

Title: The Untold Story of Late Effects: A Qualitative Analysis of Breast Cancer Survivors' Emotional Responses to Late Effects

Journal name: Supportive Care in Cancer

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Supplementary Quotes from Participants Supporting the Four Themes

Theme 1: Late Effects Awareness	Participant Identifier
<i>Well I didn't know there were any [late effects] so no [I don't worry] because you don't really miss what you don't know</i>	02
<i>Because I've talked to the doctors I know what it is it shouldn't get worse it's just how it is... as long as I can understand what it is and why it's there then it's all okay I can live with it</i>	41
<i>I come from a medical background I deliberately didn't read anything about breast cancer I didn't join any groups I didn't talk to any people I actually didn't want to be overloaded with information and worst-case scenarios</i>	52
<i>I sometimes think a little bit of knowledge doesn't do you any good... Be folly to be wise</i>	31
<i>But they [doctors] didn't talk so much about long-term side effects they were really just focused on helping me get through it</i>	46
<i>[If doctors had told me about late effects] You would not be thinking oh my god I am dying [when late effects develop] you would think well you know this happens to most people so you know I'm one of most people</i>	38
<i>Knowing about these things [late effects] earlier would sort of help me accept how things are now and build my life around it differently</i>	08
<i>Give me a few ways that I could help myself rather than me waiting to get to a point where it is quite severe and I don't even know what I can do to help myself</i>	10
<i>So I think there needs to be an ability to talk to someone at a meeting sort of a wrap up to say okay how do we manage you going forward and not just come back in 12 months time and we will see</i>	44
<i>Looking back on it, it would have been better if I got something in writing and information that I could have</i>	46

read and thought about in my own time but I don't remember getting anything like that

Theme 2: Framing and Coping with Late Effects

	<i>As long as you have physical side effects to deal with they are a constant reminder to your head about your experience [having cancer] so that can only have an impact on your life</i>	03
	<i>It [late effects] just brings the anxiety back to the fore you know it reminds me and I've got to go again and start worrying about it [cancer] whether it's going to come back stuff like that. That would happen everyday.</i>	21
	<i>I think it's just a constant reminder, it's made it very difficult to move on</i>	38
	<i>I got off so lightly compared to other people... so I was less worried</i>	13
	<i>It is easy to feel guilty about complaining because ...most oncologists have little information to give you or support because I think their general thoughts are to you know give us a break we got you through it, shut up and get on with your life sort of thing</i>	51
	<i>I hate it when people say oh it's age related [late effects] and I say to that that's bullshit, people accept that too often</i>	31
Validation	<i>When I said that I had a bit of peripheral neuritis he [oncologist] just sort of shrugged... and that was the only time that I got quite concerned</i>	44
	<i>It wasn't until I said oh look I'm having this terrible trouble concentrating and I can't remember things and I'm just a mess and they said oh yeah you've got chemo brain and I thought oh now you tell me</i>	32
	<i>What was really good for me was being able to tap into BCNA, I said is this normal or is this unusual, should I be worried... so that was really good because I was able to go to people... and feel heard</i>	34
	<i>With the medical people I've got, they're really good. They aren't dismissing they just go alright if you are worrying about this lets get it sorted... that makes a massive difference</i>	23
	<i>I think half the battle is actually talking to other people about it so that you aren't carrying the burden alone</i>	30

Theme 3: Uncertainty about Late Effects

	<i>It's always in the back of my mind, the lymphoedema risk.</i>	52
	<i>I'm a bit paranoid about doing enough but not too much</i>	
	<i>Even if I try really hard, no amount of fitness is going to take that [lung damage] away it's like I've already smoked a lot of cigarettes for the rest of my life but I haven't</i>	30
	<i>The other thing I worry about is the lymphoedema getting</i>	05

	<i>worse really</i>	
	<i>It's more just am I ever going to get back to how I was before? Like am I ever going to get back and be the person I was before</i>	50
	<i>I'm worried that my partner might look elsewhere</i>	28
	<i>If I can't have a kid, then will someone not want to be with me because I can't have a kid for him</i>	50
	<i>I worry about well just that it [arm] won't be efficient, that it will get weaker or that my range of motion will be diminished</i>	51
	<i>I didn't expect stiffness... that worried me because I didn't expect it</i>	06
Acceptance	<i>I don't wish anymore about oh wish I could have my old body back because it's gone now and I've come to terms with that</i>	40
	<i>If it's not going to kill you there is always a way of managing it</i>	53
	<i>I don't sit and worry about any of these things because it's totally out of my control</i>	03
	<i>Yeah all the little things you learn to live with yes you can rage about them and whinge and complain but it's not going to change them you just have to manage them and accept them</i>	17
	<i>We can plan to be healthy for the future and to do all those things and we can hope that in the future the treatments will be available but really it's the here and now that matters</i>	19
Avoidance	<i>The oncologist was saying if something were to arise because of the radiotherapy it would be around twenty years out from your treatment and you go alright well I'll worry about it then</i>	52
	<i>I'm not going to worry about something that may not even happen so we will cross that bridge when we get to it</i>	40

Theme 4: Management of Late Effects

	<i>It's really hard to find out what your new normal is, accept your new normal and then just try and improve on your new normal without breaking yourself... I live in a different shell now so it's just a little bit damaged. I have to take a bit more care of it</i>	18
	<i>Yeah I did get osteopenia, my bone density was really dropping. But that has kind of resolved because I've been getting these shots</i>	05
	<i>The lymphoedema is not dreadful but it's there. And I can manage it... for example if I go overseas, I wear it [compression sleeve] on the plane. But usually when I come back I find it's a bit bigger than normal. So then I</i>	05

*wear my sleeve for three weeks and it goes back down a bit
I've now got osteoarthritis... but it's fine because I've 40
learned to deal with that and with certain herbal medicine
I found that it's helped any pain so I'm no longer in as
much pain as I was before*

*You have to be realistic about worry and about concern 30
and you know if there is something that can help reduce
that then you do it*

*When I extend my left arm it is excruciating... so I find that 10
if I put out my foot higher [when putting on stockings]
rather than bending down it's very manageable*

*It takes a bit more work to get things done and to keep 28
things going but I am hanging in there*

*If my house burns down I'll probably die because I'll be 09
lying there doing my stretches [for muscle aches]*

*If I went shopping and I went to Costco that would be fine, 05
but if I then went on and went to Aldi, by the time I've done
the two I would be absolutely exhausted... you learn to
compensate*

*I have to put everything in my phone [to not forget 09
things]... I have to go to the shops with a shopping list
Writing lists and things like that to try remind myself. 41*

Something I would never have to do in the past

*My partner was very good at being my memory for a while 17
and reminding me of appointments*

*It's much of a less worry but it's only probably a less 30
worry because I've put the work in, I've understood what
the disease is, and I've managed symptoms*
