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Appendix 2S Overview of qualitative findings

Interviews were conducted with 13 patients and 10 carers, reflecting on the experiences of 20 patients. The interviews comprised: seven with female and six with male patients; three interview dyads (two wives with their husbands, one daughter and her mother); four carers alone (three daughters and one daughter-in-law); three bereaved carers (two widows and one stepson). The youngest patient interviewed was 49 years old and the oldest was 91, with an average age of 72. Similar issues emerged across the interviews conducted, which indicates that, even though the study involved a limited number of participants, the data approached saturation.

Six key themes were identified and illustrated with data extracts. Each theme is broken down further, as interview participants had differing experiences and perspectives. The main themes are:

1. Experiences prior to hospital admission
2. Delay in seeking help
3. Lung cancer campaign awareness
4. Experiences of inpatient care
5. Receiving the diagnosis
6. Experiences of outpatient/community care

1) Experiences prior to hospital admission:

Patients' experiences of contact with their GP surgeries prior to admission to hospital were varied.

1a) For some patients and carers the GP could not have done more, making appropriate decisions to refer the patient on for specialist care:

I went to the surgery, doctor's with a specific complaint, nothing related. It was dermatitis on my hands. And he took a blood test and he went Oh dear, you know, the calcium levels were high...That's right, I got an appointment with the doctor, and, he wrote a letter, sent me into the hospital straightaway (65 year old male).

I was suffering shortness of breath and she said I was short of oxygen and something else. Must go to hospital. Do I have to? Yes, you do (91 year old male).

1b) Some felt, however, that the process of referring them on for specialist care or tests was too slow:

I think, perhaps, it could have gone quicker, to be honest. Whether I was impatient or not, I don't know, but I've, yeah, I think you could have gone a little bit quicker than what it did. Whether it would have helped matters or not, I don't know...I did ask the

question if he thought I had cancer? And he didn't think that I had (81 year old female patient).

Wasn't overly impressed when I saw the GP really... You know, and, you know, when we asked about the scan, you know, we were at the beginning of May and we'd still got to wait nineteen days, no, hang on, when was his scan date? The nineteenth of April, yeah, so we were at the beginning of April and we still had to wait till the nineteenth of April for the scan (female carer of 78 year old male patient).

1c) Some patients believed that their GPs had come to the wrong conclusions about what was wrong with them and that this influenced decisions about treatment and care:

Oh, I went to the doctor's but she told me I was depressed so I went in the walk-in centre... they did a blood test. Which showed that there was white cells in my blood, and in my water And there was also blood in my water. So then, she sent me to, she phoned the doctor's and made an appointment so I went back to the doctor's and then she took another blood test and then we waited and then it came back as low sodium, and that's how I was admitted to hospital (49 year old female).

They thought it was a viral infection. And they had concerns over my neck which, at that time, I hadn't actually noticed and they thought that I'd got swollen glands and it just snowballed from there. Each week another symptom appeared until in the end, I had a, a swelling in my neck that seemed to ring alarm bells because they were sort of like, treating me for tonsillitis which, I knew at the time, wasn't tonsillitis but doctors being doctors, you can't [laughter] tell them, you know. And, but this swelling in the neck seemed to ring alarm bells and then they referred me to the hospital...In the first instance, I went to the wrong department because they sent me to maxillofacial (51 year old female).

1d) In a number of cases, patients had been seen by their GP a number of times, prior to a decision being made to seek specialist help:

The initial admission was ... he'd been to his GP a couple of times with what we thought was a chest infection, and he was given antibiotics... But he had a really, really terrible cough, never heard anything like it, it was absolutely horrendous. Anyway, he went back to the GP, partly because of the cough but also because he'd developed a problem with the sight in one eye...he'd been to see the GP in September about a number of things including his eye and his tiredness and pain and, he was a bit depressed as well, I think, because of it all. But the cough, he'd been, you know, a couple of times about that. In January (female care of male patient).

