

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Nurse)

*VENUE: High MR unit

*DATE: 15/6/2003

*ID: Nurse_BCN022

*INTERVIEWER: DJW

INT: FIRST OF ALL, THANK YOU FOR AGREEING TO BE INTERVIEWED. I WOULD LIKE TO JUST START WITH QUESTION ONE WHICH IS ...

*Q1. HOW LONG IN TOTAL HAVE YOU WORKED IN THIS BREAST UNIT?

Nurse: I've worked here since 1989 so I've worked here just over 15 years.

INT: RIGHT, OK. AND AM I RIGHT IN THINKING THAT RECENTLY YOU'VE HAD LIKE A BREAK, HAVE YOU, IS THAT RIGHT?

Nurse: I did, I, unfortunately I had a heart attack.

INT: OH DEAR, I'M SORRY TO HEAR THAT, I DIDN'T KNOW THAT ACTUALLY.

Nurse: Mm.

INT: SO HOW LONG WERE YOU OFF FOR, THEN?

Nurse: I was off about ten months in total.

INT: RIGHT, OK.

Nurse: And then I got back and, erm, had a, thought it was a [???] sarcoma but it just went so it was a sarcoma, so I've had that removed. So ...

INT: OK.

Nurse: It's not been easy this last year really.

INT: YEAH, THE LAST TWELVE MONTHS HAVE BEEN A BIT ROUGH FOR YOU, YEAH. ERM, SO THINKING ABOUT, YOU KNOW, THE LIKES AND DISLIKES, THE PHILOSOPHY IN THE UNIT, THE DAY TO RUNNING OF THE SERVICE AND THAT KIND OF STUFF ...

*Q2. WHAT IS IT LIKE TO WORK AS A SPECIALIST BREAST CARE NURSE HERE IN ...?

Nurse: In Derby?

INT: YES.

Nurse: I really like working as a specialist nurse in Derby. I wasn't always a specialist nurse, I started off as a staff nurse and worked my way through it. It can be really frustrating, it can be, some days you haven't got enough hours in the day to do what you want to do really. And my job's changed over the years, erm, which I sometimes resent a little bit because I loved

the patient contact, I really do like patient contact, but as I progressed up the ladder, if you like, my job became more managerial and I think part of the problem with me when I became ill was that I was still trying to hang onto the patient contact which I loved, and juggled all the balls in the air with the management side. But, erm, trying very hard not to do that since I've come back, but it's quite difficult, it is quite difficult because I do, I do love the interaction. I think the philosophy of this unit has always been a really good one, right from the word go it was, and we've built on that even though the team's got bigger. We were quite a small team to begin with and then as the needs and the demands of the service grew, so the team grew. And we try to hang on to the philosophy, erm, that we started off with, and I think to a great degree that we have done that, we've managed to do that. We've always said that we wanted people who came through the service to be treated as we would want our sister or our mum or our daughter, or ourselves, treated as. And I think we've managed to do that. We get very few complaints about the service, so ... in fact it is held up in the unit, in the Trust really, as a gold star service.

INT: OH, RIGHT.

Nurse: And people are continually saying with other cancer services, you need to do the way the Breasts are working, that's how you need to work, and so we are held up as the, 'This is how you should work in cancer services,' so I think we are doing it right. But, again, we are a team that will listen to criticism, and we will listen to people who don't feel that they're getting the service that they should, to see whether we can improve it, to see whether it is our fault, whether it is something that the unit can work on and improve or whether it may be just, you know, you're not gonna please everybody all the time, and I think we accept that.

INT: RIGHT, OK. SO WHEN DID YOU ACTUALLY, WHEN DID YOU ACTUALLY COME BACK?

Nurse: February.

INT: OK, FEBRUARY, OK. SO, ERM, I MEAN IN THAT TIME, I MEAN I KNOW THERE'S BEEN PHYSICAL CHANGES, YOU'VE HAD A LOT OF BUILDING WORK OUTSIDE, DO YOU THINK THERE'VE BEEN ANY CHANGES SINCE WHEN YOU FIRST LEFT, YOU KNOW ...?

Nurse: In what way?

INT: ANY SORT OF CHANGES, ANY WAY THAT THE UNIT'S BEEN RUN ...

Nurse: Functioned?

INT: YEAH, THE WAY IT FUNCTION, A DIFFERENT WAY?

Nurse: I think it was difficult for the breast care nursing team when I left, erm, because it wasn't just, just myself that went off sick, there was another nurse went off sick, and, erm, they were under a great deal of pressure. There were three of them working to five nurses so they had to cut the service down to the bare bones really and they did, they managed magnificently I think the breast care nursing team did manage extremely well, and really since I've come back it's not improved that much because Heather's gone off on maternity leave and then we've got Jill [??] in on secondment, and that was a huge learning curve for

her. And, erm, and now we've got Julie, but Julie has got such a huge experience of other areas associated with breasts, that she's actually fitted into the team really well.

INT: RIGHT, OK.

Nurse: And we knew Julie and we knew that she'd got a wealth of experience from surgery, from dealing with breast patients on the ward, she was senior sister on the ward, and then she went into booked admissions so she'd that insight into how women felt, so she's actually fitted into the team really well. And it's like she's never not been here really.

INT: RIGHT, OK.

Nurse: Erm, and we're really looking forward to having Heather back, but you're always going to get this because they are a team that are very pro-active and I wouldn't want it any other way, you can't work with a team that are just [???] and on a level all the time, and we've got a great interaction I think. It was very difficult for me when I came back, erm, because ... there was one individual who resented me coming back ... and that made it very difficult, erm, because it was like a ... it was really like a pack. I'd been out of it for a while, then I came back, and it was kind of four against one and there was a great deal of anger and resentment and hate when I came back, and I had to tackle that too, so ...

INT: OH RIGHT. SO THAT WOULD, THAT MADE YOU ...

Nurse: It wasn't easy.

INT: [???]

Nurse: It wasn't easy, and I was taken by surprise by that. I was taken by surprise. But, erm, I was very well supported by my service manager and my nurse manager, erm, but it was something that I didn't expect, and as I say it threw me a little bit. Mm.

INT: RIGHT. OK THEN. AND HAVE YOU NOTICED ANY CHANGES IN THE PRACTICE SORT OF THING, THE WAY THINGS ARE DONE NOW SINCE YOU WENT AWAY?

Nurse: There's always going to be changes in practice in this unit because that's how they are, erm, and I wouldn't have expected to have come back and not seen any changes, erm, because we do alter our practice to meet the needs, and if any research has come through that shows that this will help that particular patient through this pathway and it's been proven to be a good way of working, then we'll adapt and we will adopt it.

INT: CAN YOU THINK OF ANY SPECIFIC YOU THINK HAS CHANGED SINCE YOU'VE COME BACK?

Nurse: Recently?

INT: YEAH.

Nurse: ... I think we're more actively involved in research, which is a good thing. Erm, we weren't so involved in trials and research: we did do audit and questionnaires and the

occasional research project, but we are becoming more research-orientated, and I think that's not a bad thing because it was something that was lacking because the danger is that, when you're a unit working within a Trust, you become quite insular and we were always aware of that and we're in a, quite a unique position as nurses here, so it was really nice to come back and see that we were actually networking a little bit more. That was good. But I think that they've just built on what we've always had here and that's a good team.

INT: MM. NOW THINKING ABOUT YOUR, YOU KNOW, EVERY DAY IN THE SERVICE SORT OF THING, IS THERE ANYTHING HERE IN PARTICULAR HELPS YOU TO DO YOUR JOB AS A BREAST CARE NURSE, A SPECIALIST NURSE? ANYTHING IN PARTICULAR YOU THINK REALLY FACILITATES THE PROCESS AND THE PRACTICE OF BEING A BREAST CARE NURSE?

Nurse: I don't know where you're coming from with this, David.

INT: IS THERE ANYTHING HERE THAT SORT OF YOU THINK, OR THAT YOU THINK THAT REALLY MAKES YOUR JOB EASY, EASIER TO DO?

Nurse: I think that during the first few months I was back it was quite difficult, I would have not been able to answer that question at all because nothing was easy when I came back because of ...

INT: WHAT YOU DESCRIBED EARLIER, YES.

Nurse: ... what I talked about earlier. Erm, but I think now that things have settled and we've cleared the air, and we had to clear the air, and that's quite nice really, because everyone feels again quite comfortable in speaking their own mind, and so that's good, that's a positive thing that came out of what happened when I came back. And that helps me. Erm, I've always felt that I was approachable but this has made it ... it's highlighted that I am, so I'm really pleased with that. And I think that, once we had sorted things out and cleared the air, people felt more relaxed about working together as a team and they weren't treading on eggshells with ...

[Break in sound file]

... So although it was quite negative when we came back it turned out to be something quite positive because it's actually pulled the team together, which is good. Because you can have, when you've got five individuals with different kinds of personalities, although they all work very differently - and they do work very differently and you've got to respect that - there is a danger that they'll all go off on their own tangent. But I think what's happened is that, whilst we've maintained individuality and personality, we've managed to gel again as a team. So that's a good thing that's come out of this. Which I think probably was missing a little bit: when I think back now, it was missing [??] and they're very much a team now and I like that. So that's made it easier. I've also taken a step back from some of the clinical work and I did say to them this was what I was going to do, erm, and I think they were quite surprised because I've always sort of said I've always liked the clinical side, but I've had to accept that my job isn't too much in the clinical side, it's more on the management side, and once I'd got my head round that, and I am still struggling with that a little bit but I'm getting there, that's made my job easier because I've got, I've had to let go and I found it quite difficult to

let go because it was my baby, if you like. So I found, I found it difficult, but I had to do, and, erm, I think we've become as a team as well much stronger when we're working within the multidisciplinary team too because working with a multidisciplinary team they sometimes think that the nurses ... I went to one, I did some QA, I did QA before Veronica did QA, and I always say that Dr [??] who was our manager before, clinical director before Dr [??], used to encourage us to go out to other units to make us see how lucky we were [chuckles] working in this unit. And I always feel that ... I've got my thread now ...

INT: YOU WERE SAYING ABOUT YOU WERE WORKING IN QA ...

Nurse: Oh, so, I think now as a team we've become more vocal and we stick up for ourselves a little bit rather than, 'OK, yeah, we'll do that,' and I think it's partly what happened to me, erm, and partly because I do blame the job for a lot of what happened to me, erm, and I think it's partly what happened afterwards is that we're not going to be put on and we, you know, we will do our job and we will do it to the best, but, you know, we're not going to be the ones that just pick up all the slack every time. And so I think that's a positive thing that came out of it. Mm. We became more, yeah we are going to be a team, we will work within this team, but you're not putting on us any more.

INT: RIGHT.

