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Diagnosing cancer in the bush: a mixed methods study of symptom appraisal and help-seeking in people with cancer from rural Western Australia.

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Abstract

Background: Previous studies have focused on the treatment received by rural cancer patients and have not examined their diagnostic pathways as reasons for poorer outcomes in rural Australia.

Objectives: To compare and explore symptom appraisal and help-seeking in patients with breast, lung, prostate or colorectal cancer from rural Western Australia (WA).

Methods: Mixed methods study of people recently diagnosed with breast, lung, prostate or colorectal cancer from rural WA. The time from first symptom to diagnosis (i.e. Total Diagnostic Interval, TDI) was calculated from interviews and medical records.

Results: 66 participants were recruited (24 breast, 20 colorectal, 14 prostate and 8 lung cancers). There was a highly significant difference in time from symptom onset to seeking help between cancers (p=0.006). Geometric mean symptom appraisal for colorectal cancer was significantly longer than for breast and lung cancer (geometric mean differences (95% CI): 2.58 (0.64-4.53) p =0.01; 3.97 (1.63-6.30) p=0.001 respectively). There was a significant overall difference in arithmetic mean TDI (p=0.046); breast cancer was significantly shorter than colorectal or prostate cancer (mean difference (95% CI): 266.3 days (486.8-45.9) p=0.019; 277.0 days (521.9-32.1) p=0.027 respectively). These differences were explained by the nature and personal interpretation of symptoms, perceived as well as real problems of access to healthcare, optimism, stoicism, machismo, fear, embarrassment and competing demands.

Conclusions: Longer symptom appraisal was observed for colorectal cancer. Participants defined core characteristics of rural Australians as optimism, stoicism and machismo. These features as well as access to healthcare contribute to later presentation of cancer.
Introduction

Rural Australians are more likely to die within five years of a cancer diagnosis than people from metropolitan areas. While overall survival for most common cancers in Australia is improving, the rural-urban differential is actually widening with significant excess deaths due to lung, colorectal, breast and prostate cancer in regional Australia. Previous studies have shown that patients living in rural areas are less likely to receive curative or reconstructive surgery, radiotherapy or hormonal treatment. Policy initiatives have focused therefore on reducing disparities in access to treatment.

Access to treatment is an important determinant of outcome, but later presentation and stage at diagnosis have also been observed in rural cancer patients. International research suggests that the time taken to appraise symptoms and seek help (so-called ‘patient delay’), and management in primary care are also key determinants of cancer outcomes. Time to diagnosis is associated with poorer survival for several common cancers. Studies using administrative datasets to examine poorer cancer survival in rural patients cannot provide an explanation for reasons underlying later presentation to healthcare. Qualitative studies have suggested factors such as distance, time and availability of appointments which may contribute to later help-seeking by rural cancer patients but none has compared these issues across cancers or combined them with data on time to diagnosis. Theoretical models that explain ‘total patient delay’ have existed in the literature for many years but these have not been applied to the issue of rural cancer diagnosis.

This study aimed to explore, using a mixed methods design, factors contributing to longer diagnostic intervals in rural cancer patients in Western Australia (WA), comparing them between common cancers. This paper reports on symptom appraisal and help-seeking intervals; a separate paper will report participants’ experiences of the healthcare system leading to their cancer diagnosis.
Methods

Theoretical framework

We applied the Model of Pathways to Treatment \(^{15}\) to inform our data collection and analysis (Fig 1). This model describes two intervals prior to presentation to healthcare about a symptom: Symptom Appraisal and Help-Seeking. The Diagnostic Interval is the time from first presentation until cancer diagnosis, and the Total Diagnostic Interval the sum of these three intervals. Factors which influence the duration of these intervals relate to the patient (eg previous experience, social and cultural factors), healthcare system factors (eg access) and tumour (eg location, rate of growth).

