

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Nurse)

*VENUE: High MR unit

*DATE: 21/10/2003

*ID: BCN048

*INTERVIEWER: DJW

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

RESP: 7 years, I was on secondment from the district nursing.

INT :I suppose your opinions are going to be quite interesting because it will be great to get fresh eyes on the service.

Q2. WHAT IS IT LIKE TO WORK AS A SPECIALIST NURSE IN THIS BREAST SERVICE?

RESP: I suppose for me it enables me to focus on a speciality which I have had an interest in for sort of several years, so that's a huge benefit for me, so far it's been very rewarding and you are made to feel very much a member of the team from the word go, so I've been introduced to everybody and I feel I've been accepted and they do work very closely as a team with their decision making sort of process really.

INT: How do you find it compared to other places you've worked in?

RESP: The support is there, so you've got a lot of support from your team members and actually time is set aside for debriefing sessions and supervision, you get regular appraisals, so far it does seem a well organised team and they are sort of recognising the needs of the team members.

INT: Am I right in thinking when it comes to things that structure the service you do home visits on request only, is that right?

RESP: No not particularly on request only, everyone is obviously individual and has got very different needs and circumstances etc, so it would depend on the lady really, or on the patients as to whether a home is appropriate

INT: How well do you get on with your colleagues?

RESP: So far so good

INT: So you've got colleagues you work very close with, you've got the consultants, so how do you get on with them.

RESP: Fine, yes, there hasn't sort of been any problems, they are all reasonably approachable in their own way.

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

RESP: Yes I definitely feel that obviously we all have our own styles, I think a lot of it is probably based on individual personalities, ages, their maturity, life experiences, all those sort of factors I feel influence, and also it's perhaps their own coping mechanisms, you know dealing with such a specialist area and perhaps yes it is just people own coping mechanisms I feel sometimes to their approach. Does that make sense?

INT: Yes, is there any sort of style that particularly stand out, do you think?

RESP: Yes, the styles I'm thinking of is down to experience and their knowledge and their understanding, as I say based on sort of experience having been in the profession for some time within the speciality, and I think sort of thinking of another colleague perhaps personality has a huge impact in which they work, but again it may be their coping mechanism, you know how they sort of deal with the breast cancer side of things on a day-to-day basis, so I think some people keep themselves distanced.

INT: OK, do you think these sort of different working styles have any sort of impact on how consultations go with decision making or patient's satisfaction with the process?

RESP: I think what comes into mind is obviously breaking bad news, I think that can have a huge impact as to how it is approached, how it's done, whether it's done gently with understanding, with a bit of empathy or whether it's done bluntly, I think it has huge impact.

I'm going to move on a bit now to before consultation when the actual diagnosis is to be given, I'd like to talk about what happens just before it begins when patients hear about their diagnosis and from this point of the interview I would like you to focus on just newly diagnosed breast cancer patients if we may.

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

RESP: OK, the MDT Meetings are held on a Monday afternoon and the diagnosis is given on a Tuesday morning.

INT: Are patients discussed preoperative at this MDT?

RESP: Yes they are

*Q5. HOW DO YOU USUALLY FEEL AFTER AN MDT MEETING?

RESP: That depends obviously on the number of ladies who have been positively diagnosed, sometimes you can feel a little bit overwhelmed by the amount of ladies, although it shouldn't be but age can be a factor, and I suppose for some of us if we are a similar age group that perhaps have more of an impact and I suppose a little bit saddened by the high numbers but on the other hand sometimes relieved.

INT: Do the numbers vary dramatically or are they fairly even.

RESP: I would have said they are fairly even although the last couple of weeks there has been sort of probably larger numbers either way, but then again obviously you've got lots of factors, holidays, but I must say in the short time I've been here it has been fairly constant.

INT: What sort of numbers are we talking about, 10, 15, 20

RESP: Weekly? I would say 8-10, that is very average

INT: Just back to your feelings there for a second and you say it depends on how your work goes, ???????? lot of breast cancers come through, how do you think that sort of thing has a bearing on you and the people you are going to see later in the consultation.

RESP: For me personally I don't feel it actually impacts the way I approach an individual and they are very much individuals, it is part of role so I'm just fulfilling my role really, does that sound reasonable? Yes I suppose obviously depending on resources and staff members as well, you know who's going to be around, I mean that has an impact.

INT: Are there five of you here?

RESP: No four of us, but if sometimes on annual leave or you know at a meeting or something like that or study then obviously that has an impact because you are immediately thinking well I will be seeing so many patients, and it depends on who the consultant is as to how quickly we actually see them and again depending on who the consultant is you've got an idea of how they are going to coming round really.

