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J Health Psychol 2010 15: 291

DOI: 10.1177/1359105309351245

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Answering Patient Questions about the Role Lifestyle Factors Play in Cancer Onset and Recurrence

What Do Health Care Professionals Say?

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ACKNOWLEDGEMENTS. We would like to thank CRUK who funded the study (Grant code: C1418/A7976) and the Health Care Professionals who participated in this research.

COMPETING INTERESTS: None declared.

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Journal of Health Psychology
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Singapore and Washington DC
www.sagepublications.com
Vol 15(2) 291–298
DOI: 10.1177/1359105309351245

Abstract

This qualitative study examined how cancer specialists answer patient questions about what might have caused their cancer. Findings showed that while they were often candid about the role of smoking and drinking in cancer onset and that of diet in cancer recurrence, body weight and exercise were rarely mentioned. Any reluctance to discuss the role of lifestyle factors in cancer onset and recurrence arose from a desire to minimize patient distress, limitations in specialists' knowledge of the causes of cancer and perceived inadequacy of the available causal explanations when risk factors are multiple and probabilistic.

Keywords

- *cancer*
- *cause*
- *communication*
- *health behaviour*
- *qualitative research*

Introduction

RECENT estimates suggest that cancer incidence can be halved through lifestyle changes (Colditz, 2007) but public awareness of the modifiable causes of cancer remains low, particularly in relation to body weight, exercise and alcohol (Redeker, Wardle, Wilder, Hiom, & Miles, 2009). Awareness appears no higher among cancer survivors compared with people who have never had cancer (Lykins et al., 2008), despite the fact that cancer survivors face the possibility of developing a recurrence, as well as being at greater risk of developing a new primary cancer (Travis, 2006).

Cancer survivors frequently search for an explanation as to why they have developed the disease, often as part of a more general search for meaning following a life-threatening diagnosis (Janoff-Bulman, 1992; Willig, 2009). Nevertheless, people who have had cancer are frequently reluctant to identify health behaviours as potential causes. They are less likely to believe physical inactivity, obesity and poor diet have played a role in their own cancer compared with their type of cancer in general (Wold, Byers, Crane, & Ahnen, 2005), and are more likely to believe lifestyle factors will help prevent a recurrence than they are to believe such factors played a role in the initial onset (Costanzo, Lutgendorf, Bradley, Rose, & Anderson, 2005; Stewart et al., 2001). A number of reasons may account for such findings, including failure to recognize the personal relevance of cancer risk factors, such as not realizing one is overweight (Johnson, Cooke, Croker, & Wardle, 2008) or not believing that the cause (e.g. poor diet) matches the magnitude of the event (cancer) (Janoff-Bulman, 1992). However, one of the principal reasons forwarded for low levels of personal control beliefs surrounding cancer onset is the need to protect oneself from blame by making external causal attributions for negative events, in this case a cancer diagnosis (Kelley & Michela, 1980).

A number of studies have reported higher levels of distress among cancer patients who do blame their own behaviour for their cancer (Friedman et al., 2007), providing some support for this view. However research has also shown that people who acknowledge the role of health behaviours in their cancer aetiology are more likely to alter their health practices following a cancer diagnosis (Rabin & Pinto, 2006). In addition, post-diagnostic changes in health behaviours have been shown to attenuate

the relationship between causal beliefs and distress (Costanzo et al., 2005). Costanzo et al. (2005) found that cancer survivors who believed dietary factors had caused their cancer only showed higher levels of distress if they made no positive dietary changes following their cancer diagnosis. Together these findings suggest that cancer survivors may benefit from learning more about the link between their health behaviours and cancer onset, provided this information is accompanied by the support they require to make the recommended lifestyle changes.