Study population

From March 2009 to April 2010 we recruited patients recently diagnosed with breast, colorectal, prostate or lung cancer. Patients were eligible if their main residence was in either the Goldfields or Great Southern regions of WA. Based on the Accessibility/Remoteness Index of Australia (ARIA), all Statistical Local Areas (SLAs) in the Goldfields are considered remote or very remote. The ARIA classification aims to quantify relative remoteness in Australia based on the physical road distance to the nearest town or service centre. There are five Remoteness Area Classes: Major City, Inner Regional, Outer Regional, Remote and Very Remote. Remote and Very Remote Australia represent approximately 3% of the Australian population.\(^{16}\) In the Great Southern 93% live in SLAs classified as outer regional and the remainder in a remote area. Patients were initially approached about the study by a rural cancer nurse coordinator or via the Cancer Registry and their treating clinician, and then consented by the research interviewer. The majority of interviews occurred within three months of diagnosis.

Data collection

This was a mixed method study in which the analysis and interpretation of the quantitative data were complemented by the qualitative data.\(^{17}\) In-depth semi-structured interviews were conducted
by a researcher (CS, DE, AW) to explore the participants’ initial symptoms, their interpretation and factors contributing to their decision to seek help.

Within the interview, participants estimated the dates of onset of their symptoms and decision to seek help. A diagram depicting the separate intervals of Symptom Appraisal and Help-Seeking, including making an appointment and attending a healthcare provider, was used to support data collection. We used a calendar-landmarking technique based on personal, locally and internationally relevant events to refine recall about key dates. Participants consented to access to their general practice, specialist and hospital records to obtain dates of attendances, investigations, diagnosis and treatment. Data were extracted by a researcher (DH) using a specific proforma.

Data analysis

All interviews were transcribed and subjected to Framework analysis. The transcripts were read repeatedly, and an iterative process followed, involving familiarization with the data, identification of a thematic framework, and coding using NVivo software. The framework was developed through analysis of the initial 20 transcripts and was mapped onto the Model of Pathways to Treatment. This was applied to subsequent transcripts seeking to confirm or refute components of the framework. All transcripts were read and coded by at least two researchers (DH, CB, CS, JE, FW). Regular meetings between coders were held to discuss the framework and interpretation of individual transcripts to ensure consistency of coding. The different backgrounds of researchers were also discussed, including their potential impact on data collection and analysis. Data saturation for the qualitative data, defined as no new emergent themes, was reached before recruitment ended.

For patient-reported dates, where uncertainty existed, we applied published mid-point rules to estimate the actual date. Where necessary, a clinical consensus group (JE, FW, DH, VG) reviewed the transcripts to confirm the date of first symptom and first presentation to healthcare. Intervals
were calculated from the interviews and medical records. Date of diagnosis was based on the date on the pathology report or first date of clinical diagnosis in the medical record where no pathology was available. The Total Diagnostic Interval (TDI) was defined as the time from first symptom to diagnosis. For screen-detected cases we used the date of attendance for the screening test as the initial date in the patient pathway.

Where data were highly skewed we applied log transformation prior to conducting general linear modelling to compare intervals between cancers. We applied a Least Significant Difference correction for multiple comparisons. Quantitative data were analysed using SPSS version 18.

In order to triangulate our findings we developed a mixed methods matrix in which we identified individual cases with long or short intervals and examined how well the qualitative framework explained their diagnostic pathway. This approach to integrate data allowed us to explore convergence and discrepancy of findings across types of data as well as identify patterns across cases and types of cancer.

Results

Sixty-six people were interviewed (43 Goldfields, 23 Great Southern region; 24 breast, 20 colorectal, 14 prostate and 8 lung cancers). Thirty-eight were female and the mean age was 60.5 years. In Australia there are national screening programmes for breast, colorectal and cervical cancer. There were 19 screen-detected cases (9 breast, 2 colorectal and 8 prostate cancers). The sample represented approximately 25% of all cases of the four cancers in the two regions.

Table 1 summarises the Symptom Appraisal, Help-Seeking and Total Diagnostic Intervals (TDI) for all cases and by cancer type. Following log transformation of the data, there was a highly significant difference in Symptom Appraisal between cancers in those who presented symptomatically (geometric means (95% CI): breast 4.41 (1.14-17.14); colorectal 58.56 (15.75-217.72); lung 1.11 (0.17-7.11); prostate 21.09(3.29-135.24); p=0.006). Tests for pairwise differences showed that the
Table 1. Summary of Symptom Appraisal, Help-seeking and Total Diagnostic intervals (Arithmetic mean and median in days. IQR = Inter-quartile range.)

