Problems in Family Practice

Communicating With the Grieving Family

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The physician, skilled in facilitating communication, can help the family of a terminally ill patient cope with stress. Lowering stress levels can reduce the risk of permanent psychological and physical damage to surviving members. This article illustrates appropriate interview techniques in five common stress areas: (1) social unacceptability of presenting symptoms and of death itself; (2) helplessness, anger, and guilt; (3) sexual feelings and expectations; (4) specific preparation for death; and (5) bereavement and grief after death. The physician's investment of modest amounts of time in direct care and in building ancillary resources can result in a significant service to grieving families.

A basic tenet of family practice is that good health care begins with the physician who has a comprehensive understanding of the health problems of an entire family.[1-4] Those who espouse this philosophy need to be alert to situations that are particularly hazardous to both the mental and physical well-being of total families. One such situation is the terminal illness of a family member. The primary care physician who is treating a terminally ill patient needs to be aware of problems for the patient's family. The period during which attention is focused on the dying family member is a time of high stress for all family members.[5,6]

In the course of routine visits with the patient and his or her family, the physician can assess the ability of the family to cope with stress in ways that will minimize the risk of permanent psychological and physical damage to surviving members.[7] Early attention to family communication problems may reduce the chance that other members of this family will appear in the physician's office with complaints during the year following the death of the original patient.[8,9]

For example, asking a family member, "How are *you* doing?" takes only a moment and can be done in the course of a regular patient visit. The response, "Not very well," is a signal of difficulty. A few more questions may make it clear that

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referral to a homemaker service, a support group, or a good book on how to talk with children about death is in order.[10] This process need not take an inordinate amount of time. The important point is to inquire and then be able to refer to other resources.

This article discusses five stressful subjects that frequently cause difficulty for both patients and their families along with suggestions about interview techniques that the physician can use. The implication is not that the family physician should have either the time or the inclination to try to solve all of the problems; much of the work can be done by ancillary services. The physician is in an ideal position, however, to make an assessment that services are needed.[10,11]

The value of attention to these details may be far-reaching. The relationship between stress and illness has been documented.[12] Specifically, the effect of terminal illness and death on survivors has been researched.[8,13,14] The well-known Holmes and Rahe Social Readjustment Rating Scale found that raters ranked "death of a spouse" as the most stressful event a person can experience. "Death of a close family member" tied for fourth. The scale does not include an item for "death of a child," but one would hypothesize that the rating would be high. Some findings indicate that the terminal illness of children exacerbates family problems to a level that results in divorce or marital separation. Those two family crises rated second and third on the Holmes and Rahe scale.[15]

Stressful Areas To Assess With Families

Issues Related to Social Unacceptability of Presenting Symptoms and of Death Itself

Many of the events surrounding illness and death make people uneasy.[16,17] Such symptoms as edema and incontinence are embarrassing. Alterations in behavior are uncomfortable for everyone, and the contemplation of death is even more difficult.[18,19] People strain to behave as though nothing has happened, pretending there is no problem and everything will be all right. Denial can be a useful response to emotional pain, but in many death-related situations, denial is not a sufficient response.[20-23] The physician can help families begin to deal with the inevitable by initiating conversation about these upsetting but unmentionable issues.[6,24,25]

For example, in a family in which the mother of young children is dying, the physician can ask: Have you and the children talked about why Mom smells so bad (incontinence)? or why she talks and acts so funny (brain metastases)? Have you and the children talked about being afraid? afraid for yourselves? afraid for Mom?

If the father seems unable to discuss these issues, the physician can point out what research and experience indicate. Children are better off in the long run if they are allowed to talk about the changes and fears as they happen.[26-28] This information can then be followed up with the reminder that there are people who can help work on communication issues.

