

The role of social context in symptom appraisal and help-seeking among people with lung or colorectal symptoms: a qualitative interview study

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Abstract

Prolonged diagnostic intervals are associated with poorer outcomes and the patient interval appears to be a substantial contributor to the overall length of the diagnostic interval. This study sought to understand how the broader context of people's lives influenced symptom appraisal and help-seeking, comparing experiences by length of the patient interval. Patients referred with a suspicion of lung or colorectal cancer were invited to complete a questionnaire about their symptoms, with 26 respondents purposively sampled to take part in a semi-structured interview about their patient intervals. **Embodied** experience, appraisal, help-seeking decision making and consultation were identified as component stages of the patient interval, with the factors affecting movement between these stages located in one of four contextual domains: individual experience, interpersonal relationships, health care system interactions and social and temporal context. The length of the patient interval was related to the type of symptom(s) experienced, discussion of symptoms with others and the social responsibilities people held during symptomatic periods. A *Contextual Model of the Patient Interval* illustrates the stages and domains of the patient interval, as grounded in the data from this study. The model has potential application to future studies examining the patient interval for a range of symptoms.

Keywords: Cancer, Patient Interval, Symptom Appraisal, Help-Seeking, Diagnostic Interval

Background

Cancer is the leading cause of death worldwide (World Health Organisation, 2013) and there is an increasingly well-established association between the length of the diagnostic interval and survival (Richards, Westcombe, Love, Littlejohns, & Ramirez, 1999; Tørring et al., 2012; Tørring, Frydenberg, Hansen, Olesen, & Vedsted, 2013). The diagnostic interval comprises three time periods; the patient interval (symptom onset to first presentation to a health care practitioner (HCP)), the primary care interval (first presentation to a HCP to referral into secondary care) and the secondary care interval (referral to diagnosis) (Burgess, Ramirez, Richards, & Love, 1998). There are a number of models that illustrate the diagnostic pathway, most notably the *General Model of Total Patient Delay* (Andersen, Cacioppo, & Roberts, 1995), the *Categorisation of Delay* (Olesen, Hansen, & Vedsted, 2009) and the *Model of Pathways to Treatment* (F.M. Walter, Webster, Scott, & Emery, 2012).

The patient interval has been shown to make a significant contribution to the overall length of the diagnostic interval (Hansen, Vedsted, Sokolowski, Ondergaard, & Olesen, 2011; Lyratzopoulos et al., 2015), with longer diagnostic intervals being associated with poorer outcomes (Neal et al., 2015). There are discrepant findings as to the association between demographic characteristics and the length of the patient interval, suggesting that time to presentation is more complex than causes attributable to individual characteristics (Macleod, Mitchell, Burgess, Macdonald, & Ramirez, 2009; Mitchell, Macdonald, Campbell, Weller, & Macleod, 2008; Ramirez et al., 1999).

There are a range of factors that have been shown to influence the length of the patient interval, with poor awareness of cancer symptoms (Simon, Waller, Robb, & Wardle, 2010), misappraisal of symptoms (Gascoigne, Mason, & Roberts, 1999; Scott, Grunfeld, Main, & McGurk, 2006), fear (Balasooriya-smeeckens, Walter, & Scott, 2015; Dubayova et al., 2010), concerns about ‘wasting the doctor’s time’ (Cromme et al., 2016; Hall, Birt, Banks, & Emery, 2015) and competing life demands (Andersen, Paarup, Vedsted, Bro, & Soendergaard, 2010) all identified as barriers to presentation. There are also factors that have a positive effect on the patient interval, such as the sanctioning of help-seeking (Birt et al., 2014; Howell, Smith, & Roman, 2008), exposure to a cancer awareness raising campaign (Be Clear on Cancer) (Moffat et al., 2015) and the presence of comorbidities (Macleod et al., 2009).

This study sought to explore the patient intervals of people with symptoms of lung or colorectal cancer, considering how symptom appraisal and help-seeking experiences **were influenced by the wider context of people’s lives, such as family and work**. Specifically, we sought to ascertain whether there were any key differences in the patient intervals of people who presented quickly and those who reported prolonged intervals.

Methods

Patients with suspected lung or colorectal cancer, who were referred urgently (a referral pathway known as the ‘two week wait’) or referred for direct access chest x-ray, to the University Hospital of North Tees, UK, were identified. Participants with no previous diagnosis of a lung or colorectal cancer, aged 40 years old and over were deemed eligible to

take part. This age criteria was selected because people experiencing symptoms of these cancers who are aged 40 and over are much more likely to have a cancer diagnosis than younger individuals (Cancer Research UK, 2016a). Eligible patients were sent an invitation to take part within two weeks of their first specialist appointment or direct access chest x-ray.

Lung and colorectal cancer are the two most prevalent cancers affecting people of both sexes in the UK (Cancer Research UK, 2016b). Typical symptoms of lung cancer include cough, breathlessness and haemoptysis, and typical symptoms of colorectal cancer include a change in bowel habit, stomach pain and rectal bleeding. These symptoms are also common within the general population, although only a small number are caused by a lung or colorectal cancer (Jones, Latinovic, Charlton, & Gulliford, 2007; Weller & Campbell, 2006). Therefore, people with symptoms, as opposed to clinical diagnoses, of these cancers were identified, as this more accurately mirrored the population who experience and consult about lung and colorectal cancer symptoms. This approach enabled us to explore a range of experiences and accounts, whereby commonality was in symptomatic experience and not ultimate diagnosis, enabling us to further understand the lived realities of the symptomatic population. This is important as efforts to reduce the length of the patient interval are based on encouraging symptomatic individuals to consult sooner and understanding the range of factors that influence presentation amongst all symptomatic individuals can help to tailor and support public health efforts to encourage early presentation.

Participants completed a questionnaire about their symptoms, demographic characteristics and social context, and were asked whether they were interested in taking part in an interview. Of the 1389 patients invited to take part in the study 164 returned a completed questionnaire (12% response rate) and 129 expressed a willingness to be interviewed. Here we will present an overview of the interview findings. Interview participants were purposively sampled for length of the patient interval, symptoms and diagnosis in order to engage with a breadth of experiences. Twenty six semi-structured interviews were carried out between March 2014 and February 2015, with people with symptoms of lung (12) or colorectal cancer (14). The key characteristics of participants are outlined in Table 1.

Interviews took place in participants' homes or at the university, depending on the interviewee's preference, and participants provided informed consent immediately prior to the interview. Interviews were recorded using a digital dictaphone and transcribed verbatim. Pseudonyms were used to anonymise all participants and the names of workplaces were also removed for two participants as their roles within the companies would have made them identifiable. A topic guide was used to direct interviews, covering symptom experience, discussion of symptoms with others, lifestyle, previous illness experience, and help-seeking.

The study adopted a constructivist grounded theory approach, whereby reality is seen as dynamic, (co)constructed and temporally located, as are participants' narratives. Analysis was undertaken from the outset of fieldwork and continued concurrently. It entailed coding, constant comparison and memo writing, punctuated by points of concentrated analysis (Charmaz, 2014). The first eight transcripts were coded line by line by author 1, with four of these independently coded by author 3 to confirm coding validity. The codes from these

transcripts were drawn together to produce a matrix for use in the coding of subsequent transcripts. Any themes and codes which later emerged were incorporated into the matrix and previous transcripts revisited to identify additional incidences. Interviews ceased when emerging theories were repeatedly supported by new data, as subsequent interviews no longer challenged or altered analysis (Glaser & Strauss, 1967).

