Reading III.B CASE STUDIES: THE FAMILY, THE PATIENT/CLIENT AND YOU

Read the following and prepare answers for the questions that accompany each case.

- 1. Mrs. Chiu, a 78-year-old Chinese woman with terminal cancer of the lung, is admitted to a local hospital. Her two children inform you, the attending physician, that Mrs. Chiu has not been told of the diagnosis. The words "DO NOT REVEAL CANCER DIAGNOSIS TO PATIENT" are written in bold red ink on the front of her case record and medical charts. At no time during the course of her stay does Mrs. Chiu initiate any discussion about her diagnosis with you or any other members of the medical team. The patient's son and daughter are consulted for input on all medical decisions to be made, and Mrs. Chiu dies in hospital one week later.
 - a. What might be some of the reasons why Mrs. Chiu was not informed of the diagnosis?
 - b. How would you have handled this case? Would you have insisted on telling Mrs. Chiu of her diagnosis? Why or why not?
- 2. Mrs. Gonzalez brings her two-year-old son in to see you, their family physician, due to the spontaneous appearance of many bruises on the child's legs. Physical exam reveals petechiae all over the child's body, and Mrs. Gonzalez tells you the boy has experienced several nosebleeds over the last couple of days. You want to send the child in for bloodwork immediately, but Mrs. Gonzalez is unsure. She wants to ask her husband- who is out of town for the next three days- before taking any further action.
 - a. Explain in your own words what is going on.
 - b. What would be your next course of action?
- 3. Sahar is the 43-year-old daughter of Mansur Mahmoud. Mr. Mahmoud has been diagnosed with Alzheimer's, and Sahar has been his caretaker from the very beginning. She has a husband and three children. Sahar has been forced to quit her job as a result of the demands of her father's care, and she is clearly under a great deal of stress. You feel it would be in the best interests of both Sahar and her father if he was placed in a nursing home, and you have come to the Mahmoud residence today to discuss this as a possibility. Sahar says that it just wouldn't be the right thing to do, and that she would rather die than place her father in a home despite the toll his care is taking on her.
 - a. What reason(s) do you think Sahar might have for refusing to place her father in a nursing home?
 - b. What would you do next as the clinician in charge of this case?
- 4. Dorothy Williams is a 38-year-old Aboriginal mother of five, and she has come in to see you today to discuss birth control as she does not want to have any more children. Keeping in mind Mrs. William's age and smoking habit, you ask her if she has thought about tubule ligation. She says she has, and you respond with encouragement by saying you feel that the procedure would be a reasonable consideration. Mrs. Williams tells you she'll let you know after she's talked about it with Nanni, her grandmother.
 - a. The physician who told this story expressed feelings of frustration and annoyance with her patient's response. What is your initial reaction?
 - b. What do you think is going on here?
 - c. What would you say to Mrs. Williams?

Overhead III.3A:UNINFORMED THE UNINFORMED PATIENT/CLIENT

Possible reasons for why the family may not want the patient/ client to be aware of his/her diagnosis:

- Patient/client may become sicker as a result; may lose hope for recovery
- In some cultures it is believed that the patient/client is entitled to be treated like a child when ill, and thus should be "cushioned" from the truth
- Truth-telling signifies the withdrawing of hope on the part of the clinician- the patient/client takes this as a sign that his/her practitioner has "given up" on him/her and so comes to believe that he/she should not hold out any hope for recovery either
- If the diagnosis is terminal, the patient/client should be allowed to die in peace and with dignity. Disclosing details of the diagnosis is viewed as cruel and unnecessary.

Overhead III.3B:SUGGESTIONS THE UNINFORMED PATIENT/CLIENT

Adapted from Lee A, Wu HY, 2002.

Suggestions for dealing with relatives who insist on keeping the diagnosis from the patient/client:

- Acknowledge that you don't know the patient/client as well as they do.
 - This helps break down the family's defences and supports your role as advocate as opposed to insensitive clinician.
- Determine their reasons for wanting to withhold information from the patient/client.
 - Is it a culturally-based belief?
 - □ Is it because of something the patient/client said in the past?
 - Is it the personality of the patient/client that makes them believe that he/she could not handle or would not want to hear the truth?
 - Are there any underlying emotional or psychological stressors being experienced by the family?
- Discuss with the family the cost(s) of withholding information from the patient/client and determine whether or not your ideas regarding cost correlate with theirs.
 - If the diagnosis is terminal, there may be things that need settling that can be addressed only by the patient e.g. will, finances
- Ask for permission to speak with the patient/client alone, assuring the family that you want to determine what and how much the patient/client wants to know, not force full details of the diagnosis on him/her.
 - For example, if the diagnosis is cancer use words such as "growth" or "tumor" in your discussion with the patient/client and see whether or not he/she shies away or questions you about it further.
 - Reassure the family that you will update them with details of your conversation with the patient/client, ensuring that when you speak with the patient/client you ask him/her permission to do so.

