

EDUCATIONAL GUIDE: A SUPPLEMENT

To Be Used With

MAINTAINING COMPASSIONATE CARE: A COMPANION FOR FAMILIES EXPERIENCING THE UNCERTAINTY OF A SERIOUS AND PROLONGED ILLNESS

This educational guide should aid instructors in required coursework in the health professions or a focus for continuing education programming. Although feared to these groups, religious or other non profit organizations whose focus includes family caregiver issues also may find it a useful aid.

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EDUCATIONAL GUIDE

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The importance of teaching students or others to provide compassionate care to patients is likely agreed upon by all involved in care giving professions or activities. Often the demands for curricular time in formal preparation programs may push this subject to the back burner, to be included only as an “add-on”. The availability of the booklet, **MAINTAINING COMPASSIONATE CARE: A COMPANION FOR FAMILIES EXPERIENCING THE UNCERTAINTY OF A SERIOUS AND PROLONGED ILLNESS** and this Educational Guide supplement provides content in a readily available form for the busy faculty member or workshop facilitator, making it easier to include the concerns addressed therein in part or whole as is desired. This supplement provides discussion questions and exercises for each of the chapters.

Chapter 1. Living Through Serious Illness

Uncertainty is a concept that implies limitations to the knowledge of a given outcome. Uncertainty may range from issues concerning acknowledgement of business or educational achievement i.e. various awards, to questions concerning which educational institutions will grant a student admission, to questions of health and recovery (Bailey, Wallace & Mishel, 2007). The length of time for recovery, the degree of recovery, or the question of survival all may be tinged with uncertainty (Corbin & Strauss, 1992). Glaser and Strauss (1967) observed, in their seminal work on trajectory, that during the crisis stage, patients and families may be faced with certainty/uncertainty regarding a diagnosis/prognosis and certainty/ uncertainty as to the time when there will be clarity as the outcome of a challenge to health and/or life (Glaser & Strauss, 1965). The combination of certainty and time ”yield four types of “death

expectations” (1) certain death at a known time, (2) certain death at an unknown time, (3) uncertain death but a known time when the question will be resolved, and (4) uncertain death and uncertain time when the question will be resolved.” (p.18-19).

Exercises

1. Ask students to

- use their personal and professional experience to develop a list of questions they think might be listed by the users of “Maintaining Compassionate Care”.
- share their lists and discuss: Which issues are mentioned most frequently? Are there any issues that are mentioned by just one person?
- Identify and reflect on which issues they think are most difficult to resolve and why.

2. Invite the students to reflect back on a time of uncertainty for themselves and their families, or if need be, a patient. Have them write a brief description of the situation. Using a certainty/time framework provided by Glaser and Strauss (1965), have the students respond to the following questions;

- a. Can they identify a time when they would know the outcome?
- b. Did they know the outcome but not the time when it would occur?
- c. Did they not know the outcome but knew a time when the issue would be resolved?
- d. Did they know neither the outcome nor the time when it would be?

resolved?

Have them discuss which type of situation they thought was the most difficult and why.

Chapter 2. Uncertainty through a Physician's Perspective

With the exercises presented below, the students will be able to examine the utility and effectiveness of having specialists for ethical and comprehensive comfort care issues.

1. Ask students whether anyone has worked with an ethics committee. If no one has had this experience it would be useful for the faculty member to describe his/her experience.

Have the person(s) with the Ethics Committee experience do the following:

- a. Describe the situation where there was a consult.
- b. What was the outcome?
- c. Did the patient/family think it was useful?
- d. Did the person with the experience think it was helpful?
- e. What else might have been done?
- f. If there were no ethics committees in the facilities with which the students are familiar, could the class think of a situation where such a committee might be useful?

2. Repeat this exercise, but this time, ask students to examine the usefulness of having a palliative care service .The same questions apply with the substitution of a palliative care service for an ethics committee.

Chapter 3. Communication between Families and Health Professionals

Communicating with health care professionals is difficult for many patients and families who find themselves in an alien world. It is often the case that patients and families don't know the rules of this environment and thus don't know how to access the information they need to find the answers to their queries.

Family members have been invited to list areas of communication with which they might need assistance. Have your students develop their own list of issues that they think families might need help with in communicating with health care providers. Have the students compare their lists.

- a. What were the areas of agreement?
- b. Were there any areas of disagreement?
- c. Have the students discuss how information might be provided more effectively to patients at the clinical sites at which they practice.
- d. Invite the students to discuss how information might be provided more effectively to family members at the clinical sites at which they practice.
- e. What might be done so that these suggestions would be more widely available?
- f. How might these suggestions become part of the procedures at various facilities?

Chapter 4. Exploring Values

Values may differ by importance and the degree to which they are shared. Often, the perception of values changes with the age of the individual. Values may also differ by culture. Values affect whether and how an advance directive for care is completed. The following exercise will help the students uncover the advantages/shortcomings of an advance directive.

Have the students divide into small groups. Each group should be designated as A, B, or C with the following assignment.