Participant narratives were compared by patient interval length to explore the experiences of those who took differing periods of time to present. There is great variability as to the definition of 'long' patient intervals in this field, with categorisation ranging from one to three months (Courtney et al., 2012; Pack & Gallo, 1938). For the purposes of this study a consensus was reached between the investigators as to appropriate interval length categorisation. A short patient interval was categorised as being less than or equal to 1 week (n=8), a medium patient interval as between 1 week and 2 months (n=7), and a long patient interval as equal to or greater than 2 months (n=11). It is important to be mindful that these categorisations are simply constructs to aid analysis and were not intended to represent definitive judgements as to appropriate or acceptable length of the patient interval.

The length of the patient interval was calculated from the accounts presented by participants during the interviews. The date of symptom onset was defined as the first symptom reported by the interviewee that was attributable to this symptomatic episode. The end of the patient interval was defined as the date on which they consulted about their symptoms. These dates were elicited through open ended questions that prompted a detailed narrative of how an abnormal bodily sensation was identified and acted upon. The interviewer probed participants about these points if they did not emerge organically in participants' narratives.

The application of a theoretical framework to investigations of the diagnostic pathway is considered to be key to good practice (Weller et al., 2012), however, the use of *a priori* frameworks to design and guide research is not easily integrated with a constructivist grounded theory approach (Charmaz, 2014). To address this tension, findings were developed by the research team during the analysis phase and subsequently compared to existing models of the diagnostic pathway. Similarities and discrepancies between the two are discussed later in this paper.

Ethical approval for the study was obtained from the NHS National Research Ethics Service (NRES) North East Committee prior to the study commencing (Rec ref: 13/NE/0319).

Results

Participants were aged between 41 and 84 and 46% of the participants were women. Symptoms experienced included change in bowel habit, stomach pain and rectal bleeding for those presenting with symptoms of colorectal cancer. For those presenting with symptoms of lung cancer symptoms included cough, breathlessness, chest pain and haemoptysis (coughing up blood). Participants' final diagnoses included 'no abnormalities detected' (NAD), haemorrhoids, bronchitis, diverticulosis, Chronic Obstructive Pulmonary Disease (COPD) and cancer. Three participants had a cancer diagnosis, which comprised one participant with rectal carcinoma, one participant with Non Small Cell Lung Cancer (NSCLC) and one

participant with Small Cell Lung Cancer (SCLC). Details of all participants' symptoms, diagnoses and patient interval lengths are presented in table 1.

In this section we will present the key findings about the patient intervals of participants in this study: stages of the patient interval, contextual domains of the patient interval and comparison of patient intervals in relation to the length of the interval.

The Stages of the Patient Interval

Analysis of the interview data identified four stages within the patient interval: symptom experience, symptom appraisal, help-seeking decision making and consultation. Whilst these appear sequential, the realities of patients' help-seeking journeys were rarely linear. People moved backwards as well as forwards between stages, revisiting and revising their thoughts and actions, as a result of new information or embodied experience, for instance returning to a stage of symptom experience, and subsequently symptom appraisal, as new symptoms appeared or existing ones changed.

Embodied Experience

Interviewees reported a range of initial sensations that varied in the extent to which they deviated from normal bodily experience. Some initially experienced vague sensations, such as lethargy, whereas others experienced more distinct sensations, such as a cough or change in bowel habit, although these were not always conceived of as 'unacceptable', and therefore a symptom, immediately. Finally, some people had acute embodied experiences, such as pain or bleeding, which were seen to be drastic deviations from usual bodily functioning and universally seen to represent a symptom almost immediately.

I basically felt unwell for about three or four days...a bit lethargic, I didn't have a lot of energy. It's like I got up one morning and somebody had pulled the plug. (Christine)

Well, I just developed this cough, you know. And I never thought nothing about it, you know, it was just like a cough. (John)

It started off with, sat at the table in August having my evening meal, and rushed off upstairs, and I didn't even make it to the bathroom, and that was the first indication that there was something wrong. (Arthur)

The perceived severity of sensations in relation to acceptable parameters of bodily functioning and 'normalcy' influenced how quickly individuals conceived of them as symptoms and subsequently how soon the individual moved into the symptom appraisal phase. For some the absence of pain reinforced a belief that the sensation they were experiencing did not currently represent a 'symptom'. Whilst this sensation was considered by all to be a deviation from usual functioning, it was not seen to be a 'symptom', or to require clinical input.

Even though it's (bowel movement) loose, I think, 'well, I'm in no pain, it's not bothering me, just a nuisance, that's all.' (Roy)

Embodied experiences often changed **over time. Changes** in the nature of sensations led people to reconceive some experiences, from ‘nuisance’ sensations to ‘symptoms’. Some symptoms developed later in people’s patient intervals, **after they had already entered an appraisal phase for earlier sensations and symptoms.** New or evolving symptoms often catapulted an individual back to the primary process of ‘embodied experience’, in which they had to assess new sensations and consider whether or not they represented symptoms.

We can see how Bilal did consider his haemoptysis to be a symptom, but a symptom caused by a condition (sore throat or cold) which did not require clinical input. When the nature of the blood he was coughing up changed it prompted him to re-enter the symptom appraisal phase using the additional embodied information.

It wasn’t as much the last few years, it was specks here and there and I thought ‘oh, it’ll be alright, it’s been a sore throat or a cold’, which would accompany the symptoms. But the last year or so it got more noticeable, marked, and I was like ‘ooh, God, I don’t like the look of this.’ (Bilal)

Symptom Appraisal

The extent to which symptoms deviated from normal functioning influenced the type and gravity of explanations that individuals initially considered. When Richard’s mild cough first appeared he thought it was *just a dryness of the throat, that’s all*, whereas, Melanie, who experienced acute chest pain, immediately considered the possibility of a heart attack.

As symptoms progressed and developed people reappraised their experiences, revisiting and rejecting initial explanations and incorporating new, alternative explanations into their symptom appraisals.

My initial thought was that it was a bug, so, I mean I did, after when it started to continue, I did wonder whether it was any of the medication I was taking that might’ve caused it...But I couldn’t really, I couldn’t really pin it down. I kept a food diary for a while...IBS had gone through my mind. (Elaine)

The consideration of causality was dynamic, with symptomatic experiences repeatedly appraised against a number of possible hypotheses. A ‘best fit’ explanation was selected based on the causal condition that appeared most plausible at the time. As symptom experience evolved this hypothesis was often rejected and an alternate hypothesis selected, with ‘seriousness’ of possible cause generally heightening in severity.

In the process of appraising symptoms people engaged in a variety of responses that informed their ongoing management and appraisal of symptoms, such as dietary changes, lifestyle adjustments and self-medication, including the consumption of other people’s prescription medication.

I used to take vitamin C tablet and cod liver oil capsule each morning. I've stopped that 'cause I thought the cod liver oil may be lubricating the whole system. (Arthur)

I tried the odd tablet, my wife had a major operation about 12 years ago on her bowel, part of her bowel took away.... So a few weeks ago, I started, and it helped in the sense that you weren't going maybe on the Wednesday, then the Thursday you would start to go again, so it helped in the sense that you weren't going every day. (Roy)

Others gathered further information in order to better appraise their symptoms, either by researching symptoms or monitoring them for a defined period of time. A minority chose not to respond to their unusual bodily experiences, or to '*sweep it under the mat*' (Bilal), either because of competing demands or an assessment of symptoms as being insignificant.

I thought nothing about it at the time, or I didn't give it a great deal of thought. (Mark)

Whilst Mark did conceive of his diarrhoea as a symptom he believed it to be the result of personal stress and therefore something which did not require further scrutiny, either by himself or a HCP.

Help-Seeking Decision Making

People whose symptoms represented severe deviations from usual bodily functioning decided to consult relatively soon after symptom onset, as the expert input of a HCP was felt to be needed.

As soon as I started the bleeding that's when I thought 'I need to see somebody'. (Christine)

Amongst those who perceived their symptoms to be less drastic deviations from usual functioning, the decision to consult was based on either a need to access further information or to obtain treatment to resolve the symptoms. Many people's desire for knowledge about symptom causality was specifically a wish to know whether or not they had cancer.