A key source of information for cancer survivors about the possible causes of their cancer is their health care provider. Cancer patients prefer to receive information about cancer from healthcare professionals such as their oncologist, oncology nurse or general practitioner (O'Leary, Estabrooks, Olson, & Cumming, 2007; Piredda et al., 2008), rank healthcare professionals as the most frequently used sources of information for cancer alongside print materials (Cowan & Hoskins, 2007; Finney Rutten & Iannotti, 2003) and consider information obtained from cancer specialists to be the best quality information available (Mills & Davidson, 2002). Given the low levels of awareness of the causes of cancer, Wold et al. (2005) have called for health care professionals to play a role in educating cancer survivors about the causes of cancer, particularly in relation to obesity and lack of physical activity but little research appears to have examined this issue. The aim of this study was to explore healthcare professionals' views about discussing the possible causes of cancer with cancer patients.

Method

Participants

Twenty-one healthcare professionals whose job involved direct contact with cancer patients were recruited to the study via the North London Cancer Research Network. Interviews were conducted with people who volunteered to take part in the research, ensuring a range of participants in terms of speciality and cancer types treated. Two-thirds of participants were female, nine were consultants, seven were nursing staff and the remainder were from a variety of specialisms (General Practitioner, pharmacist, radiographer, cancer information officer and screening nurse specialist). They worked on a number of cancer types (gastrointestinal, breast, cardiothoracic, oral, prostate, leukaemia, lymphoma).

Design and procedure

Semi-structured, face-to-face interviews were conducted either at the participant's place of work ($n = 14$) or at University College London ($n = 7$) and lasted between 30 and 90 minutes. The interview covered the common misperceptions patients have about cancer, and the discussions health care providers (HCPs) had with patients about the possible causes and treatments available for cancer. Interviews were tape recorded and transcribed verbatim. Only the responses concerning discussions about cancer cause are reported here.

Analyses

Transcripts were analysed using thematic analysis (Braun & Clarke, 2006). The Atlas software package was used to facilitate this process. The analysis focused on a particular dataset within the entire data collected and on sections concerning HCP–patient discussions about the role five modifiable health behaviours might have played in the onset of their cancer. All HCP interviews were included in this analysis and all instances of the data where these topics were identified were labelled and then submitted to thematic analysis. Themes were identified in an inductive way: they had a direct link to the data and were not informed by predetermined theoretical considerations because little research has been conducted on this topic before.

Explicit meanings were analysed, focusing on what participants actually said rather than going beyond surface meanings. Data extracts were compared between and across participants for each of the five health behaviours and quotes with similar meaning were grouped together in order to help identify the relevant themes. The two major themes that were identified were differences in the way the different health behaviours were discussed, and reasons HCPs gave for their reluctance to discuss the role health behaviours might have had in their patients' cancer onset. Once completed, the analysis was reported back to the HCPs for comments for the purposes of validation.

Results

Questions by patients about why they had developed cancer were common although not universal and often arose from a desire to prevent a recurrence:

I think people would like to know they got this 'because ...' then they know what to do to stop

it coming back and a lot of people have said to me 'if I knew what caused it then I could make that change in my life'. (P20)

The HCPs suggested that questions about cause may be more likely to arise during treatment rather than at initial diagnosis, once patients had got over the initial shock of the diagnosis and had got to know their HCP a bit better.

Discussion of different health behaviours

Discussions around the link between smoking and cancer were common and were often candid, particularly around the recommendation that people quit following their diagnosis.

I would probably over-estimate the risks of smoking to try and scare them to stop ... quite a lot of people by the time they've got a diagnosis of cancer they want to stop smoking so just a little bit of help, a little bit of encouragement from us is quite useful there. (P21)

A lot of them give up smoking when they're diagnosed. Some of them don't ... but most of them give up smoking on diagnosis so they tend to feel like they've done their bit towards getting better. (P10)

Fewer conversations about the need to stop drinking were reported and were only noted in the context of head and neck cancers. For other cancers, advice about drinking was related to reducing the unpleasant effects of treatment such as radiotherapy.