I called the GP out a few times and...But I had the doctor out three times, you know, kept on calling him out, and in the end, said, no, don't want anybody else, I'm going to ED (female care of 86 year old female patient).

1e) Not all patients had been to see their GP prior to being admitted to hospital:

Well, I were short of breath, I couldn't breathe... paramedics and they come and... Brilliant service. Absolutely (78 year old male).

He, New Year's Eve, became far more breathless and didn't want an ambulance called but my mum phoned (...) told her to contact an ambulance. An ambulance then came. He was given some oxygen, then was taken ... he was taken to Q. A and E (female carer of 77 year old male patient).

2) Delay in seeking help:

Some patients interviewed were aware that they should go to their GP if they had a cough for three weeks or more, either through awareness of the advertising campaign or through other means. Seven patients had a cough and of these four sought help from their GP after three or four weeks.

2a) Those who did not seek help for their cough had differing rationales for this:

But J. also used to say, one of his medications, one of the side effects, it can produce a cough (female carer of 69 year old male patient)

I didn't believe them, because you don't...And it don't matter how many adverts you put on telly...they don't work (female patient, 61 years).

He'd had a cough. But that was nothing unusual, because he'd had the cough, I don't know how long for, he'd had it a while...it was a smoker's cough (male carer of male patient).

2b) However, not all patients had a cough as an initial symptom, and for some in this group their symptoms seemed to them to be the wrong symptoms for lung cancer. Patients and carers in this group tended to make attributions about the reasons for their symptoms which focused either on a pre-existing condition, or on something in their current circumstances:

Just with, my eyes was swelling, I had a problem with my eyes, and I'm actually diabetic as well. And, because this problem with my eyes persisted, with diabetes, you have to look after your feet and your eyes (51 year old female patient).

I wasn't fatigued, I were just a bit tired, that's all. Which I, which I assumed was my age. Didn't think I was going to be a sprinter, you know, at sixty five (65 year old male patient).

2c) Another group of patients had symptoms which did not include a cough, but which included such things as breathlessness or weight loss. While investigation might have uncovered their cancer, they also tended to attribute the symptoms to another cause:

I found that I was getting increasingly short of breath and I do suffer from asthma, so as I'd reduced my inhalers, I tended to think, oh, so I went back up to my usual dose of Seretide (76 year old female patient).

It's like the brain thing (brain metastases). Which obviously was cooking along for a little while. It didn't go on, I mean, sometimes, she was nasty to me, but I put it down to... So the, her odd behaviour now and again, I put down to pain (female carer of 86 year old female patient).

3) Lung cancer campaign awareness

3a) Some were aware of the lung cancer campaign:

I mean, they have the television adverts now and it says, you know, if you've had a cough or any symptom for longer than four weeks, you know, you should get it checked out which I agree totally with (51 year old female patient who did not have a cough).

And, you know how they put it on the television if you've had a cough for three weeks or more, you know, to go and see your doctor. Anyway, I said to him, You should go, anyway,... No, it were just this persistent cough, you know. And it was only because what they put on the television that it sort of jerks your memory...And that's when I, you know, I says to him, I says, you know, I think you ought to go and get that cough sorted (female carer of male patient who had a cough).

3b) Not everyone thought the adverts were effective:

And you see, also, there were a lot of adverts on the telly round about that time as well about coughing. And I used to make snide remarks to him, [laughter] about it. (female carer of 69 year old male patient who had a cough) Which has the reverse effect on me, because, yeah, my back goes up, you see. (69 year old male patient with cough).

And it don't matter how many adverts you put on telly...they don't work. You know that one where they had where the cigarette was burning, it showed you all these mutating cells...Laugh, just laugh at it. Nobody takes the blindest bit of notice (61 year old female patient with cough).

3c) Some participants were not aware of the campaign adverts:

I mean, the one I'm aware of is this, if you got blood in your pee...But I don't think there's much publicised, was it? But, you should, you know something's amiss, well, you should do, shouldn't you, if you've got a cough for more than three weeks? Oh yeah. Yeah. Whether they work these campaigns, I don't know...I think, really, a lot of people don't take much notice of it. Don't think they do (65 year old male patient, no cough).