Obviously with the [previous] prostate cancer, I don't understand how or where it can spread to, but that was at the back of my mind and that's what influenced me to go to the doctor. (Fred)

For those confident in their hypothesis of causality, consultation was a means of accessing resources, either in the form of investigations or treatment.

What I wanted really was some reassurance and perhaps an x-ray. (Richard)

I thought 'I need an inhaler', it might be asthma or that and when I got, I thought 'Oh he [the GP] might give me an inhaler'. (Pauline)

The final reason for seeking help was a diminished ability to tolerate symptoms, therefore the input of the clinician was needed for the symptoms to be resolved and a tolerable level of bodily functioning to be restored.

I think it had actually come to that point 'I can't go on living like this anymore, this is too much of a burden to put up with'. (Mark)

Consultation

The consultation itself was the final stage within the patient interval. Most participants reported that the transition from help-seeking decision making to consultation was straight forward, with all being able to easily schedule, and attend, an appointment within a time period that they felt to be acceptable. The exception to this was Angela who made the decision to consult about her rectal bleeding straight away, however, her pre-booked holiday prevented her from doing so.

I had blood on the toilet paper when I passed a motion and the first time was on August the, when was it? August 3rd, but we were going on a holiday of a lifetime on the 5th and I thought I don't want to cancel this two months because of this...So off we went and then on the 23rd August I had another show of blood and if I had been at home I would have gone to the doctors straightaway, but because we had this holiday I didn't...I thought of going while we were in the States but that would have been horrendously expensive and might not have been covered by the insurance and then that would have just ruined the holiday, so I just thought no, wait until I get back home.

The obligation to go on holiday, and the unattainable costs of accessing healthcare whilst abroad, meant that Angela waited until she returned home to consult about her symptoms, despite having made the decision to do so from the first episode of bleeding.

The Contextual Domains of the Patient Interval

External contextual factors substantially influenced participant's movement between the four stages of the patient interval, and could act as barriers or triggers to presentation. They were found to be located in one of four contextual domains: individual experience, interpersonal relationships, health care system interactions, and social and temporal context.

Individual Experience

People incorporated previous experiences of illness into the appraisal of their symptoms, comparing and contrasting historic and current symptom experience and remedy. Participants with previous cancers drew on this experience in the appraisal of new symptoms, irrespective of whether current symptoms related to the previous cancer site or not.

I have bladder cancer and the symptom for that is blood in the urine. So on three occasions I had blood in my urine and it was a real symptom, I did have cancer...So I thought 'blood in the rectum, tell the doctor'. (Jack)

Previous illnesses of family members, particularly familial illnesses to which individuals perceived themselves to be vulnerable, were also assimilated into symptom appraisal and decision making, often in relation to cancer, but sometimes other conditions as well.

My origins are from parts of the world where TB can be associated... we have hereditary diabetes and strokes and things in the family and, it's kind of, you then begin to self-diagnose (Bilal)

Exposure to carcinogens, both in terms of smoking history and occupational exposure to toxic chemicals was a recurrent consideration among participants experiencing respiratory symptoms. Concerns about asbestosis were particularly common among men because of the high number who had worked with asbestos historically.

I was worried about my lungs because I'd worked with asbestos, and I'd worked in very dusty atmospheres for a lot of years, all my life almost. (Tom)

Interpersonal Relationships

Most people discussed their symptoms with others, mainly with spouses, but also with children and friends. Many people discussed their symptoms in order to obtain reassurance, either that the symptoms were not significant, or, that help-seeking was the appropriate course of action in this instance.

I think sometimes you just want somebody to say 'well it isn't anything to worry about' or 'yes, really you ought to [go to the doctor's]'. (Elaine)

Others disclosed their symptoms to notify people of the possibility that the symptoms might affect their ability to perform in their usual roles and responsibilities.

It was just really making him aware that I am really poorly, well not really poorly, but that I could be really poorly. (Bilal)

A minority of participants chose not to discuss their symptoms in order to avoid worrying others, believing that they should only divulge symptoms if, and when, there was a serious diagnosis which the other person needed to know about.

I didn't want to worry them really. I'd rather tell them when there's something concrete to tell them, so I've told the other two [children] afterwards, 'well, I've had a colonoscopy and everything's fine', because I didn't see the need to worry them unnecessarily. (Angela)

Once significant others were aware of the individual's symptoms they generally encouraged help-seeking, whilst simultaneously reassuring the individual that the symptoms were 'probably nothing'. Sanctioning rarely acted as a prompt to help-seeking in isolation, but was considered by participants in conjunction with a number of other factors, as part of the help-seeking decision making stage.

Eventually, your thoughts and the thoughts of others meet, and then you say 'okay, I'm going to do something about that'. (Richard)

Health Care System Interactions

Interviewees who reported positive relationships with their GP felt confident and comfortable in seeking help, whilst those who had previous negative experiences were sometimes reluctant to consult. Recent engagement with a screening programme shaped how people appraised their symptoms, as negative screening results provided reassurance that the current symptoms could not be due to cancer, thus discouraging help-seeking.

In between all this the poo test thing came through, so I thought 'oh right, good, I'll do this'. And then it came back negative. 'Oh right, so it must be all right'. So then you go along a bit further then. (Eleanor)

People wanted to be seen as appropriately managing their health and their engagement with the health care system, only consulting for legitimate symptoms and never 'wasting the doctor's time'.

I don't want to waste my doctor's appointment. I would feel a waste of time if I went across and nothing was going on. (Sandra)

Social and Temporal Context

The impact of symptoms on people's ability to meet existing social responsibilities, and their ability to do so in the future, influenced many people's patient intervals. Work, along with caring roles, was a prominent feature in people's narratives, but people also responded to their symptoms in light of their roles in the community or upcoming events, such as Christmas or holidays.

I've got an assistant there [church], well another warden, and she's a lady and she would say to me, because I was coughing, 'I'll go'. Because we've got to hand out the bread and the wine, 'I'll go down to the altar today' because I was coughing...I wouldn't know when a cough was coming on, and when it did come on it came on viciously, it was a really rough cough. And I wouldn't like to be doing that over the sacrament. (Tom)

People also considered how the presence of certain symptoms, or conditions would affect their social standing. Bilal actively resisted seeking help as he believed doing so would result in stigmatisation from his family and the wider Asian community locally, because of the stigma he believed existed towards illness within his culture.

It's this culture, this bubble that's preserved here, especially if there's an ailment...for me personally I feel this pressure, and I really don't want to be seen as, I feel as though I'm letting everybody down. (Bilal)

Public health campaigns and news items about the importance of early diagnosis were incorporated into people's appraisal of their symptoms and help-seeking decision making.

It was when I heard, saw, all the adverts about bowel cancer, that's what sort of pushed me into going to the doctor's. (Fred)

Exposure to a Be Clear On Cancer (BCOC) campaign was reported by a number of interviewees as influential in their decision to consult.

Characteristics of Patient Intervals in Relation to their Length

All participants moved through the four processes outlined above and were, to lesser and greater extents influenced by the four different contextual domains identified. The key characteristics of short (less than one week), medium (one week to two months) and long (greater than two months) patient intervals shall be discussed here.

Short Patient Intervals

Those with short patient intervals all experienced acute sensations, of bleeding or pain, that represented severe deviations from usual bodily functioning. They were conceived of as symptoms swiftly after onset and believed to require consultation with a HCP, with the possibility of cancer being considered by most. People with short intervals tended to be experiencing 'life as normal', reporting no additional demands or pressures in their lives at that time.

Working as normal, nothing else going on in my life, everything was really normal...I had no stresses. Life was just normal. (Steve)

Most participants mentioned their symptoms to others, however, the aim of this was not to engage in discussion or seek advice as to appropriate response, but to inform them of the symptoms' presence and the intention to consult, a decision which had already been made.