Nurse: Because it was always, 'Well if we can't do it the nurses will do it.' So there is a bit of a, erm, a thing going on at the moment because the consultants will say that, they say that I'm time managing for [??] and we're trying really hard to be good at time management but the problem that we're having at the moment is that they've moved some of the results to the afternoon and it's a Friday afternoon, and to get, if we get a really heavy clinic on a Friday afternoon it's really difficult on a Friday to finish and to finish up everything so that when you come in on Monday you start again. You can't tie up all the loose ends, and it's not just us, it's the health care assistants, and it's, and it's getting people booked in for, erm, booked admissions too. So, you know, we've actually said we don't like these results on a Friday afternoon, so the comment we got was, 'Oh, that's because you don't like working Friday afternoon,' and that's not, that's not what it was about, and we've had to work really hard to say to them, 'No, listen to us, that's not what this is about. This isn't, "We don't like working Friday afternoon," this is "We're not finishing on a Friday now sometimes until six o'clock, half past six, and we've still not finished because we can't tie any ends up. WE can't, we have to wait until Monday morning. And you, you're going at five, you've finished, you're going. We're still here."'

INT: YEAH, WORKING LATE.

Nurse: And so we've ...

INT: IS THE SORT OF LIKE THE PAPERWORK, THE ADMINISTRATION KIND OF STUFF?

Nurse: It's the paperwork and the administration side [??]

INT: [??] SPENDING TIME WITH THE PATIENT AND THINGS.

Nurse: But sometimes it is spending time with the patient ...

INT: OH, RIGHT, OK THEN.

Nurse: ... because you can't say to a patient, 'Well, Mr Sibbering's given your results, it's quarter to five, sorry, we finish at five. So we can't see you, we can only see you for 15 minutes.' Because you might get a patient that only wants to see you for two minutes and that's it, 'Go, I don't want to talk about this,' or you might get a patient who needs an awful lot of support for that first getting to know you interview really.

INT: EXACTLY, YEAH.

Nurse: And that, that first counselling session can be anything from five minutes to 50 minutes to an hour, an hour and a half. And you can't let a hysterical person go out of here threatening suicide at half past five on a Friday, can you? When you know that you're not going to be here till Monday.

INT: NO, EXACTLY. THAT'S TRUE.

Nurse: So it's a difficult ... and at one time we wouldn't have said a word about it but now we're saying, you know, 'Can you re-think this?' and they are starting ... they did agree to start the results slightly earlier, erm, but then when it came to actually the practicalities of it, one surgeon can't and another surgeon wants to do them in the morning, she doesn't see any reason why we can't do them in the morning and that would suit us down to the ground really, the Friday morning because it means that we've got the afternoon then to get all the paperwork and everything else sorted out. It also gives that woman time to go home and if she needs to talk to you ...

INT: SHE CAN ALWAYS CALL BACK.

Nurse: ... she can always back. So ... we've become more vocal.

INT: OH RIGHT, OK. I KNOW THE TIME ASPECT AND THE INTERVIEWS WITH PATIENTS CERTAINLY, IN THIS STUDY [???] YOU GO TO THE PATIENT'S HOME AND THE FIRST THING I ALWAYS DO IS TAKE MY WATCH OFF, BECAUSE WHEN YOU REALISE YOU'VE, [???]

Nurse: It's why we haven't got clocks in here.

INT: YEAH, SO IT'S SO EASY TO JUST LOOK AT YOUR WATCH, LOOKING ... YOU'RE SO TIME-ORIENTED YOU'RE THINKING ABOUT, 'WELL I'VE GOT TO BE HERE AT SUCH-AND-SUCH A TIME' AND OF COURSE IF YOU DO THIS, AND YOU MIGHT BE DOING IT JUST PERFECTLY INNOCENTLY, THAT PATIENT CAN [???] LIKE 'HE'S BORED, YOU KNOW, AND HE WANTS TO BE OUT OF HERE,' OR 'WE'VE NOTHING INTERESTING TO SAY.'

Nurse: I got cross yesterday but I didn't let them see, we have a post-op clinic in neurology outpatients, and I always knew that, we try if we can, it's really difficult but we try if we can to bring them out of, it's where they're given the result of the surgery and told that they

may need chemotherapy, radiotherapy, Tamoxafen, and some people want to talk about it, some people don't. And I know that we've only got two rooms and that, if these two rooms are full, I'm not perhaps gonna get into one of these, so I was actually, and it was one of our surgeons who will say to the patient, 'Right, yes that was all right operation ... yes ... yes ... you're going down now to see my colleague at the DRI, here's your appointment. Oh, and here's some information about treatment that you might need.' And that's sometimes all he says. And I knew these two rooms were occupied so I'd got a particularly, a girl that I'd built a relationship up with over the past month because she's had a wide excision and it just showed residual disease so she's had to go on to a mastectomy, and we had lots of contact during both her surgery times and we needed, I knew she'd need time to talk about the treatment afterwards. I also knew that she didn't get on very well with this surgeon and she really didn't like, there was no relationship there, and I know that she doesn't like him. She told me. She said, 'I find him very abrupt, I don't really like him.' So I, I actually didn't move out of the room where he gave her the results and I stayed with her and I stayed with her for 20 minutes, and I got the ... and it really annoyed me, because they don't understand the nature of our job ... the sister from like the outpatients came in, 'Oh, sorry, didn't ...' and she knew I was in there, but she was like, set of notes in her hand, really she was saying to me, 'Can you get out of here?' So I ignored her and we carried on. And then she walked in again and she said, 'Can you please come out of this room?' Well that did, that was the end then, you know, we just, Karen didn't, she'd lost it, she didn't ... feel that she could talk to me now.

INT: EXACTLY, YEAH.

Nurse: So it was really, it was really annoying that was. But space is always a difficult thing.

INT: YEAH, SURE. YEAH.

Nurse: We'd like a little bit more really.

INT: I KNOW EXACTLY WHAT YOU'RE SAYING WHEN YOU SAY THAT SOME PEOPLE DON'T KNOW WHAT GOES ON AFTERWARDS, YOU KNOW, THE INTERVIEWS THAT I'VE DONE, I MEAN, THERE'S A YOUNG LADY STARTING ON A DIFFERENT PROJECT BUT SIMILAR TO WHAT WE'VE BEEN DOING HERE BUT IT'S LIKE A PILOT STUDY FOR PARTICULARLY LOOKING AT MORE ELDERLY PATIENTS, [??] AND SHE SORT OF ASKED ME, SAID 'IS IT ALL RIGHT IF I COME OUT ON A COUPLE OF INTERVIEWS WITH YOU?' I SAID, 'WELL, IF THE PATIENT'S HAPPY, YOU KNOW, I'LL RING UP, FIND ...' AND SHE CAME OUT AND THE FIRST ONE SHE WENT OUT TO, IT WASN'T IN THIS AREA, WAS AN HOUR AND A HALF INTERVIEW WITH THIS PATIENT AND THIS PATIENT WENT THROUGH ALL, SORT OF, SHE'D HAD A REALLY SORT OF DIFFICULT, STARTED OFF WITH A VERY SIMPLE SORT OF DIAGNOSIS AND A VERY SIMPLE ... YEAH, WIDE LOCAL EXCISION, THERE'LL BE NO PROBLEM, AND ALL THIS KIND OF STUFF, AND THEN THE MARGINS WEREN'T CLEAR AND THAT SHE HAD TO MAKE DIFFICULT DECISIONS, A WIDER EXCISION OR [??] AND SO IT WENT ON, AND SHE, YOU KNOW, REALLY GOT VERY VOCAL ABOUT HER FEELINGS AND ALL THE REST OF IT, WHEN ...

[Break in sound file]

... CAME OUT OF THIS [??] SHE'S AN SPR SORT OF THING, GOING ON TO BE A CONSULTANT, AND SHE JUST SAID, 'I'D NO IDEA, I'D NO IDEA WHAT THAT WAS ALL ABOUT,' SHE SAID, SHE SAID, 'I'D SEE PEOPLE FOR 10, 15 MINUTES AT THE MOST AT INTERVIEW, I'VE SEEN THEM CRY, I'VE SEEN ALL KINDS OF REACTIONS, BUT I'D NO IDEA THAT, YOU KNOW, BEING IN SOMEBODY'S HOME, LISTENING TO WHAT THEY'RE SAYING IS SUCH A DIFFERENT EXPERIENCE, I JUST NEVER DO IT,' SORT OF THING. AND THAT'S WHY WE PREFER DOING THE INTERVIEWS IN THE PATIENT'S HOMES BECAUSE THEY'VE BEEN REALLY RELAXED, THEY'VE REALLY OPENED UP AND THEY REALLY TELL YOU EXACTLY HOW THEY FEEL. SO, I CAN TOTALLY UNDERSTAND WHAT YOU MEAN THERE. [??] I'LL MOVE ON A LITTLE BIT. THE NEXT QUESTION IS, AND YOU [??]

*Q3. DO YOU FEEL THAT PROFESSIONALS HAVE DIFFERENT STYLES AND DIFFERENT WAYS OF WORKING, AND IF SO, WHAT STYLES HAVE YOU OBSERVED?

Nurse: Yeah, yeah, erm ... very much so, very much so. Erm, we've got three radiologist and they work totally differently, and I'm not saying that any of them, the styles are wrong. There's only one style I have difficulty with, and that was the one that I touched on earlier where, erm, he actually doesn't always say ... and he feels uncomfortable and when you're in that room and he's giving that result, you know that he's feeling uncomfortable and you feel uncomfortable for them, and then if you've got a woman who challenges him ... and you do get that, you know, you do some women, I always say that you get some women who, if the consultant said to them, 'Go to the edge of that cliff and do, and dive off, do three somersaults on your way down and land on your feet,' they'd do it. But equally now you've got, erm, particularly because we're screening and symptomatic, you get different types of people coming through who have looked everything up on the internet, who come with reams of things, and I know that one of our consultants is extremely uncomfortable with that. And, erm, it's quite, it's quite uncomfortable for you sometimes too. Because you want to try and rescue him but you know that then he'd resent that.

INT: YES, YEAH.

Nurse: You know, and you know that. And, but the person at the end of the day is the patient that you're going to be looking after and you're going to be building that relationship up with, so she's the most important, or he's the most important if it happens to be a male breast cancer, so, erm, you do have to be very confident as a breast nurse to chime and say your pennyworth and I think that's what we've all learnt. But the styles are very different and not all of them work but the majority of them do.

INT: MM. IS THAT JUST CONSULTANTS YOU'RE TALKING ABOUT, OR ARE YOU TALKING ABOUT CONSULTANTS AND BREAST CARE NURSES ... YOUR COLLEAGUES?

