Psychotherapeutic Intervention: From Individual Through Group to Extended Network

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THERAPEUTIC PERSPECTIVE

In Chapter 2, we were introduced to the biological, psychological, and social aspects of Kevin, Helene, and Mary, and we learned the benefit of using a wide angle lens to let us see the total picture of their lives. In the same way, the perspective selected by the psychotherapist influences the therapist's therapeutic direction, as well as the therapy outcome.

In the case of patients with HIV infection, it becomes almost impossible to narrow the lens. They are embedded in their social networks and cannot be viewed from a purely individual perspective. However the issues are presented, the AIDS patient's significant others are inevitably involved. This involvement may be limited to their concerns about their own vulnerability to infection or extend to their feelings about losing someone they love. In addition, this disease involves significant responses from the community. Community agencies, self-help groups, and medical care providers have become intensively involved. Patients may also be connected to the legal system or be a member of a political action group.

Why should the psychotherapist be concerned about these systems at the clinical level? Although Mary's therapist saw her alone, it was impossible to view her without considering her children, her mother, her boyfriend, her socioeconomic background, her hopes and dreams. It was crucial for the therapist to understand these multiple systems levels, regardless of what form of clinical intervention was to be used. In the same way, Kevin's main.

concern was the care of his mother after he was gone. He hoped his spouse/ lover would continue to be a son to her. Kevin also dreamed about leaving a legacy to the community. He wanted to contribute to AIDS prevention and education—but not at the cost of those he loved.

How can we as therapists understand enough and deal with all the systems levels that concern our patients? In Helene's case, the therapist's sensitivity not only to her nuclear family system but also to her extended family and cultural background became critical. If we apply the model described and diagrammed in Chapter 2, we can more easily identify the systems of which we need to be aware in order to provide her with good clinical care. Following the diagram, and starting with (i) the biopsychosocial level, we expand to (ii) the level of the natural support system: Helene's nuclear family, extended family, boyfriend and intimate friends; her student colleagues and work system; her minister and religious community, and her primary medical care system (family doctor), and her community agency support (AIDS community service, AIDS Hotline). This brings us to (iii), the level of ancillary or artificial support system: the specialty AIDS Clinic, Helene's nurse and psychiatrist, her group therapist, and the group members in the AIDS Women's group within the psychiatric service.

In Helene's case, in order to obtain a truly ecosystemic view, we need to consider the next level. Level (iv) includes cultural, spiritual, and philosophical world views and incorporates world events at economic, political, geographic, and even geological levels. For Helene her cultural tradition was extremely important, and her migration away from her traditional context was motivated by political/economic factors.

In certain cases, issues pertaining to membership of minority groups (either gay, racial, or ethnic), disenfranchisement, and prejudice may need to be addressed. These issues impact at a political and economic level as well as at a personal level; failure to consider them may lead to failure of therapy. Patients might also be discriminated against for their behavior patterns, such as substance abuse, (which, of course, is a very high-risk behavior for transmitting the disease). Substance abusers are engaged in self-destructive behavior and have frequently given up hope at the social levels. Risk of HIV infection, or the disease itself, requires attention to the special characteristics of substance abusers and their families in contrast, for example, to those who are at risk or have acquired the disease through blood transfusion. The issue of vulnerability in self-destructive behavior is best viewed from a larger systems perspective and will be discussed below.

Not only the disenfranchised (although this group is perhaps most vulnerable), but anyone facing the possibility of HIV infection feels guilty, deserving of blame, and shamed. These feelings make it difficult for patients to engage in therapy and particularly difficult for them to bring their significant others into therapy sessions. In the pages to follow, we will

Joining the extended family system, both literally and figuratively, of patients with HIV disease becomes critical for many reasons. These are patients facing chronic illness and death. Despite the frequency of apparent cut-offs, connection to family takes on an urgency. Time is compressed for AIDS patients and their families—development and resolution of relationships that should take many years need to occur in a very short period. The disease also distorts, even to the point of reversal, the natural family life cycle. Children become critically ill before their grandparents and parents, often leaving their children to be cared for by the elders of the family. Even the future of the next generation may be threatened, if an only child is infected with HIV and cannot continue the family line by producing descendants. This signifies far more than the loss of an individual for it may be the loss of an entire family's future. Reconnecting the family's transitional pathway across generations, while looking for meaning in their value systems and contributions, becomes essential; helping them to deal with issues of death, dying and the loss to be suffered by survivors is key.

Therapists are not usually trained to deal with the imminent loss of young patients unless they have specifically worked in the area of oncology or Medical Family Therapy.^{2,3} They may also not be attuned to dealing with the family following the loss of their patient or to helping the patient and the family plan for the death of the patient and placement of his or her children. Where does the responsibility of the therapist lie? With whom is the primary relationship? Where are the boundaries? Does the therapist visit the patient in the hospital? At home? Who attends the funeral and who helps the family after the death? When does involvement in these activities become overinvolvement, or excessive countertransference?

The threat of loss colors every aspect of the therapy. It is usually perceived in terms of its negative consequences. However, there may be major positive effects of this time compression and urgency of reconnection. If the therapist is open to engaging the extended system to its full capacity, a great deal of healing across the system becomes possible.

All of these issues can be addressed within a systems approach to therapy. The model detailed below is an adaptation of the Rochester Family Therapy Model which, in line with the seminal work of Speck and Attneave, ⁴ applies network theory as an effective means of change. Unlike Speck and Attneave, who used family networks as a component of therapy, usually as a "last resort," the Rochester Model considers it the method of first choice. ⁵⁻¹⁴ Similar to Speck and Attneave's conclusions, we've found that the more extensive the network, the more effective the treatment. Also, the earlier the involvement of the larger network in therapy, the more rapid is the healing process. Various other network therapy approaches have

developed over the years, following Speck and Attneave's work. 15-19 However, the following pages reflect the use of the Rochester Model.

THERAPEUTIC PRINCIPLES AND TECHNIQUES PART I. OUTLINE OF THE THERAPY SESSION

1. Joining and Determining the Level of Intervention

Therapists need to be particularly sensitive to generational hierarchies, non-traditional family constellations and issues of gender when working with these clients and their families. We find it helpful to encourage all present to greet each other by physical touch, which normalizes the process and helps it resemble everyday social exchange. Joining techniques such as utilizing one's position in the room and the sequence of handshakes and verbal participation are also useful.

The complexity of levels that become evident during the joining process and bear consideration when treating people who are infected with the HIV virus is further illustrated by the case of Amy:*

Amy was a 39-year-old woman who abused cocaine and was diagnosed as being HIV positive. Amy presented for therapy stating that she was severely depressed and experiencing great difficulty in managing her teenage children. Shortly into the session, Amy revealed another purpose to her visit when she produced a disability form, which required urgent signature as she was out of funds. Her economic crisis had arisen because, being only HIV positive and not diagnosed with AIDS, she had no access to medical care.

As Amy's personal history unfolded, it became apparent that her case could easily have confounded an individual therapist committed to the confidential psychiatric care of his or her patient. It could also have stymied the enthusiastic therapist committed to the immediate resolution of the patient's problems. Amy's situation raised questions of what level to intervene at, which treatment systems to include, what priorities to set, how to identify manageable goals for treatment, and how to design the process to achieve the desired outcome of therapy.

History revealed that both Amy and her fourth husband, Brian, had been heavily implicated in the cocaine trade. Both of the children hated Brian and blamed him for bringing cocaine into the house.

^{*}Therapist, Ann Zettelmaier Griepp, M.D.; supervisor, Susan McDaniel, Ph.D. This case was treated in the Family Therapy Training Program of the University of Rochester.

Violence had become a common occurrence in the home and the children had also witnessed their parents' involvement in outbursts of violence in the streets.

Amy's own family lived in Europe and was not easily accessible to her. Her move was partially an attempt to expand her family supported by including the children's own father and his extended family who were from the area. She wanted to ensure that the children would be taken care of in the event of her death. Her contact with her ex-husband had been minimal, however, and when she arrived in upstate New York she found that he was no longer living there.

Mental health status examination was essentially normal, with evidence of some anxiety and depressed mood. There was no sign of major depression or suicidality, nor was Amy psychotic. Her cognitive functioning was normal and there was no sign of neuropsychiatric problems.

From the above, the therapist determined that the issue of psychiatric disability was marginal, particularly since HIV infection was not then seen as qualifying the patient for disability. In order to resolve the therapeutic dilemma, the therapist decided to employ the patient's motivation for disability to aid her in the therapy. The therapist insisted that she was unable to make a clear determination without the assistance of Brian and the children. The therapist was now involved at both the individual/biopsychosocial and nuclear/relational family levels.

2. Establishing Strengths and Resources

Amy, Brian and the two children presented for the second session. Shortly after the therapist had developed rapport with Brian and the children, and reconnected with Amy, the session commenced with Brian's statement, "Doc, here I am, HIV positive. It's a bitch to be dying of AIDS in the 80s."

The therapist hastened to look for positive metaphors and reframes to establish what strengths the family had to draw upon to help them deal with the overwhelming events. Families facing infection with HIV are invariably anxious, fearful, and somewhat depressed. They have frequently given up hope and feel responsible and guilty, or blamed, for their predicament. Many AIDS families belong to devalued, disenfranchised, or denigrated groups. These include the gay population, minority groups, inner-city lower socioeconomic families, substance abusers, and people who sell sex. They are already acutely aware of the manner in which they are viewed by society; AIDS only intensifies the self-denigration, guilt, rejection, and inevitable blame. Their cups are always half empty and it is dif-

ficult for them to envisage a future. Thus they are less likely to seek external resources that could assist them with their problems. Helping them to view their difficulties from a more positive perspective allows them to uncover options that may not have occurred to them.

A caveat is that positive reframes and metaphors intended to assist families must always be reality-based and the therapist needs to believe in them. An empty Pollyanna promise is of little benefit, since it undercuts the credibility of the therapist and prevents the building of a trusting relationship, an essential for successful therapy. In looking for a positive perspective to share with families, it is useful to explore the relationships prior to the current problems. Helping family members to get in touch with the positive aspects of their earlier relationships helps them to gain motivation, selfconfidence, and hope for dealing with current problems.

Brian was Amy's fourth husband; they had been married for one and a half years. Amy said that this had been her longest relationship since the dissolution of the abusive first marriage to the children's father. Amy had fallen in love with Brian, a likeable, funny disc jockey living a very glamorous fast life, who provided her with constant excitement. They were both facing the loss of this lifestyle and confronting the real possibility of their death. The therapist reframed Brian's earlier statement by suggesting that they all work out a formula not for "dying with AIDS in the 80s'" but for "living with AIDS in the 90s."

This created an immediate mood shift in the therapy session by focusing their attention on living one day at a time and gaining as much enjoyment as possible from those days.

In addition to helping the immediate family gain a more positive perspective, it is important to use a multigenerational perspective. The intergenerational models of family therapy have stressed the importance of the family context through time, generally including at least three generations. 20,21,22 With AIDS cases, it is particularly crucial to provide such a perspective, since both patient and support system could be easily demoralized if they looked only at the immediate situation. The rationale for this will be described in more detail later in this chapter in Part Two on the explication of the therapy model.

We have found that the further back one goes the greater the positive information one derives. An effective method for allowing patients and families access to their own competence is encouraging them to look for strengths and resources across the multigenerational extended family and the natural support system. In order to do this, we ask them to list family strengths that have come down to them across time from previous generations and that they would wish to have perpetuated in their children and grandchildren. A list of family strengths developed by Emily's family may be seen in Table 8-B later in the chapter. The list of strengths may be compiled during the initial phase of the session as part of the joining process and then expanded during the mapping process or it may be elicited during the mapping process. In either instance, it may be added to throughout the process of the therapy.