I've seen them for a stroke, I'm terrible because I watch most of mine on video, you know, because I, I'm not usually in the house very long. I tend to watch everything on, you know, it videos, my freeview box. I haven't seen any for lung cancer. I've seen it for strokes, you know, the signs to look out for, but I can't say I've seen any for lung cancer. Are there ones for lung cancer? (76 year old female patient, no cough).

4) Experiences of inpatient care:

4a) Once patients arrived in hospital descriptions of their care were largely positive:

I have no criticism over the hospital whatsoever, they have been absolutely fantastic, you know what I mean. You know, they're very, very reassuring (55 year old female patient).

There were two (nurses) especially that were very kind and they used, every time I went in, they came to me and explained what had been happening, you know (female carer of 92 year old female patient).

4b) Despite the positive descriptions of care, however, most individuals interviewed could identify areas in which improvements could be made. In some cases this was associated with increasing staffing levels:

I've just got to press the button and they came. Okay, I had to wait occasionally because they were busy, they were short-staffed. This is the one thing I would say, they are (...), are short staffed (91 year old male patient).

4c) Or improving the quality of the food:

Oh, the food's terrible. [laughter] Absolutely terrible (88 year old male patient).

4d) But in other cases patients or carers had identified specific areas where they felt that improvements could be made:

But I think, what would have helped is that when I was initially diagnosed and admitted, if there was a system whereby the hospitals automatically informed Macmillan and somebody from Macmillan came to see you, and just sit with you, with, This is what we can do for you, this is what we can offer (51 year old female patient).

Sometimes, nurses make you feel like you're hassling them, even if you ask them one thing... she had a drip, my mum did, where she had paracetamol. And that's separate. And the paracetamol finished, and it was a good hour and a half that it had been finished and she needed to go back on a drip, and so I asked the nurse and she was like, Yeah, I'll just get another nurse, another half an hour, no one. And then I went back and they just looked at me, like, Oh, just go away. I just thought, Oh, I don't care, I've got to ask (female carer of 49 year old female patient).

5) Receiving the diagnosis

For patients and carers receiving a diagnosis of lung cancer was a significant event. How that event was handled by health professionals and experienced by patients and carers varied.

5a) For some this was a very poor experience:

I'd just seen this wally, I think, had just come out of med school, and he just drew the curtain and he talked really loud, got a real loud voice, (...) booming, you know, and he just drew the curtain and said, Well, we've found three tumours. At this stage, I

thought it was still indigestion, you know... And, I said, you know, It's not a wall, it's a curtain. (...) everybody on the ward heard it (61 year old female patient).

She (doctor) just turned and looked at us, turned the scan picture round on the photograph on the computer, turned it round and said, I'm afraid you've got lung cancer. And we just stopped and he said, can you take the lung out? And she said, No, I'm sorry, it's terminal and you're going to die (female carer of 77 year old male patient).

5b) Some patients and carers had a better experience and felt that the professional handled the encounter well:

That was awful because, you know, both mum and I were upset. But he was brilliant. They told us on the ward, with the curtains closed with the privacy and dignity. And left us. And then he came back to check that we were all right (female carer of 86 year old female patient).

She sat on the floor with me outside and she, she was, she was really, really nice... I couldn't have asked for it to come from somebody better than S., she was lovely (49 year old female patient).

5c) In some cases, learning the diagnosis was accompanied by learning of their terminal prognosis:

And then they put me through the scan, the scan, and put me through twice, didn't find anything but then put me through the big one and they come to me and said he's, very sorry, I've got cancer on both lungs...And they said, I can't tell you how long it'll be but, it's a bit serious. But we'll look after you (88 year old male patient).

He (doctor) said we've got the results back from the MRI scan...And, G. says, you know, what is it? So he says, it is cancer. And he asked him straight out, he says, How long have I got? So he says, do you really want me, do you really want me to tell you? So, he said yes. And, he says, I would say between three and six months (female carer of male patient).

