

Few recurrences experienced by all cancer patients and that is very well documented in research. It's important to keep up to date with all regular surveillance appointments to make sure that anything that is progressing or doing well is caught early. During these fearful times, it's possible for these short upsurges of grief to show up and it's fine to allow those to happen because they are realistic actions to the anxiety that one might be seeking.


In all of survivorship and all of the cancer experience support is critical and so being connected to organizations like BCAN, having family support, having counseling support, having support of the healthcare team can make the experience easier.

Now let me move to and briefly touch on loss and grief at the time of cancer recurrence and progression. When I worked at pediatric cancer, I learned that some of the progression can be in some ways more devastating than the diagnosis because people begin to feel that maybe they're going to lose hope and that treatment is not going to work. It is a very scary experience for most people who do experience it and then it's extremely important to huddle with your treatment team and talk about more options there for further treatment because often there are options for further treatment.

Even though one's worried about recurrence and how treatment is going to work, it's terribly important to continue to focus on the maintenance of the quality of life, maintain attention on the present on meaningful activities to the degree that a person can physically, if you volunteer in a school with children, if you like to garden, if you like to read and discuss books, anything that is of meaning and of interest is important to maintain because that really maintains quality of life, it maintains mental health and a sense of wellbeing.

Loss and grief at the time of cancer recurrence or progression

- Some survivors and family members experience a loss of hope, anxiety about the future, depending on the situation
- **Coping with loss and grief**
 - Explore treatment options with healthcare team
 - Focus on quality of life in the present
 - Engage in meaningful activity in spite of recurrence/progression
 - Anticipate possible positive and negative outcomes



One, of course, does anticipate possible and negative outcomes and that again is that anticipatory grief feeling of living on those two rails, being hopeful and being worried.

Loss and grief during the advanced stages of cancer

- **Coping with loss and grief**
- Work on coming to terms with the end of life – Anticipatory Grief
- Actively work on end of life planning with family and friends
 - ▣ Saying good bye
 - ▣ Planning funeral/memorial service
- Engage a social worker or counselor to help with personal or family relationship challenges
- Continue to focus on quality of life in the present and engaging in meaningful activity



Now there is of course grief during the advanced stages of cancer and at the end of life. I want to say that in my work with cancer patients, even though that is clearly a period of time where cancer patients think about death and dying, about separation, family members think about loss and separation and that definitely, a time and grief is a significant experience. It is also a very meaningful and intimate experience for family members if there is an ability to very open about it and to communicate with each other.

I remember when I was a new pediatric cancer social worker and I know I've given a lot of examples from that time because that really kind of set my career. I remember being asked to come to the floor to talk to a 10-year-old girl who was dying of brain cancer and her mother and I felt extremely inadequate going up there because I thought what can I do for them? How can I console them? How am I going to help them cope with this really sad, frightening situation?

As I walk in the room I see this skinny, bald-headed girl animatedly talking to her mother and they animated and laughing and I get closer and I realized they discussing her funeral and she's planning. She wants to know what she's going to wear, what food is going to be served, which of her friends she wants to say anything. They were very positive and I'm sitting there, I'm thinking like, who is helping who here? I am not doing anything for them but they're really inspiring me.

It made me learn that this is something that absolutely can be talked about and that one of the things that's beneficial for the patient is maintaining control and maintaining interest in the end of life as well as what's going to happen immediately afterwards and this is a very reassuring kind of a conversation for the family members because the family members then know what the person who will die wants to happen and when they are carrying out those wishes afterwards they feel very comforted and connected. It can be very, very intimate.

I recently had a patient with bladder cancer reach out to me and asked me to meet with her and her husband because she was in advanced stages and they wanted to know how to maintain sexual intimacy as long as they could because it was such an important part of their lives. When we met, we talked about that, how to do that in the face of fatigue or maybe discomfort or sad feelings. They found ways to think about it and to plan it and you know left feeling very encouraged that they would maintain that important part of their relationship for the long term.

When I talk about being active in the last stages of life with bladder cancer, people find it meaningful to say goodbye to family members and friends, plan their memorial service or funeral. If there is difficulty in family handling because some people have a hard time talking about it or so on, a social worker can help facilitate this and again, focus on quality of life even at the end of life can be very, very important and mentally healthy and helpful.

Loss and grief during the advanced stages of cancer

- Coping with loss and grief
- Develop Advance Directives
- Stay connected with loved ones and treatment team



- American Cancer Society resource: www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-financial-and-legal-matters/advance-directives.html

Most people at some point start discussing advance directives, which give the healthcare team an idea about what a person wants at the end of their life, how they want to have their pain managed. Well, not so much pain. They, obviously, don't want to be in pain. How they want to have infections managed, intubation managed, when to intervene, and when to stop intervening.

Some people actually get a health advocate which can be a family member or a friend or somebody that is trusted. Getting that

advocate doesn't mean they want to give control over to that person. For as long as the person can make their own decisions, they are in charge but it's helpful sometimes to just have others to think this through as it's happening and then trust that others will convey those desires to the healthcare team.

Staying connected all way to the end with loved ones and the treatment team is very important. The American Cancer Society has resources about advance directives and I think that's just a big topic in itself and I just wanted to touch on it. One of the things that I lastly want to mention is that at the end of life, people worry about how death is going to happen and every hospital, every healthcare provider in


cancer has a collaborating palliative care team that can help with the management of pain and comfort. Actually, in the advanced stages, not just at the end of life, in survivorship but certainly, at the end of life and that's an important team to access.

Some survivors have said to me that it's been really important for them to have advanced directives from early on, not just at the end and that's something to take into consideration because one's thinking about these things may change over time.

My final slide is just to remember that loss is a normal part of life. We all experience it. We all experience grief. It's important to allow it to flow and recognize that it's natural. Staying connected to loved ones and to one's healthcare team can be very supportive and can help with that. Staying active on one's own behalf, advocating even when we know that death is the outcome is important. It's very important to let everyone know what you need because if people know what you need, you're more likely to get it and that makes both of the person with cancer and the loved ones feel more successful and comforted as the disease progresses.

Loss is a normal part of life

- Allow grief to flow, it is natural
- Stay connected to your loved ones and to your healthcare team
- Be active on your behalf, even when death is the outcome
- Let everyone who needs to know what you want to happen



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