With alcohol ... again the doctors would often say to them 'You carry on drinking you'll be dead', and it would be as straight as [that] you know. (P20)

They'll always ask if they can drink a bit of alcohol ... I say as long as it doesn't interfere with their medication ... not many people say no I'm never going to drink again. (P10)

With our radiotherapy information for the head and neck patients we used to feel we had to take a more pragmatic approach in that telling people not to drink without supporting them is complete nonsense so we used to suggest, and it's still written in the leaflet, that they switch from spirits to beer 'cos otherwise it's going to hurt like hell. (P20)

Diet emerged as one of the most common topics of discussion, particularly around the prevention of cancer recurrence. Some HCPs noted that

patients often viewed dietary changes as a form of complementary medicine, and used diet and dietary supplements to try and prevent recurrence.

They'll ask how to prevent it coming back with diet, that's quite a common question. (P10)

They ask about [diet] to help them get over it ... I think because now there is so much on complementary and alternative therapies that a lot of them read a little bit ... about how to cure your cancer with oranges or whatever. (P1)

A lot of men will take that [name of supplement] ... it takes the PSA down by half ... And then, 'oh my PSA is down' but you've still got to times it by 2 if you're taking something like that. (P12)

Few discussions were reported by HCPs about weight as a possible cause of cancer with cancer patients. A couple of HCPs mentioned it in the context of secondary prevention but regarded it as a sensitive issue to discuss with patients and found it difficult to raise the issue of weight loss during the treatment phase when it may not be an achievable goal.

I do the BMI with them and if it is overweight I do say the recommended is between 20 and 25 ... but I think they're taken aback and upset by that ... that's quite a touchy area I think with people asking them about weight. (P11)

I think with the breast patients addressing the obesity issue is an incredibly difficult one because the hormone treatment actually makes them put on weight ... You know no matter how hard they try they're not going to lose that weight. (P20)

In view of follow-up in breast patients yes we certainly go through the diet thing and the fat content in your diet. [We say] It's good to be healthy, generally healthy, you know keep the weight off ... and this is going to be good for your breast cancer in the future ... this is going to keep you well if you look after yourself now. (P6)

No-one reported discussing exercise with cancer patients either in relation to onset or recurrence, but one person mentioned it as a means of combating the fatiguing effects of cancer treatment.

I think the exercise one is more, isn't really as linked by people towards colorectal cancer. (P19)

I bring up exercise if they are fatigued and I tell them maybe try a little bit of exercise ... So we tell them to do that, but I don't think I ever had a patient say to me I didn't ever go for a run once a week or anything like that. (P10)

HCP reluctance to discuss possible causes of cancer

Reluctance to discuss the possible causes of a cancer patient's disease stemmed from three main concerns (see Table 1). The first was strategic, such as wanting to get to know the patient, lack of clinic time to devote to potentially sensitive discussions and, more commonly, to reduce feelings of guilt and blame surrounding a cancer diagnosis. There was also reluctance to raise the issue of lifestyle change in the absence of the appropriate support needed to make lifestyle changes.

Table 1. Reasons why health care providers are reluctant to discuss the possible role of health behaviours in the development of cancer with their patients

Reasons for reluctance

i) strategic reasons

- Need to know the patient
- Lack of clinic time
- Minimizing guilt, avoiding blame
- Lack of appropriate support to make lifestyle changes

ii) limitations in provider knowledge about the causes of cancer

- Risk factors unknown to epidemiologists
- Scepticism/confusion about literature
- Risk factors known to epidemiologist but not necessarily HCPs
- Belief lifestyle change at this stage will not influence cancer risk

iii) perceived inadequacy of the available causal explanations

- Lack of 'candidate' status/not typical case
 - Absence of unitary cause makes it difficult to answer the question
-

