

Landau, J. (1997). Whispers of illness: Secrecy versus trust. In S.H. McDaniel, J. Hepworth, and W. Doherty (Eds.). *The Shared Experience of Illness*. New York: Basic Books.

CHAPTER 2

Whispers of Illness: Secrecy Versus Trust

JUDITH LANDAU

THE SOUTH AFRICA of my childhood held the magic of many voices, cultures, colors, and scents. Perhaps my favorite times were spent in the Valley of a Thousand Hills (of Alan Paton's story Cry the Beloved Country), where my father and his social medicine team had built a community health center (Kark & Steuart, 1962; Kark & Mainemer, 1977). The families of the team members—who ranged from doctors and nurses to teachers and agriculturalists—would visit the community health center for lengthy stretches; some had their primary dwelling in the rural or tribal area where it was established. As children of the tribes and of the healthcare workers, we had a sense of utter security and peace (see Byng-Hall, 1995a, 1995b) and were encouraged to explore the wonders of the environment at will while we learned about each other. I have vivid memories of laughter, running and tumbling on and off ponies and each other, and the joy of constant companionship. Loneliness was a state of being I didn't discover until later.

I was three years old when my world changed. Fear and horror came suddenly, followed shortly by intense grief and mourning as the diphtheria epidemic hit and children, especially babies, started dying. For the first time in my life, adults weren't allowing children the freedom to roam; whispers and secrets replaced the open communication on which we had relied. We didn't understand most of what was taking place and had to start pretending not to know anything, lest we upset the adults. We all knew more than we were supposed to, because the elders would talk to each other in stage whispers, ostensibly unaware that we were lis-

tening. Constant activity, exhaustion, fear, and extra people invaded our home.

Then came my fever. What I share here will be an amalgam of my own memories and the stories I heard about the events as I grew up. (I would be hard-pressed to separate the two!) For the first time in my life, I noticed panic on my mother's face. My father kept trying to reassure her and didn't quite succeed. I realized that they were both terrified and that others were trying to calm them—a role I was used to my father assuming for everyone else. All the rules changed without explanation: I was not allowed to get up, to play with my friends, or even to go to the bathroom alone. Nobody was permitted to visit me. I overheard whispers of "infection," "diphtheria," and "death." I wondered what it all meant, but I understood that it wasn't safe.

My parents struggled with their own guilt and recrimination. I vividly recall a fight in which my mother raged at my father about caring for other people's children more than his own. She wept about my being allowed to play on the dung floor of the clinic with the local children. I understood that many children were affected and later learned that my parents' close friends had lost their three-month-old baby. Many of my black African friends died, too. We moved back to our permanent home in the city, where I learned with horror that I was, by then, the sole child survivor of the epidemic.

Having always believed that our therapy models have a great deal to do with how and where we grew up, it was a challenge to return to childhood memories and discover there was more! Looking back at those scary days, I realize what a profound influence they had on who I am as a physician and therapist. Revisiting this story allowed me to learn a lot more about why I do therapy the way I do. More specifically, from these experiences sprang the principles and philosophy underlying my therapy:

Join the patient and family well, and respect their wishes and values. The family doctor's visits were of paramount importance to me. He treated us as friends and was never bored by my inane childhood chatter. He even drank my concoctions of dirt and leaf tea (honoring my yet unconscious intent to become an *isangoma* or traditional healer).

Establish trust and then develop ways for the family to trust itself—develop an awareness of competence. The doctor's presence seemed to make my parents feel safe, and then I didn't have to be scared. They really relaxed when he was with me. I remember clinging to his hand when he wanted to leave. I wished he could stay with us because I no longer trusted that my father could keep us safe, and alive. During the epidemic, both my parents cried a lot, which left me feeling helpless—they never cried when the doctor was present.

Looking back, I wondered whether there was a way that the doctor could have helped my parents develop some structure (e.g., being able to talk to an informed person when they became anxious) or acquire some knowledge that would have helped them feel more secure between visits. The more one can do to help families access their own competence,

the shorter and more effective the intervention will be (Landau-Stanton, 1985).

