

Module III

ROLE OF THE FAMILY AND COMMUNITY IN HEALTH CARE

Readings:

To be completed prior to the first session of this module.

Reading III.A: Moazam, F. Families, Patients, and Physicians in Medical Decisionmaking: A Pakistani Perspective. *Hastings Cent Rep* 2000; 30(6): 28-37. (UBC Library: available online)

Reading III.B: Case Studies: The Family, the Patient/Client and You.

Module Objectives:

Students will be able to:

1. describe several different processes by which people make decisions about their health care
Relevant sections: III.1, III.2, III.3, III.4a
2. identify possible cultural explanations for a patient's/client's behavior
Relevant sections: III.3, III.4a, III.4b
3. problem-solve in clinical scenarios involving the patient/client and his/her family members
Relevant sections: III.3, III.4b

HOUR 1: LECTURE / DISCUSSION

TIME: 15-30 minutes

III.1 Autonomy and What it Means to Your Patient/Client

Consider the following questions for discussion:

- How do you define autonomy? Autonomy can be defined as “the patient’s freedom or right to choose the treatment he believes is best for himself” (Hardwig 1990, pg. 8). Do you agree with this definition?
- What do you think characterizes an autonomous patient/client, and how does such a patient/client make decisions about his/her health care?
- What, if any, place do you feel the patient’s family has in the decision-making process?

Some health practitioners contend that a patient/client is not acting autonomously or in his/her own self-interest if he/she allows the wishes of the family or some other important figure in his/her life to influence a decision, but for many patients/clients the interests of others are components of their own interests, so when such a patient/client takes the family’s opinion into consideration the decision he/she arrives at will still qualify as his/her own and will be the one that suits him/her best.

In some cultures it is customary for the family to assume responsibility for decisions about an individual’s health, and in others it is expected that the family will at least be consulted.

While the family’s closeness to and intimate knowledge of the patient/client may be helpful in the decision-making process, their involvement may also result in exploitation of the patient/client, who may be susceptible to manipulation and coercion by family members and out of fear or guilt may ultimately end up agreeing to something he/she doesn’t approve of.

In any case, the family and other respected figures in the patient’s/client’s life play an important role in how many patients/clients handle and make decisions about their health care- so how do you effectively work with them as well as your patient/client in determining the best means of care?

III.2 Who Do You Involve in Your Health Care?

TIME: 15-30 minutes

Consider who, if anyone, you involve in your decisions about your health care:

- Do you ask the opinion of any family members? Friends? Religious or community leaders?
- Do you consult anyone in particular before making a decision, or do you rely solely on your own judgment?
- Why do you choose to consult (or not to consult) the individuals you do?

Pair up with someone that has a view different from your own (e.g. one of you doesn't talk to anyone about his/her health care, the other must hear his/her parent's opinion before making any decisions; one of you consults a sibling for advice while the other consults a friend).

Discuss why you choose to involve the person/people you do (or no one at all), and compare and contrast your reasoning with that of your partner.

Reconvene as a class and briefly discuss / generate a list of the preferences and explanations encountered.

HOUR 2: DISCUSSION

TIME: 60 minutes

MATERIALS:

Reading III.B

Overheads:

III.3A:Uninformed

III.3B:Suggestions

III.3C:Decisionmaking

III.3 The Family, the Patient/Client and You: Case Study Analysis

Discuss the cases in Reading III.B using the following guidelines:

CASE 1:

Go through Case 1 and discuss your answers to Question (a) as a class.

In this case the family does not want the patient/client informed of her diagnosis. In some cultures it is believed that knowledge of the diagnosis, especially that of a terminal nature, does more harm to the patient/client than good. It is a mutual understanding between the patient/client and his/her family that the family will make all necessary arrangements and decisions on behalf of the sick individual so as to avoid burdening him/her further. In many cases the patient/client is well-aware of his/her condition, but he/she is not expected to deal with it directly and so will not exhibit any knowledge of or concern for the proceedings.

Consider the possible reasons given in *Overhead III.3A:Uninformed* for why some individuals of various cultures believe the patient/client should not be informed of the diagnosis. Add to the list any others you came up with during the class discussion.

Discuss your answers to Question (b) as a class, then consider the suggestions given in *Overhead III.3B:Suggestions* and discuss how they compare to the answers you came up with on your own.

CASE 2:

Go through Case 2 and discuss your answers to Question (a) as a class.

In this case it is likely that Mrs. Gonzalez's husband serves as the primary decision-maker for the family, and she may feel that taking her son for any type of medical procedure is a decision she does not have the authority to make. In some families there is one specific member that can be identified as the important person with whom to deal in matters concerning the health of other family members.

Go over the points listed in *Overhead III.3C:Decisionmaking* and consider how they may be applied to the case.

Discuss your answers to Question (b), considering the benefits and drawbacks of your approach. Do your ideas about how to best handle the case differ from those of your classmates? Do you feel differently after having heard the opinions of others?

CASE 3:

Go through Case 3 and discuss your answers to Question (a) as a class, generating a list of all the reasons you come up with.

Note that in some cultures, it is a sign of respect, love and honor to sacrifice one's own needs to attend to those of one's parent in times of illness, and it is out of both obligation and desire that one will devote themselves full-time to the care of such a parent. Sahar likely shares this belief, which would explain her adamancy that her father is to remain at home. Turning over her father's care to a complete stranger may be viewed as a sign of disgrace to Sahar.