Nurse: Erm, I think we've been very careful how we choose the breast care nurses that come into the team and, erm, we would want someone who's not afraid to speak their mind and we would want someone who's not afraid to be that patient's advocate, and, so we've all got different styles, the breast care nurses have all got different styles when it comes to, erm, looking after their patients and interacting with other professionals within the multidisciplinary team and in the Trust and outside the Trust. But they're all very confident

and that's what you need, and I think that patients need to build up that trust and realise that you know what you're talking about. But also, I've always said to them, 'Don't be afraid to say to anyone, you know, "I don't know that";' because even though I've been doing this job all this time there are still things that I come across that I think, 'Oh, I've not heard of that before.' This week I've heard three patients and I've never had it before, three patients who've come along and changed to [???] and they've said, 'I'm really tired since I've gone on this [???] and is that a side effect?' ... well it's not a known side effect but I'll find out about it now because three people have said it this week. So there's always something coming along new and I think that, with the all breast care nurses, yes, we've all got different styles but we're all pretty confident I think in what we do. And if we don't know we're confident enough to say, 'I don't know.' With the radiologists they all, er, work in a different way, erm, but they're quite detached I feel, they don't really get involved. The pathologists I think are totally detached from the patient, they only see the slide and the cell and actually we've had a new pathologist from South Africa who's, who actually said to me one day, 'Please don't bring the personality of this person in. I don't wish to know that.' And, and I feel sad for him really, you know. You know, he doesn't, he didn't want to feel the pressure from us that this was a person and it was because I, you know, we were saying, 'Oh this is really a shame because we know you're having great difficulty getting this diagnosis but, you know, also realise that this patient is climbing the wall, you know, she needs to know this.' And he didn't want to know that.

INT: NO.

Nurse: So we've had to adapt our practice a little bit to protect him, which was quite surprising. Erm, and we've not had this before with the pathologists, because we'd always had very good pathologists who sorted things out and sent things off for opinions and let us know in plenty of time. But, so he's been a bit of a surprise. The consultants, or the surgeons, they work, erm, two of them work very similarly and one, erm, will never change. He says he will but he won't, and he's not going to now, he's worked here since 1989 and he's not going to change now. Erm ... one of them gets a bit ... mmm ... she can get a little bit cross with the other two because she thinks sometimes they put on her and I think sometimes she's right.

INT: RIGHT, OK.

Nurse: So there's different styles but we seem to just work well with each other.

INT: RIGHT, YEAH.

Nurse: And we've got radiographers obviously and we've recently had a service manager, which has been, again, a time of change for us because the line of management is quite strange in this unit. The nurses are all sort of, I'm their manager, but my manager, I had a nurse manager and Dr [???] the clinical director, so if ever I'd got a problem in the unit it was straight to Dr [???] which was quite difficult at times because there were so many things going on, and she's not a great people person, she's not a great communicator, and there were times when really things were very, she was working as a radiologist but also having to work as the manager, and it was really quite difficult for her and she'd get a bit ... mm, snappy. So they've now put what they call a buffer in between her and us. So the three areas - there's the admin area, the radiographers and the nurses - we now have a services which initially they all thought was going to be a brilliant idea but then Dr [???] had great difficulty letting go.

So it's been quite a time of change really. So, erm, the service manager has been a good thing and it will be a good thing, erm, when it really gets established, but it's been, I think we comple-, on the whole we complement one another and we try to work well as a team and I think we do. And what I always say is that if you've got a problem, let's sort it out now, don't let it fester. And I think we all try and do that, if there's a problem, each discipline, if there's a problem, you know, come straight out with it because, you know, you can't let it fester. No.

INT: I'D LIKE TO MOVE ON A BIT NOW.

Nurse: OK.

INT: WHERE, JUST BEFORE CONSULTATION WHERE A DIAGNOSIS IS TO BE GIVEN, I'D LIKE US FROM THIS POINT ON TO FOCUS ON NEWLY-DIAGNOSED BREAST CANCER PATIENTS. CAN YOU TELL ME...

*Q4. WHEN IS YOUR REGULAR BREAST MDT MEETING HELD IN RELATION TO WHERE PATIENTS ARE GIVEN A DIAGNOSIS OF BREAST CANCER?

Nurse: OK. We have MDT meetings twice a week: Monday lunchtime and Thursday lunchtime. Monday means that we can discuss the results that are coming through on Tuesday, and Thursday lunchtime is a, usually a mixture of people who are going to be newly-diagnosed and the post-ops, so that the newly-diagnosed we will see them on Friday, and the post-ops we'll see them Thursday afternoon, straight after the MDT meeting. So we've got an idea of what's coming through.

INT: RIGHT, OK. AND OBVIOUSLY PATIENTS ARE DISCUSSED PRE-OP AT THOSE MEETINGS?

Nurse: It's thoroughly discussed. Erm, have you ever been to one of our MDT meetings?

INT: I'VE BEEN TO MDT MEETINGS [???] [??]

Nurse: OK. Well [??] they're more or less the same, aren't they? The radiologist will get up and present the mammograms, the ultrasound and what they've found; the surgeon will tell us what they found clinically; the pathologist will present what he's found. Now if they all match up and they all agree, that's fine, and then we discuss where we're going to go. And we discuss patient choice of surgery, erm, whether a patient choice of surgery is feasible, because obviously if this is a huge area in a small breast, you know, the safest service is always discussed, but if patient choice is there, then we write on the minutes, 'Patient choice of surgery.' If the MDT meeting, during that MDT meeting, things don't add up or there's something not quite different again, we discuss how we're going to proceed with that. Obviously now that we've got core biopsies coming through, we get quite a good high rate of definitive diagnoses, so that we can discuss

[Break in sound file]

... where that patients need to go there. And that, and I do like that because, erm, I do feel that we do treat each person as an individual and that is discussed round the table and, again,

everybody can chime in, you know, it's not just the radiologists and the surgeons and the pathologists, the nurses can, the radiographers can. And we've introduced the x-ray helpers in now and it's something new because they're actually helping us tie some ends up and they've found it fascinating. They can't believe all this goes on before that patient comes in because they don't usually see all that. So, yeah, I think ...

INT: I USED TO ATTEND THE [??] MDTs IN THE FIRST STUDY.

Nurse: Sorry?

INT: THE LUNG AND COLORECTAL MDTs, I USED TO ATTEND THOSE IN MY FIRST STUDY BECAUSE THAT'S WHAT I WAS DOING [??] THOSE PATIENTS, DOING JOINT CLINICAL TRIALS, AND I KNOW I WAS JUST FASCINATED WITH WHAT WENT ON, YOU KNOW, I USED TO SIT AT THE BACK, I NEVER TOOK PART. BUT I WAS THERE TO SORT OF IDENTIFY PATIENTS AND THEN I WOULD SPEAK WITH THE CONSULTANTS AFTERWARDS REALLY, YOU KNOW, AND THE NURSING TEAM, I'D IDENTIFIED THAT X, Y, AND Z, ARE THESE PEOPLE, YOU KNOW, APPROPRIATE TO APPROACH? IS THERE ANY REASON WHY I SHOULDN'T APPROACH THEM? BECAUSE OBVIOUSLY THE SOCIAL SITUATIONS WHY YOU SHOULD NEVER APPROACH SOMEBODY, AND ALL THIS KIND OF STUFF. THERE'S ALL, YOU KNOW, AND I WAS JUST FASCINATED WITH WHAT WENT ON AND, YOU KNOW, THE DYNAMICS, THE WAY IT WORKED, THINGS THAT WERE BEING DISCUSSED. IT WAS JUST FASCINATING, IT REALLY WAS.

*Q5. SO, I MEAN, AFTER AN MDT MEETING, HOW DO YOU USUALLY FEEL WHEN YOU COME OUT?

Nurse: I feel OK when I come out. I feel that, erm, that we can discuss during that MDT meeting anything that's relative to that patient, erm, and I think that we're quite open about it. Erm, so I feel that we've, we've done a good job when we come out of the MDT meeting. If anybody's got any doubts in that MDT meeting they do voice them and they are listened to. We had one yesterday in the post-op where Veronica had built up this relationship with this patient, who is schizophrenic and has, you know, and they, she was able to give that insight into that side of it because, although she needed this treatment, would she be able to cope with this treatment? And Karen was saying, 'Ooh, will the chemotherapy do anything to her schizophrenia?' you know, because we didn't ... and people aren't afraid to, you know, answer that. And it's really nice, it bounces around nicely.

INT: RIGHT, OK.

Nurse: And I think people who observe our MDT meetings are a bit surprised really because, er, and I sometimes explain to patients, you know, that it's not just one person's decision, you know, this decision hasn't been reached by one person, it's a team decision, it's a discussion and we're looking for the safest at the end of the day.

*Q6. AND, AT A PRIOR CONSULTATION, IF IT WAS SUSPECTED THAT A PATIENT HAD A BREAST CANCER, OBVIOUSLY YOU HAVEN'T MADE THE DIAGNOSIS, IS THERE ANYTHING YOU, OR ANYONE ELSE IN THE TEAM WOULD SAY TO THEM?

Nurse: It would depend on the patient a lot really, erm, because you'll get some patients who, they're like ostriches, aren't they, they bury their head in the sand and they don't want to know anything, even though you're trying to plant a seed - particularly if, if you're talking about the two routes that we see, the screening ladies ... now with the screening ladies you do get some that come through the system and they're well women obviously and they've got really no idea why they've been called back and they really don't want to know, thank you very much. And even though you get the radiologist planting seeds here or, you know, 'Yes, I can see something here and I'd like my colleague to just investigate that ...' and he may take a sample of this tissue, they still don't want to know, they still don't want to know. And then you'll get someone who say as soon as they walk in for another mammogram, to the radiographer, 'Have they found something? Is there something there?' and I think we've all been trained and experienced enough now to say, 'Well ...' for example at the mammogram, 'We do need ... well we're actually doing another mammogram because we don't know.' and then you might get them saying to the radiologist, 'Is it a cancer?' Now we have got one that says outright, 'I think it might be,' you know, but it depends on the woman. They all use their experience and, that they've acquired, to judge whether that woman is ready to hear this. And, again, you'll get them ask outright, you get them not. With the symptomatic woman, most of them have got themselves with a breast cancer anyway, so, erm, some are so frightened that they won't ask a question anyway and some will ask questions. So you've got to use your own experience and your own judgement with that individual that's coming through the service to see what they actually want to know. And that's what we do, but with the screening I think they try and plant a seed if they that that woman's got no idea, they still try and plant a seed so that she can go home and think, 'Well maybe there is something.'

INT: YEAH, SURE.

Nurse: But it depends on your perception of it, and my perception of it, because I can try and plant a seed with you and you may just totally ignore it.

INT: YEAH, EXACTLY, YEAH, THEY DON'T WANT TO TAKE ANY NOTICE OF [???

Nurse: And we still get women who sit here totally stunned, you know, even though we've tried to say, 'We might have a problem here, let's see what we can do.'

INT: YEAH. OR [???] THERE MIGHT BE PEOPLE WHO HAVE HAD CYSTS IN THE PAST AND THEY [???] IT'S A CYST?

Nurse: Yeah, oh yeah, yeah.

INT: EVEN THOUGH THEY'VE HAD ALL THE SEEDS PLANTED, YEAH.

Nurse: Yeah, so it's very much, erm, how that patient perceives what you're saying to them, or what they want to know. I think we'd also say, if we, if it was suspected, if we suspected anything we would also stress, because I always do that, because you do get surprises, you do get things that look like they might be breast cancer and aren't, and I would, I think that we would always say, 'We don't know yet ... but we do suspect it could be ...' you know, 'But we don't know until we've done these tests.'

INT: GOT THE RESULTS, YES.

Nurse: We do get people who get really upset when they have to, and want to come and talk to the breast nurses then and we do say at that stage, 'Well, we don't know, obviously we're suspecting because we're asking you have these tests done.' OK.

