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Patient delay in presentation of possible cancer symptoms: the contribution of knowledge and attitudes in a UK population sample

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Abstract

Background—Qualitative studies implicate knowledge of cancer symptoms and attitudes towards help-seeking as important factors in patient delay. The present study uses quantitative data from a population-based survey to test the hypotheses that: i) greater knowledge of early cancer symptoms is associated with a higher likelihood of having appraised a symptom as possibly due to cancer, and ii) more negative attitudes towards help-seeking are associated with a lower likelihood of having sought medical advice for that symptom.

Methods—2071 adults were asked whether they had experienced a symptom that they worried might be cancer in the past three months, and if so, whether they had seen a doctor. Respondents also completed the Cancer Awareness Measure (CAM) assessing symptom knowledge and barriers to help-seeking.

Results—236 (11.4%) respondents reported having experienced a possible cancer symptom. In logistic regression analyses controlling for age, sex and self-rated health, higher CAM symptom knowledge scores were associated with a greater likelihood of having experienced a possible cancer symptom (OR=1.09, CI: 1.01-1.17). Of those who had experienced a symptom, 75% (177/236) had seen a doctor. Higher scores on the CAM barriers scale were associated with being less likely to have seen a doctor (OR=0.74, CI: 0.63-0.87).

Conclusions—Better knowledge of the signs and symptoms of cancer may help people recognize possible cancer symptoms and therefore reduce appraisal delay, while more positive attitudes towards help-seeking may reduce behavioral delay.

Impact—Campaigns to educate the public about cancer symptoms and reduce help-seeking barriers could play a role in promoting early diagnosis.

Keywords

cancer; delayed diagnosis; early detection of cancer

Early detection of cancer is important because of the established association between stage of diagnosis and survival (1). Diagnostic delay can be due to either providers not referring on appropriately (provider delay) or patients not visiting the provider (patient delay), but patient delay is generally agreed to play the major role (2;3). In the UK, a visit to a primary care doctor to discuss a symptom is the first step towards diagnosis for the majority (80%)

of cancer patients (4;5) and this highlights the importance of minimizing delay in presentation.

When an individual first notices a symptom, unless it is one of the ‘classics’ (e.g. a breast lump), they go through a period of trying to decide what the symptom might mean and then what to do about it. Within the patient-delay process (6), the time from the individual detecting the symptom to them recognizing that it requires medical attention has been termed ‘appraisal delay’ (7) or ‘passive detection’ (8). Appraisal delay tends to be higher in men and people from lower socioeconomic status (SES) backgrounds (9;10). Deciding that the symptom is not serious, waiting to see if it will clear up on its own, or self-medicating, are all associated with longer appraisal delay (10-12). Knowledge about cancer symptoms has been shown to be associated with paying more attention to symptoms (8;9;13), and a shorter anticipated delay in help-seeking in the event of symptoms (14), although to date only in a hypothetical context. There do not appear to have been any prospective studies examining associations between knowledge and delay (15).

The time from the individual recognizing the symptom to seeking help has been called ‘action appraisal’ (11) or ‘behavioral delay’ (7). Qualitative studies of responses to breast and oral cancer symptoms have identified negative attitudes towards health care providers as determinants of behavioral delay (16;17). This has been supported in a recent quantitative study which found that perceiving more barriers to visiting a doctor was associated with a greater intended delay for a range of possible cancer symptoms (14).

A review of 32 qualitative studies concluded that the commonest cause of appraisal delay was lack of recognition of symptoms, and the commonest cause of action delay was fear of the consultation (18). Quantitative studies exploring this topic have used hypothetical scenarios (e.g. 8,14) or retrospective recall of the delay process in patients with cancer (e.g. 12), but both these designs have limitations. Responses to a hypothetical scenario may not mirror responses in real-life, and retrospective recall in cancer survivors may be influenced by the experience of diagnosis.