Discuss your answers to Question (b), keeping in mind the principles discussed in other cases. For example:

Perhaps you might ask Sahar if there is anyone else in the family you might speak with regarding her father's care- you may be able to make advocates of other individuals whose opinions are important to Sahar, and who would likely be in a better position to convince her Mr. Mahmoud's health would stand to benefit from placement in a nursing home.

Investigate whether or not Sahar's reluctance to place her father in a home stems from any preconceived notions about nursing homes or negative experiences.

Ask Sahar if you might speak with Mr. Mahmoud on your own to discuss the situation- he may very well agree with you that placement in a nursing home would be best for both him and his daughter, and his declaration of such would likely be enough to convince her that this is the best option.

CASE 4:

Go through Case 4 and discuss your answers to the questions as a class, considering the principles you have learned thus far.

HOOR 3: ACTIVITIES

TIME: 15-30 minutes

MATERIALS:

Reading III.A: Families, Patients, and Physicians in Medical Decisionmaking: A Pakistani Perspective.

III.4 Learning Activities:

a. Discussion of Reading III.A

Type of Activity: Group discussion

Purpose: To allow students to share their perceptions and gain new insights into how culture and family contribute to decision making in health care.

Discuss the reading using the following as a guide for discussion:

- What was your initial reaction after reading the article?
- The author of the article is an American physician. Do you feel that the perspective might have been different had it been written by a Canadian clinician? If so, how?
- What aspects of the Pakistani culture as described in this article can you identify with? What aspects do you find difficult?
- Which of the author’s stories did you find most interesting? Why?
- What useful information or insight were you able to draw from the article? What makes it relevant to you as a clinician?

TIME: 30 minutes

MATERIALS:

Handout III.4A:Vignettes

b. From the Patient

Type of Activity: Group discussion

Purpose: To allow students to think critically about and devise solutions for several clinical scenarios involving parties additional to the patient/client and the clinician.

Read each vignette in *Handout III.4A:Vignettes*. Note that the stories listed are NOT suggested to be true of all members of the culture each story pertains to, but rather to be examples of the views and behaviors of some individuals of that particular culture.

Discuss as a class or in small groups to share thoughts and perceptions, using the listed questions as a guide for the discussion.

III.5 Evaluation

Sample exam questions:

1. Mrs. Chung has been diagnosed with breast cancer and her condition has been deteriorating rapidly over the last several weeks. Her family has insisted that she not be told of the diagnosis.
 - a) Give three possible reasons for why they might feel this way.

Examples of answers (based on Overhead III.3A:Uninformed):

- She may become sicker / lose hope for recovery if she learns how serious her illness is*
 - She is entitled to be treated like a child during times of serious illness, and children are often spared the weight of such difficult realities*
 - Truth-telling signifies the withdrawing of hope on the part of the clinician- Mrs. Chung will feel that her clinician has given up on her*
 - Truth-telling will rob Mrs. Chung of the peace and dignity with which she should be allowed to live out her last days*
 - There may have been a difficult death or similar experience in the family in the past, and they wish to avoid a similar situation by withholding as much information from Mrs. Chung as possible*
- b) List three things you might do in response.

Use Overhead III.3B:Suggestions as an answer key.

Sample assignments:

1. Give the questions for discussion in III.4 Learning Activity (a) along with the reading and have students bring their written answers to class. May be marked as complete/incomplete.
2. Find and read an article addressing an aspect of the interaction between family, patient/client and clinician. Give a summary of the article, including what you found most useful/important, to your small group.

III.6 References: Role of the Family and Community in Health Care

Brownlee, A. "The family and health care: explorations in cross-cultural settings." Soc Work Health Care 1978; 4(2): 179-198.

Carrillo, J.E., Green, A.R., Betancourt, J.R. "Cross-cultural primary care: a patient-based approach." Ann Intern Med 1999; 130: 829-34.

Dyck, I., Forwell, S. Stories From the Field: Students' Reflections on Culture in Practice. Vancouver, BC: U of British Columbia, 2000.

Gropper, R.C. Culture and the Clinical Encounter: An Intercultural Sensitizer for the Health Professions. Yarmouth, Maine: Intercultural Press, 1996.

Hahn, S.R., Feiner, J.S., Bellin, E.H. "The doctor-patient-family relationship: a compensatory alliance." Ann Intern Med 1988; 109: 884-889.

Hardwig, J. "What about the family?" Hastings Cent Rep 1990; 20(2): 5-10.

Lee, A., Wu, H.Y. "Diagnosis disclosure in cancer patients- when the family says 'no!'" Singapore Med J 2002; 43(10): 533-538.

Mappes, T.A., Zembaty, J.S. "Patient choices, family interests, and physician obligations." Kennedy Inst Ethics J 1994; 4(1): 27-46.

Moazam, F. "Families, patients and physicians in medical decisionmaking: a Pakistani perspective." Hastings Cent Rep 2000; 30(6): 28-37.

Muller, J.H., Desmond, B. "Ethical dilemmas in a cross-cultural context: a Chinese example." West J Med 1992; 157(3): 323-7.

Mutha, S., Allen, C., Welch, M. Toward Culturally Competent Care: A Toolbox for Teaching Communications Strategies. San Francisco, CA: Center for the Health Professions, University of California, San Francisco, 2002.

Schuwirth, L., van der Vleuten, C. "ABC of learning and teaching in medicine: written assessment." BMJ 2003; 326: 643-5.

Veatch, R.M. "Defining the family's role in treatment decisions." Health Prog 1986; 67(8): 50-2.