*Q7. WHAT WAY ARE PATIENTS THEMSELVES PREPARED FOR THE NEWS THAT THEY HAVE BREAST CANCER?

Nurse: I think it's as I said. Just that you've got the, it's so different from person to person and it depends which service they've come through, the screening or the symptomatic. Erm ... so I think it's quite difficult to give you an answer that would fit everybody there because every one's so different. And that's what you have to, to understand about, about it, that it's such an emotional disease that, I mean my partner can't understand why, erm, men see a woman as a breast, you know, but he thinks it's really awful, that they see woman as a breast and not as a person, but everybody's different, aren't they? And you have to just accept.

INT: YEAH, SURE.

Nurse: Yeah, what they want.

*Q8. PRIOR TO A CONSULTATION WHERE YOU KNOW THAT A PATIENT'S GONNA BE GIVEN A DIAGNOSIS OF BREAST CANCER, DO YOU HAVE ANY EXPECTATIONS ABOUT WHAT THE CONSULTATION WILL BE LIKE AND WHAT WOULD THEY BE BASED ON?

Nurse: No, I never have any expectations. I always go in quite open-minded and you never know, you never know, and that's where your experience comes in, you just, you sometimes, if you've seen that patient before, *think* you might know how they're going to react and how the consultation's going to know, but you never know, you've always got to be prepared for the unexpected really, because you don't know.

*Q9. AND WHAT ARE YOUR FEELINGS BEFORE SUCH A CONSULTATION WHERE YOU KNOW A DIAGNOSIS OF CANCER IS GOING TO BE GIVEN?

Nurse: My feelings?

INT: YEAH.

Nurse: I think, I think there's always to some degree, you're always sad really but you have to put that to one side because our job is to help this woman get through it or to help this man get through it, and so, erm, you have to concentrate on doing your job to the best and the highest levels that you can do it to, because you're there to help and you shouldn't be in the job, the breast care nurses shouldn't be doing this job if they aren't there to help that woman get through it. Now it might be that you've got to gently ease her through it because, erm, it could be a very advanced disease and you know that there's not really an awful lot, so you've got to ease her through it and help her through it and help her face her own mortality. So, erm, I never have any expectations, I never know, I never go in thinking that I'm going to do it in any particular way, I'm never going to go in and say, 'This is how I do my job,' because you can't, because you never know what's going to be thrown at you.

INT: [???]A SET SORT OF STYLE OR SPEECH OR SPIEL OR ANYTHING?

Nurse: I think, I think I always say to the others, we've got certain things that we have to get through, particularly if she's going through surgery, erm, but you've also got to pitch it at their level, David, because you can ... like ... you can get someone who is a really simple soul and doesn't understand cancer and doesn't understand, I mean we used to have somebody who used to say, 'This is a blur[?]' For God's sake, you know, but I always make sure that they know that we're dealing with cancer and sometimes we're probably the first people that say 'cancer' to them, although two of our consultants do say it now. Erm, but you also get a doctor who knows every single thing about cancer and they go down terrible 'What if ...' roads, you know, because they see the worst scenario, so you've got this ...

[Break in sound file]

... try and pull people back and you've got to pitch it at the level that they understand. So that's why you can't go with any expectations. You can go with, in your mind knowing what you've got to get through to them, but you might not do that the first time you see them and you might not do that the first time they've been told they've got breast cancer, because the vast majority of people I find that have been told they've got breast cancer, erm, will say afterwards, 'It was as if you were talking to someone else. It was surreal. It wasn't me and, you know, when, when I heard the word cancer I didn't hear another word after that.'

INT: YEAH, YEAH, IT STOPS THEM IT THEIR TRACKS, DOESN'T IT?

Nurse: So ...so you've just got to pitch it to that person's level, make sure, I hope that you know that when they go out of there that they know where they're going next, and that's the most important thing, and they know that they can get in touch with you if they need to. So if I know and I understand that they know they can contact me when they get home, and they know what is happening, the next step, then I don't worry too much at that stage, and I don't worry too much about style. I like to know that they feel supported, but it's quite difficult that first consultation.

INT: YEAH, OH I CAN IMAGINE IT WILL BE. ERM ...

Nurse: Has that answered your question?

INT: YEAH. ERM, DO YOU ... I WANT TO MOVE ON A LITTLE BIT NOW TO DURING A CONSULTATION A NEWLY-DIAGNOSED PATIENT.

*Q10. CAN YOU PLEASE TALK ME THROUGH WHAT HAPPENS IN A CONSULTATION WHERE A DIAGNOSIS AND TREATMENT OPTIONS ARE BEING DISCUSSED WITH A PATIENT WITH BREAST CANCER? SO YOU SIT IN WITH THE CONSULTANT, IS THAT RIGHT?

Nurse: Yes, we do.

INT: AND DO YOU WORK WITH THE SAME CONSULTANT ALL THE TIME OR ARE YOU WORKING WITH DIFFERENT CONSULTANTS?

Nurse: You're working with different consultants all the time. Erm, we didn't really want to allocate one particular breast care nurse for one particular surgeon, although, so we, we alternative, so that we can pick up different styles. And also if one person's off you've still got to cover that clinic. So we all sit with every single one. Erm, before the patient comes in, obviously we've had the MDT meeting so we've got an idea about what is going to happen during that clinic, but we always, before the patient comes, we always look through the paperwork to see again what's happened, erm, and just remind ourselves whether this patient's got a choice or what, whether that patient's going down for neo-adjuvant, because we do get that happen, and, erm ... I think a lot of consultants do it now, the consultants kind of sit themselves in a particular position with two chairs opposite to them and then if we need to bring any more in, and the nurse kind of sits to one side and slightly to the back ...

INT: RIGHT.

Nurse: ... erm, because what we've found happens is that if that woman catches the nurse's eye she tends to talk to the nurse, another woman, erm, rather than listening or discussing things with the surgeon. So we sit slightly back and to the side of the surgeon so that the woman's got the opportunity to discuss things with the consultant. And the consultants always introduce us and say, 'This is the breast care nurse ...' and don't say any more at that stage. But the problem we have is that we've started sitting in with all the patients because, erm, the patients say to us, 'I knew it was bad news as soon as I saw you sitting there.'

INT: RIGHT, OK, YEAH.

Nurse: And that's really something that we can't avoid, we can't avoid it, but we do sit in with the benign ladies as well, erm, but they all say, 'I knew as soon as you were there that it was bad news,' which is nothing that we can get over really. The consultants have got different ways of telling patients that they've got a diagnosis, but usually they do like a little recap, you know, 'When I saw you ...' or 'When my colleague saw you ...' because it may not always be the same consultant that they've seen all the way through, which is a pity, erm, sometimes. And they would sort of do a little recap, you know, 'When we saw you last week ...' or '... a few days ago, erm, you know that we found this little area we wanted to investigate ...' and they'll say something, '... and the test that you had has confirmed that this is a problem ...' that's one person will say, 'We have got a problem'. Another person will, the other two people will say, 'That is a cancer,' which is good. And at that stage you don't know how it's gonna go, erm, because people react in totally different ways. Some people are just stunned and you know that they're not taking anything on board, so it's important then that, as breast nurses, you're listening to what is being said so that you actually recap, and it's nice if they bring, the patient brings someone in with them because they can also perhaps keep themselves a little bit together to listen to what is being said. But generally, erm, the diagnosis is explained, that it is a cancer: they usually say how big the area is and they usually go through choices, so if we know that the size of the cancer in relation to the size of the breast, and the position of the cancer in the breast offers a patient choice, they will go through both the choices.

INT: YEAH.

Nurse: If we know that there is no choice, if it's smack behind the nipple and it's a huge tumour, then they will, two of them will explain the choices, but then will say, 'I really feel that you need to consider having a mastectomy because, if I take, when I take that area away

as I explained to you, if I take that area away with a good margin round it, I'm going to leave you with very little breast tissue there, which cosmetically you will not like ...' and, you know, and they always go on then to discuss reconstruction, and they go on to discuss reconstruction as an immediate option or one of them will say, if he feels that we need to go on for more treatment after this, will say, 'Reconstruction is an option but my advice to you at this particular stage is that you delay it because the treatment I feel that you will need afterwards may compromise that surgery ..' So, but you still get people who insist on, doesn't matter what you say, 'I don't care what you say, you're not taking my breast off.' And 'I don't care what you say, you take my breast off.' You know, and 'I don't care what you say, I'm having reconstruction,' so ... and our lot are really very good, they listen to what people are saying and they'll say, 'Well, go across now and talk with [???]' and that's the bit I don't really like because we have to bring very upset women across a main corridor to here. I like it when we're here, because we've come away from the area ...

INT: SO THIS CORRIDOR'S GOT OTHER PATIENTS [???] ?

Nurse: We have them to bring them across this corridor and I don't like that. And it's gonna get worse because they've got this golf cart thing where they, and it's needed because the car park is miles away, and you have to walk all the way up here and it's really needed, but they're reversing it down our corridor where we're bringing really upset patients who've just been given a diagnosis of breast cancer, and I really don't like it. But our hands are tied there. But once we're here I'm OK. And then it's really ... with the breast nurses it's really recapping on ... oh, before we come here, we've always decided when the surgery will be.

INT: RIGHT, YES.

Nurse: So we've got a date for that lady to come in. We know when that's going to be. Now sometimes they ask for the day, sometimes they don't, erm, but when we come here the nurses know when that woman's first available date is for her surgery. So we know that we've got to use our own judgement as to whether that's too soon, too late ... can she cope with it? ... can she cope with the wait? ... can she cope with having it done so quickly? So you've got to use your own judgement there, but you've also got to go through if the pa-, if she's been offered a choice you need to be able to go through the choices, you need to be able to go through the treatment that might be needed afterwards, but again it's very much patient-led. And if she doesn't want to discuss that, if she just wants, again, you need to judge whether they need 10 minutes on their own before you go in, whether they just need to see you, know where they're going next and get out of here, because some people just do, they just want to fly. Erm, or whether they just need time with you to collect their thoughts. Yes, they're gonna be devastated; yes, they're going to be upset, but you've got to ... to try to build, start the building of that relationship. And very often what I find is that that first session is very, erm, practical, erm, but also you don't know what you're going to get so you might, it might be very emotional, it might be very draining on you and on her, and on the family. But you've got to really start building a relationship up so that they're confident enough in the team and in us as a team to help them deal with it. I find that the second time that we see them is much more counselling session ...

INT: RIGHT, YOU GET THAT SORT OF FAMILIARITY THERE [???]

Nurse: ... I find, and I get a great deal of satisfaction from the second session rather than from the first one. Although I like the first one and I like working with and trying to build that up, the second session with those ladies is much more satisfactory because you're starting to get to know one another, you're starting to deal with emotions ...

[Break in sound file]

... other than the initial, it's just shock the first time I find.

INT: AND HOW DO YOU THINK PATIENTS COPE WITH THE, ERM, WHEN THEY'RE BEING TOLD THEY'VE GOT A CHOICE OF SURGERY, HOW DO YOU FEEL THEY COPE WITH THAT?