Prepare families to accept that healthcare providers are not infallible and to expect the unexpected. On a particularly bad day, when I was struggling to breathe, my trusted friend, the family doctor, was trying hard to clear away the diphtheria membrane from my throat. The swab he was using dropped off the end of the stick and down my throat. We raced to the hospital in an ambulance and then into the emergency operating room. Everyone was panicked.

Fear of death doesn't frighten children—secrets do. Help families and healthcare providers share bad news. Many years later, when I worked on a pediatric surgical unit, the children helped me understand what I'd experienced that day in the hospital. During the emergency situation, the combination of intense activity and stage whispers, and the contrast between them, had terrified me. I knew something momentous was happening, and that it had to do with me. But nobody was sharing it with me, so it was probably really dangerous. Combined with the events of the epidemic we had recently experienced, this behavior left me alone and afraid.

Strangely, the fear disappeared entirely as I felt myself floating towards the ceiling, while the rest of the room receded. I felt quite safe and outside of it all. I remember wanting to reassure the adults (especially my parents) but not being able to talk, and wondering why they didn't hear me so they could know that I'd be fine, whatever happened. I can still recall the difficulty of deciding to return to the room and to be there for my parents, rather than floating off in that serene and peaceful light.

As a young physician, talking to children before and after their surgery, I learned that young children do have a concept of death long before the established age of seven (Kübler-Ross, 1975), but that they don't perceive it with the same fear as adults do. As I learned from children how much better they do when treated with respect and openness, I wished that my parents and the staff had talked to me freely and let me know what was going on.

Secrecy is always potentially destructive, and children invariably have some sense of what's transpiring. They need to be informed of the facts so that they can feel safe. Secrecy builds barriers not only between people but between individuals and their capacity to exercise their competence. In therapy, we need to avoid esoteric words and theories; whatever we teach and apply in practice should be easily understood by trainees and patients (McDaniel, Hepworth, & Doherty, 1992). In the Rochester program, in fact, the stories we tell and the lectures we give our students are not substantively different from the information we share with our clients and patients. The continuum of confidence gained from shared knowledge is key in helping families to regain and maintain their sense of competence. Only then can they take care of the problems confronting them as they rearrange their lives.

Deal with issues of unresolved grief and loss. The silence of adults around death amplifies the child's fear. What does death mean? Will the child lose Mommy and Daddy? Where would they go? Who will take care of the child in this strange place?

It was much later that I learned that my mother and father had both lost siblings, and that my illness reawakened considerable issues of unresolved grief and loss in them. If they had been able to discuss this at the time, I feel sure that there could have been some meaningful resolution for them and the family as a whole. Perhaps my own perspective is colored by growing up exposed to storytellers and African elders, for whom there is a continuity between life and death and contact with the ancestors is a vivid reality.

Avoid isolation and discuss all procedures and plans with the patient and family. Perhaps the most frightening episodes occurred during the early days of the acute infection. At that time, medical knowledge of diphtheria was extremely limited, and there were no known successful treatments if immunization hadn't provided adequate protection. Doctors believed that the only way to stem the infection was to enhance immunity, for which the thymus gland was thought to be responsible. It was believed that irradiating the gland would do this, and many children with various ailments were treated with this method.

The isolation and fear of those visits to the hospital for irradiation of my thymus gland still haunt me when I am ill. I was acutely aware of being alone for the treatment after the people wearing lead aprons had left the room. The sound of the machine they were all avoiding terrified me. I still have trouble believing that, in fact, I underwent very few treatments and they were all brief. I remember an eternity of terror in that room with the glass walls through which everybody peered at me. I don't recall any explanation of what was happening at the time. I remember thinking that since I could kill other people, maybe this was being done so that I would no longer be dangerous to them—so that I would be sanitized.