Often people, such as the father of children whose mother is dying, need permission to ask for help. If the family does not have helping resources of its own, referral can be made. For example, many communities have grief support systems, hospices, or grief support groups. These networks of people may focus on a specific disease such as cancer or multiple sclerosis. Such organizations usually have good resource lists of books, films, and agencies. The family physician's office staff can facilitate necessary contacts with a minimal use of time.[29-31]

If the father is unable to deal with these issues, the physician may inquire about them when the father seems to feel more adequate. At times, another member of the family can be identified as a facilitator. If the physician knows the family and has its grief work in mind, the right moment can be found. It may take only a telephone call.

Issues Related to Helplessness, Anger, and Guilt

Many of the common emotional responses of terminally ill persons or survivors are culturally

unacceptable feelings, "unthinkable thoughts" that cause guilt and anxiety.[8,13,21] These intense responses are suppressed only to come up later in some form of negative behavior.[14,20] The physician as facilitator can acknowledge and accept these taboo feelings.[10,32]

Conventional wisdom suggests that prolonged illness allows family members to come to grips with the expected death. In fact, the anticipation of death is frustrating. Watching a loved one slowly slip away leaves the survivors with feelings of helplessness and lack of control.[21,24] Death evokes rage.[19] Sometimes the anger is directed at the illness and its effects. Sometimes the anger is directed at the patient for causing such inconvenience, expense, and discomfort for the survivors. Sometimes the anger is directed at the physician and medical staff for not curing the patient.[16]

The spouse or children need support in negotiating their anger. For example, a statement such as the following can be helpful: I'm sure you're very angry sometimes, even angry at your wife for dying, and angry at me for not curing her.

Such questions may evoke denial or a flood of emotion. Either response helps the physician assess the emotional health of the family and know whether the members need help.[10]

Issues Related to Sexual Feelings and Expectations

Patient and spouse or lover continue to have both their own sexual feelings and reactions to each other's sexuality. As the illness progresses, these feelings may change.[33] One partner or both may find it increasingly difficult to express the feelings, even though they continue to be an important part of the couple's relationship.

Changes can be many and varied.[34] A couple may be so overwhelmed by the presence and suggestions of well-meaning friends, relatives, and caretaking staff that they have no private time to be intimate with each other. A woman patient with a uretheral catheter may silently endure inter-

course because she has been taught that it is "her wifely duty." The physician can be helpful by taking time to discuss these issues with the patient and partner.[33,35,36]

Some of the most common survivor reactions are anxiety, repulsion, rejection, guilt, and insensitivity.[20,23] Each feeling can be clarified with simple questions. For example, the physician can ask: Do you find it difficult to be affectionate with your spouse now that his looks have changed so much? Since your partner is so ill, how have you managed your sexual needs?

Such neutral questions, which do not imply value judgments, support the survivor and facilitate a response.

The physician's inquiry helps the couple in two ways: (1) the surviving partner perceives permission to discuss sexual feelings, and (2) the couple's attention is focused on their respective sexual needs and the wish of each to talk with the other.[35]

Depending on the reaction of the surviving partner, the physician may want to make some specific suggestions. For example, the partner may indicate that he has been given signals by staff and family that his wife must be treated in an antiseptic manner because she is so sick. He is afraid to touch her for fear he will hurt her. The physician needs to reinforce the value of love and comfort.[18,37] It may even be necessary to speak to the staff or family about the importance of letting the couple have time alone and respecting their wishes. Specific instructions about how and where the patient can be touched will be reassuring to the oversensitive partner and instructive to the insensitive partner.[33]

Issues Related to Preparation for Death

Money and business matters frequently cause family tension, so it is useful to ask a few questions to assess the level of denial and anxiety over these issues.[10,38] Denial is not a helpful coping mechanism when death is imminent and the family has business or interpersonal conflicts unresolved.[20] Some post-death guilt can be forestalled by making use of the time families do have together during a terminal illness.[18]

For example, the physician can ask a spouse or adult son or daughter: Do you think you and your spouse (or parent) have any unfinished business you need to talk about? What are you going to do about that? Is there any unfinished business between your spouse (or parent) and other people, members of the family? business associates? Does your spouse (or parent) have a will, and does someone know where it is? whether it is current? Have you discussed funeral or burial arrangements as a family? Have you talked with the patient about her or his hopes for the future?