Important points to remember:

 If you encounter difficulties with obtaining a decision from a patient/client, stop and consider whether or not you have consulted the correct individual(s)- the decision-maker may not be the patient/client, but his/her parent, spouse, etc.

Some cultural examples:

From a Peace Corps volunteer working in a West African village:

"A woman motioned to me to follow her. We wound in between the huts and suddenly found an old woman writhing in pain on the mat at the door of her home. She showed me her stomach, swollen way out of proportion with an infection of some sort. She pleaded that she wanted to go to the hospital, but her husband, who soon arrived, forbade it. We debated and discussed for many minutes, finally learning that the husband would give permission if his son, the secretary of the party in the village, would give assent. I knew the son would be favourable to a trip to the hospital, as he had recently returned from a good experience there himself. So we sent for the son in the fields. He came and spoke, and his father accepted his advice that his mother be allowed to go."

From a physician working on a Navajo reservation:

"One of your difficulties with the older generation is that sometimes you go in and ask for a small child to have surgery, and they'll say, "No, he doesn't want to go." As soon as the child is able to talk, he's an individual. The older folks feel that at that point he is an individual and should make up his own mind- and if he doesn't want to go in and have his tonsils out, that is his decision. It caused a lot of problems with our people. We couldn't understand why a 3-year-old child was even consulted."

- ~ Brownlee, A. The Family and Health Care: Explorations in Cross-Cultural Settings. Social Work in Health Care; 4(2): 179-198
- Remember that style and speed of decision making varies between individuals and across cultures
- Be aware of your own style of decision making and accept that others may not follow the same processes you do
- Respect the needs of those patients/clients who wish to consult with others- approval from individuals important to the patient/ client may need to be sought before a decision can be made

Handout III.4A:VIGNETTES FROM THE PATIENT

- 1. Community Health Representatives (CHRs) can serve as very useful brokers for getting information from and out to the aboriginal community. For example, one clinician did a chart review comparing pap screening rates for elderly aboriginal versus elderly non-aboriginal women and found that the rates for the aboriginal women were significantly lower. To gain support for an intervention, the clinician consulted several CHRs about the problem and asked them what she should do; they offered to liase with the elders on her behalf. The elders agreed that this was an important concern that needed to be addressed, and an intervention was organized. The clinician's respect for the system of decision making in that community resulted in its full cooperation and collaboration with her initiative.
 - What are your clinical experiences with cultural brokers? Who were they? How did their involvement contribute to your interaction with the patient/client? Do you think it was a positive or negative contribution?
- 2. An Indo-Canadian woman was a post-operative patient at a local hospital. Members of her family were constantly coming and going, and it was not uncommon for the woman to have six or more guests at a time. The hospital staff was growing frustrated with the traffic volume and felt it was interfering with their ability to do their jobs. The patient's son was upset that the staff didn't understand the importance of the family being there with his mother: "It's a cultural thing. In our culture, it's important for all members of the family to be there, to show respect, and also because we really want to be with her and to make her feel at home."
 - Have you had an experience similar to this, either as the patient/family member or as the clinician? How was the situation resolved?
 - As the clinician in charge, what steps would you take to resolve this conflict?
- 3. A clinician was making a home visit to Mr. Yang, a patient/client who was born in Hong Kong, but who had immigrated to Canada 25 years earlier. His two children were born and raised in Vancouver. Mr. Yang's wife, also a Hong Kong native, had been caring for him at home for the last year, after he suffered multiple injuries from a serious car accident. All four family members were present for the meeting. The clinician felt Mr. Yang needed a lot more help than his wife was able to provide, and wanted to place him in a nursing home. Mrs. Yang admitted her husband's care was difficult to manage both physically and emotionally, but said her heart couldn't bear to see him put in a nursing home and was adamant that he remain with her. Shortly after this declaration Mrs. Yang left the room to answer a phone call, during which time her children took the clinician aside and pleaded with him to convince their mother to put Mr. Yang in a nursing home. They stated that they "just couldn't deal with it anymore," as they were receiving frantic phone calls from Mrs. Yang at all hours of the night and as a result were being forced to come over and help her with their father's care.
 - What do you think is going on here?
 - What cultural differences exist between the clinician and his patient/client? Between the parents and the children of the Yang family?
 - What would you say to Mrs. Yang's children?