



Family Therapy with Families Facing Catastrophic Illness: Building Internal and External Resources

by Ellen Pulleyblank Coffey

Dr. Coffey discusses common challenges and interventions for families coping with terminal illness.

Ten years ago my late husband Ronald William Pulleyblank, with the help of his doctor and with a small group of witnesses, had his ventilator turned off, after living on it for seven years. Those years and the ones since then have radically affected my life and my work as a psychologist. Ten years after his death, twenty-five family and friends dedicated a redwood tree in Ron's name. In this beautiful event, after so long, we were able to place his illness and death back in what Lawrence Langer calls chronological time.

Langer, in his book, *The Holocaust*, distinguishes between two kinds of time: chronological time and durational time. He says that we expect a life in chronological time, made up of a past, present and future. When crises become the norm of life, durational time sets in. This is time without past or future and with a recurring experience of a disturbing present that is difficult to organize, express or forget. Langer writes that because durational time cannot overflow the blocked reservoir of its own moment it never enters what we usually experience as the stream of time. Often we and the people around us expect our grief to last for a prescribed length of time. Depending on the level of stress during an illness, this experience can last for much longer than we would expect. This assumption and others often need to be challenged, if patients and families are to find ways to live with significant illness.

Challenged Assumptions, Dilemmas, Necessary Conversation

1. Assumption: We each are responsible for ourselves and must make decisions for ourselves.

The Dilemma: A particular illness belongs to the patient. How the patient perceives this illness often determines the decisions he or she wishes to make. At the same time the perception of the illness is often quite different for family members who are responsible for the patient's care.

An example: Harry, who is very ill, continues to want to drive his children to school. His wife fears that his illness makes it unsafe.

Necessary conversations: The couple has to reassess which decisions are independent decisions and which must now be mutual. The roles and the responsibilities in their household also must be reassessed. These conversations need to include the multiple perspectives of all family members and sometimes those of extended family, caregivers and the norms of the community in which they live. The tendency to focus on the needs of the patient over the needs of caregivers and family members often must be challenged.

Note: Who participates in these conversations, and in fact in all conversations, often depends upon cultural values and beliefs. Before developing a treatment plan, an assessment with the family of how decisions are to be made is essential.

Positive Choices

2. Assumption: There are always positive choices to make, actions to take.

Dilemma: Often outcomes about the course of an illness are unknown. Tolerating ambiguity is a prerequisite for making decisions.

Example: A patient has fast-growing prostate cancer. He has the choice of following a usual course of treatment with mixed outcomes or an experimental treatment with little or no clear outcome data.

Necessary Conversations: Family members work to increase their tolerance of stressful emotional states due to ambiguity. They examine strategies and past experience that may help them tolerate the unknown.

Family Resources

3. Assumption: We often hold the belief that each family should and can provide for ill family members.

Dilemma: Due to the complexity of treatment and duration of treatment, there is often too much stress on family resources. This can overload the system and make it impossible for one family to provide physical, emotional, spiritual, social and financial resources adequate for all family members.

Examples: There is an extremely high divorce rate in families with long-term illnesses and also a high illness rate in other family members.

Necessary Conversations: The family explores how to build a community of support. With this support they learn ways to advocating for the needs of all family members in the family and in the wider community vs. over-relying on already overwhelmed family resources.

Maintaining Life

4. Assumption: It is the job of the medical establishment to maintain life.

Dilemma: Though this is a central tenet of medical practice, maintaining care is not the direct responsibility of the medical world. Separation between medical decisions in emergency rooms and the implications for life following these decisions can lead to patients being kept alive beyond their capacity to enjoy life and the capacity of their families to sustain them. As part of this dilemma, there is a medical process in place to save lives, but often no ethical process in place that offers the patient and family members a voice in deciding when enough is or is not enough. In addition to life-threatening issues, realistic care plans that take into account family resources need to be part of the medical treatment plan.

Necessary Conversations: Family discussions before there is an emergency about how decisions ought to be made can be very helpful. Though health-care directives are useful in this regard, they need to be re-assessed as the situation changes. Convening multiple systems that impact family life so that there is a shared understanding of what is possible and what are the wishes of the family will sometimes address issues of fragmentation that lead to unwanted decisions. Integration of services also adds to the possibilities that families have of accessing needed resources.

Treatment Principles

Underlying these conversations are the principles of therapy, or the backdrop of any engagement in the treatment process described below:

Shared human experience: No one avoids illness and death. It is an experience that bridges, by its very nature,

the therapist/client relationship; therefore our capacity to be seen is crucial in entering the often lonely experience of illness and death.

Spiritual Practice: Thinking of the therapy room or someone's home as a sacred space. Evoking the strength of prayer, meditation, not being afraid to ask for help in facing the unknown. Starting with silence, leaving time for meditation ending with silence. Sharing one's own spiritual practice and prayer.

A Narrative Overlay: Arthur Frank, in his article about illness and deep listening, describes three different kinds of stories related to serious illness. They are: Restitution Stories in which there is a positive resolution (this kind is a favorite of us therapists), Chaos Stories in which things remain ambiguous (our least favorite kind), and Quest Stories in which the exploration of the unknown is a goal of the therapy.

Social Activism: Patients are often marginalized. They are a group fighting not to be silenced, and part of the therapy is advocating with them for their rights.