Another possible approach is to investigate associations between knowledge and responses to symptoms that occur in daily life among people who have not yet – and may never – receive a cancer diagnosis. In this context, symptom experience would be salient without being overshadowed by the emotions accompanying a cancer diagnosis. The present study used this method to test the hypotheses that: i) knowledge of the early symptoms of cancer would be associated with a greater likelihood of having perceived a symptom as possibly due to cancer, and ii) perceiving more barriers to visiting a doctor would be associated with a lower chance of having sought medical advice for the symptom, using data from a randomly selected, population-representative sample of adults in the UK.

Materials and Methods

Data were collected as part of the Office for National Statistics *Opinions Survey* in September and October 2008. This survey recruits a population-representative sample in Britain using stratified probability sampling to select 67 postal sectors from the Postcode Address File of ‘small users’ (a database of approximately 27 million British households who receive fewer than 50 items of mail each day). A random sample of addresses is chosen from each postal sector. In the survey for this data collection, this yielded 3652 households. The interviewer determines the household composition and identifies a respondent from the adults (aged over 15) in the household using a Kish grid. The Kish grid is designed to select people within a household with equal probability and is based on identifying the number of

people in the household and using a random number to select one person who is invited to complete a face-to-face, computer-assisted interview.

Symptom experience and help-seeking

Respondents were asked: 'In the last 3 months, have you had any symptoms that you worried might be cancer' (response options: 'yes', 'no', 'I already have cancer or have had cancer in the past'). Those who reported having had a worrying symptom were asked: 'Have you been to the doctor to discuss it' ('yes/no'). If the response was 'no', they were asked a further open-ended question ('Can you tell me why not') which was recorded verbatim.

Knowledge of cancer symptoms

This was assessed using the 'closed' questions from the symptom knowledge scale of the validated Cancer Awareness Measure (CAM). The CAM has good internal reliability (Cronbach's $\alpha = 0.77$) and test-retest reliability ($r = 0.81$), face validity and content validity have been established by an expert panel, it has good construct validity, with cancer experts achieving higher CAM scores than non-medical academics ($t(31) = 6.8, p < 0.001$), and it is sensitive to change following a brief educational intervention ($t(47) = 4.8, p < 0.001$) (19). The stem question for the symptom knowledge scale is phrased as: 'The following may or may not be warning signs for cancer. We are interested in your opinion'. This is followed by a list of nine symptoms (lump or swelling, persistent unexplained pain, unexplained bleeding, persistent cough or hoarseness, persistent change in bowel or bladder habits, difficulty swallowing, change in the appearance of a mole, a sore that doesn't heal, and unexplained weight loss) each of which can be identified as a warning sign for cancer or not. The number of symptoms endorsed is summed to produce a total knowledge score (range 0 to 9).

Barriers to help-seeking

The CAM Barriers stem question (19) asks: 'Sometimes people put off going to see the doctor, even when they have a symptom they think might be serious. These are some of the reasons people give for delaying. Could you say if any of these might put you off going to the doctor. The list includes four emotional barriers (e.g. too scared), three practical barriers (e.g. too busy), and three service barriers (e.g. not wanting to waste the doctor's time), with response options of 'yes often', 'yes sometimes' and 'no'. The barriers score is the number of 'yes often' or 'yes sometimes' responses (range 0 -10).

Socio-demographic characteristics and self-rated health

Socio-demographic items included in these analyses were gender, age, occupation (managerial/professional; intermediate/small employers/lower supervisory; semi-routine/routine) and ethnicity (white; other ethnic background). Self-rated health was assessed using a single item ('How is your health in general') with five response options ('very good' to 'very bad').

Analysis

Logistic regression was used to examine associations between experiencing a symptom as possibly due to cancer and the CAM Knowledge score, and between help-seeking for a possible cancer symptom and the CAM Barriers score, controlling for demographic factors and health status. Responses to open-ended questions were summarized using content analysis to identify themes and theme frequencies were reported with examples. Quantitative data were analyzed using SPSS 16.0.