3. Mapping the Natural and Artificial Support Systems

Extended family and natural support system. Another method for assisting the family in the development of a multigenerational perspective is through the construction of a genogram, which is a graphic display of the extended family over at least three generations. This allows us to explore births, deaths, marriages, separations, and divorces across the extended family system and to gain an impression of multigenerational patterns. Genograms provide ". . . a quick gestalt of complex family patterns and a rich source of hypotheses about how a clinical problem may be connected to the family context and the evolution of both problem and context over time." The method and symbols we use for our genograms are those developed by Bowen²⁴ and detailed by McGoldrick and Gerson. An example of the genogram may be found in Emily's case, in Figures 8-1 and 8-2, later in the chapter.

We then expand the genogram into a transitional map, further examining and diagramming the many facets of change across time and how they may be connected to present difficulties. In an attempt to determine how the wider context may have interfaced with family life-cycle events depicted on the genogram, we include, for example: culture and country of origin and any changes over time; changes in values, traditions, rituals, religion or spiritual culture; geographic moves; major economic or political changes; natural disasters and any other major events.

Once these have been added to the genogram, we explore with the family whether there have been any family life cycle stages or other transitions that have been difficult for them, and whether these difficulties have been repeated over time across the generations or across sibling and cousin subsystems (i.e. vertically or horizontally on the genogram). If these appear, we mark them with the symbol for transitional conflict. This stage of mapping Emily's family will be found in Figures 8-3 and 8-4.

Since we generally use a color code to simplify the interpretation of complex lines, we have divided the genogram and transitional map of Emily's family into four figures to demonstrate the stages of their development (Figures 8-1 through 8-4). The color code we use in order to consolidate the transitional mapping process into one diagram is: black for all factual information, family members, and members of the natural support system; blue for natural support system relationship lines; red for problem areas or symp-

toms, as well as for members of the ancillary support system and their relationships to the family; and green for all transitions and transitional conflict

Once the transitional map is drawn, the interpretation is completed by discussion of the strengths, resources, patterns, and themes that appear across generations. This allows the family to realize the inherent assets of their traditions, heritage, and values, seeing how these may have extended across generations and reaching a blame-free understanding of current events. 25-29 The information is then consolidated into a time line, which provides a clear graphic of the coincidence of time-events and how they impact on the current situation. 30 Emily's time line may be found in Figure

During the session, we have found that the easiest way to include the family in the mapping process is to use a large sheet of paper attached to an easel. This can then be brought to subsequent sessions for review, addition, or interpretation.

Through mapping, using the methods described above, the therapist was able to discover many strengths and resources in Amy and Brian's family, despite the obvious difficulties they faced. She began by praising them for their move, emphasizing that they had brought the children to a place of safety. The therapist then extended the transitional map to include both Brian and Amy's extended families, as well as that of the children's father. The therapist identified an apparent cut-off between Brian and his family as an area to explore later in the therapy.

In dealing with AIDS families, the process of mapping the family and exploring the strengths and resources of the extended system raises several issues of particular importance. In particular, unresolved grief, loss, and apparent cut-offs are common and deserve the therapist's special attention. The inclusion of members of importance in the support system, beyond the extended family, was also necessary in the case of Amy and Brian.

Amy had two very close friends living in the area, and one of these became her major resource during this time. Amy, Brian, and the children lived in the friend's home and the friend took very good care of them. If one fails to include the friendship network in one's questions, important information and resources may be missed. In addition to friends, inquiries should be made about linkages with other natural support system resources such as family doctors, clergy, neighbors, employers and work colleagues, and community support agencies. Amy had not had time to make these connections, and, in fact, had not even found a primary care physician by the time she presented for psychiatric help. The therapist was able during

the mapping process to identify this deficiency and took responsibility for linking her with the local AIDS clinic.

Ancillary, professional, or artificial support system. Although Amy had not had time to connect with an ancillary professional support system, her application for disability was steering her in this direction. It had begun to activate the relevant social support services. In dealing with HIV disease, therapists and counselors generally find that multiple services and professional helpers are involved during the course of therapy.

Healing losses, apparent cut-offs and unresolved grief: Amy appeared to have very little contact with her family in Britain, with the least contact occurring between Amy and her mother. Amy had left her mother, a prescription addict and alcoholic, in anger 20 years before and had no idea how to bridge the gap. The lack of contact had reached a stage of almost total cut-off between them. She had, however, maintained contact with her brother, thus keeping up with family events. She knew that her mother had cancer and was dying.

Amy's capacity to remain informed about family events despite her apparent cut-offs is not unusual. Research into substance abusers who appeared to be totally out of touch with their families has shown us that cut-offs are often more apparent than real. The substance abusers maintained detail knowledge about important family occurrences through a roundabout route of communication.³¹ In our clinical experience, the same applies within the gay population and with others at risk for this terminal illness.

Therapists may be pleasantly surprised if, in exploring this issue, they initially refrain from asking about close contact, instead asking about important family events such as births, deaths, illnesses, graduations, and marriages. Then, the inquiry can pursue the means by which this knowledge was acquired. Once the therapist has allowed the patient to express concern for the family and for to individual members, the patient will find it easier to deal with resolution of the cut-off. This is of particular urgency in HIV disease, since people die unpredictably and time for resolution and healing is limited.

Amy expressed intense guilt about the cut-off from her dying mother and sadness that she was unable to afford a trip to Britain or even a phone call. While facing her own death, she realized that she would never have contact with her mother again.

4. Establishing Treatment Goals and the Therapy Contract

When dealing with people who are overwhelmed and feeling unsure about being able to make any positive changes in their lives, it is useful

to establish clear treatment priorities and goals. Instead of identifying problems as such, the family may be encouraged to convert them into specific goals. Drawing upon the strengths and resources identified earlier in the session, the therapist might ask the patient and family, "What would you like to achieve using the multiple strengths that we have discovered?" Patients and families are frequently able to identify particular strengths that would be useful in achieving objectives that earlier in the therapy session seemed out of their reach.

Amy and Brian identified two primary goals as part of this process: their children's safety and ensuring that the children would be taken care of after their death. They were also able to express their wish, with some uncertainty as to how they would achieve it, to reconnect with their families. In addition, they agreed to work on their own issues with death and dying. Another goal was to maintain a sense of living life to the fullest while facing

The challenge for Amy and Brian's therapist at this stage was how to help them develop a realistic plan to deal with their request for disability and when (and even whether) to take on the issue of their substance abuse, since the latter was not listed among their goals. The therapist made several decisions about therapeutic choices and directions. She elected not to take on Brian and Amy's drug use at the initial family session, feeling that this would ensure their not returning for further therapy, especially since drug treatment was not their immediate priority. It was necessary to join the family and allow them to achieve some concrete sign of success in their stated goals before the other problems could be tackled. However, even if a family does not deal with an issue of this magnitude fairly early in the therapy, the addiction, and whatever other problems are being denied, will eventually have to be confronted. From the clinician's standpoint, it is primarily a matter of timing.

5. Enactment

In order to show the family that they are capable of meeting their goals, and that the strengths and resources that they have identified will enable them to do this, it is useful to employ the technique of enactment in the therapy session. 32 Patients are encouraged to identify a primary goal, to state clearly which strengths they will be drawing upon to achieve it, and to start practicing how to do it right there in the session. If this is not done and the first attempt at home fails, they may lose their confidence in themselves and in the therapist. It may be extremely difficult for the therapist to help them regain at a later stage the feeling of competence that they have lost. When one is determining the goal for enactment, it is advisable not to choose the entire goal, but rather to identify a smaller, realistic component

of it, so that success may be ensured. A little success is far better than a major failure. In Amy's case, the goal that she and Brian identified as their first priority was reconnecting with their families. They both felt that the most urgent agenda was getting in touch with Amy's dying mother.

The therapist suggested that Amy call her mother immediately from the session. Amy was too frightened and did not feel ready, so the therapist assisted Brian in working with Amy to help her prepare to make the call at the next therapy session. Once she had become more comfortable with the idea and had successfully role-played the phone call, Brian was asked to practice again with Amy at home. Amy felt better as a result of the in-session enactment, supported by the homework, and was able to speak with her mother. The healing had begun.

6. Homework

Once the enactment is successfully concluded, homework tasks need to be set, again based on goals, strengths, and successful enactment. ¹⁴ In Amy's case, the homework was an extension of the in-session enactment, drawing upon the strength of the marital relationship and the couple's determination to resolve relationships for the sake of their families of origin and their children. Homework needs to be circumscribed, realistic, and highly likely to succeed. For this reason, basing it upon the in-session enactment that the therapist and family have seen succeed is very helpful. Should the family return feeling bad about failure, the therapist needs to take full responsibility for having set unrealistic tasks. In Amy's case the therapy proceeded successfully. Amy had been able to have a meaningful talk with her mother and to resolve their cut-off in a warm and loving way during the in-session enactment. It appeared that she and Brian would be capable of following up the family networking and reconnecting outside of the therapy sessions.

The principles outlined above form a useful outline for both the first and subsequent therapy sessions. Again, it is important to establish strengths and resources early in the session, during the joining phase and while constructing the maps. Doing this makes it far easier for the family to establish realistic goals with hope of a good outcome. It is also useful to ensure that closure of the session is formalized.

7. Session Closure and Formalized Greeting

During formal closure, repetition of some of the joining techniques are very useful. For example, shaking hands with AIDS families takes on far more meaning than in other contexts. It is important during both the opening and closing joining to ensure contact between all members of the group

present (including patient and therapeutic systems). This formality also assists in normalizing the session by helping families to feel the similarity between this ritual and those of other normal family events (such as financial distress, relocating, career planning, births, weddings, and funerals).

THERAPEUTIC PRINCIPLES AND TECHNIQUES PART II. EXPLICATION OF THE THERAPY MODEL

The previous section provided some specifics for organizing the first therapy session. It gave a feeling for how treatment is initiated and for some of the particular interventions we use with such cases. This section presents the major components of the Rochester Model that apply to the treatment of

- 1. Cooperation across systems and the engagement and building of a therapeutic team
- 2. Explicating the transitional pathway.
- 3. Resolution of unresolved grief, loss and cut-offs.
- 4. Recognizing scripts, themes and issues of loyalty.
- Exposing secrets.
- 6. Resolving transitional conflict and its sequelae.
- 7. Sensitivity to issues of culture and gender.

1. Cooperation Across Systems and the Engagement and Building of a Therapeutic Team

If one is thinking systemically, one has to be aware of all of the levels of the system and their impact upon each other. In HIV disease this is crucial because the biological component will have a major impact at all levels and will cause significant stress across the system.

If therapists remain unaware of the patient's connections with other individuals and systems, they may find that their work is apparently being undercut by others. This may not be intentional, but if communication is incomplete, goals and directions may not be synchronized. As a result, despite the best of intentions all around, people may end up working at cross-purposes. At best, resources that are not pooled may be missed; yet, these cases need all the support they can get.

When one first engages the patient, it may be difficult to persuade him or her to attend the first session with other members of his or her significant network. At the same time, the further the therapy goes, the more difficult it becomes to engage these others. At the least, the therapist should make a careful effort to list all the other members of the extended family, natural

support system, and professional system interacting with the patient at a significant level. One may easily achieve this by asking the patient, "Who cares about you and what happens to you? Whom do you see regularly? With whom are you in contact by phone, letter, or visit?" It is often helpful to persuade the patient that we as therapists do not have a history with them, we haven't raised them, and care as we might, we can never love them as their family does. Stressing that we need help in order to provide the best possible therapy assures our patients that we will not blame or scapegoat beloved family members.

