

Appendix-2

Verbatim Quotations:

The select few verbatim quotations are detailed in Appendix - 2

Cost and affordability:

R: "Money is the first thing ... actually the most important factor, if they cannot afford the treatment, there is no point in telling [the patient about it]."

R: "When the patient comes to the hospital in Britain, nobody talks of money. Here, the first thing is how much it costs."

Quality of life:

R: "They do not talk about quality of life."

R: "The best option, whether it is debilitating or low quality of life, we have to offer it. He has an option of refusing it, but just because you may not like it, we should not refuse that option."

R: "When the patient comes to the hospital in Britain, nobody talks of money. Here, the first thing is how much it costs. They do not talk about quality of life that is all."

Case complexity and choice of therapy:

R: "If there is a clear-cut answer to a problem, there is no discussion. A discussion comes when there are multiple options."

Ease of communication:

R: "Patients feel [more] comfortable communicating with doctors than nurses."

Decision making:

R: "They know what was discussed here, that will be conveyed to the patient and then we come up with a decision."

Patient choice and demand:

R: "We will have some definite plan that was made, and sometimes the patient has a completely opposing treatment plan, and we strongly feel that patient needs to be counseled, therefore we try our best to counsel, but sometime the patient will be against us."

R: "We have had a few patients who come demanding for a particular type of therapy."

R: "I mean it is not really uncommon for people to come with some particular treatment in their mind, it need not be the best possible option."

Trust and beliefs:

R: "Totally curable, but patient is going to go for Siddha ayurvedic treatment. We tried to explain that this is curable, but he is against it, we cannot force the patient, but we said we will keep an eye on the patient. I am helpless."

R: "I have belief in surgery, but sometimes belief is what patients [have too]. So, all of us have certain bias based on it. Patients have their own perspective about life and treatment."

R: "A man working at a vice president level in an IT company is telling me that his uncle told him that radiotherapy will disfigure her, so she did not take radiotherapy, now she is left with an expected life survival of three months. So, it is an interesting concept, but there are lots of social issues attached to it and we will be very happy to choose the patients who get involved during decision making."

R: "One of our very senior oncologists is considered as God in India. They will go and touch his feet, the only thing he does is to tell to them, they will be cured. We know that he is giving the patient hope. He sells hope. He is so

Appendix-2

popular that he travels across India. He sees patients in the airport, anywhere and everywhere, and he is God, people love him.”

Evidence-based patient preferences, patient choice, or patient decision making:

Financially driven:

R: “In India, it is a completely different scenario. Our practice is a very bad practice. If he does not like me or the other surgeon, there are enough renowned hospitals in the city where patients can go and if, you know, there are hospitals where the doctors will do whatever the patient say. So, it is a completely different concept.”

R: “That is exactly opposite what happens in India. The patient has enough and more choices. We see so many patients who shop around the whole of the country and then come to us.”

Affordability:

R: “Affordability is the first thing that is actually the most important factor, if they cannot afford the treatment, there is no point in telling them the various options.”

R: “When the patient comes to the hospital in Britain, nobody talks of money. Here, the first thing is how much it costs. They do not talk about quality of life.”

Socio-economic and educational status:

R: “The level of understanding and education, it is very different among patients. Dr [X] has worked in a centre where the financial status of the patients was very different, so I am sure he has a perspective of that,

Appendix-2

compared to this hospital where we see more of humble background patients.”

R: “You know, lots of patients are not educated. They do not understand what is happening. In fact, they do not know what is happening with them.”

Clinician and patient knowledge:

R: “So, to involve them, you know, you can make a decision if you have knowledge. We see some patients who do extensive internet search, come to us and seek treatment. That may or may not be the right treatment for them. If somebody does not have the knowledge, it is very difficult to make the patient understand the whole process.”

R: “I am talking about patients’ knowledge. See, day before yesterday I saw one patient, a man working at a senior position in IT Company, somewhere in his 50s, came to me with his wife’s records. She had recurrent astrocytoma grade 3, operated one year back. She did not receive any radiotherapy, because his uncle told him that radiotherapy will disfigure her.”

Family and social support:

R: “They do not understand what is happening with them. There is a decision maker in the family who takes all the decision.”

R: “Sometime I do not communicate everything to the patients; difference being family psychology in India is different from UK.”

R: “Here sometimes, there is one leader in the family, or we might talk to that particular person and then they will communicate gradually to the

Appendix-2

patients. So, we may not deliver everything to the patient. The family network is very, very strong in India.”

Information technology:

R: “They could do internet search. Most of the search is done on websites like Google, which will not give you what is the best therapeutic option for the patient. It will just give some kind of a treatment and majority of the patients come with treatment options which are not actually significant.”

R: “We see a lot of patients who come [asking for] interesting drugs or techniques which are in phase 1 and phase 2 trials, because that is what forms headlines in newspapers or articles. So, we always face this problem.”

R: “We did try to divert them to more reliable sites. We offered them what we have.”

Analysis of multidisciplinary team/tumor board meetings:

R: “I think that it is the rule for the Tumor Board to make the right decision. Of course, the patient has choices to schedule the treatment.”

Patient advocate:

R: “As a clinician, we have a tradition of making the right decision for the patient.”

R: “The ultimate aim of the clinician is to work for the patient, but at the same time, it is our job to make right decision.”

Appendix-2

Communication with patients/risk communication:

R: "We fight for the patient, we try to bring the family and discuss in detail, and communication can be a problem."

R: "Let's say that, I have a break in my communication, sometimes you do not gel well with the patient, and then I feel that you should seek a colleague's help."

R: "I think that we cannot ask the nurse to communicate for you."

R: "But, we cannot delegate a nurse to communicate fully, that is not we are working for. We should make time for communication with patients."

R: "In fact, the initial communication is the key, you can step aside after the treatment is initiated, but if the initial communication is lacking, I think there is a major error."

R: "If time is an issue, increase the manpower."

R: "Nurses in the UK know the patient very well, but some patients need things to be told 10 times for them to remember. That is where those nurses kick up that extra number of conversations."

R: "I will say what the expected complications or sequela of the treatment are."

Nurses:

R: "In India, the role of nurses in communication with regard to the cancer care is minimal. Most of it is done by the clinicians."

R: "I think that we cannot ask the nurse to communicate for you."

Appendix-2

R: "But, we cannot delegate nurses to communicate fully. That is not we are working for."

R: "Nurses in the UK know the patient very well, but some patients need things to be told 10 times for them to remember. That is where those nurses kick up that extra number of conversations."

Medical social workers:

R: "Medical social worker, he plays the same role in communication as a specialist nurse practitioner. His background is science graduate, he has done a Masters in medical social work, and when they, he/she, comes to us, he may not have much experience in cancer, and they sit with us in the Tumor Board meetings, and learn what is necessary."

Sharing and support:

R: "We do not have, but we are trying to develop patient support groups."

Patient voice:

R: "I think we need the patient voice to say what is important."

Individualization of treatment:

R: "We have to individualize treatment."

Consent:

R: "The consent process is not very, very strict. We would tell everything, but we do not write down all the possible complications. I heard [that in the] US that they write down every possible individualized consent form, write everything possible. You can imagine that consent form."

R: "That will protect you, medico-legally to certain extent."