INT: So it might take longer with some patients than others

RESP: Yes, different manners

*Q6. IF, AT A PRIOR CONSULTATION, IT WAS SUSPECTED THAT A PATIENT HAD A BREAST CANCER, IS THERE ANYTHING YOU, OR ANYONE ELSE IN THE TEAM WOULD DO, OR SAY TO THEM, AT THAT STAGE?

RESP: No, I mean if the consultant is obviously there when they've seen and they are doing the triple assessment and what have you, if they really felt that they could make a diagnosis without you know just through clinical or whatever, they may perhaps sow the seeds as it were and also the patient would have the opportunity to speak to one of us if they wanted to so that is probably the only time we may see them, but we wouldn't be there to diagnose or anything more, just really to be there to support whatever the consultant said to them.

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

RESP: I think for the symptomatic ladies, the ladies that have actually noticed the problem themselves, I think their journey actually starts you know from that point when they actually notice it at home and there may be quite a delay before they actually see their GP because they feel it will disappear or you know hope it's not really a problem and that sort of thing, so I think for the symptomatic ladies that problem starts for them at home and they themselves are probably sowing the seeds so they're journey start much earlier and I think obviously they are in a psychological way actually preparing themselves already so before they get to their GP and before they see the breast consultant, and again if they have been seen in clinic by the consultant, as I just said they may perhaps

start to sow the seeds and they may suggest that it is perhaps a breast cancer, so I think you know that is how the ladies sort of prepare so that they are doing it themselves or whether it's been done through the consultant.

*Q8. PRIOR TO A CONSULTATION WHERE YOU KNOW THAT A PATIENT WILL BE GIVEN A DIAGNOSIS OF BREAST CANCER, WHAT EXPECTATIONS MIGHT YOU HAVE ABOUT WHAT THE CONSULTATION WILL BE LIKE AND WHAT ARE THEY BASED ON?

I feel I have an idea of the way the consultants work and their sort of different ways of breaking bad news and their approach to the individual, it is very much based on their bedside manner that I've actually seen for myself, but I've had the opportunity to sit in on the consultations due to sort of recent induction programme, but I also personally feel that it is useful to sit in on the consultation, but I have not actually asked the consultant's point of view how they feel about that because obviously if the breast care nurses in the room then the patient before actually being told their diagnosis may start to have a feeling that you know the breast care nurse is there, so it's not going to be good or another school of thought is there probably totally oblivious that you're there anyway, so yes that's I suppose I would base the consultation on really, and that's just little knowledge of how the consultants actually work.

*Q9. HOW WOULD YOU DESCRIBE YOUR FEELINGS BEFORE SUCH A CONSULTATION?

RESP: I suppose obviously there is always an element of sadness, but I'd like to think I'm composed and controlled as a professional, again it's part of my role so for me I'm fulfilling my role and as a breast care nurse if I can make a difference no matter how small to the individual insupporting them then I suppose that is the rewarding part of my role really.

*Q10. PLEASE TALK ME THROUGH WHAT HAPPENS IN A CONSULTATION WHERE DIAGNOSIS AND TREATMENT OPTIONS ARE BEING DISCUSSED WITH A PATIENT WITH BREAST CANCER.

RESP: This is from the breast care nurses point of view is it?

INT: That's right yes

RESP: OK

INT: No actually the whole consultation process from the moment the patient goes in

RESP: I suppose from the consultants point of view they are obviously giving the patient their diagnosis, they are discussing treatment options, if options are a possibility. They will discuss the actual surgical procedure with the patient and they may mention follow-up treatment such as. I think actually you know from the consultant's point of view, the patient whether perhaps thought they may have breast cancer, it really all depends on circumstances, if they've got no idea whatsoever obviously it is a huge shock, even if they did have some idea, it's still a huge shock, it's having a huge impact you know on a lot of things for that lady, so I think if I hadn't actually sat in on the consultation obviously they would be brought over to us, so in that sort of scenario we would you know obviously introduce ourselves to the lady and just try and find out what has been said to them by the consultant, so it's really just checking their understanding to see what they've actually absorbed and what they understand about breast cancer and the options, the surgery, treatment etc, assessing their problems and reactions and then we will sort of give a further explanation of their choices and their options and perhaps discuss the surgery with them, it's just really reinforcing what the consultant's said and what they have demonstrated. Obviously giving written and verbal information that's very dependent on the patient as to, we do give a standard information pack but it is limited because we do not want to bombard ladies with information at that time, but into eh same token they are aware that information is available should they desire it at a later stage, and again it would also be discussed at pre-clerking. So I think assessing the patients, their problems, their reactions to the diagnosis and their perception of breast cancer and the impact it's going to have on them as an individual, their life, their children, family, work, their relationships etc.