Results

From the 3652 households invited to participate, 2216 (61%) respondents agreed to be interviewed, 1093 (30%) refused, and 324 (8%) could not be contacted after three attempts. Of the 2216 people who took part in an interview, eight (0.4%) did not answer any questions from the CAM and were excluded from the sample. Participants were not asked directly if they had already had a diagnosis of cancer because of interviewer sensitivity about asking the question, but it was offered as an option in the symptom experience question, and a small number of respondents endorsed it ($n=33$, 1.5%). These participants were excluded from the subsequent analyses. This resulted in a final sample size of 2071.

The ONS survey sample is designed to be representative of the UK population, which was reflected in the characteristics of the present sample except for an excess of female respondents (56% vs an expected proportion of 51.6% (20)) and a low ethnic minority proportion (6.3% vs an expected proportion of 7.9% (21)). The majority (58%) of respondents were from non-managerial occupations. Most rated their health as 'good' or 'very good' ($n=1602$, 77.4%), with small numbers rating it as 'fair' ($n=347$, 16.8%) or 'bad/very bad' ($n=122$, 5.9%).

Symptom experience

Just over one in ten respondents (236; 11.4%) had experienced a symptom that they had worried might be cancer during the last three months. They were slightly younger (47.9 vs 51.5 years; $F(1,2070)=7.99$, $p<0.01$) than the rest of the respondents. There was a non-significant trend towards women being more likely than men to have worried that a symptom might be cancer (12.4% vs 10.0%; $X^2=2.93$, $df=1$, $p=0.08$), but no significant differences by ethnicity or SES. People with poorer health (bad/very bad) were more likely to have experienced a possible cancer symptom than those with better health (18% vs 10%; $X^2=9.06$, $df=2$, $p<0.05$).

Logistic regression was used to test the hypothesis that higher CAM knowledge scores would be associated with a greater likelihood of having experienced a possible cancer symptom, controlling for age, sex and general health (see Table 1). SES and ethnicity were not included in the model as they were not related to symptom perception. As predicted, people with higher knowledge scores were more likely to have experienced a possible cancer symptom (OR=1.09, 95% CI: 1.01-1.17). Table 2 shows the distribution of the symptom knowledge scores among those who did and did not experience a possible cancer symptom, and in the sample as a whole. The overall distribution of the scale is somewhat skewed towards the higher end (range 0-9), but even so, respondents who had experienced a possible symptom were represented in higher proportions at the top end of the scale.

Help-seeking behavior

Of the 236 respondents who had experienced a symptom they thought might be cancer, 177 (75%) had seen a doctor to discuss it. They tended to be slightly older (49.7 vs 42.5 years; $F(1,235)=8.32$, $p<0.01$) but there were no differences by sex, ethnicity, SES, or general health. Help-seeking was not associated with CAM symptom knowledge scores.

The relationship between barriers to help-seeking and visiting a doctor was assessed using logistic regression in a model controlling for age (sex, ethnicity, SES, and general health were not related to visiting a doctor). As predicted, people who endorsed more barriers to help-seeking were less likely to have seen a doctor with their suspected cancer symptom (OR=0.74, 95% CI: 0.63-0.87) (see Table 1). Table 3 shows that those who had a worrying symptom but did not see a doctor, scored higher specifically on the emotional and practical items.

Responses to the open-ended question on reasons for not seeking help among the 59/236 people who had not been to the doctor are shown in Table 4. Two people identified more than one reason, making a total of 61 comments. Some comments were similar to the practical barriers in the CAM, e.g. 'being too busy' (N=7) and 'having difficulty arranging transport' (N=2), and others were similar to the fear items (N=8). But the most common reasons related to symptom interpretation (25/61 comments). These included attempts to seek alternative sources of information, self-medicating, and re-appraising the symptom as less serious because it was mild (N=6) or went away (N=9). The responses suggested that some respondents made somewhat risky re-appraisals, e.g. 'it (mole) just changed color slightly, not black'; and 'the cough could be due to smoking'.