Need to know the patient

They normally ask the consultant who usually says we don't really know, they very rarely say because you smoked 60 cigarettes a day, they don't usually say that. And then, but I'm quite, once I've got to know them I tend to be a bit more direct with them and will say well you did smoke and you have lung cancer, so we know that's a cause, so it possibly was that ... I don't ever tell them they are to blame but I tell them the correct causal factors if there are any, sometimes there's not. (P10)

Lack of clinic time

[You mentioned earlier you said the consultants would often not say (what had caused a person's cancer). Why do you think there is that?] I don't know I think because they are limited in their clinic time perhaps and it's a long process to get into. And also at that point they don't know the patient, it's probably the first time they've met them. (P10)

Minimizing guilt, avoiding blame

I think there are misconceptions about the fact that some patients actually feel guilty that they've got it and why they've got it, and I think she [the patient] very much put it in a bracket with HIV. (P13)

There is no point criticizing them for what they've done in the past ... I tend to push them to look forwards rather than backwards ... I mean even if it is someone that smokes, there is no point now saying well you naughty person, you've only got this cancer because you smoke. (P4)

Lack of appropriate support to make lifestyle changes

With our radiotherapy information for the head and neck patients we used to feel we had to take a more pragmatic approach in that telling people not to drink without supporting them is complete nonsense. (P20)

The second set of reasons concerned limitations in provider knowledge about the causes of cancer either due to a lack of scientific information or information that was newly emerging or conflicting. For some cancers, there was lack of knowledge among the scientific community about their cause, while for others the HCPs interviewed were not necessarily aware of the current knowledge about the risk factors for cancers, such as the role of obesity and alcohol in breast cancer risk. There was also scepticism about some of

the risk factors, such as whether obesity was an independent risk factor for cancer or just associated with cancer because of a confounding with other factors such as lower socio-economic status and smoking.

Risk factors unknown to epidemiologists

A lot of patients ask us and say 'Well why do you think I got this? Why did I get this?' And a lot of time we feel in a position to say that with gastric or oesophageal cancer there isn't really a reason. You've got your two types of oesophageal cancer. You've got your squamous cell carcinoma, you've got adenocarcinoma. Squamous cell tends to be more in patients who've smoke heavily or drunk heavily ... and the majority of them have not been, I think quite shocked actually, have not been people that have smoked a lot, drank a lot, a majority have been adenocarcinomas and they've just instantly got this cancer. (P18)

Scepticism/confusion about literature

I think it was only in the last two years that I really believed that it [obesity] was such a big risk factor ... I used to think oh well there are more overweight people who are lower social class and smokers ... But I am aware now what the evidence is. (P1)

How can you possibly understand? Nobody is sure about alcohol. There was a thing about two days ago, yesterday, about alcohol ... I think we're associating alcohol with colon cancer. And then someone was fighting back saying red wine is good for you. Nobody is absolutely 100 per cent sure. (P5)

Risk factors known to epidemiologist but not necessarily HCPs

She was a bowel cancer patient, nothing to do with lung cancer, but we were just generally chatting about cancer because she just couldn't understand why she had got this and I was trying to explain to her well actually we don't really know the cause of that. (P6)

Belief lifestyle change at this stage will not influence cancer risk

Diet is something that comes up often because that is something that people can actually influence. ... the hope is always that there is one thing one could do and it would just reverse everything, [but] it's something that is much more relevant in prevention in terms of living a balanced and healthy life rather than at the moment one is diagnosed. (P3)

The third set of reasons concerned the perceived inadequacy of the available causal explanations, either because the patient did not appear to have been exposed to the relevant risk factors (was not a typical 'candidate') or because there are no clear-cut answers in a situation where the risk factors are multiple and probabilistic.

