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Decision making and referral from primary care for possible lung and colorectal cancer:

a qualitative study of patients' experiences

Abstract

Background

The challenge for GPs when assessing whether to refer a patient for cancer investigation is that many cancer symptoms are also caused by benign self-limiting illness. UK National Institute for Health and Care Excellence (NICE) referral guidelines emphasise that the patient should be involved in the decision-making process and be informed of the reasons for referral. Research to date, however, has not examined the extent to which these guidelines are borne out in practice.

Aim

To assess the degree to which patients are involved in the decision to be referred for investigation for symptoms associated with cancer and their understanding of the referral.

Design and setting

Qualitative interview study of patients referred to secondary care for symptoms suspicious of lung and colorectal cancer. Patients were recruited from two regions of England using maximum variation sampling.

Method

Transcribed interviews were analysed thematically.

Results

The analysis was based on 34 patient interviews. Patients in both symptom pathways reported little involvement in the decision to be referred for investigation. This tended to be accompanied by a patient expectation for referral, however, to explain ongoing and un-resolving symptoms. It was also found that reasons for referral tended to be couched in non-specific terms rather than cancer investigation, even when the patient was on a cancer-specific pathway.

Conclusion

GPs should consider a more overt discussion with patients when referring them for further investigation of symptoms suspicious of cancer. This would align clinical practice with NICE guidelines and encourage more open discussion between GPs and primary care patients around cancer.

Keywords

colorectal cancer; decision making; lung cancer; primary health care; qualitative research; referral and consultation

INTRODUCTION

The challenges of identifying potential cancer in primary care are well documented:¹ GPs may see around 12 cases of cancer each year but consult patients with symptoms associated with cancer on a daily basis.¹ These symptoms are usually caused by benign and often self-limiting illness. GPs need to decide whether the symptoms presented justify a referral for specialist investigation. The UK National Institute for Health and Care Excellence (NICE) guidelines for referral for suspected cancer² recognise the role of the patient in the referral decision-making process, and emphasise that patients being referred with suspected cancer should be told 'they are being referred to a cancer service'.² The guidelines reflect the general shift toward patient-centred medicine, which positions the patient at the heart of decision making.³ Research on shared decision making (SDM) has shown, however, that it has not been widely adopted in UK clinical practice.⁴ SDM may not occur for a number of reasons, including clinicians perceiving a lack of consultation time and a tendency to make decisions about whether to incorporate SDM based on patient attributes, such as age and medical condition.⁵ Research has also highlighted that patients may not value the knowledge they bring to the

consultation, and thus expect practitioners to drive decision making rather than engage in SDM themselves.⁶

To the authors' knowledge, there have been only two studies focusing on patient aspects of referral from primary to secondary care for cancer investigation. Both studies were Australian and primarily qualitative. The earlier study⁷ noted that some participants did not think they should be involved in the decision about whether they should be referred for investigation, and others felt that if they did not want the test they would not attend the appointment, rather than rejecting the decision during the primary care consultation.⁷ The more recent study found that patients did not feel they had had the opportunity to engage in decision making about the referral and, crucially, lacked the information to make an informed decision.⁸ In the present study, in-depth interviews were conducted with UK patients referred by their GP for specialist investigation for symptoms associated with lung or colorectal cancer. The extent to which patients felt involved in the decision making and were aware of the reasons for their referral were assessed.

METHOD

The individuals interviewed were taking part in a larger study called The SYMPTOM

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How this fits in

When referring patients for cancer investigation, the National Institute for Health and Care Excellence (NICE) recommends patient involvement in decision making and patients being given a full description of the referral pathway. No research to date has explored the extent to which patients feel involved and informed during the referral process. The present study indicates that current practice is not closely aligned to NICE in either of these areas. It is suggested that there is scope for GPs to increase patient involvement and engage in a more open and explicit dialogue about the referral pathway.

