

Living with the fallout of cancer

It seems we don't understand the fear of cancer recurrence and progression well enough, writes **Cordelia Galgut**



WORDS

Dr Cordelia Galgut is a BACP senior accredited counsellor/psychotherapist and an HCPC registered counselling psychologist. She has written several books and a number of articles on the psychological impact of cancer. Her latest book, *Living With The Long-Term Effects of Cancer*, expands on many of the issues that are mentioned in this article. Currently, she's setting up a website for both those living with or beyond cancer, and those supporting them, focusing on fear of cancer recurrence and progression. She hopes it will be helpful for all those needing validation of how they are feeling.

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I recently conducted a survey on Fear of Cancer Recurrence and Progression (FOCRAP), which has thrown up results that have taken me aback somewhat. These results have serious implications for mental health professionals, especially given the numbers who are living on after a cancer diagnosis, many needing emotional support, either living with a still-present cancer or beyond it.

In the UK alone, Macmillan Cancer Support¹ estimates that, whereas in 2020 there were three million people living with cancer, that number will stand at 3.5 million in 2025 and rise to 5.3 million by 2040. If that means people living with a still-present cancer or being treated for cancer, then the numbers are higher still, if people coping with cancer's long-term effects but currently free of cancer are added to these figures.

Furthermore, Macmillan asserts that the average survival in the UK, after diagnosis, is now 10 years, whereas in the 1970s, shockingly, it was only one year, and only six years in 2007.

There are therefore huge numbers of people who are now living beyond diagnosis and treatments, whether with a still-present cancer or beyond it. Macmillan says that the incidence of cancer in the UK has risen by 39% since 2002 and by 19% in the last decade. Stark statistics indeed.

Fear of cancer recurrence and progression

Obviously, the fact that many more survive cancer for longer is good news, but it's often not recognised that many don't just get over cancer and move on. If we don't, and most appear not to, conventional wisdom tends to

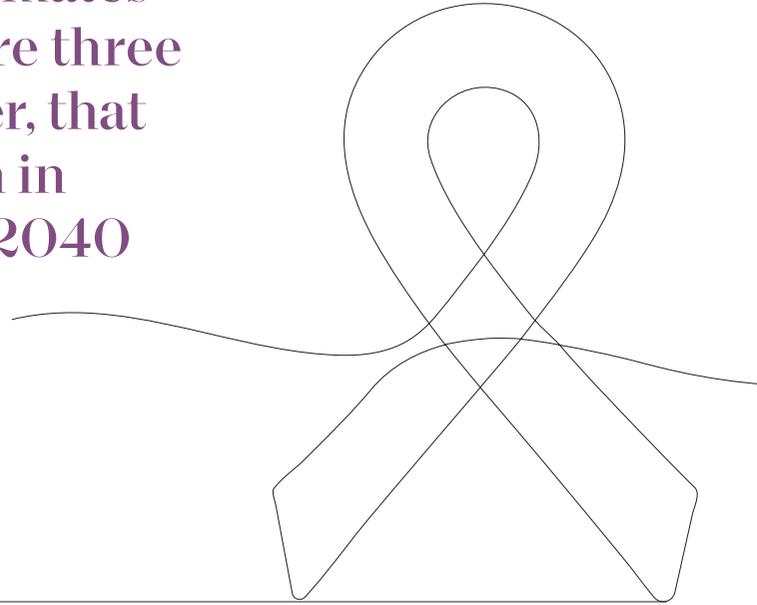
consider this an abnormal maladaptation, when it's a normal response to an extreme trauma such as cancer.

One unrecognised, ongoing and pronounced issue is the fear of cancer coming back, or getting worse, if it's still present. It's a very big deal for most of us living on after cancer, and an unavoidable stress, given that most cancers do return,² even years later. It's a widespread dread that affects everyone I've ever talked to after a cancer diagnosis. And I've talked to hundreds in this situation.

The presence of this fear is one of cancer's major consequences, no matter whether the prognosis is good or bad. And it's relatively uncharted territory, in that conventional wisdom doesn't really take this fear seriously at all. It's often just assumed that life goes back to normal after diagnosis and treatments, or at least, that it should, and there are few resources and little support to tackle this veritable epidemic of unrecognised emotional suffering. I find it gruelling when I hear stories of people living with a still-present cancer, most of whom will have to endure harsh treatments for life, who tell me people expect them to move on, get over it and be back to normal, too! How can they? And the harsh psychological reality is that, once diagnosed, even if the prognosis is good, that fear of recurrence never leaves you, me included,

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whether it's at the forefront of conscious awareness or on the periphery; it's always hovering there, like the sword of Damocles, glinting brightly.