Patients may resist involvement of their family members in order to protect them from the horror of the disease. Many of these patients (particularly those with a history of substance abuse, but also those whose families have experienced major losses through time) are scripted to die early, ³³ are extremely protective of their families, and are resistant to their coming to therapy. They may be scripted as the saviors of their families, which makes them even more protective. ³⁴ Convincing them that the family will not be harmed, judged, or blamed, but used as a major resource, with acknowledgment of their inherent strengths, lessens the patient's resistance to involving family members in the therapy. Ascribing a noble role to their resistance aids in this process. ³¹

While one is engaging key members of the system, however, the other members of the natural and professional support system need to be included in the planning of the therapy. Minimally they should all be contacted; as many as are relevant should be included in the therapy team. Therapists may be surprised by the readiness of the family doctor, the employer, the teacher, the close friends, and others to become involved in helping the patient. This may take considerable effort on the therapist's part, but the result makes the effort worthwhile.

In contacting members of the professional network, one of the basic questions is how the medical team can best work with the mental health providers, the patient, the natural support system, and the rest of the professional support system, including the therapist. In AIDS there are important medical questions, such as the side effects of AZT and DDI, that the entire team needs to take into consideration. There are negotiations with all members of the team about how involved each member should be and how roles should be delineated. Who should be informed about medical complications, or about emotional stress? Where should boundaries be drawn? If consultants are involved, how much should they be included in the intimate family information?

These issues are particularly important for mental health professionals such as psychiatric nurses, social workers, psychiatrists, psychologists, and counselors, all of whom have had some training at various levels in medical science, but who through their identification with behavioral issues may

not be regarded by the medical team as legitimate team members. We need to be cooperative team members, without being intrusive or unintentionally undercutting the medical treatment. At the same time, we need to assist the team in being aware of, and sensitive to, the patient's personal, social, and psychiatric situation. A constructive approach is to remind the medical team members of their inherent knowledge of psychiatry and families, thus drawing upon their expertise, rather than lecturing to them.

Stanton, Todd and associates describe many effective techniques ed nt ns

engagement of drug abusers and their families that may easily be applie to this population. ^{31,35} In addition, Table 8-A provides a listing of frequer resistances to involvement of both natural and professional support system and some possible responses to them.	
TABLE 8-A Engaging AIDS Patients and Their Families RESISTANCE	
Logistics & Geography	RESPONSE
"My family lives too far away; I haven't spoken to them in years." "I don't know where they are."	on the telephone." "It must be very bord and
"We live so far away and I'm afraid to drive."	you trace them." "Well maybe your Dad will make this trip when he knows how in
"They're too old to make that trip."	"Wouldn't they be burt if
"My husband couldn't possibly take a day off work." "He's in prison."	"How about meeting after work next time?" "Why don't I speak to the
"They don't even speak English."	"Why don't I speak to the warden and we can all meet there." "Well, we're fortunate to have an inter- preter in the bospital".
"My doctor/minister/therapist is far too busy to come." "Don't call my counselor/doctor. I haven't seen him/her for years.'	preter in the hospital" or "Could you or your wife translate?" "Why don't I give it a try and see if we can coordinate something?" "It would be really helpful to catch up on some of the details of your earlier history in light of the present."

Secrecy, Privacy & Protection

"They don't know about . . . my being gay . . . an addict . . . the rape . . . "

I don't want to hurt them."

"Our family doesn't talk about things."

"My mother is critically ill with heart disease. My father's been sober for so many years this would drive him back to drink and kill my mother."

"This man is my family and he would be hurt if I asked my parents in."

"I don't know who or where my father is."

"How can you make him suffer in his dying days, why can't you let him die in peace?"

"I don't want my children to know. I want their last days with me to be happy."

"My father would never forgive me if he knew. I don't want him to know. I don't want to see him because he'd find out."

"I want them to remember me as I was."

"Well, why don't we just start by asking their advice about the things they do know? You and I can decide together when it's time to share the rest with them."

"Maybe they're not as fragile as you think. When your kids are grown, would you want to be excluded from something this big?"

"Well, maybe this happened to create something so important that it had to be talked about."

"Wouldn't it be more likely to hurt them if they find out only after your death, and you're not there to help them through it?"

"Doesn't he love you enough to want what's best for you? I'm sure you have enough love for them all."

"Let's invite in the others who played a fatherly role in raising you to help me help you. Maybe they also know where we can start looking for him."

"Since we can't guarantee his dying before you, do you really want him to have to deal with this alone?"

"Perhaps it would be kinder to the children to have the mother they've always relied on to help them through tough times be there for them to deal with this? It's the toughest situation they've ever faced. Let's not let them do it alone."

"Maybe he'd rather hear it from you than from others. Are you so sure he'd never find out? I can help you share it with him in a gentle way."

"Didn't your parents change your diapers and clean your vomit when you were small? Don't you think they'd regret missing precious time with you? Would you not visit them if they were frail and smelly?"

"My family would never be able to go back to church."

"We live in a small town, everyone will

"My father/husband/wife will lose his/ her job if they find out."

"My kids will have trouble at school."

"They've lost so much, why drag them in to suffer more?"

"He really wouldn't want to see me after all these years. He wouldn't want me to see him like that."

"He thinks I don't know that he's gay/IV drug abuser/was in prison . . . "

"I don't want my mother to know my baby has AIDS."

"We'll tell them he has cancer, they're too young to understand."

"They'll just talk about their problems and not listen to his . . . it'll be more painful for him."

"Isn't that the best place for them? Is it not a truly Christian/Jewish/Muslim place of forgiveness, community and friendship? Isn't that where they'd receive their best help after your illness? Have no sinners ever been forgiven there?"

"Yes, that is hard. But it can also be a relief when everyone knows and the secret is finally shared. It will also make it easier for the family to have support through this hard time."

"Isn't it more important to give him/her an opportunity of protecting himself/herself?"

"There are very few good teachers who wouldn't want to know what the kids were going through so they could help. Why don't you start by sharing with the teacher that you're critically ill, and let's take it step by step from there?" "Aren't they going to suffer more by being excluded and having to deal with it all of a sudden? Including them now will allow you to help them get used to it all gradually."

"Wouldn't he want to make his peace with you?"

"Secrets in families are never really secret. The fact that you know shows that. He realizes as you do that people who love each other always get the news somehow."

"Don't you want your mother to be able to protect herself from infection? How can she do that if you don't tell her? Is there anyone to help you tell her?" "Well maybe that's a start."

"I have a lot of experience with family sessions like that, and you'll be pleasantly surprised at how they'll tune in when they realize how important it is to him."

Apparent Cut-offs & Scapegoating

"You're not going to be able to get them in. I won't bother to give you their address because they've never come when I've asked."

"I'm the black sheep. They really don't want anything to do with me."

"They'll come in but they're not very . . ."

"She's always been the one who causes trouble."

"We're not going to bring our brother and sisters in; they haven't been drinking; they don't have AIDS." "You'll never know if we don't try. How much worse can it get? If you were in their shoes, wouldn't you want to be given a chance?"

"Are you going to write off the possibility of a change? Maybe when they know how serious it is, they'll respond differently."

"Never mind, I'm used to dealing with that."

"Well, maybe this is her chance to turn it around. Let's give it a go."

"Maybe they've always felt helpless around you, and now there's something that they can do."

Threate

"If you bring them into the same room, they'll kill each other."

"They're all addicts, and they'll make me relapse."

"He's responsible for all this and I might kill him."

"I don't want my parents to have the children. If they come in, they'll fight my husband for custody."

"You don't really want my ex-husband here? He's never been a father to them and will just make them miserable."

"This isn't how I want to handle it. If you bring them in, I won't come back."

"We haven't had a murder in this room yet, and we've seen a lot of people who felt this way. We'll stay with the topics they agree on and avoid the rest for now."

"I don't believe that your sobriety is that fragile. Maybe you can also help them now."

"Who else needs to be here to make sure that doesn't happen?"

"And if they don't come in, they won't? Surely the only hope of negotiation is while you're still around to help them, and I've done this a lot."

"He's still their father, and maybe you can help them see the man you married while you're still alive. Otherwise, they have no hope of ever thinking enough of themselves with a father like that."

"What are you afraid might happen? I know from getting to know you that your parents must be really special people who could help us both a great deal."

Denial

"He's not that sick, if we come he'll think he's dying."

"Well, maybe you need to explain to him that it hurts you to think of missing lots of time to be together before he becomes really ill."

"I'm not ready to deal with their grief, I'm not really sick. This could take vears, why bother them now?" "Why bring in my doctor, this is just a

"Maybe you can plan a fun visit so they'll have lots to remember when you do get sick."

"Isn't he the best judge of that?"

Engaging Kevin Frost's family provided an interesting challenge to the therapist. The initial phase of engagement and joining had been easy. Both Kevin and Bill were forthright about their issues, open to the therapist's discussing the case with Dr. Brown, their family doctor, and even to inviting him to a session if necessary. They assured the therapist that there were no secrets that they had to keep from each other and each declined the opportunity to spend a portion of the session alone with the therapist.

When it came to including Kevin's mother, however, resistance was apparent. As Kevin and Bill mentioned her, they were very quick to explain why it would be inappropriate to include her at the next session: "She's old; she can't make it in because she's bedridden and in a wheelchair; and anyway, we're going to New York for a few days." The therapist went with the resistance, quietly insisting that she would work with them to resolve the physical difficulties of getting mother in. The therapist promised maximum flexibility. She offered to arrange for special transportation and to have the session at any time that suited them all; if the mother could still not be at the next session, she made it clear that the session would be devoted to planning how to get mother in.

The next session was held in the hospital. Kevin required emergency admission shortly after his return from New York. The therapist realized that time was running out and decided to invoke the assistance of other members of Kevin's network. Once the social worker was in contact with Kevin's mother, the rest was easy, as it generally is. Most mothers do choose to visit their sons in hospital and the social worker was able to organize the visit.

In cases like Kevin's where the patient is so reluctant to involve people who love him, it is often helpful to find a way to give the choice of contact to those people in order to get around the issues of protection. The therapeutic team at this stage consisted of Kevin, his spouse, his mother, his family doctor, his therapist, the case manager and members of his support group from the community service AIDS agency, the hospital social worker, and other hospital staff. The therapy could proceed.

2. Explicating the Transitional Pathway

Treatment interventions are best designed to create continuity between past, present, and future. The therapist needs to ask "Why now" when therapy is requested.³⁰ This question, asked in a gentle nonjudgmental way, allows the patient and family to explore the interface of what is happening with regards to their HIV infection in conjunction with what is happening across the nuclear and extended families. This is done by exploring family life-cycle stage, developmental stage, ethnic and cultural background, and the resolution of transitions or presence of transitional conflict. We have found that this interface allows the therapist and family to understand the context of the presenting problems. Emily's story, and her genogram, transitional map, and time line (Figures 8-3, 8-4, and 8-5) will illustrate this.

Once this is done, the information can be normalized by the therapist rephrasing it in terms of the events and changes that the patient and family have experienced. The family is able to see that earlier patterns that have become entrenched, and often problematic, were originally adaptive solutions to unavoidable events. This enables them to recognize the relationship between events over which they had no control and the emergence of their current difficulties. The transitional perspective allows them to hope for change, often for the first time, and to realize that they have a choice of whether or not to perpetuate the patterns. It also alleviates blame and guilt, since the origin of problems is understood in a logical, sequential, and broader way. They are freed to view their current problems or dilemmas in terms of past experiences across a multigenerational history, hence allowing them to make logical choices for their future. 13 This is accomplished by assisting the family and natural support system to produce an extended genogram or transitional map upon which details of changes such as geographic moves, losses, spiritual philosophies, ethnic and cultural traditions, and value systems can be mapped (as illustrated below).