Medium Patient Intervals

Participants who had medium patient intervals generally had symptoms which were not initially conceived of as alarming, with common complaints including a change in bowel habit, a cough or a general feeling of being unwell. People tended to engage in periods of symptom monitoring, making slight lifestyle adjustments, particularly dietary changes, to assist in the appraisal and control of symptoms.

I thought 'this is tied in with what I'm eating' so I started to try and analyse what I was eating...I've checked out chocolate...I've binned that and I've binned bananas, potatoes I suspect too. (Arthur)

When symptoms were not self-limiting, or did not respond to lifestyle adjustments as expected, people began to move towards more disease based explanations for their symptoms, with cancer often an emerging concern. Some people with medium patient intervals chose to discuss their symptoms with others, seeking out dialogue about the

potential causality and appropriate response, which, in some instances was a desire to obtain reassurance that the symptoms were 'nothing'. Others chose not to discuss their symptoms to 'avoid worrying others'.

I'm wanting him [husband] to say something reassuring like 'oh, you're alright, it's nothing, that's fine' but he always says 'go to the doctors, they have the answers'. (Pamela)

Most participants with medium patient intervals did not perceive their symptoms to be 'severe' or alarming. They engaged in periods of adaptation and monitoring, and worked through changing explanations of causality. Joseph was the exception to this rule. Joseph experienced a symptom, 'spitting up blood', which for him was serious and alarming, with his interpretation of, and concern about, this symptom more akin to the reports of those who had short patient intervals. What was unique to Joseph, however, was the chaotic nature of his life at that point. Joseph had recently taken a substantial amount of time off work to support his wife through cancer treatment and, as a self-employed joiner, couldn't afford to take more time off, particularly because of his demanding workload in the run up to Christmas. He tried to hide his haemoptysis from his wife, in order to postpone help-seeking until after the busy period, however, his wife 'caught' him and insisted on his consultation.

Well I tried to hide it but of course her indoors...she came in and caught me: 'What are you doing?' 'Nothing.' And then all hell broke loose...always that time of the year the work's absolutely crackers because people want stuff doing for Christmas. And I thought 'look, I'll hang on until after the busy time's over' but she wouldn't have it. (Joseph)

In contrast to Joseph, all other participants with medium patient intervals reported having relatively 'normal' lives during their symptomatic periods, with no apparent additional pressures, responsibilities or stresses that impacted their symptom management and help-seeking decision making.

Long Patient Intervals

Those with long patient intervals experienced a range of symptoms, from a wheeze or more frequent need to defecate, to haemoptysis or rectal bleeding. Most people's symptomatic experiences evolved and heightened over time, progressing from sensations perceived of as minor up to major deviations in bodily functioning. Just as symptoms progressed and changed over time, so too did people's explanations for them.

You work your way through from the simplest things up to the 'well it's whatever'. You don't go in at the 'well it's definitely cancer or something like that'. (Eleanor)

Help-seeking triggers included the wish to obtain a definitive explanation for their symptoms, with consultation being a means of accessing investigations, diagnoses and treatment. The impact that symptoms had on people's ability to perform in their everyday lives was also a key trigger to help-seeking.

Although it'd been, at that stage, 5, 6, 7, 8, times a day, it was that one particular week in January and I thought 'oh I can't'. I mean, I had some accidents, lets put it like that, so of course it became 'this really is now sort of disturbing my life' as opposed to 'I feel ill'... When you get to the stage where you're stripping off in the toilet at work and rinsing them [clothes] out in the sink and drying them with the hand dryer...that week was just the final straw that broke the camel's back. (Elaine)

People with long patient intervals often had many social commitments and were obliged to fulfil numerous roles in their lives and the lives of others, such as employment, familial care, community roles, or responsibilities that arose as a result of recent bereavements.

We did have a bit of a family trauma during that period as well. My mum was very poorly, she'd been in a nursing home for about three years with dementia, quite severe dementia actually, and she died on March 31st this year as well...I shouldn't have used it as an excuse about not going to the doctors but I probably did probably at that time and things, about getting all that sorted out, the way things, my mum's funeral and all the emotion and trauma that goes with it as well. (Mark)

Eleanor waited six months before consulting about her rectal bleeding, primarily because of the many demands on her time; her husband was undergoing cancer treatment whilst they were in the middle of renovating their own home, as well as investment properties.

All the architects and the meetings with builders and all that kind of stuff was all going on. In between we're still looking after the grand bairn, going to hospital for this, that and the other, so it's all very busy and very stressful. (Eleanor)

Many people discussed their symptoms with others, incorporating the thoughts of others into their own assessment of the situation, however, sanctioning of help-seeking by others rarely acted as a prompt in itself. Instead, it was incorporated into the assessment of the situation, alongside numerous other factors from the contextual domains of people's lives.

Multiple factors shaped movement between the stages of the patient interval and were also influenced by other contextual factors. The complexity of factors influencing the patient interval is most apparent amongst those with long patient intervals and we can use Pauline's story as an example of this.

Pauline experienced a cough for 4-5 years, which she attributed to the effects of being a smoker. Over the course of her patient interval her employees encouraged her to consult about the cough, referring to the BCOC lung campaign to support this. However, she felt that whilst the cough 'was annoying... it wasn't well, life threatening' and so consultation was not a priority, particularly given the demands of running a business. Upon retirement Pauline was excited to take part in a range of activities now she had much more free time, despite the cough persisting. Shortly after she retired Pauline developed breathlessness, which prevented her from walking any significant distance, which in turn prevented her from going into town

with her daughter. When she received a letter from her GP encouraging consultation for respiratory symptoms, she saw the letter as ‘fate’ and decided to consult.

We can see how, for Pauline there were numerous factors that influenced her movement between the stages of the patient interval. These included changing symptom experiences, perceptions of what might be acceptable bodily functioning for a smoker, sanctioning of help-seeking by her employees, commitments at work, the impact of symptoms on valued social roles, her exposure to awareness raising campaigns and personalised endorsement of help-seeking from her GP. These mediating factors were all located within the domains of the patient interval outlined above. Smoking status belonged to the domain of individual experience, colleagues’ endorsement of help-seeking part of the domain of interpersonal relationships, the GP letter an example of an interaction with the health care system and exposure to the BCOC campaign and work responsibilities belonging to the domain of social and temporal context. For this participant factors from all four contextual domains influenced how she experienced, appraised and responded to her symptoms.

Discussion

This study identified a number of differences in patient interval experiences relative to length. The symptoms experienced differed, with bleeding or pain characteristic of short patient intervals, ‘minor’, or ‘non-alarming’ symptoms characteristic of medium patient intervals (with the exception of Joseph) and changing symptoms, which evolved from minor to major bodily deviations over time, characteristic of long patient intervals. The length of the patient interval was also linked to the number, and severity of, explanations considered for symptoms. The impact of symptoms on people’s ability to function in their everyday life was greatest for those with long patient intervals, and did not appear to have any substantial impact on the lives of those with short and medium patient intervals.

People with short and medium patient intervals reported usual levels of social commitments, with life tending to be ‘normal’ at that point (again, with the exception of Joseph). Those who took the longest to present were often experiencing complex and pressured periods in their lives, with extra-ordinary responsibilities in addition to usual ones, such as dealing with a parent’s death or providing care for a spouse undergoing treatment for cancer. **Demographic characteristics such as age, cohabitation and employment status did not appear to be associated with the length of time it took an individual to consult.**

The findings from this study indicate that a range of mediating factors shaped movement between the stages of the patient interval. A number of these, such as the sanctioning of help-seeking by others (Smith, Pope, & Botha, 2005), previous negative interactions with a GP (Granek & Fergus, 2012) and competing priorities (R. S. Andersen et al., 2010; Suzanne E Scott et al., 2006) have also been identified by other scholars. Models of the diagnostic pathway illustrate the stages a patient moves through from symptom onset to diagnosis, and three key models will be discussed in relation to the findings of this study.