People are often surprised I've not 'got over' cancer, 18 years after diagnosis, both physically and psychologically. People look at me blankly and judge me when I speak of long-term effects that make my life a struggle most days. Ignorance abounds, as does denial of the problem. Referring to fear of cancer recurrence and progression, people say to me things like, 'Well, isn't it the same for everyone?', so assume we are in the same boat and there is no distinction between them and me. It's hard to know how to respond politely sometimes, especially if the person keeps telling me there's no difference. Having been on both sides of the fence, I know there's an enormous one, even if someone has had a cancer scare. That is a horrible thing, but not the same as concretely knowing you have cancer in you or are living with its consequences.

Why I did the survey

Over the years, in response to my writings on the psychological impact of cancer, I've had messages from people telling me how others' lack of understanding and dismissal of their suffering, both physical and psychological, makes them feel like frauds who've internalised

a belief that they have no legitimate right to suffer. This self-censuring can and does have a detrimental effect on mental health, as any kind of similar undermining would be likely to, in addition to coping with the actual reality of their own situations. I tried to unpick this societal tendency to dismiss the reality of cancer's aftermath in my book, *Living with the Long-Term Effects of Cancer*,³ and interviewed a lot of people for that book. But, until recently, I hadn't conducted any quantitative research, the aim of which was to explore whether word-of-mouth testimonies on fear of cancer recurrence would or wouldn't be borne out by a qualitative investigation.

After recently receiving a run of messages from distressed people living with cancer's emotional fallout, as opposed to my usual sporadic ones, I decided I had to embark on a survey on people's fear of cancer recurrence and progression (FOCRAP), to try to throw more light on this thorny subject. I formed a small focus group of those working in the cancer fields, those affected by cancer, those with a dual perspective and those with research experience. They helped me put together a short questionnaire, and this help was invaluable.

I should say that I've done research degrees and wouldn't have embarked on this project if I hadn't, as I was able to employ the skills I've

acquired over the years. Without these skills, I would have been lost. Also, I was able to tap into years of living with cancer's fallout myself and listening to others' experiences, to help me put this short survey together, execute it and process the data.

The survey

Eight days after the short survey went online, I had 183 anonymous responses. I had only put it out on Twitter, via my followers, of whom there are not many, so I really wasn't expecting many responses, maybe 30 or so. I started to panic as the responses arrived in my inbox. I was worried about the scale of the task ahead, and processing the data as thoroughly and ethically as I was committed to doing, so I closed it on day nine, having given any prospective respondents a bit of time to participate. In a way, the early closure was a

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pity because I might have got an even bigger deluge. And obviously, the more data the better. The quick response was interesting and good in that it was now big enough to give more reliable pointers than the 30 or so responses I'd been expecting.

I had determined, together with my focus group, to keep the survey short and easy to complete, and focused on areas that we already knew were key, both from word-of-mouth testimonies and from previous research studies. The questions were as follows:

1. Which kind of cancer did you have?
2. Which age group do you belong to?
3. How scared of recurrence and/or progression are you?
4. Apart from fear of death, what other reasons make you afraid of a recurrence and/or progression?
5. To what extent do you think medical professionals, mental health professionals, family and friends and society in general understand fear of cancer recurrence and progression?
6. Finally, I asked respondents to add any other comments.

The results

Seventy-six out of 183 respondents were aged between 31 and 50; 103 between 51 and 70; and four were aged between 71 and

90. Interestingly, 149 respondents had had a diagnosis of breast cancer, though I had put the survey out to everyone, irrespective of gender or type of cancer. Other cancers represented were cervical, bowel, malignant melanomas, ovarian, anal, prostate and lung cancer.

In answer to question three, 'How scared are you of recurrence and/or progression?', on a scale of one to four, with one being 'not at all scared' and four 'very scared', 54.1% (99) chose 'very scared' and 33.9% (62) chose 'scared'. This means that 88% are either 'very scared' or 'scared'. These are much greater numbers than are usually reported in research studies available on the subject, or than conventional wisdom usually believes to be the case. Of the remaining 12%, 10.38% (19) of respondents ticked two and the remaining 2.38% (3) ticked one for 'not at all'. Interestingly, comments such as 'I won't let myself' or 'I have no control if the cancer returns or not, so I cannot live my life in fear of it,' were made a lot by those who ticked number two or three. This kind of a stance is very understandable but implies attempts to control the fear, so it is still there, even in those who ticked 'not at all' or number two.