<table>
<thead>
<tr>
<th></th>
<th>Symptom Appraisal</th>
<th>Help-seeking</th>
<th>Total Diagnostic Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Arithmetic Mean</td>
<td>Geometric Mean (95% CI)</td>
<td>Median</td>
</tr>
<tr>
<td>Breast</td>
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<td>4.4 (1.1-17.1)</td>
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<tr>
<td>Colorectal</td>
<td>130</td>
<td>58.6 (15.7-217.7)</td>
<td>87</td>
</tr>
<tr>
<td>Lung</td>
<td>36</td>
<td>1.11 (0.2-7.1)</td>
<td>2</td>
</tr>
<tr>
<td>Prostate</td>
<td>309</td>
<td>21.1 (3.3-135.2)</td>
<td>42</td>
</tr>
</tbody>
</table>
The geometric mean Symptom Appraisal for colorectal cancer was significantly longer than for breast and lung cancer (geometric mean differences (95% CI): 2.58 (0.64-4.53) p =0.01; 3.97 (1.63-6.30) p=0.001 respectively). The geometric mean Symptom Appraisal for prostate cancer was longer than for lung cancer (geometric mean difference 2.94 (95% CI 0.24-5.65) p=0.033). There was a significant overall difference in arithmetic mean TDI (p=0.046): breast cancer was significantly shorter than colorectal or prostate cancer (mean difference (95% CI): 266.3 days (486.8-45.9) p=0.019; 277.0 days (521.9-32.1) p=0.027 respectively). There was no significant difference in arithmetic mean TDI in those with early versus late stage disease (geometric mean (95% CI) early stage 129.54 (90.50-185.43); late stage 93.88 (60.16-146.48); p=0.27 for difference).

**Qualitative data**

Analysis of the qualitative data identified several key themes which helped explain differences between cancers and individual cases (see Table 2).

The nature of the symptoms strongly influenced appraisal and help-seeking. Symptoms that were intermittent, perceived as mild or increased gradually over time were more likely to present later. Participants with more severe symptoms, such as pain or dyspnoea, presented more promptly. Specific symptoms such as a breast lump or visible haematuria were recognised as ‘red flag’ symptoms; in contrast, blood in the stools and even haemoptysis did not necessarily prompt early help-seeking. Several women described uncertainties about the presence of a breast lump, either in the context of ‘lumpy breasts’ or inability to consistently find a lump when examining themselves. This self-doubt around the existence of a symptom contributed to longer symptom appraisal.

Participants interpreted their symptoms on the basis of personal models of illness which influenced decisions to self-manage or seek help. The absence of pain or the presence of only a single symptom were perceived as markers of less severe illness. Alternative explanations for symptoms were common; ageing, excessive workload, dietary change and piles were used to justify urinary
symptoms, fatigue, weight loss and rectal bleeding respectively. A previous benign diagnosis for similar symptoms and reassurance from previous normal investigations contributed to longer periods appraising symptoms. Pre-existing conditions, such as urinary frequency from diuretics, or tiredness as part of depression, were normalised and contributed to longer symptom appraisal. Most participants with lung cancer discussed their long term respiratory symptoms as separate to their cancer diagnosis and presented with acute worsening of dyspnoea or cough.

Perceptions of being at low risk of cancer and over-optimism towards their health meant some participants were more likely to find alternative benign explanations for their symptoms. While optimism was a separate factor contributing to longer help-seeking, it was associated with stoic responses to symptoms which meant that severe and continuous symptoms were self-managed. For example, a man in his early 70s, who had developed such marked diarrhoea that he was using incontinence pads, waited for many weeks before seeking help and being diagnosed with colorectal cancer. Related to such stoicism in men, was the need to be perceived as tough or macho and less willing to seek help. Many participants discussed these characteristics of optimism, stoicism and machismo as core features of what being ‘rural’ in Australia meant; these characteristics contributed to longer symptom appraisal in our sample.