The *General Model of Total Patient Delay*, a development of Safer et al’s three stage model of delay (Safer, Tharps, Jackson, & Leventhal, 1979), identifies five stages leading to

consultation, which are similar to those here (Andersen et al., 1995), however, it fails to consider how factors outside of the realm of the individual influence the journey to consultation. The *Categorisation of Delay* depicts the stages of the diagnostic pathway, considering points of potential delay and to whom delays may be attributable (Andersen, Vedsted, Olesen, Bro, & Søndergaard, 2009). The patient interval is represented as two defining stages (first symptom and first contact with the GP) but this model does not expand upon the stages, or events, which occur between the two. Neither of these models are helpful when seeking to describe the findings of this study, as they are unable to reflect the complexity of the patient interval, either in terms of its component stages or the wider influences that shape movement between them.

The *Model of Pathways to Treatment* illustrates the events, processes and intervals of the diagnostic pathway, along with the contributing factors that influence progression along it (F.M. Walter et al., 2012). The first two intervals (appraisal and help-seeking) represent what is commonly referred to as the patient interval, and commence with the event 'detection of bodily change'. For participants in this study, symptom experience was rarely a discrete event but an embodied experience, and interpretation of that experience, which took place over a period of time, the length of which was influenced by perceived symptom severity, and so was more akin to a process than an event. The *Model of Pathways to Treatment* includes contributing factors (patient, health care provider & system, and disease) that influence the processes, events and length of intervals (Scott, Walter, Webster, Sutton, & Emery, 2013). Contributing factors determine the speed and direction of movement and so it is important to gain a deeper understanding of what they are, how they influence movement through the pathway and how they relate to one another. This study identified factors from the health care system, such as expectations of consultation and engagement with screening, that influenced patient intervals and underlying disease undoubtedly affected the sensations and symptoms that people experienced.

The category of patient factors includes demographic, comorbidities, psychological, social, cultural and previous experience as components, and we can see influences of these factors in the narratives of participants in this study. However, the attribution of these factors to the realm of the individual is somewhat problematic, as this implies that these factors are, to an extent, within the control of the individual. This places accountability, or potential attribution of blame, to the individual, should one of these factors hinder swift progression to diagnosis. It is clear from the findings of this study that the majority of factors that influenced movement between the stages of the patient interval were outwith the control of the individual. It is important to contextualise these factors within the wider context, acknowledging the constraints that they may impose on an individual, along with their dynamic nature. For instance, how do social structures (e.g. governmental bodies and their policies), culture (e.g. beliefs about illness and management of illness) and social discourses (i.e. appropriate use of health care resources) exert influence over the individual and their range of available responses to episodes of illness? The *Model of Pathways to Treatment* poses problems when trying to unpick the complex contextual factors that influenced movement between stages of the patient interval for participants in this study, as it locates

~~such factors within the realm of the individual, as opposed to the broader social context, thereby not acknowledging the structural impositions they may place on individual's lives.~~

The reason why existing models do not effectively illustrate the multiplicity and interconnectivity of factors which mediate movement through the patient interval ~~for participants in this study~~ may be because they illustrate the diagnostic pathway in its entirety. Therefore, they may be too overarching to adequately capture the fine detail of the patient interval specifically. As a result, we developed a new model to describe and reflect upon the patient interval, grounded in the findings of this study. The *Contextual Model of the Patient Interval* (Figure 1) illustrates the stages from sensation onset to consultation and locates them within the contextual domains identified. These four stages are depicted with bilateral arrows between them, indicating the potentiality for movement, both backwards and forwards, as mirrors actual patient experience. This model incorporates the contextual factors of patient intervals, in an effort to effectively consider how they shape this time period, as well as the broader context from which they arise.

The first stage, **embodied experience**, refers to the period from which an 'abnormal' bodily sensation is first identified to the point at which the individual perceives this sensation to be a 'symptom'. At the beginning of the embodied experience process an individual experiences a sensation that they perceive to be abnormal, a sensation that transcends the 'silence' of usual bodily functioning (Malterud, Guassora, Graungaard, & Reventlow, 2015). Whilst some of these sensations are accepted, those which fall beyond an individual's parameters of usual bodily experience come to be conceived of as symptoms. The **embodied** experience stage contains both the experience of sensation(s) and the process of acknowledging the sensation as an unacceptable deviation from usual functioning and therefore a symptom. Whilst all sensations have the potential to become symptoms, it is the attribution of the symptom label that introduces the potential for help-seeking and engagement with the health care system, **and progression to the process of symptom appraisal**.

Symptom appraisal is the second stage of the patient interval, in which individuals reflect upon, and respond to, their symptom(s) to impart meaning and potential resolution. People engaged in a number of activities through which they attempted to ameliorate their symptoms, such as self-medication, dietary changes or obtaining further information to aid their appraisal of causality. **All these strategies have been common responses to symptoms in other studies of help-seeking (Oberoi, Jiwa, McManus, Hodder, & de Nooijer, 2015; S.E. Scott, McGurk, & Grunfeld, 2007)**. This is an iterative process, whereby hypotheses of potential causality feed into symptom management, with information gleaned from management activities feeding back into ongoing appraisal and consideration of causality.

Help-seeking decision making is the period in which an individual considers the necessity of consultation, reflecting on the range of information that informs their decisions as to whether consultation is necessary. Someone may enter this stage a number of times, through their reflection on the necessity of consultation, but return to the symptom appraisal stage when consultation is deemed to be unnecessary. A decision to seek help does not automatically propel an individual into the consultation stage as contextual factors can prevent progression.

Factors such as transport or finances may be a barrier to accessing health care and moving from the help-seeking decision making stage to consultation. We can see from Angela's experience that her pre-booked holiday, combined with the unattainable cost of consulting whilst abroad, contributed 3 months to the overall length of her patient interval.

The final stage is the consultation itself, the point at which the individual attends a health care setting and engages in a discussion with a HCP about their symptoms. **During this encounter individuals must present their experiences in a manner which is acceptable to the GP, striving to articulate embodied sensations through the constraints of language (Heath, 2008). People must also negotiate the interaction in order to ensure that the GP responds to their complaints in an acceptable and timely manner, therefore transforming reported symptoms into signs of pathology (Andersen & Vedsted, 2015).**

The four contextual domains incorporate the range of mediating factors that influenced movement between stages of the patient interval, highlighting the uncontrollable nature of many of these factors for individuals. The contextual domains are contemporaneous and factors located within one domain can affect, and be affected by, factors from another.

~~Individual experience refers to a person's past experiences and conceptions of themselves. Whilst the processes depicted in the centre of the model are the experiences of the individual within the moment~~ The domain of individual experience refers to the individual's conceptions of themselves in other times, both past and future. Historically, people reflect on previous illness, including cancer, carcinogenic exposure and lifestyle factors. Prospectively, people integrate their conceptions of themselves as 'healthy' into their decisions making, often rejecting cancer as a viable part of their future (R. S. Andersen et al., 2010; Gascoigne et al., 1999; Molassiotis, Wilson, Brunton, & Chandler, 2010).