Lack of 'candidate' status/not typical case

We get patients who have never smoked, who do work out and don't live a sedentary life and have a good diet so there's no real reason, unless of course there's a genetic factor, and there doesn't tend to be hugely with bowel cancer. (P13)

Absence of unitary cause makes it difficult to answer the question

I mean with smoking obviously people know that it's the smoking and that's what's done it but with other things I don't think you can really do that. It's a lot of factors. (P19)

Discussion

Consistent with other research, we found that decisions about when and whether to disclose information about the possible causes of cancer were influenced by HCPs' concerns to reduce the feelings of guilt and blame patients might feel if they told them about possible links between their health practices and cancer onset (Mystakidou, Lioffi, Vlachos, & Papadimitriou, 1996). But other factors also emerged such as lack of HCP knowledge or confusion about the role some health behaviours play in cancer aetiology (such as body weight, exercise and alcohol), and the multifactorial and probabilistic nature of the causes of cancer which meant that there was often no clear-cut causal explanation. However although the latter means that HCPs cannot state with certainty what caused an individual's cancer, this does not stop them from discussing factors that can increase a person's chances of developing the disease. While discussions about risk factors were reported by some HCPs, others appeared reluctant, and there was a much greater willingness to discuss the role of smoking compared with other factors, notably body weight. Although this was partly due to the stronger link that exists between smoking and certain cancers (particularly lung), it was also affected by the sensitivity surrounding issues such as body weight.

The results of this study suggest that patient unwillingness to endorse lifestyle factors as possible causes of their cancer may be inadvertently reinforced by their HCPs. Patients often ask about the causes of their cancer because of their desire to prevent a recurrence and there is some evidence that health behaviour change may be beneficial in this regard (Holick et al., 2008; Thomas & Davies, 2007). In addition, there is research, noted in the introduction, that knowledge of health behaviours in cancer aetiology promotes health behaviour change (Rabin & Pinto, 2006) and does not increase distress provided the relevant behavioural changes are made (Costanzo et al., 2005). This suggests that HCPs could discuss the lifestyle causes of cancer provided people were motivated to make changes and were offered the necessary support they needed to translate such intentions into action.

Another reason for having more frank discussions with patients about the role of lifestyle factors in cancer aetiology is the effect that HCP responses may have on beliefs about cancer cause throughout the patient's social network. The view that cancer survivors could influence the beliefs about cancer causes among the general population has been raised by other researchers (Wold et al., 2005) and it is possible that if HCPs do not raise the issue of lifestyle factors in particular cancers that this may undermine messages from other sources about the modifiable factors that cause cancer.

The results of the present study offer some insight into the finding that cancer patients are more willing to endorse lifestyle factors as playing a role in preventing cancer recurrence compared with promoting its initial onset. It was notable that in the context of diet HCPs felt patients perceived dietary change as a type of treatment of its own (complementary therapy). Hence, rather than being perceived as initiating cancer, diet was perceived as helping defend against the disease once the individual had shown themselves to be susceptible. This account suggests that it is not simply a matter of trying to avoid self-blame that may underlie different patterns of casual attributions for cancer onset as opposed to cancer recurrence, but may also be due to that fact that people hold different causal models in relation to onset versus recurrence.

The belief that lifestyle factors help prevent cancer returning may help people maintain a sense of personal control over their future health. Where there is evidence that lifestyle changes could prevent a

recurrence, research should examine the best way to communicate this and to facilitate such behaviour change. Providing explicit information about what caused the initial cancer onset may increase patient motivation to make lifestyle changes but this issue needs further research in order to ensure that the provision of such information does not compromise patient well-being. Advice about lifestyle change may conflict with and undermine individual attempts to come to terms with a cancer diagnosis (Willig, 2009). In addition, there are likely to be individual differences in the desire for and response to information about the possible causes of cancer (Brashers, 2001; Lucas, Alexander, Firestone, & Lebreton, 2009). For example, people may prefer to stay in a state of uncertainty about the likelihood of a cancer recurrence in order to maintain a sense of optimism about the future and hence may not wish to have explicit discussions about the degree to which lifestyle changes may alter the risk of a recurrence. Such patient preferences for information would need to be carefully assessed prior to any discussions about the role of lifestyle in cancer.

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