The confluence of events, both vertically down through generations and laterally across sibling systems, allows both therapist and family to understand themes, scripts^{25,28,29,36} and current events in terms of where the family came from. ¹³ When the transitional pathway has been explicated—that is, once they understand where they come from—they are able to envisage where they are and to take control of where they wish to go. ¹³ The transitional pathway is thus connected from past through present to future. This is explored further in the section describing the importance of family themes and scripts. A graphic method for drawing these confluences that is particularly easy for families to follow is the time line. ³⁰

Where families have major difficulties in negotiating a particularly problematic phase of their lives, normalizing this difficulty is therapeutically very helpful. By explaining to families that it is normal to experience difficulty when under siege, one frees them up to be able to start the resolution process. ^{37,38,39,40,41} Landau also determined that more than three stress events happening concurrently or within a short time period precipitated

symptoms in the family. 13 Many families, surprisingly, do not realize how many stressful events are involved in the current problem. When they do, they can appreciate that their difficulties may serve a purpose and may, in fact, be a means for adapting to the stress.

Kevin's therapist, with the assistance of his natural support system, was able to construct a transitional map that formed a key component of the therapy. Kevin's older brother had committed suicide at a young age and his only other brother had been taken from the family through a court order while in his teens.

Clara, Kevin's mother, was extremely attached to Kevin and constantly reminded him of his importance to her since the loss of her other two sons. As is common in families who have lost children, the remaining child has an enormous responsibility to fulfill the roles of those who are lost. As a result, he never wandered very far from home and he and his mother had not managed to negotiate the "leaving home" family life-cycle stage. 42 Losing children is a reversal of the natural family life cycle and frequently results in unresolved grief and difficulty in negotiating subsequent life-cycle stages. 43,44,45

When a confluence of life cycle or externally induced events results in a member, or members, of a subsystem moving at a pace or direction different from the rest of the system, a transitional conflict results.8 This delays the resolution of the next stage. Families may appear to be stuck at that transitional or life-cycle stage. However, in reality, family members are oscillating rapidly between the extremes of the transitional poles, but not moving forward to resolution, thus appearing stuck. For example, in Kevin's case, he tried very hard to leave home, moving halfway across the country, but failed abysmally, and returned to his hometown, where, inevitably he ended up living with his mother.

The therapist subsequently learned that Kevin's father had died a long, lingering death from cancer five years before and that Kevin felt that his father had died in an extremely brave and honorable way. Kevin had been able to deal with the probability of his own impending death, but struggled with his mother's pain. His strength was a script handed down by his father. Kevin was determined to follow his father's example and die with as much dignity as he felt his father had. In fact, he believed that this way of dying would serve as a memorial to his father and leave a very meaningful legacy to the family left behind.

In addition to all these losses, Kevin's mother had experienced a recent illness that made it impossible for her to live independently, necessitating the move to Kevin and Bill's apartment. Kevin's mother had not really dealt successfully with all her grief and, with Kevin being her only remaining child, it was not surprising how reluctant he was to put her through more pain or to have her know that he, too, was going to leave her. Once the therapist understood this, she also understood his resistance to involving his mother in the therapy and realized the critical significance of doing so.

3. Resolution of Unresolved Grief, Loss and Cut-Offs

Kevin's mother more than met the criteria of three or more major transitions occurring around the same time in her life. Two of the losses were both unpredictable and out of synchrony with the expected family life cycle. Loss of children in itself constitutes a reversal of the family life cycle, and parents have enormous difficulty resolving this type of event. 46

In most AIDS cases, the reversal is a probability; however, in this familys case these losses represent not only a reversal of the life cycle, but losses of an atypical and overwhelming magnitude. 38 Patients dying with AIDS who are able, like Kevin, to find a spiritual strength and come to terms with dying, often unintentionally aggravate the reversal of roles by becoming parental caretakers for their elders' grief.

The three central principles in dealing with loss (as with other transitional conflicts) are reconnection, continuity, and recalibration. These need to be achieved in order for the family to perceive the complete transitional pathway so that they are free to hope and to plan for a meaningful future. The therapist's first task, after identifying cut-offs and losses through the mapping process, is to help the family assess the possibility of physical reconnection. By drawing upon the family strengths and with the assistance of any or all members of the natural support network (and where necessary, the professional support system), connections that have not been dreamed of become possible. Unfortunately, in this case, reconnection with Kevin's brother proved an impossibility since the social service agency was unwilling to facilitate its happening and would not disclose his new identity or place of residence.

When Kevin's family realized that reparation of the cut-off was impossible, they nonetheless felt a great deal better for having tried. The guilt associated with the cut-off had been very destructive and some of this was relieved by the effort. In this instance, as in most cut-offs, the disconnection was associated with considerable ambivalence, which is an invariable component of the loss and guilt. In Kevin's case, he had taken responsibility for being the "good son" replacement for two brothers and the energy and discussion around the reconnection attempt relieved him considerably. This allowed the therapist to question his need to remain the "good son" around his process of dying and around the "secret" of his homosexuality.

Once contact or the possibility of contact across a cut-off has been initiated and the family is feeling more competent and hopeful, issues of loss through chronic illness and death may be dealt with. With AIDS cases, one

is dealing not only with resolution of past losses but also with the probable or real loss of the patient.

AIDS, unlike many chronic illnesses, may resemble the intermittent course of cancer, or even of malaria, in some ways. This potential rapid recycling of the illness makes it very difficult for both the patient and the people who love him or her to continuously readjust. At one moment they are in deep grief, saying their farewells and planning the reorganization of their lives (for example, who will take care of the children, where the patient will be buried, who will carry on his or her role in the family). Then, at another moment, a sudden remission occurs, and he or she is back at work, taking care of the children, and needing to be taken back immediately into his or

Therapists need to help families prepare not just for the eventuality of death, saying farewell, and planning the ongoing life of the remaining family members, but also for helping the patient and family plan how to deal with dying—and living—dying—and living—possibly numerous times. This is particularly difficult for the parents of the patient and for any children he or she may have. This cycling may happen with remarkable rapidity. Family members may eventually get to the point where, having said their goodbyes several times and gone through as much anguish and grief as they can handle, they wish the patient dead. This causes unutterable guilt and remorse. Unless the therapist is particularly sensitive to this issue, it will never be mentioned and may leave long-term

Therapists need to normalize the reaction of family members to this intermittent cycle, explaining that when people love deeply, the pain of constant leave-taking and the peaks and valleys of hope and despair become intolerable to anyone. When something becomes unbearable, we all wish it away. Helping family members share their feelings with the patient allows the patient to forgive them feelings that he or she is bound to understand, if not share. This also allows the patient to expose his or her wish to be out of this impossible situation, without feeling the guilt of the suicidal person who chooses to leave beloved family members behind to suffer). În fact, his level of sharing can increase the closeness between patient and family, naking the rest of the time they do have together much more meaningful. also allows families additional time, for which, once the guilt is alleviated, ney may be grateful. They have more time than expected to redefine the ussion of the family, reallocate family roles and expectations, plan the meral together with the patient, and decide which family strengths and ilues precious to the patient will be continued to future generations, and whom. In this way, patients and families may consciously take charge recalibration, so the family is not disorganized by the death. HIV disease is both chronic and debilitating, resulting in many significant physical losses for both patient and family. Patients frequently fade away, losing their physical attractiveness and sex drive. Their faces change, they lose their hair, and they may be covered with unsightly lesions. They generally lose their energy and as a result lose their jobs and their capacity to support themselves. Their social life is inevitably curtailed, and they frequently feel like pariahs of society. Their self-confidence and self-image are badly impaired. They may become significantly depressed and, in addition, may develop neurological symptoms and signs, including dementia—a loss, at best, of intelligence, and, at worst, of self as has been described in Chapter 7.

In Kevin's case, he developed mild cognitive impairment, leading to episodes of confusion. He needed to learn several techniques to organize his memory, such as the use of a daily pillbox for his medication so that he could check at any time and know what he had taken. He also kept a notebook and diary, so that he would be able to reacquaint himself with periods of time that might otherwise have been lost to him. The therapist worked very closely with Kevin's spouse, Bill, and other family members to assist them in both developing and maintaining these tasks.

How can a therapist help a family deal with unresolved loss and grief from the past, while not losing sight of the enormity of present issues? Because of compression of the time-clock with these cases, therapy needs to be particularly goal-oriented and brief, as discussed earlier. Tasks that are past-related need to be very clearly defined in terms of present gains. They need to be both practical and concrete, with clear reward to patient and family. Kevin's mother was about to lose her last son, and Kevin was about to end the family line. Connection with the extended family was clearly of critical significance in this case (as in all AIDS cases) since continuity of the family values and heritage would have to occur through extended family. Guaranteeing this continuity allows hope to emerge and energy for dealing with emotional pain. The therapist was able to help Kevin identify members of the family who he felt would remain connected with his mother, in addition to ensuring that she and Bill would remain in touch. In order to take care of Bill, and his mother, Kevin also made close ties with the local AIDS community service agency.

In terms of Kevin's passing on the baton of his mission and value system, he decided that he wanted to leave a legacy of education about HIV disease that would be a constant reminder to his family that he was still with them in spirit. Many AIDS patients have chosen this means of contribution and connecting.

In addition, Kevin helped his family to design a quilt piece that they would always know contained his thoughts and emotions as well as theirs. The Names (Quilt) Project,⁴⁷ similarly to the Vietnam war memorial, serves the function of a communal graveside marker that can be shared in the

abstract by many and at a personal level by those who are directly involved. This Project is a collection of quilt pieces handmade by families, friends, and loved ones as mementos of persons who have died of AIDS. It is now 10 football fields in length and too large to be transported intact. Sections of the Quilt are exhibited throughout the U.S. and memorial rituals are held. In this way, families, health care providers, and communities may share their losses and their hopes for the future.

In order to allow patients and families to deal with impending death, therapists need to pay specific attention to resolving prior losses. In Kevin's case, the grief that was in some part unresolved was recent in the family's history. Frequently, unresolved loss may go back generations. It may include loss of a country in the cases of immigrants; it may result from divorce and subsequent cut-off; it may have been initiated by the loss of many babies through spontaneous abortion or during an epidemic (the 1918 Influenza Pandemic, the Ethiopian Famine of the 1980s) or through genocide (the Armenian and Jewish holocausts). Even where several losses are apparent in the present or recent generations, therapists need to inquire carefully about past losses, geographic moves, divorces, and migrations, since prior losses might well be aggravating the lack of resolution of present losses. 44,45,46,48 Unresolved mourning and loss within the nuclear or extended family are commonly associated with suicidality, as is illustrated by the following case.