INT: So it's always the consultant obviously that tells them the bad news

RESP: Initially, yes

INT: So who else is typically in the room at the time when they are told?

RESP: There would probably be an x-ray helper or an assistant then the consultant, the patient and if they have come with a relative or a friend, they are invited in if the patient would like them to be in there.

INT: Is the breast care nurse in there as well?

RESP: Not routinely at the moment, as I say for me I have found it to be beneficial but I don't know is that's because I see it differently, I mean I have spoken about it recently to colleagues and I think they are actually sort of thinking is it a good idea or not. It really depends how you look upon it.

INT: Is that different from anywhere else you've worked.

RESP: Well I haven't been in the breast care role before, so I don't really know and I don't know whether breast care nurses do tend to be in on the consultation. I think some areas do, I think it's varied and I think it is something we probably will think about here.

INT: So when a patient comes to you from a consultant, how do you then know what the consultant's said?

do you speak to the consultant directly

Int: Yes

, the nurse helper will bring the patient over, we quickly introduce ourselves and again I think it's nice for the patient and perhaps their partner to have some time on their own, so normally in one of these you know sort of the counselling rooms, obviously you know suggest if they would like a drink to help themselves but also just give the a bit of space just to be on their own for a few quiet moments for whatever reasons and then we would go over and have a word with the consultant and find out what the consultant has actually said if you haven't been present during the consultation. So it's only a matter of a few minutes but that we would sort of come over.

Int: So it gives them a chance to be by themselves.

RESP: Yes it gives them a bit of space and obviously gives us the opportunity to hear it from the consultant

INT: Do you have a preferred style of approach towards occasions when you've come in and spoke to the consultant, do you have a way of approaching patients and then seeing how it goes, or do you just go in and say well I'm just going to see what happens or....

RESP: Obviously I always go in and introduce myself and just let them know that I'm going to have a word with the doctor, when I go in again I'll probably introduce myself again and explain members of the team again, and it just depends on the individual as to how the process goes. It really does depend on the impact it had on the patient, I mean obviously if they are very shocked and emotional demonstrating you know sort of tears, then that has a different approach to someone who might seem very matter of factly and appears to be taking it very much in their stride, it rally, really does depend as to how it will go and I think you just go with it, so you go with the individual patient really.

INT: So who tends to do more of the talking, who asks most of the questions?

RESP: I think again that's very varied, patients who..., I don't know David I can't really answer that one, I mean sometimes you don't really get any interaction from the patient, it might be they just want out, you know they don't even want to be sitting there, they just want to go home and I think you know you just have to accept that, you would perhaps give them the information pack and contact them the following day.

INT: You say the information pack, is there only the two that you use to describe what you are trying to get across, you know the treatment options.

INTO: There is nothing standard, I personally will sort of mimic very much what the consultant's actually done, if it's regarding wide local excision and talking about clear margins I will actually draw picture to sort of re-emphasise what the consultant has already done and said, I mean there are many many sort of literature books that we would use for diagrams if patients wanted to actually see you know, see what the procedure might look like, and there is also an patient diary treatment record that has very basic drawings regarding sort of the anatomy of the breast and you know breast surgery techniques, so there are various tools that can be used and will be used if felt appropriate.

INT: How are your feelings about when you've been discussing all these things on the consultation?

RESP: How are my feelings?

INT: Yes, cos that's quite a quality time you've got with these patients and they're sort in a very different scenario from the consultant's going to be in you know whether sort of.....

RESP: Yes we do have the quality of time, yes

INT: I suppose you get to know the patients quite well

RESP: Yes, and I suppose sometimes you will sort of come out and think well that's gone really well or you know well that really hasn't gone really well, or I didn't explain myself very well or I didn't feel that they were hearing me, I didn't feel they were understanding or I did not sort of mention this that or the other, so I think it's important to come out and perhaps reflect as to how well it has gone or how poorly it's gone because by doing so you are giving yourself the opportunity to think right Ok I'll contact that patient by phone or I'll invite them back in or if they have been extremely distressed and shocked you know if they are allowed time to absorb what they have been told they may be more willing to be a little bit more open sort of a couple of days down the line. It's very individual but I do think it's important to look at how the process has gone for yourself and the patient.

INT: Yes, feedback...

RESP: Yes, so you know you can then make the decision to either telephone contact or invite them in or go and do a home visit whatever, because I think it's really important to ensure that the patient really has got the information that they need and they do understand the information that's given to them, that the information is appropriate, so I think a lot of issues to consider following each consultation really.

Int: Just going back a little bit, you mentioned earlier about different work styles and things and the different ways colleagues approach things, when you come into a consultation and if the patient has come from a particular consultant, right and there's obviously different consultants here does the knowledge of that working style influence how you will report to that patient?