Nurse: Erm, again, it's an individual reaction. Erm, you get some people who can't cope with the choice and they'd rather that the doctor just said to them, 'This is what you need,' and then you get people who are so indecisive it's awful. And I've had one this week where she's gone from wide excision to mastectomy, to wide excision to mastectomy ... from wide excising to mastectomy, and then the day, the third, on the third, she said, 'I've made my mind up, I'm having a mastectomy,' and her daughter sat with her and she said, 'I think that's a good idea, Mum, yes.' 'Do you think so?' 'Yes.' So she said, 'I'm having a mastectomy. I'd rather have a mastectomy.' And this is a woman who's got a history of bowel cancer as well, so she's really, you know, up on cancers. And then she rang me yesterday and she said to Julie, 'Will you tell [???] I've change my mind again?'

INT: OH NO.

Nurse: I want a wide excision, so I've actually documented it now and [chuckles] she's going for wide excision. So people who are really indecisive, and some people can't cope with being given a choice, and equally other people are quite relieved that they're given a choice, you know, 'It can't be as bad if I'm being given a choice,' erm, which isn't always true, erm, so, you know, 'Well, if you're giving me a choice then this cancer can't be as bad, because if it was bad I'd have to have a mastectomy.'

INT: YEAH, I'VE HAD ONE OR TWO PATIENTS SAY THAT AS WELL, AND [???] YEAH, THAT IS TRUE.

Nurse: Yeah, it's really, erm, our job as nurses really is to go through the choices and to give them the pros and the cons of both choices and they sometimes have to go through that several times. But some people say, 'Ooh, no, it can't be as bad so I'll have a wide excision,' and then other people say for the tiniest, little tiny cancer of 3 mms, 'I want a mastectomy.' So you never know, you're never going to know, you're never going to know. You never, you never ... each person that comes through - and that's what makes the job interesting really - they're so different and they've got different reasons. But you have to be sure that when they're given a choice that they do know both sides of the coin so that they can make an informed decision. And hopefully they will.

INT: THINKING ABOUT THE CONSULTATION PROCESS, BOTH WITH THE CONSULTANT AND YOURSELVES, ERM, DO YOU USE ANY VISUAL AIDS, ANY DIAGRAMS, X-RAYS, PHOTOGRAPHS, ANYTHING OF THAT INFORMATION?

Nurse: Yes ... yeah. You know when I said earlier you pitch it at the level that that patient wants, you sometimes do have to use diagrams so that, especially at that first consultation, because their mind's just whizzing round and they'll say, sometimes say, 'Can I take that home with me?' and that's what you do need things, you need written information, you need pictures, erm, because they need to take that home to get their heads round it as well when they get home.

[*Q11. PLEASE TELL ME ABOUT ANY ADDITIONAL TIME YOU USUALLY HAVE WITH A PATIENT AFTER THE PART OF THE CONSULTATION WHERE THE DOCTOR IS PRESENT?] not asked

INT: OK. SO I'D JUST WANT TO MOVE ON NOW TO, WE'VE TALKED A LITTLE BIT PATIENTS' INFORMATION NEEDS ...

*Q12. IN YOUR EXPERIENCE, WHAT DO PATIENTS TEND TO KNOW ABOUT BREAST CANCER AND ITS TREATMENT OPTIONS BEFORE THEY COME IN TO SEE YOU? QUESTION ELEVEN ...

Nurse: Right, OK. I think over the years I've found that patients are much more informed about breast cancer, and I also think that in October it's a terrible month for them because ...

INT: IT'S BREAST AWARENESS.

Nurse: ... yeah, it's just in their face all the time, erm, but you still get some people, erm, and you can't really pin it down to any particular age group I don't think, erm, say which particular group don't know anything about breast cancer. Erm ... a lot of them, a lot of them have got ghosts and histories and that's difficult because they'll just see themselves going down the same pathway there, but, erm, it varies, it varies. There are some people who are extremely well informed and there are some people who don't understand about breast cancer and how it can affect the rest of their system. With the treatment options, again, it varies. You'll get people who are extremely well informed and will tell us about sentinel [?] nodes, erm, and then equally you'll get people who get mixed with radiotherapy and chemotherapy and still don't know the difference. So it's, erm, a very wide umbrella of reactions and experience and knowledge.

INT: DO YOU THINK THIS MAKES FOR AN EASIER OR HARDER CONSULTATION IF SOMEONE KNOWS A LOT OR A LITTLE ABOUT THESE THINGS?

Nurse: I always say that a little knowledge is a dangerous thing but a lot of knowledge is even worse.

INT: RIGHT.

Nurse: Because, erm, with the people who come along with a lot of knowledge, they just, they just see that side of it and they can't move away from it, and it's really quite difficult. I had an experience the other week with a GP and his wife was diagnosed and their best friend's

wife had had breast cancer. Now he was going through all his experience and knowledge from his experience as a GP in the community and his friend's wife, and was totally going down the wrong track because his wife had got GCIS, and he was going down the wrong track totally with it. So, erm, a lot of knowledge is sometimes a dangerous thing.

INT: RIGHT, YEAH. THAT'S ... I INTERVIEWED A PATIENT THE OTHER WEEK WHO HAD GONE TO SEE HER GP, I THINK, ONE OF THE NURSE MANAGERS OR SOMETHING THERE AT THE PRACTICE OR WHATEVER, SAID, 'I HEARD YOU'VE GOT BREAST CANCER, DO YOU KNOW ANYTHING ABOUT CANCER?' AND SHE SPENT HALF AN HOUR TELLING HER ABOUT EVERY POSSIBLE CANCER THERE WAS AND TALKED ABOUT PALLIATIVE CARE AND ...

Nurse: Ooh ...

INT: [???] AND ALL THAT AND SHE WAS [???]

*Q13. WHAT DO YOU THINK ARE THE MOST IMPORTANT PIECES OF INFORMATION PATIENTS NEED OR WANT TO KNOW ABOUT THEIR DIAGNOSIS AND WHEN ARE THEY RAISED? JUST GENERALLY.

Nurse: I think the most important piece of information that they will want to know is, 'Am I going to die?' and we can't answer that, so that's, erm, quite difficult to tackle. A lot of them want to know how soon the treatment's gonna start and that's easy enough for us to get that answered because we've got such a good system going with admissions now. And, erm, they're all raised at different times in different areas: you'll get someone who wants to go through every single thing as soon as they're diagnosed, and someone who wants to take things a step at a time. And no one way is wrong, you know, it's what's, down to you as an individual as to how you cope with things. So I mean I'd want to know everything and I'd need to know it, but I also know that I've got a sister who would just want to know things, you know, 'Just tell me as you're going to do it.' So you've just got to, you know that you've got certain things that you've got to get over and you know you've got certain things that that patient needs to know, but you've just got to take it at that patient's level and pitch it at that level. So it's, erm, they're raised at different times, the questions are raised at different times, and that's not wrong, you know, it's how you can cope with it, what you can take in, erm, but I think they want to know when everything's going to happen, that's quite important to them. And they need to know, I think they need to know that you ... they need to feel that you know what you're doing. They need to feel, have that confidence, and not be ... because when you've been given a diagnosis of breast cancer, it doesn't matter what we say to start off with, erm, you just think you're going to die. And, er, you have to try and re-focus.

*Q14. AND A SIMILAR SORT OF QUESTION, WHAT DO YOU THINK ARE THE MOST IMPORTANT PIECES OF INFORMATION PATIENTS NEED OR WANT TO KNOW ABOUT TREATMENT OPTIONS?

Nurse: I think a lot of the patients recently that have come through, when they're given treatment options, they still, they kind of focus on statistics and survival, and they're sort of saying to us, 'Well, what is the survival rate for that?' you know, 'What is the difference, if I have that treatment does that mean that you've got rid of my breast cancer? Does that mean I'm cured?' and it's, they need to know ... I think it's quite difficult to say what you think the

most important pieces of information patients need or want to know. They want to know that you're going to treat them, they want to know when it's going to happen, erm, some people want to know every little detail about the kind of breast cancer they've got, some people don't want to know anything. And I can think of two people where she ...

[Break in sound file]

... she had quite an aggressive tumour but she lived for 12 years and she lived because she didn't want to know and while-ever there was a bad piece of news all she wanted to know was, 'Can you treat it?' She didn't want to know that this is another step along the way to your cancer worsening, she just wanted to know, 'Can you treat it?' So it's, I think that's quite a difficult question to answer.

INT: YEAH, IT IS, IT'S A VERY GENERAL QUESTION AS WELL, THAT'S THE THING.

Nurse: Yeah, because you're saying what are the most important pieces of information patients need to know - I've got probably a different idea of what they need to know to start them on the journey.

INT: EXACTLY YEAH.

Nurse: And I just go with what she leaves me with or what he leaves me with, so I let them have that information and as they need, and as they can cope with it.

INT: YEAH, YEAH. WELL, YEAH, BECAUSE WHAT YOU NEED TO KNOW YOU MIGHT NOT WANT TO KNOW.

Nurse: Yeah.

INT: AND WHAT YOU WANT TO KNOW YOU MIGHT NOT NEED TO KNOW.

Nurse: That's true.

INT: YEAH. SO, YEAH ...

Nurse: So it's quite difficult to answer. And they raise it at different times, you know, it's as that person can cope with it.

INT: OK. I'D LIKE TO MOVE ON TO NOW WHAT A PATIENT IS OFFERED.

*Q15. IN THE CONTEXT OF YOUR UNIT'S GUIDELINES AND PUBLISHED RESEARCH, CAN YOU DESCRIBE THE FACTORS THAT WOULD LEAD YOUR TEAM TO OFFER A PATIENT...

*a. ONLY BREAST CONSERVATION SURGERY?

Nurse: ... I don't think we offer breast conservation surgery only. I think that we always offer, if breast conservation is on the cards we always offer a choice because you're gonna

get that one person that says, 'I don't care what you say, I want a mastectomy.' We usually offer choice.

***b. AND WHAT FACTORS WOULD LEAD THE TEAM TO OFFER A PATIENT ONLY A MASTECTOMY**

Nurse: The factors that we'd offer the patient only a mastectomy would be if it was widespread disease, erm, if it was widespread ductal carcinoma in situ, that would be the one patient that would be offered immediate reconstruction. If it was a huge tumour in a small breast, if it was a tumour above 35 mms then we would need to think about mastectomy, also if there was vascular invasion, you'd need to talk about mastectomy. Erm ... and it would depend on the size of the tumour, the position of the tumour in relation to the size of the breast, with mastectomy. And also you would get a person that would ask for mastectomy.

***c. AND WHAT SORT OF FACTORS WOULD LEAD THE TEAM TO OFFER A PATIENT A CHOICE BETWEEN THE TWO TYPES OF SURGERY?**

Nurse: All the things that I said before, it would be the position of the breast cancer, the size of the breast cancer in relation to the size of the breast, erm ... and we will offer to choice to small tumours.

***d. AND WHAT FACTORS WOULD LEAD THE TEAM TO OFFER A PATIENT ANY OTHER TREATMENTS?**

Nurse: Do you mean like chemotherapy first?

INT: YEAH, IMMEDIATE.