Families may not deliberately conceal such losses, but instead may actually be unaware of how these losses could relate to the suicidal family member. 14 Therapists can take the family directly into the mourning process, compressing them to the original and unresolved point of transitional conflict and then moving them through this point in a new way so "they can complete the transitional pathway from the past, through the present and into the future. Because the different family subsystems may, perhaps, have been 'out of synch' ever since the point(s) of loss, this approach takes them phenomenologically, experientially, and structurally to an earlier point, holds them there briefly, and guides them forward."7,14

Julian Levine's losses covered many generations, including the loss of three of his nephews and nieces (i.e. the next generation). Julian, a 30-year-old homosexual Jewish son of divorced parents, was admitted to the psychiatric inpatient ward with AIDS and suicidality.* He had

^{*}The therapy team consisted of A. Griepp, M.D., the referring psychiatrist; S. Scheibel, M.D., the infectious disease specialist; S. Baldwin, A.C.S.W., C.S.W., the family therapist (originally functioning as the supervisor to B. Grimstead, C.S.W.); J. Landau-Stanton, M.B., Ch.B., D.P.M., supervisor of S. Baldwin; the inpatient activities therapist, Laura Napolitano; the inpatient social worker, Yvorune Dohr; the outpatient social worker, K. Deuter, C.W.W.; and a chemical dependence counselor, R. Tocco, M.S., C.A.C.

been depressed for about 10 months with increasing vegetative symptoms (sleeping much of the time, and eating little) and had become progressively more isolated. He was not complying with his medical treatment, nor was he reliable in taking his medication.

Julian lived with a female maternal second cousin, Cathy. Cathy was the same generation as his mother, the daughter of his grand-mother's brother. Prior to this he had resided consecutively with his mother and father throughout and after their divorce, which occurred when he was eighteen, until their subsequent remarniages. He had made a brief excursion to California during the stress of the divorce.

Julian was the youngest of three siblings, from an upper middle class family. John, the oldest, was married to Pamela and had one surviving child, a little boy aged nine months. John and Pamela had lost two babies through miscarriage, and their little boy was a surviving twin. John's and Julian's sister, Willa, the middle child, had a two-yearold son and was pregnant. Julian and John were not at all close, but Julian was extremely close to both Willa and Pamela, and shared time with them equally. However, after the death of Pamela's twin baby, Julian spent more and more time with her. Pamela's sister had died from suicide following a severe depression, and she really understood Julian's suicidality. Without AIDS, suicidality is extremely common in families that have experienced catastrophic losses. In Julian's case, his physical malaise and the knowledge that he was going to die, along with the family grief, created in him the wish to die quickly. In fact, the metaphor used by the therapy team was, "the horizontal man." It was as though he were already dead.

Apart from family, Julian had no close relationships. He had never been involved in a long-term relationship and had come to terms with his homosexuality. The family therapy team encouraged Julian and his parents to bring in all the members of the family and friendship circle who cared about Julian, and would want to help the therapists. The members of the extended family who attended various therapy sessions, sometimes together and sometimes in subgroups, were Julian, his mother and stepfather, his mother's sister, his father, his brother John and wife Pamela, his sister Willa, and Cathy, the cousin with whom he lived. The natural support system was further augmented by a close grandmotherly friend of the family and the case worker from the local AIDS community agency.

In addition, the professional network was mobilized and participated actively, in varying combinations, throughout the therapy process. This professional group included the referring psychiatrist and infectious disease specialist, the in-patient team comprising the primary nurse, the social worker and the activities therapist, and an outpatient team of family therapists, social worker, and substance abuse counselor.

In the case of severe depression or suicidality, it is extremely helpful to mobilize as extensive a support network as possible to amplify the immediate family's efforts to save the life, or improve the quality of life, of someone they love. 14 Where immediate family members are intimately involved in the depression or suicidality, they may be rendered incompetent since the stressors impacting on the patient are also affecting them. In order to look for resources whose competence is not undermined by the acute stress, the therapist needs to expand the system by involving extended family and natural support systems. This invariably results in the inclusion of network members with a different perspective and without the same loyalty and other binds. A positive shift occurs and the patient and immediate family are influenced by the larger system, becoming more hopeful, and working together towards healing.

After the joining process, a family transitional map was constructed and an extensive list of family strengths established, as were goals for Julian. These focused on his quality of life and survival. The metaphor used by the team was Julian's converting from "horizontal man" to "vertical man."

An enactment based on these goals and utilizing the family strengths followed. The family had listed supportiveness and loyalty as key strengths, and their wish to take care of Julian as a primary goal. They identified his taking his pills as the most urgent priority. The enactment incorporating all of this was for mother to take Julian around the room to ask each member of the network in turn whether he or she would be there for him if he took his pills. They responded by surrounding him physically and all wept quietly while reassuring him of their love. He was able to tolerate this, at least briefly.

The task of Julian's taking his pills was reinforced by subsequent homework. This was designed while his parents sat on either side of him, ensuring him of their support. They promised to purchase a special daily pillbox, so that he would always know which pills were needed. They also promised to assist him by supervising his pilltaking. The family agreed to be there as backup.

The therapy team realized that Julian's suicidality could not be resolved until he understood the larger issues of loss in the family and how it was that he felt the only way he could serve the family was by dying. Pamela was able to describe how she had experienced the loss of her babies. She wept copiously and begged Julian to enjoy each day of his life. The older members of the family were also able to share their grief at the loss of their elders, as well as the loss of the family future. They added their pleas to Pamela's.

Rather than oppose the natural direction of the family, which at this stage was rather morbid and leaning towards an intense concentration on the impending death of Julian, the therapy team commenced an intense compression move 10 by going with the natural direction of the system. 8

The therapists encouraged Julian to "explore death with clarity." They encouraged him to go with his father to view the burial plot that his father had selected for himself to see whether he would like one there, too. The therapists advised him to go with his father to choose a coffin, but discovered that since he was an observing Jew the box had to be simple pine. In addition, they advised Julian to write a living will with the assistance of those who loved him.

While dealing with intensity in this manner, it is very helpful to employ the polarization technique of the "Pick-a-Dali Circus" approach, maintaining intensity at both poles equally and simultaneously. 11,12 In Julian's case, the poles being dealt with at this time were "to live" or "to die." It is important to maintain intensity at both extremes so as to avoid pushing the patient and family to either extreme. By the therapists going further at each end than the family would dare, the exaggeration allows the family members to moderate their positions and move towards a less extreme stand.

At the other pole, the therapists suggested that Julian affirm his status as a member of the living by joining his father and stepmother for dinner at his brother's house.

In this manner, planning for his death and experiencing the intensity of what dying would mean were balanced by the proposal that he really enjoy each day of his life by reconnecting closely with the family who wished to enjoy it with him. Another important component of the compression move was to advise the family that Julian should go home to live with one of his parents, since in many ways he was living like a three-year old who could not make life-preserving decisions for himself (refusing to eat, take his medication, and sleeping all the time). Sending him back home again (even hypothetically) would allow him to grow to the leaving home stage sufficiently to take care of himself and leave home properly later. 14.22

The outcome of the therapy was that, shortly after moving home and being taken care of, Julian decided to take responsibility for himself and become a "vertical man."

In Julian's case, the unresolved grief was dealt with by exposure, compression, and helping Julian and his family to understand the role of previous losses in Julian's current suicidality and to bless his living. In some instances, it is useful to go further with the unresolved bereavement, to the extent of a memorial service or graveside visit. 14,49 As in Julian's case,

however, families first need, through a process of mapping and gentle revelation, to get in touch with the impact of the losses they have suffered. The therapist also needs to help both patient and family understand the role of the patient vis á vis those lost. Once this has been achieved, a ritual memorial ceremony may be extremely helpful in order to give the patient the motivation to go on living and to successfully stop the scripting with those dead.

The memorial ceremony, or graveside visit needs to be designed in a culturally and spiritually appropriate way for each family. Careful consideration also needs to be given to the member(s) lost in terms of what would be most fitting. In some instances, a key ancestor may be identified, frequently someone whom the current index patient has been selected to follow and represent within the family. Additionally, there may be other losses, such as the children of the next generation, as in Julian's case. Where the loss covers both past and present in this way, it is important to ensure that both are honored. It is usually better, and of more impact, to select the most powerful deceased member's grave as the symbolic center of the grieving. Surprisingly, many family members in a family dealing with unresolved grief may not even have attended the original funeral or visited the grave in the past.

These ceremonies need to be planned by as many members of the natural support network as are accessible. Those who are unable to be included in the therapy sessions may be contacted by telephone from the session, or receive letters from the natural and professional networks present at the session, or be given audio or videotaped recordings of the session in which the planning occurs. In addition to the members included in this way, special effort should be made to ensure that any religious traditions appropriate to the family be considered and that ministers should be included in the planning where appropriate. If the grave identified is too far away for the ceremony to be held there, a spiritually appropriate alternative should be selected by the family, with the therapist's assistance.

In the case of Sal Bertoli, an 18-year-old adolescent with AIDS, the family had never resolved the immense grief resulting from the loss of the patriarch, Sal's maternal grandfather, Vince. Šal, like many AIDS patients, had lost the will to live. The family felt that a memorial graveside visit at Vince's gravestone would mean a great deal to them all. Sal's grandmother had not been to the grave since the funeral and was very reluctant to face the emotional pain of this ceremony. However, as she said to the therapist* at the graveside during the cer-

^{*}Therapist, R. Epstein, M.D.; Supervisor, S. Baldwin, A.C.S.W., C.S.W.; Supervisor of Supervision, J. Landau-Stanton, M.B., Ch.B.; D.P.M. This case was treated in the Family Therapy Training Program of the University of Rochester.

emony, "I didn't want this thing tonight, but I did it to help my grandson."

Close family members are often reluctant to face this kind of ceremony, but, as with Sal's grandmother, can usually be motivated to participate for the love of the living. Generally, the reluctant member(s) are the ones who most need to resolve their own grief in order to free both themselves and other members of the family—most especially, the index patient who is frequently scripted to represent or replace the lost member. Grandparents are extremely important members of the family. Their distress can reverberate across the system, and their assistance as resources in therapy can be crucial. 50,51,52

The underlying principle of this intervention is to join the contributions made by deceased members (rather than the grief and loss of the past) with the potential of the future."The ceremony (should) include a joyful recognition both of the valuable attributes and unique gifts of those who have died, and of the ways in which these have been, and would continue to be, carried into the future by succeeding generations."14 In this manner the transitional pathway is reconnected with hope.

In order to achieve this, members are asked to prepare statements recalling beloved, joyful, or special moments and shared experiences, to bring photographs and other memorabilia, poems, stories, musical recordings, and so forth. In some instances, families have asked ministers to give the same sermon that was given at the original funeral, so that younger members of the family might share it. This can be a very powerful experience for all involved. Older members of the group are asked to share with younger members of the group particular ways in which they may represent the best of their forebears in their own future lives. This allows them "to ascertain where they had come from and where they are going, (so that) they (can) see a pathway along which they could proceed." ¹⁴ Family members are encouraged to design the ceremony in the most natural way for their particular family. They may bring food and drink, arrange to get together socially afterwards, or find some other means of being together to continue the process.

The whole Bertoli family met at the gravesite in the pouring rain. The therapist welcomed the family by saying,"We are here together to grieve the death and also to choose life. Now is the time to remember the lessons, the values, and also the caring that grandpa Vince gave to you as a family. This is a time for each to take from back generations what he would want for the generations to come." The therapist then asked the family to bring out the objects they had brought to share with each other and to describe why they were of significance. Family members had brought a variety of things, including photographs, poems, flowers, and music, in addition to items of personal significance.

Vince's niece, Marianne, shared first: "I brought coleus seeds. Your grandfather had real beautiful coleus plants in his yard. I figure that you could put them in the ground yourself and watch them grow."

Vince's wife, Millie, closed with a moving, tearful statement to her husband: "We miss you and we'll always love you." The atmosphere at the graveside changed as Millie said goodbye to her husband for the first time. Others wept quietly and felt free to share their feelings.