Study.⁹ The SYMPTOM Study recruited patients aged ≥ 40 years, who had been referred to secondary care, and who had been identified by research nurses as having one of a number of specified respiratory and lower gastrointestinal (GI) symptoms potentially associated with lung and colorectal cancer, respectively. Recruitment was from secondary care sites in the east and north eastern regions of England. Some patients in the north East were also recruited from a tertiary referral centre for people with respiratory symptoms, which received referrals from all the general hospitals in the region. Patients had been referred via two main pathways. The first was the fast-track, 2-week wait (2WW) route, whereby patients were expected to be seen by a cancer specialist within 2 weeks of referral, for which the patient would normally have met the symptom-based referral criteria in the NICE guidelines.² The second route was via referral to a routine clinic, with a longer waiting time, at which the patient would not necessarily see a cancer specialist. In The SYMPTOM Study, patients were asked to complete a questionnaire and to indicate their willingness to undertake an interview. This group of patients was purposively sampled for individuals to interview who varied in relation to age, sex, education level, diagnosis, and referral pathway.

A topic guide was used to ensure consistency across the interviews. It was based on the aims of both The SYMPTOM Study and the present study, and on the authors' knowledge of literature in the areas of cancer, diagnostic testing, and referral. Questions specifically relating to the present study focused on decision making and referral, patients' understanding of the referral, and patients' experiences of diagnostic testing.

The patient information sheet made no mention of cancer or cancer pathways, and the issues were not raised in the interview unless initiated by the patient. This was because, although patients were referred with symptoms suspicious of cancer, the authors had no idea whether cancer had been discussed with them, and thus did not want to raise it as part of the research interview. Patients gave written consent to participate. The interviews were conducted between 12 January 2011 and 29 November 2011, usually at the patient's home, and lasted between 30 and 90 minutes. They were audiorecorded, fully transcribed, and anonymised. Interviews were conducted until data saturation was reached.

Interviewing patients with respiratory and lower GI symptoms allowed comparison of contrasting diagnostic and referral experiences. Patients with respiratory symptoms may have a chest X-ray (CXR) arranged by their GP in primary care; the findings from this strongly influence whether they are recommended for secondary care assessment by respiratory specialists. In contrast, after primary care assessment and tests, patients with lower GI symptoms are generally referred to secondary care, with colonoscopy being the main diagnostic test. These two pathways offer markedly different experiences for patients in terms of cancer investigation.

Data analysis

Data were analysed thematically.¹⁰ A sample of transcripts were read and re-read, and an initial coding frame developed, applied, and refined until codes were agreed and applied consistently. The full data set was then coded using Atlas.ti (version 5.5) to aid data organisation and analysis. Coded data were organised into themes generated inductively, although the nature of the topic guide and the focus of the research brought a degree of deductive analyses to the process. Each interview was read and flow charts were constructed detailing patient pathways from symptom recognition, to referral, and on to secondary care investigation. All coded data were cross-referenced against the charts to contextualise and validate the meaning of the interview data. Because of the different characteristics of the two diagnostic pathways, they were analysed separately, then compared to identify similarities and differences.

RESULTS

Of the SYMPTOM responders, 1108 indicated that they were willing to be interviewed

Table 1. Participant characteristics at time of interview

Interviewees, n = 34	Total	Lower GI symptoms	Respiratory symptoms
Sex			
Male	18	10	8
Female	16	9	7
Age, years			
<50	7	4	3
50–59	8	4	4
60–69	11	8	3
≥70	8	3	5
Referral type			
2-Week Wait (2WW)	17	8	9
Routine	12	7	5
Routine (urgent) ^a	3	3	0
Tertiary ^b	1	0	1
Missing data	1	1	0
Education			
Degree	12	6	6
A level/diploma/professional/ vocational	13	9	4
GCSE/O level	2	1	1
None/unknown	7	3	4
Ethnic group			
White British	31	18	13
White other	1	0	1
Pakistani	1	1	0
Black African	1	0	1
Diagnosis at interview			
Cancer	3	1	2
Not cancer	15	9	6
Diagnosis not known at interview	16	9	7
Interview			
Mean time, days, from referral to interview ^c	64.2	73.1	52.8

^aGPs did not use a formal 2WW pathway but identified the referral as requiring urgent attention. ^bPatient admitted to secondary care after a chest X-ray and subsequently referred to tertiary respiratory clinic. ^cn = 32, two patients missing data.