Discussion

Failure to recognize a symptom as serious has long been identified as contributing to patient-reported delay (7;10), but most of the research is based on retrospective recall among people who have already received a diagnosis of cancer. The results from this study indicate that better knowledge about cancer symptoms is associated with an increased chance of considering the possibility that a symptom is due to cancer. This is consistent with studies showing that greater knowledge is associated with paying more attention to cancer symptoms using hypothetical symptom scenarios (8;9;13), and takes these results forward by applying the model to symptoms that have been personally experienced and using a validated measure of knowledge of cancer symptoms.

A range of practical and emotional barriers to help-seeking have been identified as additional factors in delay in seeking help after a symptom has been appraised as worrying (16;17;22), but again most of these findings either come from recall of help-seeking by cancer survivors or rely on behavioral intentions as outcomes (e.g. 14). The present study adds to the evidence by showing that people who identify more emotional or practical barriers to help-seeking were less likely to have seen a doctor for advice on a worrying symptom. In the free response section, respondents who had not sought medical help also mentioned seeking alternative sources of help and deciding to self-medicate as reasons for not seeing a doctor, as well as re-appraising the symptom as not serious.

The greater share of diagnostic delay has been attributed to patients rather than providers (2;3), but patient delay may itself be influenced by the doctor-patient relationship. Although this study does not directly address physician delay, the association between delay and perceived barriers to visiting a physician points to the possibility that changing the way doctors interact with patients could reduce delay. Interestingly, knowledge of the nine cancer symptoms in the CAM was not associated with being more likely to have seen a doctor. This could give some reassurance that raising public awareness of these symptoms will not inevitably increase demands from the 'worried well', but equally it could be seen as indicative of the need to encourage people to seek help when they are concerned.

Among the strengths of this study are that the responses concerned actual symptoms and actual help-seeking behavior, and the sample was population-based. Also the knowledge measure (the CAM) was a recently developed, validated instrument. However there are also significant limitations. We did not ask any details about the specific symptoms that respondents had worried about because it would have been intrusive in the survey context and therefore did not know if they were actually possible signs of cancer or how closely related they were to the nine symptoms in the CAM list. However, as part of the free response section, respondents mentioned symptoms such as skin changes and coughs; which suggested that at least some of the symptoms would have merited help-seeking. We did not ask systematically about cancer diagnoses (again because it was considered too intrusive in a

general interview), although some people (1.5%) used the option to say they already had a cancer diagnosis in the symptom question. This was not intended to generate a formal estimate of prevalence but to allow people to exclude themselves from the interview. The true prevalence of cancer survivors in the population is likely to be at least twice as high (approximately 3%) (23). However, even the true prevalence rate is low in absolute terms in a sample across all ages, and therefore this omission is not likely to materially influence our conclusions. A second limitation was that symptom experience and help-seeking were reported retrospectively and could be subject to recall errors.

Because this was a cross-sectional study, we cannot infer causation; knowledge could influence symptom interpretation or people who worry about cancer may know more about its symptoms. Prospective studies would help distinguish these options and also make it possible to examine relationships between knowledge, symptom recognition, barriers and behavior, but intervention trials in which knowledge or attitudes are modified and effects on symptom presentation are assessed are required to demonstrate causation. A recent report on the future for studies of patient delay in cancer advocates further research on symptom interpretation with fully prospective designs (15). The present study is one step along the way, and helps make the case for larger-scale studies.

Delays in diagnosis have been identified as a potential contributing factor to the UK-European survival gap (1;24-27). The present study did not involve international comparisons, but the results indicated some themes that have also been associated with patient delay in other countries, such as lack of knowledge, non-recognition of symptom seriousness, and fear and embarrassment. If patient delay is a contributing factor to the poor survival in the UK, the issue may be one of magnitude, rather than qualitative differences, but an international study is needed to discover whether lack of symptom knowledge and barriers to help-seeking are more significant in the UK than other countries. The results of this study support the idea that raising awareness of the early signs and symptoms of cancer may increase people's ability to identify cancer symptoms. They also indicate that knowledge alone is insufficient to promote appropriate help-seeking (28) and addressing barriers to seeking medical care is an important target that will require action at both patient and provider level.