5d) Patients and their carers did not necessarily have the same perspective about process involved in being given the diagnosis. One carer, for example, wanted to know how long her husband had to live while he did not wish to know the prognosis. In this case the patient's wish prevailed:

When we first, they first told us, I, just came out my mouth without thinking, I asked, if it, what the prognosis was. And they very obviously turned from me to B. and said,

Do you want to know? And he said no. Because I'd not thought, it just came out my mouth. But then I was glad that he did say that because we prefer not to know everything, and they did respect that (female carer of 65 year old male patient).

Another carer wanted as much information as possible about what she might expect in the future, whereas her husband was less concerned:

I wanted all the facts. I wanted as much as possible, because I had to get it straight in my head. Yeah. You know. I wanted to know what I was going to be dealing with, because if J. couldn't fight this off, or whatever, how I was going to be involved with nursing J., and helping him through it. I wanted to know what it would look like, how it would present itself, all of those details and I didn't get any of those details. And I just felt we were told he'd got cancer and we were sent away, that's how I felt (female carer of 69 year old male patient).

He (doctor) said, I'm afraid it's not good news. So I said, okay, well, tell me. You know. Because, you know, my attitude is, it is what it is. I ain't going to, I'm not going to panic (69 year old male patient).

6) Experiences of outpatient/community care

6a) Some patients reported undergoing chemotherapy as a positive experience:

Well, in the chemo clinic, I mean, obviously, you know, you, you can't fault the way, you know, how professional it is and what have you (76 year old female patient).

It's a bit scary now, you feel as though you're out on your own a bit now, you know, in a, in a, in a warped sense of way, these few months when I've been having the chemotherapy, it's like ... comforting, it's security because you know some thing's being done and it, it's, it's hard to explain but now that's finished, it's like that bit of security has been taken away (51 year old female patient).

6b) This was not universal, however, and some patients were critical of some aspects of the chemotherapy process:

And the only problem is the waiting time before you get it (chemotherapy). It is horrendous at times. This last session, I was there at quarter to two and I didn't get home until turned eight o'clock. And it's a long day (81 year old female patient).

6c) There is variation in how well supported patients and carers feel. Some feel that they receive the support they need:

My own GP, and he's wonderful, he's wonderful. He seemed as though he comes every time to me, and, he'll (kneel) in front on me. And, and he'll go through everything with me and he'll say, he'll explain, I'll tell him I've got this and I've got that, and he'll explain the reason why I've got it and, puts me at ease and that, and he's fantastic...The Macmillan nurses have been, NHS nurse has been, I've got a nurse from C. who's in, she's like my care nurse when I go to the clinics (82 year old female patient).

She's the trial nurse, so if I've got any questions, I just, I can ring her at any time. And she does, well, she does look after you, don't she?...We'll get a phone call from her, she says, Just to see how you guys are going on. She'll just ring up out the blue and ask us if we're okay, so that is really nice (female carer of 65 year old male patient).

6d) Other patients and carers, however, feel that they are not well supported:

No. I hadn't had anything, I don't think the GP, don't think I ever, might have had a letter from my GP this week (78 year old male patient).

Well, no one's helped me in myself, at all, not once. At all. (49 year old female patient).

And [laughs] my God, there was so much help to die and no help to live, is what we found. But all the help to die wasn't practical help. A great deal of it was all about, to my mum, How are you? How are you? And my mum doesn't want that (female carer of 78 year old male patient).

6e) Family and friends are a common source of support for patients:

I'm very fortunate, I've got a very, very good family and partnership, relationship so, yes, fantastic support, fantastic support. I'm very fortunate in that respect, very good friends, very good family, and a very good partner (55 year old female patient).

I've got good family support, and, the church, you know, I go to church regularly, so.....they're very supportive, and got some very good friends. So I'm very fortunate, you know, so that I've not really needed, at this point in time, up to this point in time, I've not really needed anybody else to really talk to (76 year old female patient).