(765 respiratory and 343 lower GI). From this group, 40 patients were purposively selected and interviewed. The analysis, however, was based on 34 transcripts (Table 1). Five transcripts were excluded because, although the patients met the selection criteria for interview, it was not possible to untangle their referral pathway relating to symptoms suspicious of cancer, as they had complex multiple morbidities and multiple points of contact with healthcare providers. A further transcript was excluded because the individual had undergone initial diagnostic testing and diagnosis abroad, and so the account did not detail UK clinical practice.

Findings for each diagnostic pathway are presented according to two themes: patient involvement in the referral decision for diagnostic testing and/or secondary care assessment; and information provided and

discussed at the time of referral. Data that show the impact of the referral dialogue on the patient experience are then detailed.

Patient involvement in decision making: lower GI symptoms

Most patients in this group described their GP as taking the decision to refer them. Patients did not view this negatively; decisions were seen to be made on their behalf by 'trusted' 'experts':

'I trusted her, so if she said I needed the test then I needed the test, yeah, I would do anything that Dr[X] said.' (P31, lower GI; 2WW; diagnosis not known at interview)

'I felt like she was acting in my best interests, so, I'm sure if I'd decided I didn't like the idea I could have said "No".' (P27, lower GI; 2WW; diagnosis – not cancer)

Also, for some patients, referral for further investigation represented the course of action they expected or wanted:

'The doctor thought that perhaps it could be piles but they wanted it checked out dear, which is what I wanted as well ... And if they hadn't of suggested [that] I would have said "Well look I am bleeding and I would like it looked further into".' (P1, lower GI; routine; diagnosis not known at interview)

There was greater evidence of involvement when expectations were not met. In the following data, the patient describes her efforts to redirect the GP away from previous diagnostic suggestions:

'Well, I thought [a physical examination] might not be a good idea because it was, she might get the wrong impression, she might think the [stool] flatness is down to the piles or something, and I knew it wasn't, because sometimes I feel like these doctors they don't really listen, you know? So I think I was trying to stress the point that I knew what was, something was wrong, and that it wasn't down to the piles and ... Like before when they'd said 'anal fissure'; I accepted that then, but afterwards I wondered whether I should have accepted that as that doctor just saying that, you know, and I think I had mentioned blood in between, when we've mentioned going to other appointments, I think I might have mentioned blood, but they can be dismissive of these things, so I was being really definite about my symptoms on that occasion.' (P27, lower GI; 2WW; diagnosis – not cancer)

Having been 'definite' about her symptoms, this patient was referred.

A more inclusive patient experience was identified, however. This was underpinned by GPs responding to patient concerns about persistent symptoms and/or giving patients the opportunity to voice their concerns. In the following quote, the patient describes the GP's referral decision after his expression of concern about cancer:

'We talked about my bowel movements and she said "is there anything that you're actually worried about?" I said "well yeah, cancer is the word you see", "okay", she said "well let's take it a stage further", so she arranged for me to have a blood test to check my um, whatever it is, PSA, for the prostate, she said "and we'll see about getting you in to see, for an endoscopy for your issues with your bowel", and that was it.' (P23, lower GI; 2WW; diagnosis — not cancer)

The referral dialogue: lower GI symptoms

Many patients recalled a vague and non-specific account of the reasons for referral, even when a 2WW appointment had been made. These patients tended not to see this as problematic:

'He just said "we'll see what they find", because I don't think he wants, he wanted to like um, get me to dwell on what it might be and what it, you know, because some people do, it's like having the internet isn't it, you've got an ache and you're looking up on Google and you end up you've got Calvin syndrome and whatever haven't you, you know?' (P43, lower GI; 2WW; diagnosis — not cancer)