The domain of interpersonal relationships refers to the ways in which 'others', such as family, friends and colleagues, influence the help-seeking journey. These relationships are the location of interactions about embodied experiences and appropriate responses to symptoms, which can help to legitimise concerns, obtain additional information and endorse help-seeking (de Nooijer, Lechner, & de Vries, 2001; Mwaka, Okello, Wabinga, & Walter, 2015). Interpersonal relationships were also considered by individuals in their responses to symptoms, for instance, through non-disclosure of symptoms to avoid causing undue worry to others, **a behaviour which has also been found among other cancer patients (Leydon, Bynoe-Sutherland, & Coleman, 2003).**

Health care system interactions refers to people's previous, current, and projected engagement with the health care system. Previous encounters entail both consultation and engagement with screening programmes and shape how people conceive of their symptoms and respond to them. Anticipations of consultation also influence help-seeking, including beliefs about what the consultation will entail, or a wish to 'not waste the doctor's time', **a barrier which is being increasingly identified by scholars in this field (Cromme et al., 2016; Hall et al., 2015).**

The final domain refers to the social and temporal context in which the individual is located. This domain comprises the societal, structural and political contexts, including social responsibilities and commitment (C. Burgess, Hunter, & Ramirez, 2001; Emery et al., 2013), exposure to governmental messages delivered through public health campaigns (Ironmonger et al., 2014) and cultural beliefs about health and illness, all of which are temporally located.

~~For instance, the cost of consultation in countries where health care is not free at the point of access, as it is in the UK, may be a barrier for some people. Further research is needed to assess the applicability of the model to different populations. although it is conceivable that the stages and contextual domains identified would be versatile and broad enough to incorporate a range of modifying factors.~~ The *Contextual Model of the Patient Interval* helps us to consider how social context may influence the patient interval and how time to presentation results from an interplay of numerous mediating factors. When considering the length of the patient interval this study highlighted how as interval length increased so too did the number of factors, and contextual domains within which they were located, which influenced people's journey to the doctor's. The *Contextual Model of the Patient Interval* is grounded in the reports of patient intervals presented by participants in this study and it is plausible that additional barriers and triggers to presentation would be identified in different populations.

Strengths and Limitations

A strength of this study is that it recruited patients with a range of diagnoses, all of whom experienced and presented with symptoms compatible with a lung or colorectal cancer. In recruiting people who were symptomatic, this is one of the few studies that explores a range of accounts whereby commonality lay in symptomatic experience, as opposed to eventual diagnosis (R. S. Andersen et al., 2010; Birt et al., 2014; Hall et al., 2015). This means that the findings presented here more accurately align with the experiences of the group who are ultimately the target of public health efforts to modify behaviours and increase early presentation, namely the symptomatic population.

Interviews took place within 7 and 165 weeks of symptom onset, with a median of 20 weeks having elapsed between symptom onset and interview. The passage of this amount of time may have affected participant's ability to recall events. The fact that participants had undergone investigations and discussed diagnoses with health care practitioners will also have influenced how people conceived of, and reframed, both their experiences and the narratives that they presented (Andersen & Risør, 2014; Scott & Walter, 2010). It is important to remember the time lapse when considering the data presented here. However, we Whilst this passage of time is important in our interpretation of these findings, we would argue that reframing of experiences will take place irrespective of the point at which someone is asked to discuss their symptomatic and help-seeking experiences. This is because, in asking people to articulate their experiences, if it is only moments after the symptom was 'felt', people will always reframe their narratives based on both events that have since occurred and the implied value that is placed on that specific experience because it has become the objects of research inquiry.

thus placing value on these events which will undoubtedly prompt a reconsideration of them by participants. Therefore, whilst the narratives of participants in this study will have been recast in light of their investigations and discussion of possible diagnoses, including cancer, from a constructivist grounded theory perspective, these narratives are still valid and legitimate.

This study reports the experiences of those who *did* consult a HCP about their symptoms, a population referred to as the visible part of the ‘symptom iceberg’ (Hannay, 1979). Around 80% of people who experience a symptom will never consult about it, instead choosing to manage it within the ‘popular sector’, or not respond to it (Kleinman, 1980). Therefore, the narratives of the symptomatic majority are absent from this account, meaning that findings may not reflect the experiences of those who never consult. Although these individuals’ accounts are absent, the model may still have application with this group, explaining how symptom experience and appraisal are bound by wider contextual domains. Further work with a community-based sample would enable the authors to test the robustness of the model and its efficacy for the non-consulting symptomatic population.

Conclusion

As our understanding of the diagnostic pathway increases, flaws in existing models become more apparent. Whilst these models are varyingly successful at illustrating the diagnostic pathway in its entirety, they are less adept as tools for examining specific intervals, as detail is inevitably lost. We have presented a new model, the *Contextual Model of the Patient Interval*, that is grounded in the experiences of people with symptoms of lung or colorectal cancer. The model has application as a tool to assist in the design, conduct and analysis of research into the patient interval, acting as a framework through which its component stages, barriers and triggers to presentation, and the contextual domains in which they are located, can be considered. The model has the potential to accommodate the experiences of people experiencing different symptoms, different underlying diseases, or from different populations. Further work is needed to understand the efficacy of this model in other populations.

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References

- Andersen, B. L., Cacioppo, J., & Roberts, D. (1995). Delay in seeking a cancer diagnosis: Delay stages and psychophysiological comparison processes. *British Journal of Social Psychology*, 34, 33–52.

- Andersen, R. S., Paarup, B., Vedsted, P., Bro, F., & Soendergaard, J. (2010). "Containment" as an analytical framework for understanding patient delay: a qualitative study of cancer patients' symptom interpretation processes. *Social Science & Medicine (1982)*, 71(2), 378–85. <http://doi.org/10.1016/j.socscimed.2010.03.044>
- Andersen, R. S., & Risør, M. B. (2014). The importance of contextualization. Anthropological reflections on descriptive analysis, its limitations and implications. *Anthropology & Medicine*, 0(0), 1–12. <http://doi.org/10.1080/13648470.2013.876355>
- Andersen, R. S., & Vedsted, P. (2015). Juggling efficiency. An ethnographic study exploring healthcare seeking practices and institutional logics in Danish primary care settings. *Social Science and Medicine*, 128, 239–245. <http://doi.org/10.1016/j.socscimed.2015.01.037>
- Andersen, R. S., Vedsted, P., Olesen, F., Bro, F., & Søndergaard, J. (2009). Patient delay in cancer studies: a discussion of methods and measures. *BMC Health Services Research*, 9, 189. <http://doi.org/10.1186/1472-6963-9-189>
- Balasoorya-smeeckens, C., Walter, F. M., & Scott, S. (2015). The role of emotions in time to presentation for symptoms suggestive of cancer : a systematic literature review of quantitative studies.
- Birt, L., Hall, N., Emery, J., Banks, J., Mills, K., Johnson, M., ... Walter, F. M. (2014). Responding to symptoms suggestive of lung cancer: a qualitative interview study. *BMJ Open Respiratory Research*, 1(1), e000067–e000067. <http://doi.org/10.1136/bmjresp-2014-000067>
- Burgess, C. C., Ramirez, A. J., Richards, M. A., & Love, S. B. (1998). Who and what influences delayed presentation in breast cancer? *British Journal of Cancer*, 77(8), 1343–8. Retrieved from <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2150175&tool=pmcentrez&rendertype=abstract>
- Burgess, C., Hunter, M. S., & Ramirez, A. J. (2001). A qualitative study of delay among women reporting symptoms of breast cancer. *The British Journal of General Practice : The Journal of the Royal College of General Practitioners*, 51(473), 967–71. Retrieved from <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1314188&tool=pmcentrez&rendertype=abstract>
- Cancer Research UK. (2016a). Cancer Incidence by Age. Retrieved October 4, 2017, from <http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/age#heading-Zero>
- Cancer Research UK. (2016b). Cancer Incidence for Common Cancers. Retrieved June 13, 2016, from <http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/common-cancers-compared#heading-One>
- Charmaz, K. (2014). *Constructing Grounded Theory* (Second Edi). London: Sage Publications Ltd.