In answer to my question, 'Apart from fear of death, what other reasons make you afraid of recurrence and/or progression?', the longer-term 'side effects of treatment'

scored highest, with 120 ticking that option. Ninety-one ticked 'side effects of treatment shorter term' and 43 'other reasons'. Seventy-one ticked more than one option. It's not commonly recognised that these fears of treatment effects drive fear of recurrence and progression the way they seem to among my respondents. Indeed, some respondents spoke of death being less of a fear than suffering the effects of treatments yet again.

I asked respondents to tell me how well they thought four groups of people understood fear of recurrence and progression. The results made for shocking reading, even for me:

Medical professionals:

- 105 'not really'
- 56 'fairly well'
- 22 'well'.

Mental health professionals:

- 76 'not really'
- 87 'fairly well'
- 16 'well'
- Four people didn't tick anything.

Family and friends:

- 147 'not really'
- 32 'fairly well',
- 4 'well'.

Society in general:

- 175 'not really'
- 4 'fairly well'
- 4 'well'.

The results give clear pointers. The sample, though not huge, is enough to be quite reliable. Although, as expected, more people responded who had been diagnosed up to four-and-a-half years ago (113), the remaining 70 respondents had been diagnosed between five and 25 years ago. These figures certainly question conventional wisdom that fear disappears after a year or two. There are many issues I could focus on because of my survey's results. The ones that would seem to be most useful for us as mental health professionals are the following.

Mental health professionals' lack of understanding

The most concerning result is that only 16 people (8.74%) thought mental health professionals understood fear of recurrence and progression well; 41.53% (76) said, 'not really'; and 47.54% (87) said we understood 'fairly well'. Four people didn't answer this section, hence the discrepancy in the percentages. I have no idea why they didn't respond – maybe because of a technical hitch, or maybe because they didn't have direct experience.

Realistically, it's hard to understand something well when you have no personal experience of it, and follow-up research on what clients need from their therapists to help support them with these fears is now needed. I've asked people this a lot informally over the years. What they say is that they need a very accepting stance from their therapists, whom they don't expect to understand, unless they know from first-hand experience. They want to know if their therapists have had a diagnosis of cancer, as a way of finding out if there is any commonality of experience and understanding. But, if they haven't, the very willingness to say they don't or can't understand but will try to take on board the enduring nature of these fears and the reasons

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why, can be a great help therapeutically. I've heard that a therapist who tries to box off and sanitise a client's fears, suggesting they can be rationalised, is far from helpful. One of the respondents said, 'I'm in a self-supportive programme at the hospital, which is unhelpful and doesn't work.' I don't know why this person said this, since it was an isolated comment, but it could well be for the reasons given previously.

During the process of doing this survey, someone mentioned how they felt about their CBT therapy. I suspect this is just the tip of the iceberg, based on word-of-mouth accounts of others' experiences of other approaches, not just CBT. However, it could also be CBT specific in some ways. Further research is needed. Elizabeth was diagnosed with cancer a few years ago. She is in her 30s. She says: 'My personal experience of CBT as a cancer survivor was that CBT was unhelpful and invalidating of my experiences. My major issues were fear of recurrence and living with uncertainty. CBT therapy made me feel like my concerns were irrational, and the only way forward was to pretend my fears were not real. It also made me feel that my cancer experience was now in the past and should have no effect on my life. It feels as if there is little understanding of the lived experiences of people who have had cancer in mental healthcare.'

The reasons people fear recurrence and/or progression

There appears to be a dearth of data on this topic, from those affected. This study does throw more light on this area, but obviously more data are needed. And, as therapists, if we are to support this large and growing client group well, we urgently need to understand better than we appear to, what the issues are that drive this fear. The 318 comments generated from my study throw a pretty clear light on this area. Some of the comments were short, some were several paragraphs long.

Lack of understanding

The theme of change, struggling to adapt, emotional and physical suffering and others' lack of understanding dominate the comments. For example:

- 'The fear never goes away – you just have to adapt and learn to live with it. Life is no longer the same. No one really helps you to voice and come to terms with these enormous

feelings. Friends and family just think you've done it. You've beaten cancer. How I hate those phrases.'