In this way, during a memorial ceremony, the family inevitably finds a positive way to say farewell to the lost ones, and to give blessing for the living to continue without grief, but rather in celebration of the good contributed by those deceased. In addition, the intense emotional atmosphere generated at the graveside and the feeling of forgiveness that goes with it frequently allow the freeing of former binds, such as those of loyalty and scripting, and allow the family to voice their appreciation of the deceased, along with separateness. They are then ready to resolve past problems and employ the transitional perspective to give them and the next generation hope and direction for the future, based on the wisdom and strength of the past. This ceremony frees the family to share both information and "secrets" openly in a warm and trusting environment, permitting the effective use of the family's combined resources to cope with the future.

Frequently, the ritual expands to include memories and experiences of the people who were not directly involved with the deceased, but have their own grief to share about other situations. When appropriate, the professional network may become involved in this process as a way of sharing the intensity, and showing the family the universality of grief and loss.

4. Recognizing Scripts, Themes and Issues of Loyalty

In Sal's case, he was scripted by the family to represent his grandfather in the grandchild generation. Families operate under three basic sets of rules: (i) the interactions within the immediate family, (ii) the interface with external systems, and (iii) the extended family system's heritage. As a number of investigators have noted, this third area is passed down from previous generations to the present: the family responds intrinsically to guidelines from the past.25 Such guidelines affect the extended family's decisionmaking both as a family and in terms of "how its various members are regarded and differentially treated or reinforced." Although these rules are often preconscious, everyone in the family knows them.

As families develop concepts of themselves that are passed on, *ideas or themes* make each family distinctive and give it a sense of shared identity. Such themes provide a sense of continuity and are sometimes called historical themes⁵³ or legacies^{54,55,56} or scripts and legends.⁵⁷ Themes can include ethnicity/culture, vocations, recreation, values, stories and legends, health, personality descriptions, or death and dying. Themes may also exhibit *generation-skipping*, in which themes disappear in one generation only to reappear in the next. The disappearing theme is retained in the family's memory and is expressed later down in the line. Even if there is no generation-skipping, some mechanism of balance appears to be operating in a family.

The vehicle by which a family's identity (theme) is specifically conveyed to its members is the concept of the family script. ²⁹ Certain individuals are encouraged or reinforced to carry out specific scripts. These scripts (i) maintain a family's theme and (ii) ensure that themes are balanced across a generation. "Family scripts, themes, and balance are the cornerstone of this theoretical paradigm of multigenerational family functioning." ¹³ Scripts are conveyed and reinforced by many people in a family and generally predate the birth of the scripted person, unlike roles, which are present-oriented, more flexibly assigned, and may circulate within a family. Scripts may also be crossgenerational, as was the case with Sal, who was scripted to represent and replace his grandfather, Vince.

As with Sal, scripts may extend from the death of a family member. Young or even unborn children can be identified with recently deceased loved ones, keeping the memory of the deceased alive and alleviating the sense of loss. The child becomes a "revenant," a revered replacement of the one lost, and represents that person to the entire family. ^{13,48} In Sal's case, as with other AIDS cases, the family was being threatened with the loss of the "revenant" and their reaction to his illness was thus greatly intensified. If measures are not taken to resolve the prior loss of the key family member and to deal openly with issues of continuity of themes, the stress to the revenant is extreme and the family as a whole may be threatened. In fact, there appears to be a dynamic process involving three general stages: ²⁵

"Onslaught: If an extended family's system of themes, scripts and balance is assaulted by a combination of (a) societal pressures that challenge it . . .; (b) a series of both normal and stressful life cycle events . . . especially involving the unexpected loss or incapacitation of central family figures . . .; and (c) these events impinge concomitantly or in close succession, an onslaught has occurred.

"Rigidification: To protect itself in the face of onslaught, a family will tend to 'dig in,' clinging to its traditions and its identity in almost ter-

rified desperation. Commonly it will resort to stereotyped, tried-andtrue coping methods and strategies—whether they work or not across a wide range of problem situations and contexts.

"Isolation: . . . The family closes itself off from outside influences . . . and the extended family's cohesion . . . is sacrificed as it attempts to ignore the world as best it can. In addition, its ties to the kinship network may begin to erode. . . .

In the case of Sal and his family, the therapy culminating in the graveside memorial ceremony dealt specifically with the issues of celebrating the lives of those deceased and renewing the family's pledge to perpetuate the strengths and gifts of the family. These actions ensure the continuation of healthy family themes across the entire family system, as opposed to their remaining the responsibility of one "revenant." In addition, preventive work was done during the ceremony to prepare the family for their farewell to Sal, the "revenant," thereby freeing him up to enjoy the rest of his life rather than hastening to join his grandfather.

5. Exposing Secrets

Secrecy is invariably an issue when one is treating HIV disease. The question always arises about, "Who should know? Whom should I tell? Whom do I dare not tell? What will happen if so-and-so finds out?" There are real concerns with these issues that might apply to any illness. Where HIV is involved, they become particularly critical in light of the political, economic, and ethical considerations associated with this diagnosis. How does this impact on psychotherapy?

In the case of Emily, a 25-year old student and mother, the issue of secrecy became important. Emily and her two-year old son, Mike, were both HIV positive. Emily, unlike many other HIV positive patients, was willing to share the news with her family soon after the diagnosis, but was hesitant to tell her friends and other members of her community. She wanted desperately to protect her little boy from the potential dangers of ostracism and cruelty.

As in the case of Emily, parents struggle far more with the secret of HIV disease in their children than with their own diagnosis. Gillian Walker, in describing one of her cases involving the secret of a child who had contracted AIDS from a blood transfusion, discusses both the good and bad consequences of secrecy:58

"Secrecy permits the child to have as normal a life as possible. But secrecy also torments the wife, who worries about the inevitable ostracism if the child's illness were revealed; who worries that someone could become infected because he or she was not informed. Secrecy also binds the couple together, strengthening a fragile alliance, placing boundaries between them and their families of origin, to whom they are both deeply attached." (page 131)

Emily's openness about sharing her HIV status early with her family was unusual. Her wishing to keep it secret from others, outside of the family, was not. Most HIV positive people are embarrassed, ashamed, and concerned about prejudice. More importantly, they do not trust the response of their family and friends, expecting rejection and punishment. Even if people are comfortable sharing their HIV status with family and friends, informing the community at large may be seen as highly dangerous. In Central Africa, HIV status remains a highly guarded secret because of the community's typical reaction to the information. The individual and family can be ostracized, and people with AIDS are expected to die quietly and out of sight. It took a great deal of effort for the media in those countries to even mention AIDS. In one African country, it was only by the President's meeting a popular singer who was known to be HIV positive that AIDS education and prevention could be initiated.

During a family therapy session that included Emily's natural support system, Sandra, her best friend, expressed her admiration for Emily's mother who, "Had such courage with the HIV (diagnosis). To her there was no choice but to accept Emily and to love Emily." Sandra also shared her sorrow that, "You know a lot of parents don't know that."

Many HIV positive patients feel certain of rejection by their parents and families. It is difficult for them not to interpret as rejection and blame what is frequently a desperate response.

During a session, Emily's mother shared how she had felt when Emily told her of the diagnosis. She described her intense feelings of identification with the mother in the movie "Steel Magnolias" as follows: "The daughter had been told not to have a baby (because it could kill her). She was standing at the grave saying, 'I'm mad, and I hate the world, and I don't know why it happened to me.' . . . She's standing there stamping on the grave, and I'm sitting there crying. But I have the feeling that I can't face the world that way every day."

The therapist's* response to this intense emotional statement was, "What would life be worth if you did? . . . What you're doing is living

^{*}Therapist J. Landau-Stanton, M.B., Ch.B., D.P.M. accompanied by faculty of the AIDS Training Project: Colleen Clements, Ph.D., Ann Z. Griepp, M.D., Jackie Nudd, Alexander Tartaglia, D.Min., Robert Tocco, M.S., C.S.A.C.

and enjoying these kids. Angry? Yes, like 'Steel Magnolias,' angry at her; furious at times, or for periods of time, because she's killing herself. But loving doesn't stop, because the anger comes from the intensity of loving. Youngsters with HIV run and hide from their parents because they think their parents will judge them. Every set of parents that we've grown to know loves their children."

Therapists can rest assured that most parents, when dealt with in this straightforward manner and when given an opportunity to share with their children, will do so without rejecting them. Since they may also express anger, or even fury, which chases the children away by confirming their worst fears of rejection, therapists need to predict this response in advance so it can be expected and dealt with appropriately. Therapists should explain that such a reaction is caused by the pain of loving and the fear of loss as in parents tempted to beat little children who have exposed themselves to danger or returned from a brief period of hiding away. By sharing these dynamics with families, the therapist frees them up to express their feelings and to become closer.

While Emily was able to share her news with her family, dealing with the community posed a more serious problem for them all. Her older brother, Adam, was really concerned that anybody outside the family might find out that his sister was HIV positive. "We didn't want to tell anyone. We thought we'd say she was sick-say it was cancer or something."

As Adam stated, a level of knowledge about HIV disease makes it far easier for people to share the diagnosis. Therapists can assist in this process by offering to educate family, friends, and other members of the natural support system concurrently with the patient. This makes it far easier for everyone to deal with the issue. People are automatically far more frightened of something they don't understand. They feel vulnerable to infection and are frequently unaware of how to protect themselves. This colors their reaction, often leading to apparent rejection of the patient.

In counseling these families, therapists need to exercise caution while advising patients of the costs of secrecy. There are many instances, such as Adam's work situation, where people are not ready to hear the diagnosis of AIDS. Where there is no direct danger of transmission, as in this case, we generally leave the decision to the patient and family. In the case of the natural support system of the patient, however, we feel that the cost of secrecy outweighs the benefit of exposing the secret. We therefore encourage the patient to share the diagnosis, additionally offering either direct education for friends or a list of available resources where they can acquire

the information needed to deal positively with the news. A model of how to access this information in your community is given in Chapter 5.

Many patients faced with a positive diagnosis of HIV disease are not just dealing with the stigma of AIDS, but have many other secrets embedded within their family systems. Such secrets may be guarded from the outside world by the family. Secrets may not be known by the entire family, but only by a few members. The populations at risk for HIV are frequently driven to secrecy because of prejudice and the fear of rejection by both family and community. These secrets include such issues as grief and loss, homosexuality, alcoholism and drug addiction, forms of family violence, physical and sexual abuse, and incest. Legal and law enforcement problems may also be secret from all or part of the nuclear or extended families.

Family secrets develop as protective mechanisms, but do not adequately function in that role over time. As was described in the section and table on resistance, secrets invariably end up creating coalitions within the family and dividing family members or subsystems from each other. The burden of secrecy is usually carried lovingly by certain family members and unknowingly by others. In an attempt to protect each other, families may end up being disrupted and pulled apart by secrets. The burden of the secret(s) may also make it difficult for individual family members to function well both within the family and in other parts of their lives, for example with their friends and in their work settings. Secrecy also may divide the patient and his or her surrogate family from their families of origin, creating rifts when they most need to be close to the people they love.

In the case of gay people, where the family is being protected from knowledge of their sexual orientation, this form of rift is extremely common. In the case of Kevin, discussed earlier in the chapter, events had made it difficult to maintain such secrets. His ailing widowed mother had to come to live with him and his spouse, Bill; she had to know about his homosexuality and his illness. However, even in this case, the therapy team had to take responsibility for helping the family overcome the barrier of secrecy and protection before Kevin was comfortable revealing either his sexual orientation or his illness.

In the case of Peter, a young man who had been separated from his parents and all but one sibling for many years, his homosexuality was still a secret when he was diagnosed with AIDS. The therapist was eventually able, using Peter's older brother's assistance along with many of the techniques listed in table 8-A for overcoming resistance, to gain Peter's permission to call the parents. The session in which Peter shared his history and current problems with them was extremely moving. They all wept and his parents were able to hug him and tell him how much they had missed him. They were able

to forgive him both for their pain and for his choice of an alternative life style, expressing their wish that he had trusted them enough not to exclude them.