- Courtney, R. J., Paul, C. L., Sanson-Fisher, R. W., Macrae, F. A., Attia, J., & McEvoy, M. (2012). Factors associated with consultation behaviour for primary symptoms potentially indicating colorectal cancer: a cross-sectional study on response to symptoms. *BMC Gastroenterology*, *12*(1), 100. <http://doi.org/10.1186/1471-230X-12-100>
- Cromme, S. K., Whitaker, K. L., Winstanley, K., Renzi, C., Smith, C. F., & Wardle, J. (2016). Worrying about wasting GP time as a barrier to help-seeking: a community-based, qualitative study. *British Journal of General Practice*, *66*(648), e474–e482. <http://doi.org/10.3399/bjgp16X685621>
- De Nooijer, J., Lechner, L., & de Vries, H. (2001). A qualitative study on detecting cancer symptoms and seeking medical help; an application of Andersen's model of total patient delay. *Patient Education and Counseling*, *42*(2), 145–157. [http://doi.org/10.1016/S0738-3991\(00\)00104-X](http://doi.org/10.1016/S0738-3991(00)00104-X)
- Dubayova, T., van Dijk, J. P., Nagyova, I., Rosenberger, J., Havlikova, E., Gdovinova, Z., ... Groothoff, J. W. (2010). The impact of the intensity of fear on patient's delay regarding health care seeking behavior: a systematic review. *International Journal of Public Health*, *55*(5), 459–68. <http://doi.org/10.1007/s00038-010-0149-0>
- Emery, J. D., Walter, F. M., Gray, V., Sinclair, C., Howting, D., Bulsara, M., ... D'Arcy Holmand, C. (2013). Diagnosing cancer in the bush: A mixed-methods study of symptom appraisal and help-seeking behaviour in people with cancer from rural Western Australia. *Family Practice*, *30*(3), 294–301. <http://doi.org/10.1093/fampra/cms087>
- Gascoigne, P., Mason, M. D., & Roberts, E. (1999). Factors affecting presentation and delay in patients with testicular cancer: results of a qualitative study. *Psycho-Oncology*, *8*(2), 144–54. [http://doi.org/10.1002/\(SICI\)1099-1611\(199903/04\)8:2<144::AID-PON349>3.0.CO;2-P](http://doi.org/10.1002/(SICI)1099-1611(199903/04)8:2<144::AID-PON349>3.0.CO;2-P)
- Glaser, B., & Strauss, A. (1967). *The Discovery of Grounded Theory*. Chicago: Aldine.
- Granek, L., & Fergus, K. (2012). Resistance, agency, and liminality in women's accounts of symptom appraisal and help-seeking upon discovery of a breast irregularity. *Social Science & Medicine* (1982), *75*(10), 1753–61. <http://doi.org/10.1016/j.socscimed.2012.07.016>
- Hall, N., Birt, L., Banks, J., & Emery, J. (2015). Symptom appraisal and healthcare-seeking for symptoms suggestive of colorectal cancer: a qualitative study. *BMJ Open*, *5*(10), e008448. <http://doi.org/10.1136/bmjopen-2015-008448>
- Hannay, D. (1979). *The Symptom Iceberg*. London: Routledge & Kegan Paul.
- Hansen, R., Vedsted, P., Sokolowski, I., Ondergaard, J., & Olesen, F. (2011). Time intervals from first symptom to treatment of cancer: a cohort study of 2,212 newly diagnosed cancer patients. *BMC Health Services Research*.
- Heath, I. (2008). Issues of privacy and intimacy at the beginnings of illness. In *Medical Humanities Companion: Symptom*. Oxon: Radcliffe Publishing Ltd.

- Howell, D. A., Smith, A. G., & Roman, E. (2008). Help-seeking behaviour in patients with lymphoma. *European Journal of Cancer Care*, *17*(4), 394–403. <http://doi.org/10.1111/j.1365-2354.2007.00897.x>
- Ironmonger, L., Ohuma, E., Ormiston-Smith, N., Gildea, C., Thomson, C. S., & Peake, M. D. (2014). An evaluation of the impact of large-scale interventions to raise public awareness of a lung cancer symptom. *British Journal of Cancer*, *112*(1), 207–216. <http://doi.org/10.1038/bjc.2014.596>
- Jones, R., Latinovic, R., Charlton, J., & Gulliford, M. (2007). Alarm symptoms in early diagnosis of cancer in primary care: cohort study using General Practice Research Database. *British Medical Journal*, *334*(7602), 1040.
- Kleinman, A. (1980). *Patients and Healers in the Context of Culture: an exploration of the borderland between anthropology, medicine, and psychiatry*. London: University of California Press.
- Leydon, G. M., Bynoe-Sutherland, J., & Coleman, M. P. (2003). The journey towards a cancer diagnosis: the experiences of people with cancer, their family and carers. *European Journal of Cancer Care*, *12*(4), 317–26. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/14982310>
- Lyratzopoulos, G., Saunders, C. L., Abel, G. a, McPhail, S., Neal, R. D., Wardle, J., & Rubin, G. P. (2015). The relative length of the patient and the primary care interval in patients with 28 common and rarer cancers. *British Journal of Cancer*, *112*(s1), S35–S40. <http://doi.org/10.1038/bjc.2015.40>
- Macleod, U., Mitchell, E. D., Burgess, C., Macdonald, S., & Ramirez, A. J. (2009). Risk factors for delayed presentation and referral of symptomatic cancer: evidence for common cancers. *British Journal of Cancer*, *101* Suppl(S2), S92–S101. <http://doi.org/10.1038/sj.bjc.6605398>
- Malterud, K., Guassora, A. D., Graungaard, A. H., & Reventlow, S. (2015). Understanding medical symptoms: a conceptual review and analysis. *Theoretical Medicine and Bioethics*, *36*(6), 411–424. <http://doi.org/10.1007/s11017-015-9347-3>
- Mitchell, E., Macdonald, S., Campbell, N. C., Weller, D., & Macleod, U. (2008). Influences on pre-hospital delay in the diagnosis of colorectal cancer: a systematic review. *British Journal of Cancer*, *98*(1), 60–70. <http://doi.org/10.1038/sj.bjc.6604096>
- Moffat, J., Bentley, a, Ironmonger, L., Boughey, a, Radford, G., & Duffy, S. (2015). The impact of national cancer awareness campaigns for bowel and lung cancer symptoms on sociodemographic inequalities in immediate key symptom awareness and GP attendances. *British Journal of Cancer*, *112*(s1), S14–S21. <http://doi.org/10.1038/bjc.2015.31>
- Molassiotis, A., Wilson, B., Brunton, L., & Chandler, C. (2010). Mapping patients' experiences from initial change in health to cancer diagnosis: a qualitative exploration of patient and system factors mediating this process. *European Journal of Cancer Care*, *19*(1), 98–109. <http://doi.org/10.1111/j.1365-2354.2008.01020.x>