Nurse: Right, if, if that tumour looks as if we couldn't clear the margins satisfactorily, then they may offer chemotherapy first to shrink the tumour down and then look for a window during that treatment time to offer surgery. If that woman actually said she was, even though it was a large tumour and we were advising mastectomy, if she said she was, 'I really don't a mastectomy,' then we might offer her chemotherapy first to shrink the tumour to see whether we could get a good margin with a wide excision, and that has worked quite well. Erm ... if it was a very advanced disease then we would offer chemotherapy first and then see whether we need, we would be able to surgically removed the tumour. Erm, I think that's about all.

INT: THE LITERATURE SUGGESTS THAT PATIENTS VARY IN THE DEGREE OF INVOLVEMENT THEY WANT WHEN MAKING DECISIONS ABOUT WHAT SURGERY TO HAVE: SOME WANT FULL CONTROL OF THE DECISION MAKING PROCESS, SOME PREFER TO SHARE THE CONTROL, AND OTHERS PREFER IT IF THE PROFESSIONALS TAKE FULL CONTROL. FIRST OF ALL ...

***Q16. DO YOU THINK PATIENTS ARE GETTING THE DEGREE OF CHOICE THEY WANT?**

Nurse: Yes I do. Yes I do. And I think that, again, with the breast care nurse's involvement, I think that's quite important because you're the patient's advocate and I think that they, you should see that that happens so the patient does get the choice.

*Q17. AND THINKING ABOUT YOUR EXPERIENCE WITH THE PATIENTS THAT YOU SEE, THERE'S FIVE CHOICES THERE [???] CAN YOU LOOK AT THOSE CHOICES AND CAN YOU TELL ME, DURING CONSULTATIONS, WHO GENERALLY MAKES THE FINAL DECISION ABOUT WHAT SURGICAL TREATMENT TO HAVE?

Nurse: ... Is this talking about the breast care nurses, 'the patient and I generally share the responsibility'?

INT: WELL, WELL IT CAN BE THE SURGEON AS WELL.

Nurse: Oh, right.

INT: THIS IS A GENERAL ...

Nurse: Well I think the patient tend, in this unit I think the patient tends to make the final decision about the treatment after they have seriously considered the opinion of the consultant and then discussed it with the breast care nurse.

INT: RIGHT, OK. SO IT THAT THE SECOND ONE DOWN, YEAH?

Nurse: Yes.

INT: I'D LIKE TO MOVE ON TO THE NEXT SECTION WITH IS COMMUNICATING WITH PATIENTS WITH BREAST CANCER. AT THIS POINT I'D LIKE US TO TALK ABOUT YOUR EXPERIENCES COMMUNICATING WITH PATIENTS. IN PARTICULAR I WANT TO, I'D LIKE FOCUS ON PATIENTS IN, FOR WHOM CLINICAL REASONS MASTECTOMY IS NOT THE ONLY OPTION.

Nurse: Yes.

INT: RESEARCH HAS IDENTIFIED THAT PATIENTS WITH BREAST CANCER TEND TO FALL INTO THREE DECISION-MAKING STYLES: THAT'S ACTIVE, COLLABORATIVE AND PASSIVE DECISION-MAKERS, AND I'M AWARE THAT YOU MIGHT NOT EVEN USE THESE TERMS ...

Nurse: No, we do, active ... yes, we do.

INT: IN THIS FINAL SECTION HER WE WOULD LIKE TO ASK YOU A FEW QUESTIONS ABOUT HOW YOU FIND COMMUNICATING WITH EACH OF THESE TYPES OF PATIENT DURING THE CONSULTANT PROCESS THAT LEADS TO FINAL TREATMENT DECISIONS. I WOULD LIKE TO START WITH THE SITUATION WITH ACTIVE DECISION-MAKERS, AND THERE'S A DEFINITION THERE, WHICH I'D LIKE YOU TO READ YOURSELF ABOUT HOW WE DEFINE DECISION MAKERS ...

Nurse: Yeah.

*Q18. FIRSTLY, I WOULD LIKE YOU TO THINK ABOUT A SITUATION YOU'VE HAD WITH A PATIENT WHO YOU THOUGHT WAS ACTIVE ABOUT MAKING DECISIONS.

WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE.

Nurse: Yeah, I can think of one there. Erm, at the first consulta-, she was quite surprising really because she was very practical from the word go and had asked questions all the way through her assessment process, and by the time she came to getting the diagnosis she'd got a folder about this big ...

INT: RIGHT, OK.

Nurse: ... with things that she'd got from the internet and other kinds of information from various groups of people and it was, she was, it was really quite nice, it was really quite challenging in a lot of ways, erm, and she actually insisted that she had sentinel [?] node biopsy too, so, and this is the way she decided she wanted her treatment, and this is the way that it was going to go, thank you very much. And, erm, and if it didn't work then she would go on and have a mastectomy afterwards. So she decided that she wanted a wide excision but she wanted sentinel [?] node biopsy too, and that this is the way ... and she understood that that margin ... it's really very, very good, but she did break down later on. She did break down on and show some emotion because she actually showed no emotion whatsoever, but she was also a woman, and I think it's sometimes your background life that comes into it, where her husband had got killed and she'd been left with, he was on a motorbike and got killed while he was coming home, and she'd got two young children, she was left with two young children. And so, 'Thank you very much, I can't, nothing can happen to me because I've got these two girls to bring up.'

INT: RIGHT, OK.

Nurse: And the girls were very similar to her too. They'd had to cope with the father dying and being left on their own, and this had happened about five years previous to this, and the girls were then 14 and 15, they were 14 and 15, and they actually came in on another consultation with her and they discussed between the three of them how Mum was going to be treated. So they were very active in the way that they [??] ...

INT: RIGHT, OK.

Nurse: ... and they decided between them. And it was wonderful.

INT: RIGHT. HOW OLD WAS THIS LADY ABOUT?

Nurse: Sorry?

INT: HOW OLD WAS SHE, THIS LADY? WAS SHE ...?

Nurse: She was about 38.

INT: RIGHT, OK.

Nurse: Mm. She was very ... and this had got to happen and the girls had got to be very aware of what was happening because they'd lost their Dad, there was no-one else, you know, this is what was happening to Mum and we've all got to work out now what's going to happen. But she'd also research breast cancer very, very thoroughly and researched the kind of treatment that she thought that she would need afterwards. And she actually went on to decide, 'Yes I'm having chemotherapy, this is ...' and it was totally, 'This is what I'm going to do. What do you think about that?' you know, but she'd discuss it with you. 'And what is that affect going to have on me personally too? How is this going to affect my children? Will I be able to cope?' So she didn't just research the breast cancer, she researched the treatment and she wanted to know how it would affect her and her family during that treatment.

INT: RIGHT, OK. SO WHAT OPERATION DID SHE GO FOR IN THE END?

Nurse: She had a bi- ...

[Break in sound file]

... excision. Mm. She had to have chemotherapy and she had to have, erm, radiotherapy and Tamoxafen, she had the lot.

INT: MM, OK. AND HOW DO YOU FEEL YOU GOT ON WITH THE PATIENT?

Nurse: I enjoyed her, I enjoyed ... she's the first person that had ever done that with me, and I find it quite ... Oh! But I enjoyed it, she challenged me. She actually challenged me and I, I enjoyed that.

INT: YEAH?

Nurse: Yeah.

INT: AND HOW DO YOU FEEL GOT ON WITH THE CONSULTANT?

Nurse: She got on very well with him, erm, I think she was, she was very fortunate in that, in that she got the surgeon that she got because he was also, he's also quite proactive too, so she was very fortunate then.

INT: OH RIGHT, OK. ERM ..

Nurse: But she got on well, but she was gonna get on well with you anyway, you know, she was gonna, she needed to know everything because she'd got these two children that she'd got to bring up, there was no-one else to do that, you know, and that's what she had to do, and she was gonna do it. So it was no good me saying, 'Ooh, sorry, you can't do that,' you know, 'Sorry, you can't do that, no.' I enjoyed it, she challenged.

INT: SO WHAT INFLUENCES DO YOU THINK WERE APPARENT ON HER DECISION MAKING? I MEAN OBVIOUSLY YOU MENTIONED THE TWO CHILDREN ... ANY OTHER INFLUENCES?

Nurse: I think it was her life experience, you know, she'd lost her husband, she knew that she'd got to sort out this disease, and she knew that it threatened her life and she wanted these children to be very aware of it. They were very, they were very much like her, you know, they had to face this and they faced it together, but they asked and they knew ... they wanted to know everything. Very well prepared they were. We did have times when she was frightened though.

INT: YEAH, SURE. SO LOOKING, I MEAN, HAS SHE HAD HER SURGERY NOW ...

Nurse: Yeah.

INT: ... AND TREATMENT, YEAH. SO LOOKING BACK NOW, I MEAN, HOW SATISFIED WERE YOU WITH THE EXPERIENCE OF CONSULTING WITH THIS PERSON?

Nurse: I got a great deal of satisfaction from it because, as I said before, she challenged me and she asked me things and, erm, it wasn't, 'I'll accept what you say,' which a great deal of people do, a great number of people will just accept what you say as if ...' she went away and looked that up and she came back with, with all kinds of information. And we were able to go through some of it and say, 'No, that's not true,' you know, 'And I've got some information that actually contradicts that, so let me give you that,' you know. So she challenged, I thought it was wonderful. I wish other people were like that.

INT: [CHUCKLES] AND HOW SATISFIED DO YOU THINK SHE WAS WITH THE EXPERIENCE?

Nurse: I think she was extremely satisfied with it. Because we were meeting her needs, we weren't sort of patting her on the head and saying, 'Go away,' and we weren't saying to her, 'Why are you bringing all this in, we know best?' because we don't, do we? And I think what we did was we rose to her challenge and we met her needs but equally she gave us an insight into a different approach and that was good, that was positive. So I quite enjoyed it and I think that she ... she respected us then because, and she was confident in us then because she knew we weren't going to say, 'Well that load of stuff that you've just pulled off the internet is a load of crap,' she knew we weren't going to say that. She knew that we were going to listen to her and we were going to look at what she'd got and actually either, yes, agree with that, 'Yeah we do agree with that,' or not. And at that time we weren't routinely doing sentinel node biopsy: we were involved in a trial but we weren't routinely doing it. So ...

INT: DURING A CONSULTATION, AT WHAT POINT DO YOU BECOME AWARE YOU THINK THAT YOU'RE TALKING TO AN ACTIVE DECISION-MAKER? YOU KNOW, WHEN YOU'RE ACTUALLY CONSULTING WITH SOMEBODY, AT WHAT POINT DO YOU THINK, IF YOU EVEN DO, 'THIS PERSON IS QUITE AN ACTIVE DECISION-MAKER'?

Nurse: You usually know within a few minutes of you meeting that person.

INT: RIGHT, WHAT SORT OF CLUES DO YOU FIND?

Nurse: What kind of clues do I get?

INT: YEAH.

Nurse: I get kind of ... again I can think of one that started off, she was quite, her and her husband were quite defensive and resentful to start off with and, because they were worried that I might think they were challenging me, I knew that that was ... when I got about ten minutes into the interview I realised what was behind them, but it's usually because they're inquiring, they're asking question, they've done a little bit of homework and they're asking questions rather than you giving them the information.