RESP: Well to be very honest, yes.

INT: Can you give me examples without giving confidential information away?

RESP: Some of the different approaches that I have been aware of is perhaps bluntness, brusqueness and they way it's actually delivered, very matter of factly, and partners have actually felt excluded, that has actually been voiced. So obviously they will perhaps come over, it's very difficult to put into words, but it may be a very different scenario who has been approached with empathy, understanding, time, gentleness so yes different style have a huge impact definitely.

*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?

RESP: WE see them following diagnosis, we then see them at pre-clerking which is basically pre-admission so they are invited prior to their surgery to ensure that they are fit for surgery basically, so they are assessed by a nurse and they actually see the physiotherapist, then they have the opportunity to see us again as well.

Int: What might you discuss with them at that point

RESP: I would normally say to the patient obviously if you've got any queries concerns, questions, niggles and anxieties please contact us, don't let them fester. They may seem a very small and petty sort of thing but obviously at the time they are not, it is a huge issue and it is better to discuss them at the time so I will sort of say to them and ask questions are forming in your mind do try and write them down, either phone us at the time with your questions or bring those questions to the pre-clerking appointment and I think it is also very useful if they have somebody come with them and perhaps the partner, friend or relative can write down the responses so again they can take those questions and answers home with them and discuss them at a time that's calmer and quieter for them, it depends on the individual, so I always do suggest that to them again depends on the individual and always emphasise that we are here and we would like to sort of try and support them during their journey again depending on the individual you may decide to contact them by telephone depending on how they reacted or sort of feelings that you get, you may do a home visit, you may invite them in again, so it really just depends on the individual.

INT: When a patient has been diagnosed, how long do you think it takes them to decide about what treatment they are going to have?

RESP: Again I think there is a lot of influences there, if they've had previous family members who have had breast cancer and that they've had experiences from family members or friends, media, there's a lot of influence out there, it just depends what their knowledge and level of understanding is really. So I think you know all of those influences and impact as to when they make their decision

They may be very clear right at the beginning that if they have given a choice... I think it just depends on the patient's level of understanding and perhaps yes their experience of breast cancer as to when they make that decision, it may be immediately, some may say that the younger lady may want to try and preserve breast so their treatment choice may be very different to an older lady. Some will think that by having a mastectomy it's going to remove all the cancer rather than having a wide local and they've got fears and doubts that you know that bits and bobs might be left behind. Suppose generally lady's will have made a decision by the time they come back for pre-clerking and that can vary it can be perhaps a week or 10 days and there is always going to ladies that actually want your opinion but it's got to be the patient's choice and that's always stressed. You know it's always down to the individual as to how they perceive breast cancer, how they perceive treatment, surgery whether their age comes in to it, whether they are in a new relationship, whether they are not in a relationship and whether that comes into it, how many family members they, their age, whether they are thinking of work if they are the only sole financial person then I think that would have an impact, because if they think about how much time they are having off work, whether they are self employed, a single mum, definitely yes, is a wide local going to be quicker and easier for me to get over with than a mastectomy or they might be thinking about adjuvant treatments and does that mean a longer period off work, so there's a huge amount of different factors that would influence the patient's decision, most definitely.

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

RESP: OK, so yes definitely some ladies are better informed than others, dare I say it dependent on their social class, cultural awareness, ethnic minorities etc. and it's their levels of understanding.

INT: So generally would you say that the majority if patients know a fair amount, or the majority know very little..

RESP: The well informed ladies and less well informed ladies whether it's due to their level of understanding, whether it's due to the availability of information and if the information is available again their understanding of it, though how it's written and are they in areas where the information is available, do they access to it, do they have access to the internet, do they not.

INT: Do you think these factors that we've talked about and the levels of information, what they know and their experience does this makes for an easier or harder consultation process?

RESP: I think personally may be this is due to my lack of experience being in this role, I would say for me the less well informed lady would probably be a more rewarding consultation.

INT: In what way rewarding?

RESP: I think because it would give an opportunity for me to say what I wanted to say and get across what I wanted to get across.

INT: Can you give me an example of a patient you have dealt with at some point, obviously without giving any confidential details?

RESP: Not particularly, there was a lady who was going to have immediate reconstruction, the husband had been on the internet and felt that he knew everything there was to know about his wife's type of cancer, not so much about the actual reconstruction but, you know h thought he was well informed about the type of cancer that she'd got and he knew more than anyone, which was fine. I didn't particularly know very much about this type of cancer so I suppose I was feeling a little bit disadvantaged but I didn't feel threatened, but just disadvantaged really, and I suppose I sort of not turned it around but to gain some form of control, I asked what websites he had been accessing and I tried to or suggested to him that he use alternative websites that were more reputable, but I suppose that is a poor example and I can't think of another one at the moment.