- Mwaka, A. D., Okello, E. S., Wabinga, H., & Walter, F. M. (2015). Symptomatic presentation with cervical cancer in Uganda: a qualitative study assessing the pathways to diagnosis in a low-income country. *BMC Women's Health*, *15*(1), 15. <http://doi.org/10.1186/s12905-015-0167-4>
- Neal, R. D., Nafees, S., Pasterfield, D., Hood, K., Hendry, M., Gollins, S., ... Robling, M. (2014). Patient-reported measurement of time to diagnosis in cancer: development of the Cancer Symptom Interval Measure (C-SIM) and randomised controlled trial of method of delivery. *BMC Health Services Research*, *14*, 3. <http://doi.org/10.1186/1472-6963-14-3>
- Neal, R. D., Tharmanathan, P., France, B., Din, N. U., Cotton, S., Fallon-Ferguson, J., ... Emery, J. (2015). Is increased time to diagnosis and treatment in symptomatic cancer associated with poorer outcomes? Systematic review. *British Journal of Cancer*, *112 Suppl*(4), S92–107. <http://doi.org/10.1038/bjc.2015.48>
- Oberoi, D. V., Jiwa, M., McManus, a., Hodder, R., & de Nooijer, J. (2015). Help-seeking experiences of men diagnosed with colorectal cancer: a qualitative study. *European Journal of Cancer Care*, n/a–n/a. <http://doi.org/10.1111/ecc.12271>
- Olesen, F., Hansen, R. P., & Vedsted, P. (2009). Delay in diagnosis: the experience in Denmark. *British Journal of Cancer*, *101 Suppl* (S2), S5–8. <http://doi.org/10.1038/sj.bjc.6605383>
- Pack, G., & Gallo, J. (1938). The culpability for delay in the treatment of cancer. *American Journal of Cancer*, *33*, 443–462. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/13993746>
- Ramirez, A. J., Westcombe, A. M., Burgess, C. C., Sutton, S., Littlejohns, P., & Richards, M. A. (1999). Factors predicting delayed presentation of symptomatic breast cancer: a systematic review. *Lancet*, *353*(9159), 1127–31. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/10209975>
- Richards, M. A., Westcombe, A. M., Love, S. B., Littlejohns, P., & Ramirez, A. J. (1999). Influence of delay on survival in patients with breast cancer: a systematic review. *Lancet*, *353*(9159), 1119–26. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/10209974>
- Safer, M., Tharps, Q., Jackson, T., & Leventhal, H. (1979). Determinants of Three Stages of Delay in Seeking Care at a Medical Clinic. *Medical Care*, *17*, 11–29.
- Scott, S. E., Grunfeld, E. A., Main, J., & McGurk, M. (2006). Patient delay in oral cancer: a qualitative study of patients' experiences. *Psycho-Oncology*, *15*(6), 474–85. <http://doi.org/10.1002/pon.976>
- Scott, S. E., McGurk, M., & Grunfeld, E. A. (2007). The process of symptom appraisal: cognitive and emotional responses to detecting potentially malignant oral symptoms. *Journal of Psychosomatic Research*, *62*(6), 621–30. <http://doi.org/10.1016/j.jpsychores.2006.12.020>

- Scott, S. E., & Walter, F. (2010). Studying Help-Seeking for Symptoms: The Challenges of Methods and Models. *Social and Personality Psychology Compass*, 4(8), 531–547. <http://doi.org/10.1111/j.1751-9004.2010.00287.x>
- Scott, S. E., Walter, F. M., Webster, A., Sutton, S., & Emery, J. (2013). The model of pathways to treatment: Conceptualization and integration with existing theory. *British Journal of Health Psychology*, 18(1), 45–64. <http://doi.org/10.1111/j.2044-8287.2012.02077.x>
- Simon, A. E., Waller, J., Robb, K., & Wardle, J. (2010). Patient delay in presentation of possible cancer symptoms: the contribution of knowledge and attitudes in a population sample from the United Kingdom. *Cancer Epidemiology, Biomarkers & Prevention: A Publication of the American Association for Cancer Research, Cosponsored by the American Society of Preventive Oncology*, 19(9), 2272–7. <http://doi.org/10.1158/1055-9965.EPI-10-0219>
- Smith, L. K., Pope, C., & Botha, J. L. (2005). Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis. *Lancet*, 366(9488), 825–31. [http://doi.org/10.1016/S0140-6736\(05\)67030-4](http://doi.org/10.1016/S0140-6736(05)67030-4)
- Tørring, M. L., Frydenberg, M., Hamilton, W., Hansen, R. P., Lautrup, M. D., & Vedsted, P. (2012). Diagnostic interval and mortality in colorectal cancer: U-shaped association demonstrated for three different datasets. *Journal of Clinical Epidemiology*, 65(6), 669–78. <http://doi.org/10.1016/j.jclinepi.2011.12.006>
- Tørring, M. L., Frydenberg, M., Hansen, R. P., Olesen, F., & Vedsted, P. (2013). Evidence of increasing mortality with longer diagnostic intervals for five common cancers: a cohort study in primary care. *European Journal of Cancer (Oxford, England: 1990)*, 49(9), 2187–98. <http://doi.org/10.1016/j.ejca.2013.01.025>
- Walter, F. M., Webster, A., Scott, S., & Emery, J. (2012). The Andersen Model of Total Patient Delay: a systematic review of its application in cancer diagnosis. *Journal of Health Services Research & Policy*, 17(2), 110–8. <http://doi.org/10.1258/jhsrp.2011.010113>
- Weller, D., & Campbell, C. (2006). Early lung cancer detection: the role of primary care. *Primary Care Respiratory Journal: Journal of the General Practice Airways Group*, 15(6), 323–5. <http://doi.org/10.1016/j.pcrj.2006.09.001>
- Weller, D., Vedsted, P., Rubin, G., Walter, F. M., Emery, J., Scott, S., ... Neal, R. D. (2012). The Aarhus statement: improving design and reporting of studies on early cancer diagnosis. *British Journal of Cancer*, 106(7), 1262–7. <http://doi.org/10.1038/bjc.2012.68>
- World Health Organisation. (2013). Cancer Mortality and Morbidity. Retrieved from http://www.who.int/gho/ncd/mortality_morbidity/cancer_text/en/index.html

Table 1: Participant Characteristics

Name	Age	Symptoms	Length of the Patient Interval	Categorisation of Length of the Patient Interval ¹	Diagnosis
<i>Melanie</i>	48	Chest and Back Pain	Same day	Short	Small Cell Lung Cancer
<i>Audrey</i>	73	Coughing up Blood	2 days	Short	Resolving Infection
<i>Sandra</i>	55	Cough, Chest Pain, Breathlessness	2 days	Short	Inflammation
<i>Jack</i>	84	Rectal Bleeding	3 days	Short	Diverticulosis
<i>Steve</i>	50	Rectal Bleeding	3 days	Short	NAD
<i>Christine</i>	50	Rectal Bleeding, Stomach Pain	4 days	Short	NAD
<i>Julie</i>	59	Diarrhoea, Stomach Pain	4/5 days	Short	NAD
<i>Mary</i>	78	Rectal Bleeding	5/6 days	Short	Diverticulosis
<i>Des</i>	64	Cough	7 days	Medium	Non-Small Cell lung cancer
<i>Maggie</i>	70	Cough, Fainting, Tiredness	9 days	Medium	Pneumonia
<i>Joseph</i>	65	Coughing up Blood	11 days	Medium	NAD
<i>Arthur</i>	80	Diarrhoea	2 weeks	Medium	Diverticulosis
<i>Pamela</i>	71	Productive Cough	'A few weeks'	Medium	Bronchiectasis
<i>Fred</i>	78	Change in Bowel Habit	6 weeks	Medium	NAD
<i>James</i>	74	Stomach Pain	6 weeks	Medium	Diverticulosis
<i>Angela</i>	67	Rectal Bleeding	3 months	Long	Haemorrhoids
<i>Elaine</i>	65	Diarrhoea	4 months	Long	Diverticulosis
<i>Harry</i>	79	Change in Bowel Habit	4 months	Long	Microscopic Colitis
<i>Richard</i>	69	Cough, Chest 'Irritation'	5 months	Long	Reflux Disease
<i>Eleanor</i>	67	Rectal Bleeding	6 months	Long	Diverticulosis
<i>Mark</i>	63	Change in Bowel Habit	6 months	Long	Rectal Carcinoma
<i>John</i>	70	Cough, Breathlessness	9 months	Long	NAD
<i>Roy</i>	65	Diarrhoea	18 months	Long	Spirochetosis
<i>Tom</i>	74	Wheezing, Breathlessness	2 years	Long	Chronic Bronchitis
<i>Bilal</i>	41	Cough & Coughing up Blood	3-4 years	Long	Inflammation
<i>Pauline</i>	66	Cough, Breathlessness	4-5 years	Long	COPD

¹ Short patient interval – less than, or equal to, one week
Medium patient interval – between one week and two months
Long patient interval – greater than, or equal to, two months

Figure 1: The Contextual Model of the Patient Interval