INT: RIGHT, OK. AND WHEN YOU, YOU KNOW, WHEN YOU'VE GOT AN AWARENESS THAT THEY'RE A MORE ACTIVE TYPE OF PATIENT, DOES THAT SORT OF CHANGE THE WAY YOU CONSULT WITH THAT PERSON? DOES IT CHANGE YOUR APPROACH IN ANY SORT OF WAY?

Nurse: ... I think it's got to, hasn't it? Because, erm, I think you rise to a challenge, don't you? You're, yeah, you rise to their challenge. Mm.

INT: I'D LIKE TO MOVE ON NOW TO SITUATIONS WITH COLLABORATIVE DECISION-MAKERS, FOR THIS STUDY WE DEFINE COLLABORATIVE AS PATIENTS WHO TEND TO SHARE FINAL DECISION TREATMENT RESPONSIBILITIES WITH OTHERS ...

*Q19. AND I'D LIKE YOU TO THINK AGAIN OF SITUATIONS YOU'VE HAD WITH A PATIENT WHO YOU THINK WAS A COLLABORATIVE DECISION-MAKER. AND, AGAIN, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE.

Nurse: OK. Yeah, I can think of one that's happened recently. Again, there was, they asked for a lot of information but ... they didn't go and research it an awful lot, but they came back and we shared things and we discussed things, and she'd been given a choice of surgery, either wide excision or mastectomy, and didn't really know how to meet that decision, make that decision, and we had a lot of to-ing and fro-ing and she came here quite a lot, she was ringing me a lot, and we talked it through several times as to why, what the advantages and disadvantages of each operation was. And in the end she did choose wide excision, but then had to go on to have a mastectomy.

INT: RIGHT, IS THAT AFTER THE WIDE EXCISION? AH, WHAT A SHAME.

Nurse: Yeah, yeah.

INT: OH DEAR.

Nurse: Because there was some early [?] disease there, and she actually, we actually talked about it the other day, erm, and she said she doesn't regret going for the wide excision because, given the information that we'd got, you know, it was worth going for that, you know, it was worth trying. So she didn't regret it, erm, and, but she needed, we needed to talk things through and it was ... the difficulty is when you've got a collaborative patient, I feel, is that you have to be so careful that you're not the one that pushes them into making that decision, because, although it's sometimes a collaboration, sometimes they're actually asking you ... to push. Although she didn't, I have had it where, where, I've had to say quite

categorically, they'll say, 'Well what would you do?' and I say, 'It's not what I would do, you know, I can give you the information that's the good and the bad on that side and the information that's good and bad on the other side, but I'm not the one that's got to wake up every morning to the surgery. I'm not the one that's going to have to get dressed and undressed with the surgery. You are. You're the one, and so that's why it's got to be your decision.' So I think with collaboratives you've got to be so careful that you don't tip into pushing them.

INT: RIGHT, MM. THINKING ABOUT THIS PERSON, I MEAN HOW DID YOU GET ON WITH THEM?

Nurse: To begin with I didn't ... to begin with I will be honest now and say that I didn't think that I was going to get on with them very well, and, erm ... but I think I felt that, 'cos her husband was there all the time and he'd got loads of questions and he was writing everything down that I said, and I'm not always comfortable with people writing down everything that you say. And if that ... [laughs] and if that, and sometimes we were really getting into ... the lady and myself were really getting into lots of in-depth questions that she was asking me and he'd stop and say, 'Can I just stop you there? Can you just repeat what you've said?' and I was thinking, 'Ooh ...' and he'd [???] with books and books of this, that, and it was like, 'Ooh, I'm not really comfortable.' But then I got used to them and, erm, I didn't feel so bad. In fact I used to say to him, 'Have you got your book then?' you know, 'Have you brought your book with you?' you know, and 'Have you written anything down?' you know. So in the end it was like, we did get on quite well, but to begin with it was ... 'Ooh, I don't know if I like this 'cos he's writing everything down.' But he needed to do that and I didn't realise that he needed to do that. But we had quite a joke the other day because when she got her results this last time, erm, he said, 'Karen's written a question this time.' [chuckles] So it was really, erm, you know, it was like, it did ... but to begin with I was really uncomfortable with that.

INT: YEAH, YEAH. AND HOW DID THE LADY GET ON WITH THE CONSULTANT THAT SHE SAW?

Nurse: She didn't get on with him at all.

INT: OH, RIGHT.

Nurse: No.

INT: OK.

Nurse: She found him quite brusque and abrupt. And, but what I did was I went and had a word with him.

INT: OH RIGHT, WHAT DID YOU SAY? [chuckles]

Nurse: Yeah, and told him, erm, and he's quite used ...

[Break in sound file]

... because what happens with this particular consultant is that there are some people who never want to see him again, you know, and they'll say, 'I don't want to see this,' and what we always say, and I don't know if the others have told you this, is that, you know, we're the breast care nurses, you know, we say 'Well there are five breast care nurses, you know, personality-wise you may not get on with one of them, and we don't take offence. Although I'm your named nurse, we don't offence if when you meet the others you find that you get on better on with them.' And so when a patient tells me that they can't get on with that particular surgeon, and it's usually the same one, erm, he doesn't take offence. I think he gets hurt sometimes but, erm, I wouldn't be human if he didn't, would he? But we usually say to the patient, 'That's not a worry, don't worry about it, erm, you know, people aren't always going to get on with everybody that they meet, and we don't worry about it, so if you want to change, that's fine.' You know, and so we do that. But I did go and have a word with him because, erm, particularly when she had to come back for a second lot of surgery, and it was that surgeon, because sometimes you can come back for a second lot of surgery and it can be a different surgeon, but it was the same one, so I did go and have a word with him. And actually he was quite good with her after that.

INT: YEAH?

Nurse: And she ... yeah ... and he kind of, erm, mellowed a little bit and warmed, and they warmed to him then. Yeah. Oh he's not too bad, you know.

INT: [CHUCKLES] THINKING ABOUT THE DECISION THAT SHE ARRIVED AT, ERM, WHAT INFLUENCES DO YOU THINK WERE APPARENT IN THE ACTUAL CONSULTATION?

Nurse: I think, I think with this particular person she really desperately wanted to keep her breast and she was, she's a very attractive woman who keeps herself very nice, and she wears quite close, tight-fitting clothes, and she desperately wanted to keep her image and didn't want to lose her breast at all. And, erm, I think that was the deciding factor with her and why she chose wide excision, and in fact now she can't wait to have reconstruction, she's desperate to have reconstruction but obviously she's got to have some treatment. The other thing that's, can you remember earlier on when I said if you have a wide excision it's not as bad ...

INT: YEAH.

Nurse: ... erm, and she was going along those lines, she was, but she's quite ... she knows now exactly what she's dealing with, and the unfortunate thing is that she's going to have to have chemotherapy and she's got very long, beautiful hair.

INT: OH RIGHT.

Nurse: And it's devastating her. So she's now, you know, she said, 'I'm leaping from one crisis to another,' and now we're having to talk through the pros and cons of the cool cap.

INT: OH YEAH, I'VE HEARD ABOUT THIS, YEAH.

Nurse: You see. So now we've got this going now about the cool cap and [???

INT: DOES THAT REALLY WORK, DOES IT?

Nurse: It doesn't always work. Erm, we've still had some people who've had the cool cap and they've still lost, or their hair's thinned.

INT: RIGHT OK.

Nurse: And on occasions there have been a couple just recently who've lost their hair.

INT: RIGHT.

Nurse: But there is, there are people who've got a sense of humour around the hair loss because by the time they get there they've either got to develop a huge sense of humour or totally go under, and one girl had gone, she'd had, she was on her second lot of chemo and had had the cool cap and it was a few weeks when the winds were really bad - can you remember a few weeks ago?

INT: YEAH.

Nurse: And she went to Whitby and ...

INT: IT'S ALWAYS WINDY THERE ANYWAY.

Nurse: ... yeah, well she goes to Whitby and she's walking along the seafront and it's really blowing and she hadn't got her wig with her and she said, 'And I looked down, and I thought, oh, [???' and she'd had the cool cap ... and she says, 'And then I looked in one of the shop windows and I thought, "I'm going bald!"' She said, 'I said to my husband, and I said, 'Is my hair blowing out?' and he went, "No, no, it's fine." She said, 'And so I continued walking,' and she said, 'And the wind kept blowing,' and in the end the wind took all her hair. She had to go buy a scarf, but she said it was hilarious. She said, 'I kept thinking ...

INT: OH RIGHT, HER HUSBAND KEPT SAYING 'NO IT'LL BE ALL RIGHT.'

Nurse: She said, 'I could have hit him.' She said, 'I wanted, I went and bought myself a scarf and tied it round, but the wind blew it all away.' So the cool cap didn't work for her.

INT: OH.

Nurse: But it does with some but not with other.

INT: ERM, LOOKING BACK, HOW SATISFIED DO YOU THINK YOU WERE WITH THE EXPERIENCE OF CONSULTING WITH THIS PATIENT?

Nurse: Erm, to begin with I wasn't, I was really uncomfortable with them, erm, because of the note-taking as much as anything, but as I began to know them and realise that this was their way of having to deal with it, I enjoyed it, yeah, I enjoyed it.

INT: MM, AND HOW SATISFIED DO YOU THINK SHE WAS WITH THE EXPERIENCE?

Nurse: Erm, I think that, that if you asked her now, erm ... yes, I think she was because I actually, she actually met one of the other breast nurses and I thought that she would stick with her, and now, but she, no, no, she's asks for me, so she must be fairly happy with the relationship that we've got and, actually when I was on holiday and didn't get in to see one of the consultations, and she rang me afterwards to let me know what had happened, and she said, 'I really missed you, I wish you'd been there.' And, er, yeah, so I think she, she [???

INT: OH, OK. ERM, THINKING ABOUT COLLABORATIVES IN GENERAL, HOW SOON DO YOU THINK YOU KNOW YOU'RE TALKING TO A COLLABORATIVE DECISION-MAKER?

Nurse: I think you usually know within ... I think with her it was difficult because I didn't really, I wouldn't have said that she was collaborative in the first interview, I would have said by the time I saw her the second time I realised that's what she was wanting from me. Erm, because I think I felt a little bit ... threatened by the note-taking.

INT: RIGHT, OK.

Nurse: Mm. But that might be my experience come from the past when I've had a note-taker who I didn't really get on very well with. So probably that was a little bit of that with me.

INT: OK.

Nurse: Mm. So probably by the second one.

INT: RIGHT, OK. AND WHEN YOU'VE GOT THAT AWARENESS DO YOU THINK IT CHANGES HOW YOU?

Nurse: Yes, I think it does. It did change [???

INT: WHY DO YOU THINK IT DOES?

Nurse: I think I wasn't, I didn't [???] so I relaxed.