- 'Professionals work on statistics. Someone has to be the statistic, no matter how low (the chances), and I feel they don't understand what they see as an illogical fear that I will be that statistic.'
- 'Professionals are amazing in their own right, but they are blinkered.'
- 'My consultant doesn't like being questioned.'

And the pressure people put themselves under to not feel what they are feeling is evident in many comments from my respondents, for example:

- 'I feel like my life is over. I can't plan for the future that I might never have. I should be embracing every moment, but I'm in constant fear.'
 - 'I don't live with daily fear. I won't let myself.'
- Some of the enormous fears and uncertainty those living on after cancer grapple with feed into fear of recurrence and progression. For example:
- 'It's scary that it might come back, and I might not know and then it would be too late. What if there's no "sign" of it? What if it does come up in my yearly mammogram? What if it's in my brain and I think my headache is a regular headache?'
 - 'I'm just waiting for the other shoe to drop. Constantly in fear of recurrence.'

Physical symptoms feeding into the fear

Many of the other 318 comments highlighted another driver that people tend not to understand about life after a cancer diagnosis: how ongoing symptoms feed into this fear. Are they more cancer, are they not?

- 'My body suffers from aches, pains, nausea, blood in my poo. No two days are the same. There's no such thing as normal. So how do I tell what's normal and what isn't? I should be happy to be five years from cancer, but I'm not, I'm scared.'
- 'I'm paranoid that every little ache and pain I have could be cancer.'
- 'Always worrying if I have a cough, (this was one of the signs of the first cancer I had).'
- 'It's a constant fear as I have no access to diagnostic testing.' Or 'This fear of recurrence is fed by lack of proper care from my hospital.'

Dread of more treatment

The theme of fear of more treatments looms large as a reason why people fear recurrence and progression. This fear of more treatment being a driving force behind the fear of recurrence or progression isn't adequately recognised within the cancer world generally. Fear of death is deemed more of an underlying reason, whereas many stark comments were made, such as, 'I'm not afraid of death, I'm afraid of the treatments.'

There were many comments other than the following, but these are representative of my sample:

- 'Unfortunately, all cancer treatments cause unwanted damage to the body and mind. Going through one treatment was more than enough and I don't want to experience a secondary treatment. If I have to, I will, but it will cause even more damage.'
- 'The treatment was horrible the second time and I'm not sure I can go through it again, if necessary. I also fear that if it returns, I'll be in so much pain and die hurting and scared.'

Fear of recurrence and progression being fuelled by fear of leaving their children and families was mentioned by some respondents. Comments were made, such as:

- 'Pain towards the end. Sorrow at leaving my children.'

- 'Missing out on my children's life events, either due to treatment or death.'
- 'I worry that my husband will have to care for me and that I'm going to leave him on his own.'

I'm not able to include all the comments respondents made, or all the themes that came up, but the above were the most spoken about.

Existing research is worryingly problematic

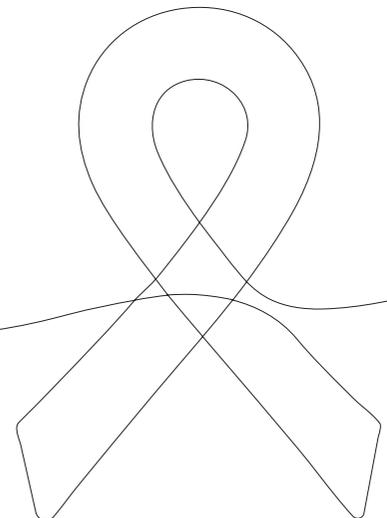
As I've been navigating my way through setting up this survey, writing about it and having its results published, I've been very aware that I've been asking myself many questions about research in general. I did so while doing my research degrees and beyond, but my recent thinking has taken on a different hue. For example, the extent to which the questions that underpin research studies will inevitably affect outcomes, is preoccupying me a lot. Entrenched attitudes will affect the kind of questions we ask, for example. One respondent's comment particularly sticks in my mind, and I think it's pivotal. In my opinion, it's crucial that we take on what this person says if we want to both offer better service to this huge and ever-increasing client group and conduct research that better maximises the chances of getting nearer to the truth.