It may be necessary gently to remind the family that when the patient is able to think clearly, it is important to settle any business affairs that may be pending. Questions such as these keep the physician in touch with the adequacy of family response to the reality of the impending death.

Support groups are valuable during the terminal phase of illness. If the family has ties to religious or fraternal organizations, they are usually helpful. If your community has a hospice or other death-related organizations, they usually have support groups for families. Some people can talk about death with other people who are facing the same issue better than they can talk with their own family or friends.[39-43]

Techniques

A Specific Appointment Focused on the Survivor

Many times survivors' questions and concerns can be handled by the physician and staff during the patient's regular visits to the physician. Questions about the survivor's own stress may require more time. One strategy is to suggest that the potential survivor make an appointment to see the physician in his office. This appointment can be defined as the health check that it is. (Some routine procedures such as monitoring blood pressure are certainly in order during this highly stressful time.) This appointment provides an ideal time to ask about troublesome issues noticed by the physician during incidental exchanges with this

person. Survivors do not feel well and may erroneously attribute all of their discomfort to "feelings." If the physician does not take the initiative and suggest an appointment to assess the survivor's well-being, such assessment probably will not occur until there are significant problems.

A File of Community Resources

An office receptionist or health technician who is involved with helping patients and their families is a natural person to put in charge of building a resource file. Community agencies make a good beginning point. These agencies vary in their effectiveness, and experience will clarify which ones deliver services that help patients and their families. The listings can be expanded to include resources not related to terminal illness and grief. An annotated file that includes names of staff, as well as such resources as movies and books, transportation, or homemaking aides, can be an excellent reference. The more specific the referral, the better. Knowing the name and telephone number of a person within an agency will facilitate the family's inclination to follow through in asking for help (as it does with referral to another physician).

Another resource is a list of names and addresses of people who through experience work well with patients and their families. The list may include housekeepers as well as social workers, nurses, and clergy. Keeping the file current can be a rewarding task to a staff person who sees that the file is useful to the patients and their families.

Books

Numerous annotated bibliographies are available that have proved useful in practice. Since new resources are developed continuously, being placed on the mailing list of a hospice or grief institute gives the physician access to new bibliographies and other such resources.[30]

Conclusion

If the physician's goal is to reduce the risk of stress-related illness in the survivors whose loved ones have died, the family physician is in a good position to anticipate problems.[10] A few minutes of preventive attention to these grief and coping issues can reduce the risk of serious psychological and physical damage to survivors.[12,13] The physician may not be able to solve all these problems, but she can assess the risk of potential damage and make referrals when they seem appropriate.