Reinforce the natural support system and resources (at the biological, psychological, social/spiritual, and ecological levels) rather than be overwhelmed by deficits. When my lower limbs became paralyzed, we went through a new round of fear. Was it polio? Fortunately for us, it was only polyneuropathy, an aftermath of the diphtheria. For six months, my parents carried me out to the porch so that I wouldn't become too isolated from the outside world—how important the garden, its flowers and birds, and the local pets became to me. Mother taught me to recognize cloud creatures and to make up stories about them to tell my father when he came home. Father taught me to read so that I would never be scared or lonely. (To this day, I carry a book with me wherever I travel and feel the magic of its protection.)

Build collaboration across systems and share information with the whole team. The physical therapist responsible for the torture of my rehabilitation was young and clearly uninformed about the background of my ill-

ness. She was committed to my fast and disciplined recovery. I understand now that the process would have been far easier for both of us had she been apprised of the friends I'd lost and the intensely difficult time I'd had during the acute phase of the illness. She might have taken more time to talk with me and I might have understood and felt less guilty and ashamed about my clumsiness and not being able to do what other kids could do (e.g., running and performing faultless cartwheels).

Simplify goals and tasks so that patients and families understand them. Appreciate the small achievements. Perhaps if the physical therapist had been kinder to herself and had greater confidence in her capacity to achieve success, she'd have been able to express pleasure when I completed some small step of a larger task. That might in turn have left me feeling encouraged and ready to try harder, rather than defeated by my inability to manage my limbs.

While I was revisiting my childhood illness, Bridget Connelly came to mind. She had been exposed to our current epidemic of HIV/AIDS while still in utero. Her mother's struggles with secrecy and guilt brought back memories of the shame and guilt that I might have been responsible for the death of the three-month-old baby of my parents' friends—the baby I had cuddled before finding out that I was infected and could "kill."

The referral call came from a nurse at the hospital AIDS clinic: Could I see a mother and child who had been recently diagnosed with AIDS? They were found to be HIV-positive when baby Bridget was seven months old. The nurse explained that Ms. Connelly was acutely depressed and felt guilty that her lifestyle had exposed her baby to a lethal illness. Further, she had not revealed her problems to her family and thus had no support system because of her guilt, shame, and secrecy. Bridget was two and a half years old at the time of referral; her mother worried that the little girl was not speaking as well as she should and was also concerned about how clingy and weepy she was. Bridget was also not eating well. Bridget's father had left the family at the time of the HIV-positive diagnosis.

The initial session included Ms. Connelly and Bridget, Ms. Connelly's substance abuse counselor, the referring nurse clinician from the infectious disease clinic, and a paraprofessional from the local community-based organization. We find it essential to include as many members of the professional support system in the collaborative team as possible. It is also helpful to invite as many members of the extended family and natural support network as we can, since the more people there are present who care about the patient and the outcome of the therapy, the more successful the therapy is likely to be. However, when invited by the nurse clinician, Bridget's father had refused to attend the therapy session, stating that he wanted nothing to do with either mother or child. He had moved on, and his life was now in order. Ms. Connelly said that it would not be possible for her to invite her parents or any of her friends to the session.

The therapy started with an exploration of the medical realities and a comprehensive psychiatric assessment of both mother and child to determine the danger of suicidality of the mother as well as the possibility of neuropsychiatric involvement in either patient. Ms. Connelly was greatly relieved to be able to share her story. The openness of the team and their willingness to keep her informed about the illness helped her deal with Bridget and her own fears. She also felt competent to make informed decisions about concrete goals for the future.

Once the joining had occurred and a sense of commitment to working together had been achieved, the team helped Ms. Connelly construct a genogram. I explained to her that we could gain an understanding of the strengths, resources, and themes available to her by getting a sense of the journey of the extended family as it had moved through time. I also suggested that we pay particular attention to times of transition (e.g., geographic, cultural, and individual and family life cycle). I stressed that we needed to consider both positive and negative life events, since multiple events (three or more within a short space of time) are more likely to result in family stress (Garmezy & Rutter, 1983; Landau-Stanton, Clements, & Associates, 1993; McCubbin & McCubbin, 1988).