- A. Develop arguments in favor of completing an advance directive.
- B. Develop arguments in opposition to completing an advanced directive.
- C. The jury will determine which side has made the most compelling, substantiated argument.

During this time, Group C can examine the issue from both perspectives. After 20-30 minutes of preparation, ask Groups A and B to designate their lawyer/advocate. Depending on the size of the class, there may be several representatives for A and B. The lawyer/advocates can request time to consult with their groups of origin or with each other. Allow 10 minutes each for initial arguments for A and B and another 15 minutes for cross challenges. Have one or two students from Group C maintain order.

At the conclusion of the cross challenges, allow 3-5 minutes for summations of salient points by representatives from Groups A and B. Thereafter allow up to 5 minutes for Group C (the jury) to deliberate and

determine which group has made the best argument and why. The Chief Judge (a representative of Group C) will present the jury's conclusions.

The purpose of this exercise is that the case for advance directives is not cut and dry. What one wishes at one point in time may change when the reality of reduced function or the alternative is confronted.

2. Have the students identify the values that undergird the arguments propounded for and against advance directives. Are these values that the students find in accord with their own beliefs? Would the results be different if the patient considering the advance directive were from a country where the family makes all decisions?

The purpose of this exercise is to have the students acknowledge their own values and learn to respect others who may have different values. Clearly there are limits to this as our culture does not support physical and/or mental abuse/neglect of others.

Chapter 5.

Critical junctures are often described in an either /or manner. Have the students break into small groups and each group consider one or more of the "critical junctures" mentioned in Chapter 5 of "Maintaining Compassionate Care" to determine whether there are any "third ways" possible in any of these junctures. For example, no longer providing food or fluids does not mean that moistening the lips, ice chips, or 1cc of water cannot be provided for the patients' comfort.

The goal of the exercise is to have the students think outside the box.

Chapter 6.

Coping styles have been described in a classic text by Lazarus and Folkman (1984) as problem-focused or emotion-focused. While the primary appraisal is whether the appraisal is stressful or not, the secondary appraisal focuses on approaches to coping- emotion or problem focused. Further, "How well a person can cope is influenced by the ability to resolve uncertainty in the situation" (Mishel, 1983, p.324). Have the students consider how they cope with stress. Is their style emotion-focused or problem-focused? Do they consider their coping a healthy approach or deleterious to their health?

1. Have the students examine a problem and write about what they did to cope with the problem. Ask them to share the problem with one other person and discuss whether:
 - a. The coping approach was problem-focused, emotion-focused or some combination?
 - b. To what degree was uncertainty a factor in the problem?
 - c. Was this an approach used previously with other problems?
 - d. Did the coping approach have a negative or potentially negative effect on the student's health?

- e. Can the students identify when they use which type of coping approach or is their approach consistent with different types of problems?
2. Have a class discussion on how students handle:
 - a. fear
 - b. anger
 - c. sadness
 - d. death of a loved one
3. Hope has been defined “as a positive future orientation and is an important coping strategy in critical stages of life” (Davidson, Dracup, Phillips, Daly, & Padilla, 2007, p.160). Have the students discuss the degree to which hope affected their coping strategy.
4. This is a good time to discuss caring for the caregiver whether as family member or as professional. Have half of the students come up with a list of ways in which family members might care for themselves and the remainder of the class develop a list for professionals. Discuss how these lists are the same and different. Are any of the approaches deleterious to health and well-being?

Chapter 7. Closing

Hospitals are bureaucracies that serve to facilitate the work that transpires within their system. There are many “rules” that control the behavior of patients, family members, and friends, as well as professionals.

1. What would the students change to make the environment more patient/family friendly?
2. How would they go about implementing the changes they propose?
3. Close with a discussion as to how the students think their practice will change as a result of this educational exercise.

References

- Bailey, D.D., Wallace, M., & Mishel, M.H. (2007). Watching, waiting and uncertainty in prostate cancer. *Journal of Clinical Nursing*. 16, 734-741.
- Corbin, J.M. & Strauss, A.(1992). A nursing model for chronic illness management based upon the trajectory framework. In P. Wood [Ed.] *The Chronic Illness Trajectory Framework*. New York: Springer, New York: 9-28.
- Davidson, P.M., Dracup, K., Phillips, J., Daly, J., Padilla, G. (2007). Preparing for the worst while hoping for the best. *Journal of Cardiovascular Nursing*. 22(3): 159-165.
- Glaser, B. & Strauss, A. (1965). *Awareness of Dying*. Chicago; Aldine Publishing Company.
- Glaser, B. & Strauss, A. (1967). *The Discovery of Grounded Theory*. Chicago; Aldine Publishing Company.
- Lazarus, R., & Folkman, S. (1984). *Stress, Appraisal, and Coping*. New York: Springer Publishing Company.
- Mishel, M. H. (1983). Patients' perceptions of uncertainty concerning their hospitalized child. *Nursing Research*. 32(6):324-330.