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References

1. Curry HB: The family as our patient. J Fam Pract 1977; 4:757-758
2. Geyman JP: The family as the object of care in family practice. J Fam Pract 1977; 5:571-575
3. Authier J, Land T: Family: The unique component of family medicine. J Fam Pract 1978; 7:1066-1068
4. Christie-Seely J: Teaching the family system concept in family medicine. J Fam Pract 1981; 13:391-401
5. Bruhn JG: Effects of chronic illness on the family. J Fam Pract 1977; 4:1057-1060
6. Bertman SL: Lingering terminal illness and the family: Insights from literature. Fam Process 1980; 19:341-348
7. Schmidt DD: When is it helpful to convene the family? J Fam Pract 1983; 16:967-973
8. Parks CM: Bereavement. London, Tavistock, 1973
9. Lynch JL: The Broken Heart: The Medical Consequences of Loneliness. New York, Basic Books, 1977
10. Bauman MH, Nicholas TG: Family process and family practice. J Fam Pract 1977; 4:1135-1137
11. Geyman JP: Family practice in evolution: Progress, problems and projections. N Engl J Med 1978; 298:593-601
12. Mumford E: The social significance of work, and studies on the stress of life events. In Simons RC, Pardes H (eds): Understanding Human Behavior in Health and Illness, ed 2. Baltimore, Williams & Wilkins, 1981, pp 383-391
13. Lindemann E, Lindemann EB: Beyond Grief: Studies in Crisis Intervention. New York, Jason Aronson, 1979
14. Bowlby J: Attachment and Loss, III: Loss: Sadness and Depression. New York, Basic Books, 1980
15. Holmes TH, Rahe RH: The social readjustment rating scale. J Psychosom Res 1967; 11:213-218
16. Glaser B, Strauss A: Awareness of Dying. Chicago, Aldine Publishing, 1965
17. DeBeauvoir S: A Very Easy Death. New York, Warner Books, 1964
18. Werkman S: Only A Little Time. Boston, Little, Brown, 1972
19. Kubler-Ross E: On Death and Dying. New York, MacMillan, 1969
20. Weisman AD: On Dying and Denying: A Psychiatric Study of Terminality. New York, Behavioral Publications, 1972
21. Kastenbaum R, Aisenberg R: The Psychology of Death. New York, Springer Publishing, 1972
22. Blumenfield M, Thompson TL: The psychological reactions to physical illness. In Simons RC, Pardes H (eds): Understanding Human Behavior in Health and Illness, ed 2. Baltimore, Williams & Wilkins, 1981, pp 46-56
23. Shneidman ES: Deaths of Man. New York, Quadrangle/The New York Times Book Co, 1973
24. Schoenberg B: Anticipatory Grief. New York, Columbia University Press, 1974
25. Grollman EA (ed): What Helped Me When My Loved One Died. Boston, Beacon Press, 1981
26. LeShan E: Learning to Say Goodbye: When a Parent Dies. New York, MacMillan, 1976
27. Kubler-Ross E: Remember the Secret. Mulbrae, Calif, Celestial Arts, 1982
28. Furman E (ed): A Child's Parent Dies. New Haven, Yale University Press, 1974
29. Hamilton M, Reid H (eds): A Hospice Handbook: A New Way To Care For The Dying. Grand Rapids, William B. Eerdmans, 1980
30. Corr C, Bertman H (eds): The media exchange. Death Educ 1982; 6:175-188
31. Corr C, Wass H (eds): Helping Children Cope With Death: Guidelines and Resources. New York, Hemisphere, 1982
32. Fuller RL: The participants in the doctor-patient relationship. In Simons RC, Pardes H (eds): Understanding Human Behavior in Health and Illness, ed 2. Baltimore, Williams & Wilkins, 1981, pp 12-16
33. Green R (ed): Human Sexuality, ed 2. Baltimore, Williams & Wilkins, 1979
34. Streltzer J: Psychiatric aspects of oncology: A review of recent research. Hosp Commun Psychiatry 1983; 34:716-724
35. Tyler EA: Sex and medical illness. In Sadock BJ, Kaplan HL, Freedman AM (eds): The Sexual Experience. Baltimore, Williams & Wilkins, 1976, pp 313-318
36. Schover LR, von Eschenbach AC, Smith DB, Gonzalez J: Sexual rehabilitation of urologic cancer patients: A practical approach. CA 1984; 34:66-74
37. Grollman E: Concerning Death. Boston, Beacon Press, 1974
38. Counseling your dying client and his family. In Kliman AS, Schlesinger ES: Successful Estate Planning: Ideas and Methods. New York, Prentice-Hall, 1/7/80, vol 2, paragraphs 12008-12012
39. Decker B: After The Flowers Have Gone. Grand Rapids, Mich, Zondervan, 1973
40. Miles MS: The Grief Of Parents When A Child Dies. Oak Brook, Ill, Compassionate Friends, 1978
41. Helmrath TA, Steinitz EM: Death of an infant: Parental grieving and the failure of social support. J Fam Pract 1978; 6:785-790
42. Kushner H: When Bad Things Happen To Good People. New York, Schocken Books, 1981
43. Worden JW: Grief Counseling And Grief Therapy. New York, Springer, 1982