Ms. Connelly was the youngest adoptive child of a first-generation Irish American workaholic father born in the United States. Her paternal grandfather (PGF) left Ireland in his early teens to make a new life in the United States and to save money for the rest of the family to join him. He never realized this dream and completely lost touch with his family of origin. Her paternal grandmother (PGM) was third-generation Irish American, born to a family that suffered considerable losses in the potato famine. The family sent several of its younger members to the United States in its quest for survival. They left behind them a trail of heartrending stories of family starvation, murders by landlords and thugs, and deaths in the influenza epidemic. Not one American member of either of these families (PGF's or PGM's) had been to Ireland to search for any living family members, to trace roots, or to visit graves.

Throughout the early sessions of the therapy, as the information regarding transitions was added to the genogram, Ms. Connelly began to understand why her father had become a workaholic. She began to see how money had come to mean the survival and continuity of the family. Eventually, she was able to forgive him for his lengthy absences from the family and to appreciate his loyalty and sacrifice (Stanton, 1977).

The construction of a transitional map can be very helpful in alleviating blame: Family members become aware that a set of behaviors (in this instance, workaholicism) developed as an adaptation or reaction to life events. If these behaviors are successful, they frequently become patterns that continue across the family (horizontally and longitudinally on the genogram) even when they are at best redundant and at worst dysfunctional (Landau-Stanton, 1990).

On further exploration of Ms. Connelly's mother's family, we learned

that her mother was the oldest child of seven, two of whom had died in early childhood or infancy. We also learned that her mother's birth followed several miscarriages. From the time when her maternal grandfather (MGF) died in a farming accident, Ms. Connelly's maternal grandmother (MGM) had not left the house. Ms. Connelly's mother "raised the children and held things together."

It became progressively clearer that both sides of the family had experienced catastrophic losses and that Ms. Connelly's drug habit, which started in her early teens, had prevented her from successfully leaving home (Stanton & Todd, 1982). Ms. Connelly initially told the team that she was not in contact with her mother and saw no reason to make contact with her at that time. Over the course of the next few sessions, however, it emerged that family information was always shared through informal but constant channels.

When confronted with the possibility that she and her mother were in touch, and that her mother might be helpful to the therapy team, Ms. Connelly described her mother as "too frail to make the trip to the clinic" and also as "too busy trying to keep her own life together for me to worry her with this." Ms. Connelly had made a firm decision to keep Bridget and the news of the AIDS away from her mother to spare her any more pain and loss. She was also very concerned that her mother not find out that she had been promiscuous, since the family had always been deeply committed to the Catholic faith and she didn't want them to incur any more shame.

Ms. Connelly's reluctance to include her mother in her therapy is very much in line with what those who investigate substance abuse and AIDS have seen; the secrecy is largely an attempt to keep the family safe from the pain. In fact, despite public impressions to the contrary, most young people with AIDS are taken care of during their terminal illness by a family member, usually the mother (Celentano et al., 1994). Ms. Connelly had to be persuaded very gently to regain contact with her extended family; the team helped her to realize that her death and that of her little daughter would cause even more grief if the family was totally deprived of their company while they were still alive and relatively well.

The interventions applied in this case were "here and now," "intergenerational," and "ecosystemic," as described in our model of integrative Transitional Family Therapy (Seaburn, Landau-Stanton, & Horwitz, 1995). As Ms. Connelly began to understand the perspective of the family's transitions, she became ready to involve family members in the therapy and in planning for the future. When her mother and father first joined us, I made every effort to elevate them and award them their rightful place in the hierarchy. This relieved Ms. Connelly from the burden of protecting them and allowed them to participate actively in the tasks at hand. Their initial grief was extremely difficult for Ms. Connelly to bear, but they assured her that knowing what was happening was preferable to the isolation they'd felt. They were also glad that they'd be

able to help their daughter and have an opportunity to know their granddaughter. Mr. Connelly expressed the feelings of them all when he said, "There have been enough lost souls in this family."

Once the extended family was included in the sessions and the story had been openly discussed, Bridget began to speak and eat again. It was almost as though she had been silenced by the burden of secrecy and was now free to express herself without worrying that it would destroy her mother.