The decision to seek help was influenced by several additional factors. If symptoms did not interfere with daily activities, participants were less likely to seek help. Competing priorities such as being self-employed, a close relative’s illness, Christmas and holidays were explanations for postponing help-seeking. Fear of the diagnosis of cancer and fear or embarrassment about potential examinations or investigations also led to later help-seeking. This was common to people with symptoms related to breast, prostate or colorectal cancer. Participants had often discussed their symptoms with others; many women with breast lumps with shorter help-seeking intervals had asked a partner or friend to examine them to confirm the presence of a lump thereby reducing self-doubt. Discussing symptoms
with colleagues did not necessarily result in earlier help-seeking as it often reinforced benign explanations for symptoms or confirmed fears about examinations.

Perceptions about the healthcare system also affected decisions to seek help. Rural workforce shortages create both real and perceived difficulties of access to general practice and concerns about not wasting their doctor’s time. Few participants though actually experienced difficulty making a timely appointment with a GP. Some participants discussed continuity with a regular GP and deliberately delayed an appointment to maintain continuity. People living further from a general practice postponed help-seeking due to the burden of travel and needed several reasons to visit town.

Table 3 presents a mixed methods matrix highlighting the factors associated with longer (>50 days) or shorter symptom appraisal intervals (<10 days). These cut-offs were arbitrarily defined on the basis of the spread of observed intervals and their likely clinical significance. Those with longer appraisal intervals all had alternative benign explanations for their symptoms; their symptoms were intermittent or perceived as milder. Many only presented when they developed an additional ‘severe’ symptom such as pain. Optimism, stoicism, embarrassment and fear were evident in many with longer appraisal intervals. All these factors were more commonly seen with colorectal cancer. The two women with breast cancer with longer appraisal intervals doubted their self-examination findings and had not discussed the lump with anyone else. In contrast, many women with breast cancer with shorter intervals had discussed their lump with someone close and had been re-examined by them.

**Discussion**

This is the first paper to apply a mixed methods approach to examine diagnostic intervals for rural cancer patients internationally. We showed significant differences in Symptom Appraisal and Total Diagnostic Intervals between cancers which were explained by several common underlying factors.
Nature of symptoms
“The trouble is with cancer, I think you know it creeps in on you and ... and like there’s a bit of blood there but no pain and you think well if there’d been some pain there you’d have definitely said oh shit there’s something wrong here. No pain whatsoever.” Colorectal M.

“Yeah, but that [breathlessness] was sort of so permanent that you just ... live with it.” Lung, F.

Personal models of illness and discussion with colleagues
“I used to talk to people that had prostate cancer ... and that’s my friends, close friends, and I used to say well do you know you’ve got it? They said, well Jesus, your belly swells up and you can’t pass your ... your urine and ... ...pain and that and that’s when they go to the doctor and I thought, no I had no problems. I used to wee, wee, wee all the time. Yeah. And I thought well I must be all right, you see and bloody hell, no it was doing me over for quite a while.” Prostate.

“Well once I’d really felt the lump and my girlfriend confirmed that I was feeling a lump, it wasn’t my imagination I sort of did think of cancer” Breast.

Alternative explanations
“...I’ve never had a barrier about checking things out medically. I just think that I was working these crazy, crazy hours, you know, why wouldn’t you be tired.” Colorectal, M.

“I, I didn’t even give cancer a thought, or polyps or anything else like that, but ... I just thought well maybe, maybe the ... the bowel was irritated from ... parasites. I, I really didn’t know. I didn’t even give cancer a thought at all. Colorectal, M.

Low risk perception
“yeah well I was shocked because um, you expect people who smoked and went out drinking and things like that, you know. Um, and you think if you look after yourself and be healthy and not being obese, ah, rather surprised me. I mean, if I was obese or something like that I would expect it I suppose.” Lung, F, 65-69.

Optimism
“It was the sort of thing I think you think it happens to other people, it’s like most things in life isn’t it? Oh it’s not going to happen to me. Oh, got news for you sunshine.” Colorectal, M.