'Our culture has a narrative about cancer that emphasises triumphant return to normal. I think that makes patients feel like they need to speak about their experiences as if they are stories with a definitive ending, even though cancer is mentally, and very often physically, something that never fully goes away. That leads to medical professionals not understanding what we really go through, flawed research models with skewed results, and intense feelings of isolation for us patients who do not know that we aren't alone in our fears. Cancer never stops, even when you don't know it's still there. It's a ghost that is always in the room with you. Sometimes you feel its presence, and sometimes you can forget it for a bit. But – even for those of us who are early stage – cancer is a permanently altered state of being into which we have been unwillingly thrust, not a story with a clean and definitive end point.'

I don't believe that any ethical researcher would deliberately set out to disadvantage the very target group they're seeking to investigate. However, unconscious bias is there in all of us, including me. And the way an issue to be investigated is defined, prior to setting up research aims, questions etc, will affect a research outcome. If, for example, you're researching the area of fear of cancer

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recurrence and/or progression, and your unconscious, or even more conscious, entrenched position is that enduring fear is an abnormal response etc, then that will likely skew your data. Obviously, my insider bias can be cited as a reason why my data could be skewed. I set out to do the purest study I could, but I will have my critics, for sure.

One could also argue that my question in the survey, 'Apart from fear of death, what other reasons make you afraid of recurrence?', consisting of me giving the options: 'Side effects of treatment both longer and shorter term' as well as 'Other reasons', led the respondents. An open question might have been better, even though I did invite 'any other comments', of which there were many.

However, there's a whole discussion we need to have about how people whose voices are being silenced by conventional wisdom's insistence on pathologising cancer patients, need encouragement to speak about issues that we all know are controversial; that the balance needs righting before people feel able to speak out. The fact my survey was anonymous hopefully empowered people to some degree, but I was asking them questions that are normally taboo. And hopefully, me naming treatment as an option sent a message that it was OK to speak out. I can imagine that some people might say, well, if people are participating, they will feel able, and to an extent that's probably so, but, in my experience, not always.

Alex Stokes, an Australian contact with research interests, sent me the following

interesting summary of the available up-to-date research on fear of cancer recurrence and progression. It is very illuminating: 'The research around fear of cancer recurrence (FCR) is frequently problematic. Some examples are the frequently touted risk factors for FCR, such as low level of education or intelligence. A recent review found no strong evidence for intelligence playing a role.⁴ However, it is frequently cited in research and in general web information. Sample size is another problematic aspect of FCR research. In a sample of current intervention trials, around one-third had fewer than 50 participants, and few had over 200.⁴ Similarly, in a review using literature citing prevalence of FCR, around one-third of studies had fewer than 100 participants. This makes reliable⁵ conclusions difficult to draw. A further issue is reported prevalence of FCR. Another systematic review⁶ found that across the current literature, an average of 50% of respondents reported FCR, 30% of whom reported this at a high level. This is at odds with Cordelia's research.

'This may be in part because of the way FCR is described in research. Often presented as a maladaptation, abnormal response or lack of resilience,^{7,8} these judgments may incline respondents to not want to disclose their FCR and be labelled thusly. In fact, there is very little research asking individuals why they fear cancer recurrence,⁹ which would help dispel some of the stigma surrounding FCR. Cordelia's research is breaking new ground in this area. It is important we dig deeper into the actual prevalence and reasons behind FCR, to find useful ways to increase quality of life and reduce distress among cancer survivors.'¹⁰

Where do we go from here?

Considering both the findings of my research and Alex's summary of existing research, it's clear that the topic of fear of cancer recurrence and progression needs more consideration urgently. We need to challenge entrenched thinking and reconsider by whom and how research on the subject is conducted. For those mental health practitioners working at the chalk face who read this and find the results of my study concerning, I hope that my findings and the comments made by the respondents have thrown a different kind

of light on what anyone coping with this predicament might need from those supporting them.

Following on from this survey, I've set up a Twitter FOCRAP working party to try and forge a way forward. There are 58 members so far, comprising a variety of health professionals and those coping longer term, either with a still-present cancer or beyond it, some of whom have a dual perspective. If you're interested in joining the group, contact me at drcngalgut@yahoo.com.

Many thanks to Alex Stokes for her contribution to this article and for her help, and to Stephanie Pearson and those who took part in the survey.

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YOUR THOUGHTS, PLEASE

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