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Table 1

Results of logistic regression analyses predicting i) perceiving a symptom as possibly due to cancer and ii) seeing a doctor about the symptom

Experiencing a possible cancer symptom (N = 2071)		Odds Ratio (95% CI)		P
Age		0.98	(0.98-0.99)	<0.001
Sex	Female	1.00	(1.00)	
	Male	0.83	(0.63-1.10)	0.193
Self-rated Health	Good/very good	1.00	(1.00)	
	Fair	1.71	(1.19-2.46)	0.004
	Bad/very bad	2.49	(1.50-4.14)	<0.001
Symptom knowledge		1.09	(1.01-1.17)	0.021
Seeing a doctor about the symptom (N = 236)				
Age		0.98	0.97-1.00	0.110
Barriers to help-seeking		0.74	0.63-0.87	<0.001

Table 2

Knowledge of cancer symptoms scores by symptom experience

Symptom knowledge score	Symptom experience N (%)		Total sample N = 2071
	Yes N = 236	No N = 1835	
0	0 (0.0)	24 (1.3)	24 (1.2)
1	1 (0.4)	16 (0.9)	17 (0.8)
2	6 (2.5)	35 (1.9)	41 (2.0)
3	8 (3.4)	54 (2.9)	62 (3.0)
4	7 (3.0)	73 (4.0)	80 (3.9)
5	15 (6.4)	116 (6.3)	131 (6.3)
6	15 (6.4)	202 (11.0)	217 (10.5)
7	38 (16.1)	271 (14.8)	309 (14.9)
8	45 (19.1)	326 (17.8)	371 (17.9)
9	101 (42.8)	717 (39.1)	818 (39.5)
Missing	0 (0.0)	1 (0.1)	1 (0.1)

Table 3

Relationship between barriers to help-seeking and visiting the doctor with a cancer symptom

		Visited doctor		
		Barriers to help-seeking		X ²
		No %(N)	Yes %(N)	
Emotional	Too embarrassed	33.9 (20)	15.9 (28)	8.80, df = 1, p<0.01
	Too scared	43.1 (25)	25.3 (44)	6.61, df = 1, p<0.01
	Worried what doctor might find	55.9 (33)	39.0 (69)	5.18, df = 1, p<0.05
	Not confident to talk about symptom	23.7 (14)	11.4 (20)	5.46, df = 1, p<0.05
Service	Worried about wasting doctor's time	54.2 (32)	40.3 (71)	3.47, df = 1, p = 0.063
	Doctor difficult to talk to	29.8 (17)	17.8 (31)	3.76, df = 1, p = 0.052
	Difficult to make an appointment	52.5 (31)	42.4 (75)	1.85, df = 1, p = 0.17
Practical	Too busy	51.7 (30)	31.1 (55)	9.07, df = 1, p<0.01
	Other things to worry about	42.4 (25)	25.4 (45)	6.09, df = 1, p<0.01
	Difficult to arrange transport	5.1 (3)	2.8 (5)	0.69, df = 1, p = 0.406
Anything else	(verbatim response)	18.6 (11)	11.3 (20)	2.09, df = 1, p = 0.148

Table 4

Reasons given for not seeing a doctor with a symptom

Topic area	Example	N
Service barriers	Never know which doctor you are going to see	1
	Because I do not like talking to my GP	1
	Can't figure how to book appointment on the net	1
	Was awaiting regular hospital specialist appointment	5
	Not registered	1
Practical barriers	Not had time, been busy	7
	Difficulty in getting someone to take me	2
Emotional barriers	Because I don't want to know	8
	Not sure if I'm being silly	5
Symptom interpretation	Forgotten and believe the symptom has gone away	9
	Talked to others/googled symptoms on the doctor's website	4
	It's alright really, (e.g. 'it's only a few freckles')	6
	Thought it might have been something else	3
	Tried self-medication (e.g. for cough) and it cured it	1
Other	Could be caused by something else (e.g. cough caused by smoking)	2
	Don't know/only recently noticed	5
	Total	61