

The coding tree: Negative recollections of patients about doctor's words and attitudes regarding disclosure of cancer diagnosis (n=17)

[Surprised at the abrupt disclosure of the diagnosis]

Surprised at the sudden disclosure of the diagnosis during a routine palpation.

It was first said to me when the doctor put his hand in for the palpation [...] and he said, "This, um, may be cancer". I was really shocked; Dx75(2005), Int77(2007)

Surprised at being abruptly diagnosed: "You already have terminal cancer."

I was told, "I'd say that a case like this is already terminal. [...] such a sudden delivery of that news really took me off guard; Dx57(2005), Int60(2008)

[Displeased by the direct disclosure of the diagnosis to the patient in the absence of family members]

Displeased by the casual and direct disclosure of the cancer diagnosis in the absence of family members

They just said, "You've got cancer," matter-of-factly [...] Usually they call your wife in, or tell your children first in secret without the patient knowing. That was the type of world I was expecting, but instead they just said it directly to me, and I thought "W-What?"; Dx64(2001), Int71(2008)

[Unable to accept the doctor's negative words in the explanations]

Felt despair after hearing the doctor's words: "bad-looking cancer"

When I was told I have "bad-looking cancer," I began to feel hopeless; Dx73(2005), Int 76(2008)

Shocked by the words of "very bad, undifferentiated cancer"

They said it was very bad, and well, undifferentiated, or not very differentiated. [...] I was really shocked at that time; Dx73(2005), Int76(2008)

Surprised at the words of "very bad, highly malignant cancer"

The Gleason score is a measure of how it looks, and a score of 4 + 5 is quite bad. It was then that

I first realised that I had very bad cancer. After that, I was shocked by a lot of other things too; Dx 50(2006), Int 52(2008)

Shocked by the doctor's words, "This cancer is the worst kind" and could not catch the subsequent explanation

It started out with, 5 and 4. That means it has a Gleason score of 9, but this is the worst possible kind [...] They explained a lot to me at the time, though. I didn't quite come into my mind what the doctor explained. I was in shock [laughs], and I didn't really understand; Dx49(2005), Int53(2009)

It was a shock to be told "Progressive terminal cancer and you are expected to live only half a year".

Progressive terminal cancer. You have about... 6 months to live. [...] Of course I was in shock; Dx74(2001), Int81(2008)

It was like a thunderbolt out of the blue to hear "Very serious stage 4' out of 4 cancer stages."

They said that they ran some tests, and it was prostate cancer. Not only that, but if there were 4 levels, it was a 4', which is a very serious figure. It was like a thunderbolt out of the blue; I was so shocked; Dx 57(2007), Int 58(2008)

I hated to see the doctor because he always scared me with negative words.

I was always told really negative things like, "your tumour markers are 100x higher," or "your cancer is advanced, and malignant," and things like that, which was threatening. Yeah, that's why I hated going to see the doctor; Dx57(2005), Int60(2009)

[Unable to understand the doctor's technical jargon]

Unable to understand the explanations with technical jargon (for example, invasive cancer or well-differentiated cancer, etc.).

I was only told, “Your cancer is 3 plus 3, so 6. It is a highly differentiated cancer,” but I did not know what that meant at all, and they would not explain it for me clearly, so all I understood was that it was early stage; Dx76(2006), Int78(2008)

They said that, “It has completely, kind of, um, infiltrated up to your seminal vesicle,” but I couldn't make sense of what that meant; Dx75(2005), Int77(2007)

[Distrust due to failure in the diagnosis based on previous examinations]

I felt uneasy about a possible examination error when I heard “There was a cancer on the opposite side of CT scan.”

When you take a CT scan, everything should be more or less visible. I heard that they were aiming there, but the cancer was on the other side, so I thought that I would definitely not take any more radiation. Yeah. It would cause me more trouble if they made mistakes; Dx66(2003), Int72(2008)

[Aggrieved at doctor's unwillingness to allow questions]

I was angry about the doctor's attitude forcing me to leave, not allowing questions when I tried to ask.

Instead of talking about the results, I was told, “Okay, please come back in this month on this day,” and that was it. Then, when I tried to ask questions, they said, “Oh, um, take care, take care, take care,” which was more like get out of here, get out of here, get out of here. I thought that was unacceptable, but what could I do? So, I decided to leave then; Dx71(2007), Int72(2008)

[Dissatisfied with explanations involving facts only]

I also wanted heartfelt words, not just simple facts.

What should we do [for treatment]? Instead of asking me what we should do, [...] I would have wanted some heartfelt words, or something more like that; Dx60(2007), Int61(2008)

When I was notified of cancer, I was shocked and said “What?” I was disappointed by the doctor’s response with only factual medical explanations.

I was told “You only have a few months to left to live.” When I said, “Huh? What do you mean?” the doctor explained that, “The prostate cancer cells have already metastasised throughout your entire body.” At the time, I just thought, ‘huh?’ It was a huge shock; Dx64(2001), Int71(2008)

[Indignant over the unexpected disclosure of life expectancy]

Resentment at unexpected disclosure of life expectancy after being asked if I wished to know the status of my cancer.

I was asked, “About your illness... would you like me to give it to you straight?” I didn’t think anything of it (life prognosis disclosure) at the time, so I said “Yes, of course I want to know.” Yes. Then I was told “You only have a few months left to live.” [...] At the time, I just thought, ‘huh?’ It was a huge shock; (Dx 64(2001), Int71(2008)

Resentment at unexpected disclosure of life expectancy.

When I was notified about my cancer, I mentioned life expectancy, so I was told ‘well, at this rate, the chance that you will be alive in 5 years is probably about 70%’ [...] I thought, why did they have to tell me that?; Dx65(2004), Int69(2009)

[Unable to accept the doctors’ blame for the delay in the initial hospital visit]

Vexed to hear “It would have been OK if you came one month earlier.” (Felt helpless being told now).

I was told “If you came here a month ago, it would have been fine.” What? It makes no difference to what I could do now (whether or not you say that now). Yeah, I had no idea about (the fact that I needed an urgent diagnosis); Dx64(2001), Int71(2008)

[Uncomfortable with the usage of inappropriate metaphors]

The doctor's words, "An unwelcome present for the New Year" didn't click with me.

They said, "It's December 26, and this is my last job before the New Year. So, this is a New Year's present that you won't really want to accept, but here are your results," But it didn't really occur to me what was meant by that; Dx77(2006), Int79(2008)

[Pessimistic thoughts despite optimistic explanations]

Although described as a good-looking cancer, I was unhappy about the cancer diagnosis at such an early age.

...So, they only showed me one, and I was told that the cancer looked good. [...] I thought, "this happened to me 10 years earlier than it does for other people."; Dx61(2007), Int62(2008)

Although being explained as not malignant type of cancer, I felt I would die of pain.

They explained that the cancer was described as not such a bad kind. [...] Of course, in my head the first thing I thought was that cancer kills you, and I had heard that it is incredibly painful; Dx76(2006), Int78(2008)

Dx: Age at diagnosis of prostate cancer; Int: Age at interview; (): Christian era

[Blue text]: category names; Bold black text: subcategory names; Italicized text: quotations in each subcategory