Examples of Treatment Issues at Different Stages of Illness

At diagnosis: Keeping things the same—a wish not to tell. A man 77 years old is diagnosed with fast-growing prostate cancer. He is experiencing a profound sense of disbelief because, though he has been having difficulty with urination, he has been told over the last three years that this is normal. He's also been told that if he does have prostate cancer it is most likely to be slow moving and he will die of something else. No tests are done until very recently, when it is discovered that the cancer is fast-moving and advanced. While he is dealing with this disbelief, he has at the same time to decide about whether or not to choose the conventional treatment or an experimental treatment, and where to get treatment. His children are scattered. His wife is highly anxious and wants a decision to be made immediately. He wants to go slowly, still focused on his disbelief that the doctors he had had faith in seemed to have made a mistake in his case. His focus is on keeping things the same. His wife's focus is on fixing things. Slowly his adult children, who up until this time have never participated in their parents' decision-making process, join their parents in making a decision—the best decision that they can make, but still a decision with uncertainty. In this family, this has a surprising enlivening effect as if everyone knows that they don't know what will happen, and so they reach out to each other and build on the strengths of their relationships.

Note: There are many reasons for patients and families to wish not to speak of illness. It often creates a sense of isolation as one is seen as different. It can be seen as weakening. Around particular illnesses there are many fears and judgments. Communicating about illness can have negative effects on employment and parenting responsibilities. *Understanding the reasons that people avoid talking about the illness can help the therapist work with the unique timing and pace issues within each family.*

Ongoing Crises: Living with Ambiguity

In another family that I am working with, the father, age 50, has fast-advancing ALS. He cannot communicate except with a raise of his eyebrow. Though he has decided not to go on a ventilator, there are many caregivers, involved and the ALS Center continues to try to find ways to relieve his symptoms. His mood vacillates between passive acceptance and depression. He is on antidepressants. His wife is overwhelmed. She is angry that everyone keeps expecting her to do more. She cannot sleep at night. One daughter has begun her first year at college; another daughter is away at a boarding school. We meet together as a family. Each family member has extraordinary pressing needs that seem to conflict with each other. We have a series of conversations in which the grief that is the strongest shared experience is brought into their conversation with each other. With this shared experience, sorting out who needs what, who else might help, becomes clearer, though this is a good example of an ongoing chaos story that has no good ending in sight. Sometimes even taking the time for therapy feels like a burden since there are so many people providing different services.

Death and Dying: Letting Go

Sometimes people can make a conscious choice to die, as Ron did in turning off his ventilator. It took many months for him to make this decision. We had conversations with family members, ethicists, psychotherapists and spiritual teachers. Once he decided to turn off the ventilator off, he went through the process of saying goodbye to the important people in his life, even though he could barely speak. More often death is not planned, but sudden, and often a crisis. Inviting families to include conversations about death and dying can be helpful, but often patients resist this fiercely as they hold onto life. Sometimes these conversations work better not all together but separately, with different family members at first and then leading to a wider discussion. When families with adult children come back together as a family often old hurts reappear. These need to be addressed and everyone needs some time to catch up with each other in order to move forward together. Families with younger children have to match conversations about death and dying with the age of each child.

After Death: Going Forward

As I said at the beginning, many issues of distress last much longer than people expect. Careful assessment is often needed. Different family members have different responses. When working with children in particular, it is sometimes difficult to sort out what is PTSD and what is grief. If supported in these differences, family members and the family as a whole often mobilizes new resources to transform itself.

Summary of Suggested Therapeutic Practices

Diagnosis

Dilemma: Maintaining the familiar with radical change

1. Providing a safe container for the expression of intense shock and disbelief.
2. Facilitating conversations about the diagnosis with children and extended family members.
3. Bearing with the family the ambiguity of not-knowing the outcome.
4. Searching for ways to maintain the normal everyday of life, especially for children.
5. Shifting anxiety about not knowing to finding out information from others.
6. Discussing ways that other family members and/or friends can participate in the crisis.
7. Helping families make and/or face medical decisions and prepare questions for meetings with doctors.
8. Advocating for families in their dialogues with medical and insurance systems.

Ongoing Crises

Dilemma: Sustaining hope with continuing loss

1. Normalizing a distorted sense of time and feelings of anxiety and depression as predictable responses to ongoing crises.
2. Including your experiences with catastrophic illness and death.
3. Paying attention for and treating overwhelming depression or anxiety in the patient and family members.
4. Facilitating conversations about the meanings of illness and death in the family and in the wider social context.
5. Searching out underlying values, beliefs and family history that have led to these meanings.
6. Looking for stories and practices in the family and in the wider culture that offer other possible meanings and responses to illness and death.
7. Bearing and talking about the ongoing pain with the patient and the family as they witness the illness worsen.
8. Finding creative ways for the family to spend good times together within their limited circumstances.
9. Allowing for the different experiences and needs of the patient and family members.
10. Facilitating dialogues and planning that take into account these differences.

11. Convening a wider circle of friends and family to facilitate ongoing support networks.
12. Bringing nursing, medical, spiritual and social service providers together with the family to assess ongoing needs and to provide coordinated services.

Conscious death and dying

Dilemma: Knowing the unknowable

1. Providing openings for conversations about death and dying.
2. Tolerating and experiencing intense grief with family members.
3. Exploring beliefs, meanings and family stories about death and dying.
4. Participating with families in discussions about the economic, ethical, social and spiritual implications of life support systems.
5. Offering opportunities for friends, family members and spiritual teachers to participate in these conversations.
6. Discussing desired rituals and practices in preparation for dying and death.

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Learning objectives:

- Recognize assumptions and dilemmas faced by families facing catastrophic illness.
- Consider how principles of psychotherapy can be applied to working with issues of death and dying in the present.
- Understand some needs that can be addressed in therapy which are common to many families coping with these issues.