Even though these cases may take a great deal of gentle persuasion, the reward for the therapist is well worth his efforts. Secrecy, despite having its origin in loving protection and privacy, is always painful, nor is it ever rewarding to the individual, family, or therapist, in the long term.

6. Resolving Transitional Conflict and Its Sequelae

In the case of Emily's family, a family secret around both alcoholism and loss emerged during the drawing of the transitional map. It became a central issue for resolving the transitional conflict that was at the nexus of Emily's problems. Emily had started drinking at the age of nine and had commenced the use of cocaine by the time she was in her early teens. As the therapist drew the genogram (see Figure 8-1), depicting relationships (Figure 8-2), expanded it into a transitional map (see Figures 8-3 and 8-4), and added a timeline (see Figure 8-5), the chronology around the origins of Emily's addiction and the transitional conflicts became apparent.

From the genogram it became clear that Emily's paternal family of origin had experienced multiple, catastrophic losses. Her paternal grandparents had married in Ireland and left their families there to immigrate to the United States. They never saw any of them again. They had lost their first three children; Emily's father, the last-born, was their sole surviving child. Emily's paternal grandfather had died in 1967, her paternal grandmother in 1975, and her maternal grandfather in 1961 According to the genogram, both Emily and her brother, Adam, were adopted since their parents were unable to have babies of their own.

The transitional map further revealed that Emily's paternal grandfather had been senile with Alzheimer's disease around 1961, the year that Emily's maternal grandfather died. Her paternal grandmother had to be hospitalized at one point.

Emily's brother was adopted at birth in 1963, and Emily in 1966. Emily's paternal grandfather died in 1967 while she was still a baby. Both children grew up knowing that after his death the paternal grandmother became a secret drinker and that she was always sad. Emily and Adam were clearly very important to their grandmother, who had lost everyone in her family except her son, daughter-in-law, and two grandchildren. In fact, one might suppose that the grandchildren were, in some way, a replacement for her lost family, particularly Emily, who was born shortly before the death of her husband. Her son and she were extremely

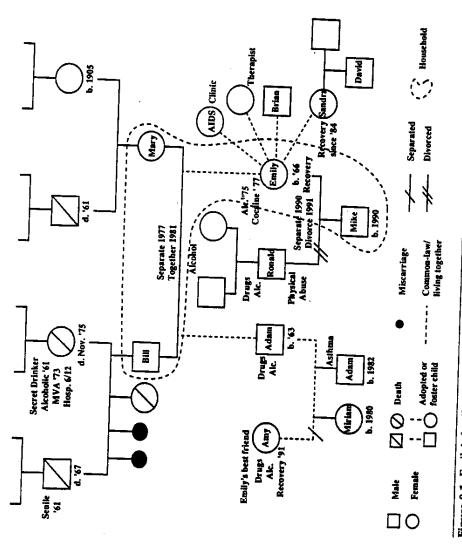


Figure 8-1. Emily's family genogram with problem areas and household

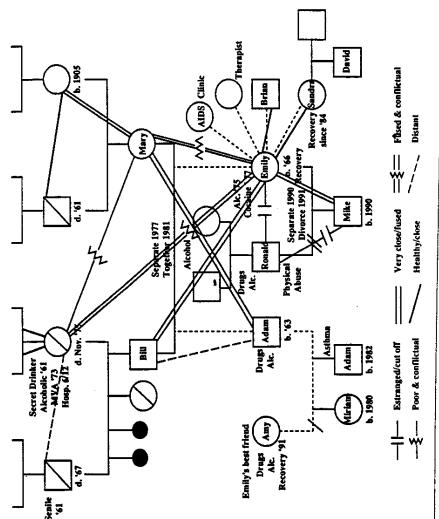
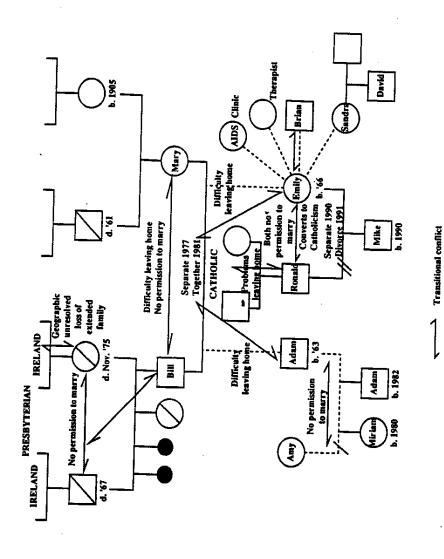
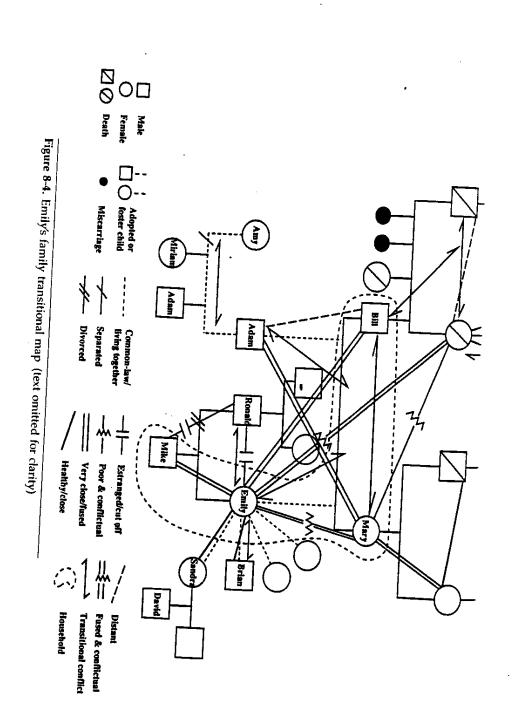


Figure 8-2. Emily's family genogram with relationship lines



the 8-3. Emilys family genogram with transitional conflict lines



close, since he was the sole survivor, and hence the replacement for her other three lost children.

Emily's paternal grandmother died in 1975, and that was the year when Emily, aged nine at the time, began drinking herself. Even though Emily did not express closeness with her grandmother and was almost derogatory about her in the family session, it was apparent to the therapy team that she was scripted to replace the grandmother. The therapist, concentrating on the positive aspects of the transitional pathway in order to start sharing a transitional frame with the family, had the following conversation with

Therapist: "Are you the first recoverer in your family?"

Emily: "I guess."

Therapist: "Then you're a pioneer."

Emily (laughing): "I guess."

Therapist: "Are you also the first addict?"

Emily: "Well, my dad's mother was a drinker. She was a drunk. She was independent."

The therapist then proceeded further with the frame by reframing the addicted behavior as follows:

Therapist: "Go back enough generations to see how it starts—as adaptation, trying to save the family, not to hurt anyone. People who sacrifice themselves to addiction are usually extremely loyal, extremely loving, and in some way are trying to balance the family and keep it going at a point where it is going through a lot of stress."

Emily: "My addiction started when the family was in turmoil, I was the

Therapist: "We see it more as savior than scapegoat. Somebody who is ready to draw the attention to themselves to detour from what else is going on in the family."

The onset of substance abuse in a family is frequently associated with multiple concurrent life cycle transitions, especially when loss is involved, particularly the chronic disability or loss of a grandparent. 59 A family that has successfully negotiated life cycle stages previously may find the stress too great to deal with and develop transitional conflict as a result. 13 The family life cycle stages that are most likely to be impacted are puberty, adolescence, and leaving home. 31,42,60 If this is not resolved, the transitional conflict may be repeated from generation to generation, becoming a chronic problem and resulting in repeated transitional conflicts. Also, if a particular

life cycle stage is not adequately negotiated, subsequent stages will also not be successful. 42,59

"In some cases, generation after generation has repeated the same problematic patterns; conflicts have been perpetuated around similar points of transition.^{7,31} One may see cross-generational coalitions, with grandparents parenting grandchildren, and parents failing to become competent. Frequently, the stages of growing up, leaving home, ⁴² getting permission to marry, ⁶¹ and becoming competent parents to an adolescent are not adequately achieved in these families. The therapeutic task is one of helping the family through the transition period." (p. 330)⁵⁹

During this same period, Emily's parents, Bill and Mary, developed serious marital difficulties, perhaps as a result of the change in family structure with the death of Bill's mother. The therapy team postulated that Emily's drinking problem was also a way of keeping her parents focused on her as a detour from their marital difficulties. Emily's brother, Adam, also began to drink and act out around the same time. Bill and Mary separated in 1977, leaving Mary alone in the home with Emily and Adam. Adam took over as the man of the house, holding wild parties and not attending school with any regularity. Emily added cocaine to her drinking.

The situation deteriorated progressively. Adam became sexually involved with Emily's best friend, Amy, also a substance abuser. Amy became pregnant, Adam dropped out of school and left home—only to return in 1980 with Amy and her baby, plus a new pregnancy. He had pulled himself together, taken the high school General Equivalency Diploma examination (G.E.D.), and found a job. Shortly after the birth of the second child, Adam moved out once more. For a brief time Emily and Mary were alone. Father Bill returned to take up his position as head of the household shortly after and Adam gained custody of his two children. Adam brought both babies to live with his parents and found a home of his own. The crossgenerational coalitions were complete.

Upon further examination of the transitional map, it became apparent that once Emily's parents were safely together again, she began to flirt with recovery. Her entry into recovery was assisted by her mother, a close friend, and her boyfriend. Emily started attending a 12-step fellowship program and building relationships within the group.

Emily's mother attended Al-Anon meetings and described the hopelessness of trying to be a successful parent: "When she (Emily) was first dry, she got a job in her favorite watering hole. She had it all planned. No matter what I said, I was always in the wrong. I never wanted to kick her out, but

Thus the tension between the parents would be enacted, through their daughter, who not only struggled with her sobriety, but also failed repeatedly, maintaining her parents' concentration on her problems and keeping them together. Emily also made repeated efforts to leave home. Madanes stresses that the way in which a therapist views the situation will determine the strategy to be used. 62 In Madanes' framework, Emily could be viewed as having been disobedient and out of parental control, misunderstood, and mistreated, or as a pawn in a parental power struggle. The perspective of Madanes that we feel to be the most accurate and helpful is that Emily was concerned and protective of her parents. Each failure of Emily's to leave home resulted in a renewal of joint parental activity, thus also serving to maintain the marriage. 42 As Emily described in the therapy session, "I'd get an apartment and not even move my furniture—live out of boxes and a sleeping bag, since I knew I'd run out of money and go home again."

Unfortunately, as is common during the recovery from substance abuse, Emily substituted sexual addiction for her free-basing cocaine habit. She embarked on a clearly self-destructive relationship with an intravenous drug abuser, who was openly bisexual. Therapists and substance abuse counselors need to be aware of the importance of sexual counseling during the initial phase of abstinence, since sexual substitution is as common as nicotine, gambling, and eating addictions at this time. In fact, Emily's behavior might be viewed as a combination of sexual addiction and gambling—with her life. Abstinence alone does not resolve the transitional conflicts that lead to self-destructive behavior. Attention to the family factors is a critical component of therapy.

Self-destructive individuals are frequently in denial, not only about the magnitude of their substance abuse, but also about other risk behaviors and the importance of safer sex. Emily later told her therapist that she had assumed that the 12-step fellowship group was a safe haven from the risks of the outside world. She also, like most heavy users, was out of contact with the media and able to maintain a heavy denial about the risk of HIV disease and its connection with substance abuse.