'Dr[X], she said to me "I'm going to have this checked out at hospital", and I said "Right" and she said "The hospital will be in contact in the next 7 to 14 days" she said "And we'll just double check". And I said "Right, okay" I don't think I asked any questions of Dr [X] and I don't think she gave any, and I'll explain why. Dr [X]'s a fantastic doctor and I'd trust her with my life.' (P31, lower GI; 2WW; diagnosis — not cancer)

The dialogue was often accompanied by a narrative of reassurance and safety-netting:

'She said "I don't think there's anything to worry about" she said "But we've obviously got to have the bleeding investigated" (P31, lower GI; 2WW; diagnosis — not cancer)

It was rare that patients reported GPs

introducing the possibility of cancer or explaining the investigations in terms of testing for cancer. In the few cases where cancer was discussed, patients described GPs emphasising the safety-netting aspect of the decision, that is, to rule out cancer rather than to find it:

'I think the last time I went to see her she did say "Obviously you are concerned", and I said "Well I'm bound to be concerned because I value my health and I know when there's something wrong with me", and she said "Right, I'm not saying that it's cancer, I'm not saying that it isn't cancer, because I can't say until you have all these tests, that's why I'm sending you for all these tests to find out", she said "Ticking things off to find out what is actually wrong with you. Obviously there's something wrong because you're feeling like this". So it was just like a ticking box really, ticking things off, you know, that's clear, that's clear.' (P29, lower GI; routine; diagnosis — not cancer)

A dialogue around cancer also entered the consultation from patients concerned their symptoms were caused by cancer. Again, the GP was reported as describing the investigation in non-specific terms and minimising the possibility of cancer:

'I said "I hope it's not cancer or anything like that" and he said, "oh no, no", he said "It's just a routine check done in 5 minutes and I'll get the results 24 hours later" (P24, lower GI; routine; diagnosis — not cancer)

Patient involvement in decision making: respiratory symptoms

For patients with respiratory symptoms the decision to refer to secondary care tended to follow a CXR in primary care (some are referred direct to secondary care if they have overt high-risk cancer symptoms). This CXR played a highly significant role in shaping the patients' referral and investigative pathway, as it is recognised as 'the best first line test for suspected lung cancer'.¹¹

Most patients recalled the CXR as part of a general investigation and something they expected given their symptoms. At this stage, GPs did not tend to introduce the issue of cancer either:

'I mean, he just examined me and said I needed an X-ray, could tell from tapping my chest that there was something not right. ... Just that he'd diagnosed something that needed to be explored really.' (P17,

respiratory; tertiary; diagnosis — cancer)

Most patients did not feel directly involved in the decision to have a CXR but the test was seen as routine and the next 'logical' step to be taken:

'It was entirely his [decision], I'd never even considered it.' (P36, respiratory; 2WW; diagnosis — not cancer)

As with the lower GI patients, patients expected the GP to take an action that would represent progress and the notion of patient involvement was not relevant to them. Indeed, when invited by their GP to comment, some patients found it strange:

'Yeah, he asked if I minded and I thought "well why would I mind?" I'd rather sort of if there is something going on, I'd rather know than sort of hide my head but he did say "I think I'm going to send you for a chest X-ray, do you mind?" So, which I found really strange.' (P38, respiratory; routine; diagnosis — not cancer)

This sense of GP decision making endorsing patient expectations was also evident in the way that patients saw the referral decision as a positive step, in that it indicated both they and their symptoms were being taken seriously:

'[On being sent for CXR] A mixture of, again, pleasure that, pleasure, wrong word, you know, satisfaction that I was being taken seriously and given a test that made sense, and should obviously be done and sort of slight hesitation about why that would be necessary.' (P14, respiratory; 2WW; diagnosis — cancer)