Fear and machismo
“Yeah. Being a real hero bloke, you know, you don’t go to the doctor about that. I’m not going there ... going where they wanna go, nup.” Colorectal, M.

“Yes, I didn’t want to go to the doctors, I didn’t want to go and get a finger shoved up me bum. You know, I feared it. And, for that reason and talking to all the blokes at work and one thing and another and they said they’d never get that done.” Prostate.

Stoicism
 “[I didn’t see a doctor then because] I was a young strong buck then wasn’t I? I didn’t sort of tend to ... not take notice of these things. And um, yes but it wasn’t ... like I thought it was just an inconvenience.” Prostate, 55-59.

“But ... but ah, you know a lot of people in the country sort of shrug it off and have another beer or whatever, or get back to work and say you’re being stupid let’s get on with it, and then they put off something I think.” Colorectal, F.
“And the country men are worse than the women, by a long shot. They’re, you know, bush blokes. You know, “I’m not going to the doctor. I’ll be right, mate.” Lung, F.

**Stoicism and perception of access**
“But half the reasons why people like myself, you know we’re pretty tough guys out in the bush there, and all shearers. They don’t go to the doctor, because why go to the doctor, it takes you three weeks to four weeks to get to the doctor.” Colorectal, M.

**No interference with work**
“Um, if I had of been an inside worker I’d have probably been worried. But see when you’re outside worker you can just walk over behind the shed and have a squirt you know? Ah, an inside worker he’d have to be getting out of ... going down the hall to have a ... walking past everyone to have a pee all day. You know?” Prostate.

**Competing demands**
“I’ve worked for myself 90 per cent of my working life. And you don’t take time off ‘cause you’re crook. In the farming environment. You just don’t do it. I mean you could be bloody dead on your feet. You know, I’ve been, you know, spikes in my legs, I’ve been knocked over by cattle and can’t ... walk but you’ve got to keep working. Prostate.

“I knew that there was something wrong and um, so I waited till my little granddaughter was born and then I was straight off to hospital.” Breast.

**Distance to healthcare**
“And I’m thinking that, no this ... this could get better without a trip into town. Because we ... because we’re 40 k’s out, you think twice about coming in for every little cough and sniffle.” Lung, F.

Table 2. Illustrative quotations of factors related to longer Symptom Appraisal and Help-Seeking Intervals.
<table>
<thead>
<tr>
<th>Cancer</th>
<th>Stage</th>
<th>Appraisal Interval (days)</th>
<th>Gender</th>
<th>Age range</th>
<th>Alternative explanation</th>
<th>Intermittent symptoms</th>
<th>‘Mild’ symptoms</th>
<th>Gradual increase in symptom</th>
<th>Red flag symptom</th>
<th>Absence of other symptom</th>
<th>Severity trigger</th>
<th>Uncertain self-examination</th>
<th>Self-management</th>
<th>Previous benign Dx</th>
<th>False reassurance from tests</th>
<th>Optimistic/low risk perception</th>
<th>Stoicism/machismo</th>
<th>Embarrassment/fear</th>
<th>No Interference with work</th>
<th>Discussion with others</th>
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## Table 3. Mixed methods matrix. ↓-prompted help seeking, ↑ - delayed help seeking.

1 – Subsequent symptom; 2- Comorbidity – depression; 3 – Comorbidity – COPD. Age range presented to protect anonymity.
including the nature of the symptoms, optimism, stoicism, fear and embarrassment. This was a particular problem for colorectal cancer.

Our study is strengthened by the explicit application of a theoretical model of patient pathways to diagnosis and treatment commencement and by the application of formal mixed methods analyses. The quantitative differences we observed could therefore be better understood through complementary analysis of the qualitative data. We used a range of techniques to improve the accuracy of patient recall about their symptom duration and help-seeking, although inevitably with this type of study design, potential recall bias cannot be eliminated. A limitation of this study is that we recruited approximately 25% of all the cases of the four cancers in the two regions\textsuperscript{22}, and in particular, we had relatively few lung cancer patients. This was partly because several people with lung cancer died before we were able to interview them. For logistical reasons interviews were conducted by three interviewers which may have affected the data collected between participants. We held regular meetings with all interviewers to reflect on the data collection and analysis to reduce the potential effect of this. We reached data saturation in our qualitative analyses before the total sample had been interviewed, suggesting that our findings are robust. We recruited people with one of the four commonest cancers; while this created heterogeneity of the sample, it allowed us to make important comparisons between cancers. We do not have comparable data from a metropolitan cohort and it is possible that we would have observed similar patterns between cancers.