INT: How was his wife in all this then?

RESP: Just quiet in the background.

*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?

RESP: I think something that has frequently probably come up is am I going to die, I think anybody that is faced with the word or diagnosis of cancer think initially again that's down to their own personal experiences of breast cancer, but I think death is always an issue, can it be treated or am I going to die whatever, can it be cured, and I think the time of diagnosis to them actually having their surgery, I think that has a huge influence on the individual because they are wondering is it going to spread or grow within those few days, so I think those sort of issue that I have been aware of, you know patients want to know about the procedure, they may want to know a little bit about you know further treatments depending on their own circumstances they may need to know how long they are going to be off work, they may need to know how long will it take to recover, so I think as individuals they all have different needs.

Int: Do you think when you are discussing diagnosis in particular, what do you think patients understand well about what's been told to them?

RESP: I think the actual surgical procedure, because I think that's sort of fairly easy to explain, so I think that part really is fairly well understood.

INT: Do think there is anything that understood poorly about diagnosis that you find very hard to get across?

RESP: I can't think of anything in particular. I can't think with regard to diagnosis, no.

*Q14. WHAT DO YOU THINK ARE THE MOST IMPORTANT PIECES OF INFORMATION PATIENTS NEED OR WANT TO KNOW ABOUT TREATMENT AND WHEN ARE THEY RAISED?

RESP: That's probably at diagnosis, again it's probably reiterated at their pre-assessment pre-clerking, we do give them a sort of a patient diary which is a very informative little booklet and I personally tend to suggest that if they..

INT: A diary?

RESP: Yes it's not actually a diary of their events,

INT: Is it their records?

RESP: No do you want me to show you one?

Int: Yes:

RESP: Yes so it's a lovely little booklet that is very easy to read, it will take the patient through what it's like being an inpatient, the actual surgery and procedure, what they can expect following the operation, what happen when they are discharged, that sort of thing, and contact numbers as well, so yes as I say I personally would suggest to a patient if they don't feel up to reading anything else, then perhaps they could just have a little glance at this booklet also because it may raise some questions for them or it may actually help to answer some of the questions that are already forming.

INT: Is there anything that patients understand particularly well when it comes to discussing treatment options, is the anything they really understand.

RESP; Again it just depends on the individual, yes, I mean obviously no two ladies are the same.

Int: Is there any information which is generally understood poorly?

Res: I think it depends on how much they want to know at that time and to how much they're actually absorbing, you know, obviously you know, what they're actually going to be understanding at that time. If they are asking about treatments following surgery then I think that's an area that's probably poorly understood at the time of diagnosis because although they need to know it's not too relevant really because the surgery

Int: ... histology afterwards aren't they?

Res: Yes, that's right

Int: .. and that might change things anyway.

Res: Yes, quite so I mean that is explained to them that we actually don't know any more at this point and we won't know until obviously following surgery.

Int: One thing we did do when we designed this interview schedule we piloted it on a breast care nurse who'd just left the service. One of the things that she raised up which we thought might be interesting was she said that a lot of

patients that she came across couldn't quite understand why they had a choice, where they did have choice..

Res: No, yes, I think patients generally find choice extremely difficult. People don't deal with choices especially not, at the impact, you know they're coping with the impact of the sort of the diagnosis, they can't possibly cope with the choice although we expect them to.

Int: *What do you think are the main queries around choice. What do you think they find difficult to understand about*

Res: Perhaps it's their level of understanding, perhaps it's you know, level of breast cancer, or lack of knowledge of breast cancer. They just want what's best for them and as I say, some ladies just have great difficulty in actually making that choice so, you know, other ladies might not have a problem for example a younger lady, she might not hesitate or she may say do breast conserving or it may be that she's had a poor experience with perhaps her mother at a young age or, there's a lot of things which are going to influence that lady's decision. She might, you know, even the younger lady whose perhaps seen her mother die will say 'No I'll have a mastectomy' you know, because I wouldn't want to go through..

Int: *.. what her mother went through.*

Res: Whatever, whatever.

Int: *.. based on a very traumatic experience*

Res: Yes, I think it's based on life's experiences and knowledge.

Int: *I'd like to move on a bit now to another section which is what the patient is offered. It's a lovely question this isn't it?*

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

***a. ONLY BREAST CONSERVATION SURGERY**

Int: *Is there any instances where your team would recommend only breast conservation surgery?*

Res: No

Int: *No*

Res: No

***b. ONLY A MASTECTOMY**

Int: *What would lead a team to offer a patient only mastectomy*

Res: Ahem, it would depend on the size of the tumour, whether it's invasive or not, the grading, no, because that would just be from biopsy wouldn't it? It would be on the results from the biopsies as to whether a mastectomy only was suggested.