The family and other members of the collaborative team developed clear goals. Primary was keeping Ms. Connelly and Bridget well and safe (from the illness as well as from suicide). The family undertook a family safety watch in which all members of the extended family and friendship circle would guarantee that Ms. Connelly was not alone until she was out of danger (Landau-Stanton & Stanton, 1985). Long-term goals included planning for when their condition worsened and ensuring that they would not be alone.

Plans were made for Bridget's grandmother and a maternal aunt to take care of Bridget if her mother died first, and during sessions the family practiced with Bridget how things would be if Mom went to the hospital for a long time—or if she died. Dolls and puppets replaced the players as they experimented to see what worked best for Bridget. In one poignant session, Bridget kept putting her doll in the hospital, with Ms. Connelly's doll visiting her, insisting that she was going to be the sick one, not Mom. In one exercise, Ms. Connelly went behind the one-way screen to "play" that she was "going away for a long, long time" and that someone else would take care of Bridget.

Bridget started to spend weekends with her grandparents, who bought her a puppy to accompany her from one home to the next. Many hours were spent pouring over family albums.

Together the family was able to plan for their future rituals, including the funerals. They discussed previous family funerals and what had been most meaningful for them all. They decided what music to play, whom to invite, and which pictures and poems to share in celebration of the lives of the people they loved. When Bridget's grandparents disclosed that their parish priest was a close support, he was invited to join the planning network. Several family members who had dropped out of the church objected to his inclusion and refused to attend. The others accepted this, believing it was time for the family to learn to tolerate difference and live with uncertainty.

Therapy continued with the ritual planning of who would continue the family scripts that Bridget and her mother were meant to carry forward through time. Further exploration of the transitional map led to the identification of these themes and scripts, and family members were then able to allocate them across the family. The family strengths identified were spirituality, loyalty, humor, drive for survival, and pioneering. The

family's sense of humor carried them through what could have been a morbid session as they allocated the most unlikely scripts to each other. They decided that the greatest gift to the two sick members would be to ask people to stretch themselves as far as they could. There was much teasing as a very quiet aunt was identified as the member to tell stories at Thanksgiving to the whole family. When she demurred, somebody said, "Don't be picky, it's better than being dead."

Once the family had accepted that they would face the future together, they dealt with preserving the health of other members. Ms. Connelly was able to share how important it was to her that family members use universal precautions against AIDS/HIV, stop their substance abuse, and engage only in safe sex. The family was able to thank Ms. Connelly for bringing them back together and to forgive her for the path her life had taken, since it had ultimately restored family unity.

This family story is not over. The Connellys are all in regular contact and supporting each other. All feel that they've gained a great deal and that they will be able to deal with the inevitable deaths. Meanwhile, they're really enjoying each other by "living"—rather than dying—with AIDS. Open communication and hope have become very important to them, as has rediscovery of their religion.

It is connections with families like the Connellys that make my work and my life converge—and gain meaning.

REFERENCES

- Byng-Hall, J. (1995a). Creating a secure family base: Some implications of attachment theory for family therapy. *Family Process* 34(1), 45–58.
- Byng-Hall, J. (1995b). *Rewriting family scripts*. New York: Guilford.
- Celentano, D. D., Latkin, C., Knowlton, A., & Ensiniger, A. (1994, July). Social network approaches in HIV prevention studies—Family, support, and IDU's. Paper presented at the NIMH Office of AIDS 2nd annual meeting of the Role of Families in Preventing and Adapting to HIV/AIDS, Washington, DC.
- Garmezy, N., & Rutter, M. (1983). *Stress, coping, and development in children*. New York: McGraw-Hill.
- Kark, S. L., & Steuart, G. W. (1962). *A practice of social medicine: A South African team's experiences in different African communities*. London: Livingston.
- Kark, S. L., & Mainemer, N. (1977). Integrating psychiatry into community healthcare epidemiologic foundations. *Israeli Annals of Psychiatry and Related Disciplines*, 15(3), 181–198.
- Kübler-Ross, E. (1975). *Death: The final stage of growth*. Englewood Cliffs, NJ: Prentice-Hall.
- Landau-Stanton, J. (1985). Competence, impermanence, and transitional