The durations of Total Diagnostic and Symptom Appraisal Intervals observed in this study are associated with poorer outcomes. A TDI of more than three months is associated with 12% lower five-year survival from breast cancer.\textsuperscript{11} A U-shaped association has been shown between symptom duration and colorectal cancer survival, such that three-year mortality increases with a symptom appraisal interval greater than five weeks.\textsuperscript{12} Similar U-shaped associations have been demonstrated
for lung and prostate cancer. We did not find an association between stage at diagnosis and TDI but this may be explained by this U-shaped association or limited power.

Other studies of rural cancer diagnostic intervals in Australia have found that rural men are more likely to present symptomatically, that women with ovarian cancer from remote Australia have longer symptom appraisal, and people with colorectal cancer from regional Australia are more likely to present with advanced disease. None of these studies has been designed to explore why.

Previous systematic reviews of ‘patient delay’ have shown the nature of symptoms is an important predictor of help-seeking; pain or bleeding are associated with shorter intervals but non-specific symptoms, or those which do not interfere with daily activities, tend to present later. Failure to recognise the seriousness of symptoms or misattributing them to existing conditions or another more common cause has been previously described. Fear of the diagnosis or embarrassment about possible examination has been associated with later help-seeking. Social support and discussing symptoms with someone close reduces help-seeking intervals for breast cancer. Our findings are consistent with this but demonstrate the potential for false affirmation of alternative explanations in discussions with friends or work colleagues.

Although we have no comparable data from an urban cohort, we identified several features that were defined by participants as specific to rural Australia which we believe contribute to later help-seeking for symptoms of cancer. A previous study from Queensland suggested that some cancer patients self-identify as urban while living rurally and vice versa. We did not find this in our study and we were unable to examine whether people’s attitudes, such as stoicism or optimism, alter when they move from a rural to urban setting. Optimism, stoicism and machismo were frequently discussed as core features of the rural Australian character by participants in this study which we found contributed to later help-seeking. Stoicism is defined as ‘The endurance of pain or hardship without the display of feelings and without complaint’. We have not identified any studies which directly compare the prevalence of stoical responses between rural and urban Australians. However,
research has found that rural Australians may have a different concept of well-being and their decisions to seek help may be more related to effects on productivity rather than viewing health as an absence of symptoms.\textsuperscript{31, 32} Furthermore, stoicism in rural Australians has been shown to predict help-seeking for mental health problems.\textsuperscript{33} While stoicism has been discussed as a possible factor underlying poorer cancer outcomes in rural Australia,\textsuperscript{28} our paper presents novel data to support this assertion. We recognise that additional research comparing stoic responses in urban and rural Australians would be informative.

The other rural-specific issue we identified related to access to healthcare. Improving access to primary care in rural Australia is a national priority.\textsuperscript{34} Many participants discussed workforce shortages and access to their GP as factors they considered when deciding to make an appointment. This was exacerbated if they lived some distance from the town where the nearest practice was based. However, despite perceptions of poor access to general practice few of our participants experienced problems seeing a GP promptly regarding their symptoms.

Internationally there is significant interest in symptom appraisal and attempts to reduce diagnostic intervals, especially in countries which have poorer cancer outcomes.\textsuperscript{35} Our robust methods could be applied to conduct further comparative research on symptom appraisal internationally in rural and urban cancer patients. This study provides a rich understanding of key factors underlying later presentation by rural Australians, and could inform the development of targeted interventions to promote earlier presentation of symptoms suggestive of cancer.

**Disclosures and Acknowledgements**

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No conflicts of interest disclosed.
References