***c. A CHOICE BETWEEN MASTECTOMY & BREAST CONSERVATION SURGERY**

Int: *What would lead the team to offer the patient a choice between mastectomy and breast conservation surgery.*

Res: If a patient had got a local or a localised carcinoma depending on breast size and depending obviously on the results of the biopsy they may be offered either a wide local excision or a mastectomy.

***d. OTHER TREATMENTS**

Int: And what about any other treatments such as radiotherapy, chemotherapy, what sort of factors would lead the team to offer a patient radiotherapy, chemotherapy.

Res: Patients are sort of told that a wide local excision is on the whole followed up by radiotherapy routinely and that the overall benefits of a wide local excision with radiotherapy is sort of as equal to a mastectomy. Sorry can you repeat the question again please.

Int: Yes, can you describe the factors that would lead the team, well your team, to offer a patient any other treatment such as radiotherapy or chemotherapy. What sort of factors would you..

Res: Yeah, so if a lady was having, if a lady was given a choice of a mastectomy or a wide local excision she would probably be under the impression that she was to have a wide local excision that would be followed up with radiotherapy. The patients are always told that surgery is the main choice of treatment for breast cancer and radiotherapy are sort of follow-up, mopping up exercises really. They would also be told that it would be dependent on their results from surgery as to whether or not they may or may not require radiotherapy, chemotherapy or endocrine therapy and they were also told that they may require one or two or all three so they're given an idea.

Int: The next part, I'll read this out. The literature suggests that patients vary in the degree of involvement they want in making decisions about what surgery to have. Some patients want full control, some patients prefer to share that control and others prefer the professionals to take full control in the decision making process. First of all -

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

Res: Yes. The patients are encouraged to make their own choice. So yes, no the patients make their own choice.

***Q17. THINKING ABOUT YOUR EXPERIENCES WITH THE PATIENTS YOU SEE PLEASE LOOK AT THE RESPONSES ON THE CARD AND TELL ME, DURING CONSULTATIONS, WHO GENERALLY MAKES THE FINAL DECISION ABOUT WHAT SURGICAL TREATMENT TO HAVE?**

Res: Is this the breast care nurse or is this the consultant?

Int: This is the breast care nurse because you've both obviously spoke to the patient at this point.

Res: Well the first one, the patient tends to make the final decision regarding the treatment they will have. Most definitely. I have actually put my own description 'I think I will try and support the patient during the decision making process by ensuring patient can make an informed decision by fully understanding the procedures etc.'

Int: Do you wish to keep that or can I have that back so that I can have a look at it or do you want to keep it?

Res: Oh no you can have it if you want to. I can photocopy it.

Int: Absolutely, yeah that's fine. Just, you know, it could be very valuable that's just in case for some reason this hasn't recorded. Well it should have, it seems to be working. I'd like to move on now to the next section which is communicating with patients who have breast cancer. At this point I would like us to talk about your experiences communicating with patients, in particular I would like us to focus on patients in whom for clinical reasons mastectomy is not the only option. So patients have got a choice. Researchers have identified that patients with breast cancer tend to fall into one of three different decision-making styles. There's the active decision makers, collaborative decision makers and passive decision makers. In this final section of the interview I'd like to ask a few questions about how you find communicating with

each of these types of patient during the consultation process that leads to a final treatment decision. I would like to start with a situation with active decision makers. For the purpose of the study we define active decision makers as patients who tend to make their own final treatment decisions either with or without seriously considering their specialist's opinion. So essentially it's just the first two categories here.

***Q18. FIRSTLY, I WOULD LIKE YOU TO THINK ABOUT A SITUATION YOU HAVE HAD WITH A PATIENT WHO 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.**

Int: So can you think of an instance where you've had a patient who was quite determined about what they were going to have? Can you sort of tell me about them, how you first came to meet them and their story sort of thing.

Res: Yes, ok, I sort of met the lady following diagnosis. She was quite definitely adamant about, she was given the choice of the, yeah, a wide local excision or a mastectomy, but due to family history, so her sort of experience of family history and her knowledge of it, she was quite adamant that she wanted a mastectomy.

Int: And did she help, she knew if from the start, right from the outset, the moment she'd been diagnosed she was, or did she have this sort of on her mind 'even if I get diagnosed I'm..'

Res: No, she.. I mean only having seen her following diagnosis..

Int: Oh right, ok..

Res: ..you know, she knew right from the word go that, you know, mastectomy was for her, that was her choice.

Int: So how did you get on with her, the patient themselves. Do you get on with them just generally?

Res: Me personally? I like to think I get on really well with them.