The referral dialogue: respiratory symptoms

After CXR, patients reported that referrals to secondary care on a 2WW pathway were not always accompanied by a discussion of the reasons for referral but tended to be of a general and non-specific nature:

'Having had the X-ray, I got a phone call on the Friday from the doctor, to say that he got the results back and that I needed to go to a hospital and did I want to go to [hospital 1] or [hospital 2]. After discussion we chose [hospital 2]. So clearly he could see something on the X-ray that needed attention.' (P17, respiratory; 2WW; diagnosis — cancer)

'Just that there was this patch on the

lung that was showing up and that he wanted me to go and see the specialist when they would take another photo, you know, another X-ray, and if it cleared up, fair enough. If it hadn't you know, they would decide what to do. I think that was around with all the blood tests were clear, no problem with them.' (P36, respiratory; 2WW; diagnosis — not cancer)

'Nothing, just, no all he said was the lung health clinic. He said "you're going to the lung health clinic" so ... No, he didn't do anything at all. Oh he had a listen at my chest and the old tapping bits, just, but nothing else ... Well as I say when I got this little lump on the chest he said "right, you're in".' (P33, respiratory; 2WW; diagnosis — not cancer)

For patients referred to secondary care for routine appointments, the dialogue tended to revolve around the theme of no further investigations being available in primary care:

'And then he said "I don't know what to do with you so I'd better refer you to the lung clinic" he said "this is not good and this has been going on for such a long time so we'll refer you there".' (P12, respiratory; routine; diagnosis — not cancer)

The referral dialogue: impact (lower GI and respiratory)

It was clear from the data that patients' experiences of referral in both investigative pathways were positive and generally followed an expected path. There were negative outcomes, however, from this type of referral. Many patients entered secondary care assessment on a 2WW pathway with symptoms suspicious of cancer having not had a substantive discussion with their GP about the possibility of cancer. The 2WW pathway moves events very quickly, and it was apparent that the lack of a clear explanation at the point of referral could lead to feelings of uncertainty and anxiety:

'The fact that they'd bothered to ring up and get me in early, that began to ring a few alarm bells. There must be something there that makes it important that we short-circuit the system that the doctor had set up.' (P14, respiratory; 2WW; diagnosis not known at interview)

'I think, because I was a bit concerned about the speed that this was going through, you know, I thought "well I'd only gone with a little pain, why is he sending me to see

consultants and chest X-rays and things"... you know, I've got a slight pain down here, why are they sending me for a chest X-ray?. So I suppose I was a bit, you know, I was a bit concerned as to why everything seemed to go through at a fairly rapid pace.' (P36, respiratory; 2WW; diagnosis not known at interview)

The next quote highlights the potential practical and ethical issues that arise when patients are not given an explanation for their referral. The patient recalls seeing her details on the computer screen, prior to her secondary care appointment:

'I was looking at the screen, they don't actually say it, but I was reading on the screen it said 'cancer referral' now nobody had said that to me, and I was looking at it and that made me upset when I saw it on the screen ... it was a bit scary and I was already upset, so I got really upset.' (P27, lower GI; 2WW; diagnosis not known at interview)

The next extract illustrates the paradox and confusion that can arise between the wider macrosphere of public health campaigning and the microsphere of the GP consultation. Although the present data highlight a minimisation of cancer dialogue where patients exhibit potential cancer symptoms, at the same time there are public health campaigns running¹² that try and raise awareness of cancer symptoms and encourage a dialogue between patients and their GPs around cancer, without fear and embarrassment:

'You see, on the internet, when you find all these things, they say "Oh, go to your doctor immediately blah de blah" but the response you get when you go to the doctor is to tell you "Oh, it's only this, it's only that, only an anal fissure" or something, you know what I mean? So it's different, it doesn't match up.' (P27, lower GI; 2WW; diagnosis not known at interview)

DISCUSSION

Summary

Data from the present study indicate that patients' experiences of referral for cancer investigation are some way from NICE referral guidance, in terms of patient involvement in decision making and communication about the reasons for referral. It is suggested that patients had a minimal role in decision making. In many cases, their expectations were met by the GPs' decisions and they saw referral as a

progression rather than a decision.