Emily did finally recover from both her addictions, but by then she was already HIV positive, although she did not discover this until 10 months after her son was born. She had married a verbally abusive, drug-addicted man. Her worst fears came true when the marriage ended very stormily once her diagnosis was made. Her husband blamed her not only for her own disease, but for "killing our son." Emily and her baby, Mike, moved home with Bill and Mary. She had selected a marriage unlikely to last; once it failed, she was moved back in the life cycle to the adolescent stage.

The therapist was able to reframe Emily's moving back home as a highly successful choice on the part of Emily and her family. It would give them the opportunity to let her relive her adolescence in a controlled, loving, and appropriate environment. Had she not moved home herself, the therapist would have prescribed this move as a "compression" backwards on the transitional pathway, going in the natural direction of the flow of the family system in order to effect the successful completion of a transitional stage. 13

Thus, the transitional map was completed. The therapist proceeded with the help of the family to translate it into a structural time line³⁰

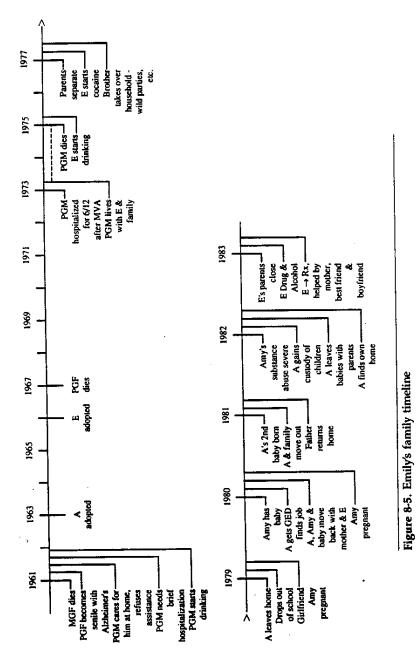
Emily's family had also come up with a lengthy list of strengths that could be perpetuated in future generations. The combination of transitional map, family strengths, and time line showed clearly how events had clustered and how themes and scripts were being handed down across generations.

TABLE 8-B List of Family Strengths

	. 0		
Humor	Parents never left		
Togetherness	Close grandparenting		
Helpfulness	Tolerance		
Teamwork	Intelligence		
We were chosen by people who	Capacity to use		
really wanted us	resources		
Loving	Socially active		
No negatives	Sense of mission		
Honesty	Sounding board		
Patience	Share freely and know		
Wanting to be understood	others can be		
Open-mindedness	objective		
Never prejudge	Parents validate		
Trust/Acceptance	children's feelings		
Freedom to children	Independence		
Guts			

These techniques allowed the therapist to construct a transitional perspective for the family that would help them to understand and forgive themselves for their current difficulties in terms of their past history and facilitate their taking charge of designing their future path.

The transitional perspective is given in stages throughout therapy sessions, as relevant information is shared with the therapist by the family. A final summary is given at the end of the total mapping process. In Emily's case, the family was praised for its intense loyalty and togetherness, as well as for not allowing family members to go off alone until they were really ready, even though they were to be praised as a family for their pioneering



spirit. In this way, both the closeness and distance poles were simultaneously validated. ^{11,12} The family had needed to stay close together since they had suffered such extreme losses and concomitant life cycle changes. The therapist described these as starting back in Emily's grandparents' generation, when her paternal grandparents had left Ireland and their families to come to the United States as pioneers. The family was absolved of all blame, understood the events in terms of loyalty²¹ and family ties, and was congratulated upon finding their own solution—bringing Emily back home again. ²²

The transitional pathway was now complete, with past explaining present, and the family feeling that the future was in their hands. The therapist underscored the family's sense of mission. Emily's paternal grandfather, a Presbyterian minister, had come to the United States on a mission; now Emily was determined to fulfill a mission of her own. She planned to embark on a series of talks and educational activities centered around AIDS prevention. She was determined to ensure that she would leave a legacy of pride and meaning for her family. Her father planned to join her in her mission once he had retired from his full-time job. The family was ready to plan for the inevitable deaths of Emily and Mike, knowing that they would leave behind them significant markers of their impact on the world.

7. Sensitivity to Issues of Culture and Gender

The cultural and gender context of HIV disease is extremely rich. Members of any ethnic group may contract AIDS, as may individuals with alternative life styles and variations of gender identity. A quick review of the cases discussed shows rich variability of language, religion, education, and lifestyle. Helene came from Haitian descent and her cultural norms were an integral part both of her contracting the disease and of her clinical management. Kevin and Julian were both members of the gay community, living an alternative lifestyle with surrogate families, but of different religious faiths. Julian's family were practicing orthodox Jews, while Kevin's were Catholic. Their religions made a real difference in the planning of the rituals and ceremonies not only around their deaths and reorganization of the family, but also around their living with HIV disease.

In terms of ethnicity and heritage, Mary Porter was an American of many generations, from a rural background and living in a healthy nuclear family. Amy, married to Brian, was British and an American immigrant, while Brian was a nonpracticing Jew. Sal, on the other hand, was of mixed Irish-Italian descent. Emily came from a typical American background, with first generation parents of Irish-Presbyterian descent. She had converted to Catholicism when she married into an Italian Catholic family. Peter came

from an old mainline American family, basically atheists who rediscovered their religious roots at Peter's deathbed.

How does the therapist take all of these factors into account in the therapy process? Why are they important? In Sal's case, the therapist was greatly aided by her knowledge of Irish culture and her understanding of the difficulty that Sal's maternal (Irish) family members had in expressing their emotions. The therapist was able to draw upon Sal's father's Italian expressiveness to help the Irish side of the family through their pain. Therapists should attempt to learn, both from the literature and from their patients, as much as they can about the impact of different cultures on the patients and families they treat. ⁶³ However, it is not possible for therapists to learn all about the myriad of cultures with which they may work. Families, as the experts on their own family system and culture, can be excellent teachers; therapists may benefit from allowing families to share their cultural norms and customs with them:⁷

It is assumed that the family knows more about itself and its culture than the therapist ever could. The therapeutic system is, therefore, composed of two subsystems of "experts"—the family (and extended family), and the therapist aided by the community network (natural support system) where appropriate (experts on the theory and means for bringing about change). (p. 260)

In addition, the therapist may draw upon therapy models that are relatively culture-neutral and employ a methodology that utilizes what knowledge of the family culture the therapist has or is able to acquire. The transitional theory and therapy described in this chapter form such a model. All families are involved in the transitional pathway, so that the transitional frame may be used regardless of culture. ¹³ In instances where the family is unavailable, for cultural or geographic reasons, a link therapist (a family member who functions as therapist for the family) may be selected, to be supervised by the professional therapist. ^{13,64} Another transitional method that may be useful in dealing with families where language is a problem is that of *transitional sculpting*. This is a nonverbal, experiential technique for physically explicating the transitional pathway. ¹³

The Roman Catholic religious culture of Emily's in-laws became an important part of Emily's experience with HIV disease. When Emily and Mike were first diagnosed, the family took the two of them to healing masses, blessed them with holy oil, and said many rosaries over them. An intolerant physician or therapist might have opposed these measures and alienated the family. In fact, Emily was touched by their tangible concern.

A more problematic experience with religion arose in the case of the

Piccolo family, a very religious Catholic Italian family. Their son's wife, Maria, had been diagnosed as HIV positive. The family believed that wearing garlic around the neck was healing and that novenas were more powerful than modern medicine. They also wanted Maria to have a baby, saying, "We want you to live. We want you to produce an offspring. Even though everybody here is positive, we want you to take a chance."

Gino loved his wife dearly, but was also the first son of parents to whom he was very loyal and devoted. He was able to resolve some of his ethical dilemma by refusing to be tested for the virus, despite knowing that his beliefs had put him at risk.

As the editor of *The Family Therapy Networker*, Richard Simon, points out, the power of traditional alliances such as race, class, ethnicity, or culture is very powerful; in addition, gender alliances are also very powerful and the health care professional needs to be sensitive to that power. ⁶⁵ Homophobia, or fear of homosexuality, is one of the effects of "these primitive tribal forces," creating a "them/us" feeling that therapists need to recognize in themselves and their colleagues. Failure to recognize and deal with gender issue countertransference can seriously impact quality of care and the outcome of treatment, particularly in clients and patients who are already vulnerable. In Kevin's case, his homosexual orientation had the potential of interfering with the therapy if his therapist had not dealt with her own feelings. The special issue of *The Networker* underlines the need to know more about the homosexual and lesbian community, and their family constellations. ⁶⁵

Markowitz describes faulty assumptions that therapists still make about homosexuality. 66 She sees these as tending to fall between two extremes. One is that whatever the patient's presenting complaint, homosexuality is seen as the fundamental problem. The other extreme is the therapist's belief that homosexuality makes absolutely no difference at all, downplaying its relevance to the therapy.

Another central problem in providing gender-sensitive therapy to the gay population is the therapist's conception of family. ⁶⁷ Kevin's therapist's acceptance of the role of Bill as Kevin's spouse was integral to the success of the therapy. Dahlheimer and Feigal describe the varieties of nontraditional families that have previously not been recognized or considered in the context of therapy and how best to approach their treatment. One of their suggestions for therapists who are not experienced in dealing with gay clients and their families is to use gay co-therapists. A second suggestion is to have a gay or lesbian colleague supervise the first few cases involving homosexual clients. Finally, they recommend reading a broad spectrum of gay/lesbian novels and autobiographies for insight into the specific gender issues that

arise. There is a wealth of literature of this type written by the homosexual and lesbian community, dealing specifically with the issues of HIV infection and its impact on this community.

Gender issues in therapy can also originate because of male-female differences in the heterosexual community. The different ways in which men and women experience reality, as well as the change in attitudes across generations, also need to be considered by health care professionals, who are not themselves immune to the same attitudes. Walters et al. suggest a list of guidelines which incorporate sensitivity to feminist issues:

- Identification of the gender message that conditions behavior and sex roles;
- 2. Recognition of women's limited access to social and economic resources;
- Awareness of sexist thinking that limits women's options to direct their lives;
- Acknowledgment that women are socialized to assume primary responsibility for family relationships;
- Recognition of the problems of child-bearing and child-rearing in our society;
- Awareness of family patterns that can result in women competing with each other for power, splitting them from each other;
- Affirmation of female values such as connectedness, nurturing, and emotionality;
- Recognition and support for lifestyles outside of marriage and family; and
- 9. Recognition that no intervention is gender free.

They conclude that good clinical work needs to recognize the client's gender socialization. This is clearly of prime importance when one is dealing with HIV disease, since even those clients who are not homosexual or lesbian are still facing a disease with major sexual and gender implications. For example, the primary partner of an intravenous drug abuser, because of her gender socialization and lack of personal authority, ⁶⁹ may be reluctant to ask that her partner use a condom.

Sensitivity to culture and gender is clearly of paramount importance in dealing with HIV disease, not only since cultural traditions and values impact on human decision-making (see Chapters 9 and 10), but also because of the vulnerability of inner-city populations in which cultural minority groups are over-represented (see Chapter 3).

CONCLUSION

We have presented a model for the psychotherapeutic treatment of HIV positive and AIDS cases that attempts to be both integrative and comprehensive. It is based on a theory of human and family development which attends to intergenerational structure, support systems and the dynamics surrounding grief and loss. While space prohibits full explication of this "Rochester Model" (for instance, a number of its dimensions are not described here), we hope the reader has gained enough of a sense of it to begin applying it with cases of this type. Those interested in a more complete exposition are referred to the various publications cited.

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