Int: Oh no, this patient actually..

Res: Oh this patient in particular? Oh I'm sorry, sorry. Well there was no sort of difference, nothing, no. That was absolutely fine. The patient had made her choice and that was fine.

Int: And so how do you think their relationship with the consultant was, the patient and the consultant. How do you think they, were they..

Res: How the news had been broken?

In: Yeah, just how they got on with their doctor sort of thing, if you like.

Res: Right. I think they had had sort of a good, a good consultation, this particular lady and perhaps she'd already had an idea, you know, that she had got breast cancer. So, yeah, a well informed lady really.

Int: Ah ok. So, how was this decision finally arrived at? You said she had it in her mind that she was going to have a mastectomy.

Res: Yeah.

Int: That's right, yeah?

Res: Yeah.

Int: And is that what she ended up having yeah? OK. How did you, how are your feelings about sort of how the, your part of the consultation went? You know, from the moment you came in and first met her, how were your feelings?

Res: I felt that the consultation had one well. The patient was sort of, as I say, you know, she knew what she wanted. She'd got a good level of understanding.

Int: Did she display any sort of influences apart from was it her grandmother I think or was it her?

Res: She'd got family, yeah. There had been sort of a family history. Did she display..?

Int: Any other influences, you know from external or internal, nothing else?

Res: No, no.

Int: Or is it just this family history that was..?

Res: Yes, that was her, obviously the main reason as to why, prompted her, or yeah, enforced that decision I should say.

Int: And do you think you, looking back at that particular consultation, do you think you were satisfied with the experience and the outcome?

Res: Yes.

Int: And do you think she was sort of satisfied with the consultation and the treatment?

Res: Yes, yes.

Int: This is an interesting thing from my point of view is, when you first meet a patient, you've never met them before and they are an active sort of decision maker, quite headstrong, how soon do you realise what kind of decision maker you're dealing with? How long does it take you to..?

Res: Probably not very long if they're active.

Int: And does that sort of change your approach to how that consultation's going to go and in what way?

Res: It's something that you would focus on more because they have already made that choice so obviously you wouldn't, you know, you would focus more on the choice that they had made probably unless you felt it was appropriate to, you know, go through the options again. I suppose if you felt they were a little unsure or, again level of understanding, if you felt that they hadn't perhaps fully understood what had been said or what the procedure involved..

Int: ..or the implications

Res: ..or the implications of, yeah, yeah. So I think you would obviously, again, it's just judging each individual and assessing their needs really and their level of information that they need.

***Q19. THIS TIME I WOULD LIKE YOU TO THINK ABOUT A SITUATION YOU HAVE HAD WITH A PATIENT WHO WAS COLLABORATIVE ABOUT MAKING DECISIONS. AGAIN, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE.**

Int: I'd like to do a very similar sort of thing. Now, I want you to think of situations with collaborative decision makers. In other words patients who tend to share final treatment responsibilities with their specialists. I would like you to think about a situation you've had with a patient who you think would fit that description of collaborative about making decisions and again, don't reveal any confidential details, but if you can think of a patient can you please tell me about your experience of them up to the point where they made their treatment decision. So can you, can you think of anybody you would think was a collaborative decision maker?

Res: Oh gosh. Obviously we wouldn't and certainly would most definitely not make a decision for them but we can certainly help in the decision making process by ensuring that they're informed so I, you know, that's probably the only instance where I sort of think, well I've probably tried to ensure that the patient has a full understanding of the surgical options offered.

Int: Do you have a particular patient in mind that you're talking about?

Res: No, I can't really think of any one individual. No because I can't then perhaps there's two or three, I don't know, I don't know. No, I can't David, sorry.

Int: No, no that's fine. If you can't, you can't. It's quite hard I think for collaborative to think of a, because collaboratives don't immediately stand out I think.

Res No, and perhaps you're not even aware sometimes that you are actually..

Int: ..an active one is bound to stand out because they're just like, you know they know what they want and they're not going to be swayed.

Res: I mean I have sort of been asked you know 'What would you do?' and it's, you know this isn't my decision to make. So again you would just go through and check, you know, how much do they understand and, or how much do they want to know. Do they need further information, you know, should we go over it again. I mean I think it's just checking all the time, checking and assessing.

Int: How are your feelings about how things go with what we would call collaborative decision makers? How do you feel things tend to go with these type of patients, the decision makers?

Res: Well I don't know, sometimes you know, you might think that they've made a decision and they'll telephone you the following day and it's changed and so it goes on. But again you've just got to think well ok they're not sure or they don't understand so let's go over it again, you know and that's just about informed treatment, decision making I think really.