INT: RIGHT, OK. I'M BEING AWARE OF THE TIME, IT'S BEEN LIKE AN HOUR AND A HALF NOW, SO WE'LL PRESS ON QUICKLY NOW TO THE THIRD TYPE OF DECISION-MAKER, WHICH IS THE PASSIVE DECISION-MAKER, PATIENTS WHO TEND TO WANT TO LEAVE THE FINAL TREATMENT DECISIONS TO THE SPECIALISTS, EITHER WITH OR WITHOUT THE SPECIALIST SERIOUSLY CONSIDERING THEIR OPINION.

*Q20. JUST AS WE'VE DONE BEFORE, I'D LIKE YOU TO DISCUSS AN INCIDENT YOU'VE HAD WITH A, CONSULTING WITH A PASSIVE DECISION-MAKER, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS.

Nurse: I find these the most difficult to deal with really.

INT: DO YOU HAVE ONE IN PARTICULAR IN MIND?

Nurse: ... Yeah. I find them very, very difficult. I think out of the three groups that we're discussing, erm ... I think mainly because in my experience I've had a couple where it was ... it's just so difficult with them. Let me focus on one ... OK. Erm ... I find them difficult, more difficult than the other two, erm, because these are the ones that I would say, you know when I said they'd go to the end of the cliff and jump off, do three somersaults and they'll just accept everything that you say without challenging it and, erm ... this says something bad about me really. But I find them the most difficult because I really want them to be sure that this is the way they really want to go. Erm, I don't worry so much about those who go for wide excisions, but I worry about the ones that are going for mastectomy for the, sometimes I feel it's the wrong reason, but I can't say that ...

INT: RIGHT, OK.

Nurse: ... you see, because I'm very strict with myself about giving opinions about what kind of surgery they should have and what kind of treatment they may have or may not. And, erm, I think that, I sometimes feel quite impatient with them, because I think 'Make your own mind up,' whereas if I've got quite a domineering husband with them who is saying what his wife should have ...

INT: SHOULD HAVE, YEAH.

Nurse: ... then I really find it, I have to bite my tongue because that's obviously their relationship and I can't interfere in that relationship, erm, but I sometimes think, er, particularly if I get a man who says, 'You're not having your breast off,' that goes against everything I feel inside because I don't think that man should make that decision for her.

INT: IT'S HER BODY.

Nurse: And that really upsets me.

INT: OK. What sort of clues do you get from that this person's going to be passive?

[Break in sound file]

Nurse: ... Erm ... it's really, they just say, 'Well I'll just do whatever you say,' or ... to the consultant, because I'm very careful that I don't do that, but they'll just say, 'Well, whatever you say, doctor, I'll do.' Or 'Whatever you say, darling, I'll do,' and I think, 'For God's sake, haven't you got a mind of your own?' [chuckles] you know, erm, with that, but with the consultant, and I think our consultants deal with it reasonably well.

INT: YEAH.

Nurse: Reasonably well, yeah, and don't get pushed into a corner, because sometimes they try and push you into that corner to make that decision for them and then they can blame you when things go wrong, cant they...

INT: SURE. AND, ERM, WELL, I WAS GOING TO SAY DOES THAT AWARENESS CHANGE, YOUR APPROACH TO THE PERSON?

Nurse: I try ever so hard not to let it, but I think it does, because, erm ... it's quite difficult because you want them to make their own mind up and you want to make that decision, and it's frustrating sometimes because they won't. And then I, I've just now say very categorically when they say, when they've said it to the surgeon you usually know that that's what's gonna happen, they're gonna ask you the same question when you're there, and I usually say, 'I can't make that decision for you.' Erm, you know, 'I'm sorry that I can't make that decision for you but this is your choice and you're the one that has to make it.' I mean I probably would say something like, 'If you can't make that final choice, then I will say to you then that the consultant won't do a mastectomy, because a mastectomy is extremely final, so if you can't make that decision, he won't take your breast off.' And he's only ever let me know once, [chuckles] where I had a passive lady who said, 'I can't make that decision,' and I had actually said to her, 'Well the surgeon won't take your breast off,' and when we were on the ward, on the ward round, before she went down to theatre, she said, 'Well what do you think I should do doctor?' and he said, 'I think you should have a mastectomy,' [chuckles] and I thought ... you know. He's only ever done that to me once though, in 15 years, so that's [???

INT: ERM, THINK ABOUT ALL THE DECISION-MAKERS, ALL OF THE PATIENTS THAT HAVE A CHANCE OF SURGERY, IN GENERAL HOW SOON DO YOU THINK IT TAKES THEM TO MAKE UP THEIR MIND TO SAY [???

Nurse: It varies so much, it varies so much. Erm, even if someone who has made their mind up before they've walked across from there to here, erm, and then you'll get some who'll say, 'I just need to sleep on it, when do you need to know my answer?' and then you'll get some people who, like that lady this week who's going, she's swinging from one decision to another, so it varies very much. You can't really say one way or the other which way it goes, not really.

INT: OK. LAST COUPLE OF QUESTIONS. THE LITERATURE TELLS US THERE'S A VARIETY OF INFLUENCES ON PATIENT DECISION ABOUT MAKING WHICH [???] SURGICAL TREATMENT ...

*Q21. THINKING FIRST OF ALL IN A WIDER SENSE, BEYOND THE UNIT, WHO OR WHAT DO YOU THINK HAS THE GREATEST INFLUENCE ON PATIENTS' DECISIONS ABOUT WHICH SURGICAL TREATMENT TO HAVE?

Nurse: I think the internet's come into it's own recently, over these last years. Prior to that, erm, people used to gather information from people that they knew, work colleagues' wives and the local community, and then the Breast Cancer Care areas, getting their information from there. Erm, I also think a big influence on patients' decision is their experience of breast cancer and what's gone on in their particular family. If you get, for example we had twins who got breast cancer, and then the Mom came along and had breast cancer, and what happened to her daughters actually influenced ...

INT: RIGHT.

Nurse: ... her decision on what she was doing. So I think if you've got family history and I call them ghosts, that influences, and then we've had, again we've had recently a couple of men whose first wives died with breast cancer and then they've married again and now the second wives have got breast cancer, and that's been very difficult because these blokes have still

got unfinished business, and their influence, they're strongly trying to influence their second wives into ...

INT: BASED ON WHAT HAPPENED TO THE FIRST WIFE.

Nurse ... based on what happened to them in the past. And so, erm, I think a lot of decisions are to do with your life experience of breast cancer.

*Q22. AND THINKING WITHIN THE CONTEXT OF THE BREAST TEAM HERE, WHO OR WHAT DO YOU THINK HAS THE GREATEST INFLUENCE ON PATIENTS' DECISIONS ABOUT WHICH SURGICAL TREATMENT TO HAVE?

Nurse: I think the whole team, erm, influences to a degree. I think the way that we work where you sit down and talk, the consultant sits down and talks to them and discusses their options, and we sit down and talk to them and discuss their options - I think out of, I think the whole team influences but I think the surgeons have the most influence.

INT: RIGHT, OK.

Nurse: And that, I think, is tradition, because I think that in the older age group, if the doctor says, then you do it. In the younger age group they listen to what everyone's got to say, but I still think that most people see the surgeon's as the person who knows ...

INT: RIGHT.

Nurse: ... and because they've, they don't always get the concept of the team and they don't see the multidisciplinary team.

INT: RIGHT, OK.

Nurse: So I think it's the surgeons.

INT: THERE'S A QUESTION WHICH IS NOT ON YOUR SHEET BUT I WANT TO THROW IT IN AT THE END ANYWAY. IF YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE SYSTEM HERE, WHAT DO YOU THINK IT WOULD BE?

Nurse: ... Mm ...

INT: I ALWAYS KEEP THE HARD ONES TILL LAST.

Nurse: I'd like to have no waiting list really because I'd like all those people who'd like their surgery done yesterday to have it done today, and I'd like all those people that want the time to think about things to have that time and not have to be within the constrictions of the NHS waiting list. So I would like to have no waiting [???

INT: RIGHT, OK.

Nurse: Is that all right?

INT: YEAH, THAT'S FINE. IT'S YOUR [???

Nurse: My money.

INT: YOUR MONEY, YOUR POWER, YOU WANT TO CHANGE IT.

*Q23. FINALLY, IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD TO WHAT WE HAVE BEEN TALKING ABOUT TODAY? DO YOU THINK THERE'S ANYTHING WE'VE MISSED?

Nurse: I don't know. I've enjoyed it, erm, it's been ... yeah, I didn't think it was going to be like that. Yeah, I've enjoyed it.

*Q24. THE REST OF THE TAPE HERE...

INT: RIGHT, OK. WELL YOU DID MENTION A COUPLE OF THINGS LIKE, ERM, YOU MENTIONED RECONSTRUCTION A FEW TIMES, I MEAN HAS THAT CHANGED RECENTLY? IS IT MORE AVAILABLE NOW OR ...?

Nurse: Erm, yes.

INT: ... THAN IT USED TO BE.

Nurse: Yes, yes. Thank goodness, it is. Erm ... because ...

INT: AND THAT'S BROUGHT THAT ABOUT THEN?

Nurse: Erm, I think that it's because we're such a proactive team and, erm, when I first started in breast care people had to go to Nottingham for reconstruction, there was a huge waiting list, you had to be waiting two and three or four years, and it was dreadful for them. And now that we've got this service which, I will tell you what happened, it was really funny ... 'We're going to start a reconstruction service, [???' 'Oh, that's good,' this was Tuesday. 'When are we starting it?' 'Friday. And we're just going to have four patients a week.' No way! It's always, we always laugh in this unit, you know, when people come and say, 'We're going to do a one-off,' or 'This is only going to be such-and-such,' and we laugh because we know that that is never gonna happen and that this one-off becomes every week and four patients becomes eight patients and ... and the reconstruction service has been, erm, a wonderful introduction into this unit because it means that ...

INT: IT IS DONE ON THIS SITE, IS IT?

Nurse: We do two lots of reconstruction here: erm, on Friday, it's always done on a Friday. We do the tissue expanders and the LD flaps, but if ladies want a tran-flap [?] they have to go to Nottingham, but again the waiting list isn't as it used to be, it used to be two, three, four years, and now it's six months for a tran-flap, which is brilliant. Erm, there's no waiting list for tissue expanders, so if you want to go down that process, if that's the right way for you, then there's no waiting list for that, and the LD flaps it's about a couple of months. So it's brilliant. But we have to do an awful lot, er, we give an awful lot of input into

reconstruction I think and it's quite difficult because people have got, erm, the body image perception is like Jordan, you know, or anyone that's going for these enhancements, and the actual reality of reconstruction is not always, erm, what the patient expects, so we have to be very careful that they do understand what reconstruction is about. It's not going to be a breast, it's going to be a breast mound that looks reasonably good in a bra, and that's the aim. The aim isn't to give that patient a breast back. And we're quite brutal really when we talk about it, and you get really good results and you get really bad results, and, erm, that can be more devastating to a woman than a mastectomy sometimes.

INT: RIGHT, MM.

Nurse: So you have to be quite brutal about the expectations.

INT: OK. THAT'S FINE, THAT'S BRILLIANT. THANK YOU VERY MUCH. I'LL SWITCH OFF NOW.