Patient accounts of the primary care consultations indicated a tendency for GPs to keep referral dialogue non-specific, without an overt discussion about the possibility of cancer, even when it was a 2WW referral. Having sampled across a number of different patient attributes (for example, age and sex) and across two different referral pathways, and compared participants' accounts, it was found that issues identified around patient involvement and communication were common across patient groups and pathways.

Strengths and limitations

Only patients referred for investigation were interviewed. To get a fuller perspective of this process, future research could look at the perspectives of patients presenting with similar symptoms who are not referred, and video or audiorecord the consultation itself to capture how different individuals and perspectives interact. Also, patients in secondary care were interviewed, and so there was a passage of time between their referral and the interviews. Ideally patients would have been interviewed immediately after referral to avoid recall bias and the possibility of post hoc reconstruction. However, to the authors' knowledge, the study is the first to examine GP-patient communication around referral for cancer investigation. This is quite striking considering the prominence the NICE cancer referral guidelines give to patient involvement and communication.

Comparison with existing literature

In terms of SDM, it appeared that participants did not recognise the point of referral as warranting their involvement. In addition, the data suggest that some practitioners did not try to encourage an open discussion. This could be because clinicians may make a priori decisions about the appropriateness of SDM based on time, clinical condition, and patient characteristics.⁵ In relation to the wider literature on cancer diagnosis in primary care, research has highlighted the primary care consultation as a particular sticking point in the diagnostic pathway for cancer¹³ and as having significant potential for reducing the diagnostic interval¹⁴ (the period between presentation to a clinician and diagnosis).¹⁵ Qualitative studies have identified issues around communication that contribute to such delays, for example, patients expressing guilt about presenting their symptoms and 'wasting' the GP's time,¹⁶ and normalising symptoms, which prevented disclosure during consultations.¹⁷

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Ethical approval

Ethical approval was granted by the Cambridgeshire 3 Research Ethics Committee (10/H0306/50).

Provenance

Freely submitted; externally peer reviewed.

Competing interests

William Hamilton is the clinical lead for the ongoing revision of the NICE 2005 guidance on suspected cancer. His contribution to this article is in a personal capacity, and is not to be interpreted as representing the view of the Guideline Development Group, or of NICE itself. The remaining authors have no conflict of interest relevant to this research.

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Although the focus of the study was not delay in symptom presentation, the findings resonate with these studies in highlighting a difficulty that cancer, or in this case, the possibility of cancer, appears to inhibit or block open and clear communication about the meaning of symptoms.

Implications for practice

It is known that GP referral for specialist investigation is determined by social interaction as well as clinical information,¹⁸ and one of the key social characteristics of cancer is the fear that it generates.¹⁹ Thus a GP referring a patient with symptoms indicating risk levels around 5% (most NICE-based symptoms are at or above this level of risk)²⁰ may withhold discussion about cancer because they do not want to raise patient anxiety, and it is known that patients can find being referred for cancer particularly stressful;² furthermore, it is worth remembering that GPs generally manage a higher level of risk than their secondary care colleagues.¹⁸ The present data indicate, however, that the 'tipping

point' for discussing cancer alongside referral for investigation could be set too high. It is suggested that the tipping point for discussing the possibility of cancer should be moved to a lower level of risk for the following reasons:

- the importance of patient involvement in decision making and health care is recognised by the NHS as a core value.²¹ The present data illustrate the problems that can occur when a full dialogue about the referral is withheld.
- currently there are public health cancer awareness campaigns²² that encourage attendance in primary care for what patients may perceive as everyday ailments, albeit they have persisted for longer than usual. The message is that it is appropriate to discuss these symptoms and the possibility of cancer with the GP. The present data suggest that there is a discrepancy between the aims of the campaigns to encourage a cancer-based dialogue, and what is happening in clinical practice.

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