***Q20. FINALLY IN THIS SECTION, I WOULD LIKE YOU TO THINK ABOUT A SITUATION YOU HAVE WITH A PATIENT WHO WAS PASSIVE ABOUT MAKING DECISIONS. AGAIN, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE.**

Int: Ok, if you can't think of anybody in particular I'm going to move on to the final one which is I would now like you to think about situations with passive decision makers and for these purposes we tend to think of passive decision makers as patients who tend to want to leave final treatment issues to the specialists either with or without concerning those specialists' opinions. In this section I'd like you to think about a situation that you've had with a patient who was passive about making decisions. Again, without revealing any confidential details please tell me about your experience with them up to the point when a decision was made. Now can you think of anybody in particular..?

Res No David, I'm sorry I can't, no. Whether it's because I haven't been in the role very long or, but no, I can't and I'm sure that would certainly stick out if, you know, if I had been asked to. But it's not a situation I would put myself in anyway, just wouldn't, you know it wouldn't happen. I suppose if a patient was really really undecided and..

Int: ..Well that was the next question I was going to say well if you can't think of anybody, can you imagine hypothetically now, you know, you'd come into the room and there was a patient here who was just like, well you know, what do you think I should have? How would you deal with that?

Res: No, I would go through obviously options, treatments etc. etc. but if at the end of the day they weren't really listening and they really just wanted me to make a decision I would ask them to see the consultant again, yeah. I would do.

Int: I'm going to move on now to the last couple of questions. You've answered one or two of these already so I don't want to spend too much time on these. I mean you said, you know, literature tells us there are a wide variety of influences on patients in making decisions about surgical treatment.

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

Res: Yeah, greatest influence. Probably patients' friends, their family, family friends, partners, media, magazines, newspapers..

Int: Is it just media in general, that kind of, the written and spoken word sort of thing?

Res: Yeah, definitely.

Int: Are you saying it's, I'm just trying to get it exact, is almost like, are you ranking these now, you're sort of saying friends and family first and then media generally..

Res: It depends where people get their sources of information really.

Int: I'm trying to pull out from your experience what you've heard and said in consultations.

Res: From experience I would say, probably family, friends and partners in their relationship, yeah. I would probably rank those sort of as the top three as to what influences.. but again it's very individual David, you know, some people don't have much of a family or they're not a close family or you know, their friends are more important to them than their families so, again it differs.

***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?**

Int: So now thinking within the context of the breast team here, the unit here, who do you think, or who or what do you think has the greatest influence on patients decisions about what surgical treatment to have?

Res: Consultants.

Int: In what way do you think?

Res: I suppose if the patient was wondering whether they should actually have any treatment at all a consultant could obviously see that it's you know, going to benefit the patient then they would probably use, what's the word I'm looking for, matters of persuasion really to try and persuade the patient to make the right choice.

Int: Given that, if then you come into the consultation from your perspective, from your end, how do you then approach that when you kind of know that background?

Res: What, would we sort of support the consultant do you mean?

Int: Who would you support I suppose.

Res: I mean I suppose terminology it's sort of coming into my head as probably thinking it's like living with a time bomb or if you were my wife you know, I might sort of, or I would certainly want you to have this so I suppose it's a very roundabout way isn't it really? But it is influencing the patient. I think I would just you know, tend to keep my own personal thoughts, feelings and beliefs to myself. Yeah, I can't really answer that one David.

Int: That's ok, don't worry.

***Q23. IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD TO WHAT WE HAVE BEEN TALKING ABOUT TODAY?**

Int: Anything you think I've missed?

Res: Thank you. No, no.

Int: I've just got one little thing right at the end and this is a funny little question that sort of one of my colleagues, well I think it's quite a good one. If you had the money and the power to change one thing about the system here what would it be?

Res: The consultants' approach.

Int: In what way?

Res: Just remember that..

Int: How would you do it?

Res: How would I do it?

Int: Yeah.

Res: God. How would I do it? I've got no idea. I think sometimes, and not by any means all of them, but at the end of the day, I mean it's difficult because yes they're dealing with breast cancer day in day out, as we all are, but I think you know you really have to remember that every person we see is very unique, very individual, very different, very different needs, very different everything and they really are individual and they've got to be treated as such you know. And the impact of breast cancer for that patient is again, just very individual and I think it's just important to remember. Have no preconceptions as to how you approach that counselling room or that consultation. But I don't know how I'd do it.

***Q23. IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD TO WHAT WE HAVE BEEN TALKING ABOUT TODAY?**

Int: Ok then. That's the end of the interview. Thank you very much for your time. I understand you're very busy. It's been a great pleasure talking to you.

Res: Thank you David and I'm sorry I lost track a bit.

Int: No, no, it's ok. I'm just going to make sure. That's all right.