REFLECTIONS:

NARRATIVES OF PROFESSIONAL HELPING

VOLUME 5 WINTER 1999 NUMBER 1

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Dear Editor,

I thoroughly enjoyed the issue "Forgiveness." Congratulations on an in-depth examination of an issue important to the social work profession but unlikely to receive systematic coverage in other journals. Another important contribution from *Reflections* to an ongoing dialogue among social workers.

I was immediately drawn to Tropman's article on unforgiveness, having myself never been comfortable with the notion of forgiving my enemies. Try as I might to forgive in my heart, I in fact await opportunities for revenge against those who have wronged me. Fortunately, these opportunities do not arise, but contemplating the possibilities gives me comfort. I admire Tropman's courage in considering unforgiveness, because doing so lacks the moral attractiveness of the other articles, whose authors seem to have transcended the base need for revenge.

Tropman reminded me that the source of my discomfort with forgiving comes from an overly developed internal sense of 'justice'. But Tropman's description of justice is incomplete. Forgiving is what we do to our enemies. What of our friends? Surely a complete sense of justice must include rewards as well as punishments. What of the boy who risked the scorn of our peers by coming to my aid after I was pummeled by the schoolyard bully? The anonymous man who stopped by the side of the freeway to change the tire on my stranded wife's car? The senior professor who insisted that I be first author because I needed it more than he did? Friends are those who go out of their way to help you when they have neither an obligation to do so, nor any expectation of reward. I remember every one of these people, and I anxiously await opportunities to repay them in kind.

Forgiveness focuses our attention toward our enemies, but this is only half of the story. Perhaps a discussion of the entire issue is incomplete without considering our behavior toward our friends. In any case, for me, doing so completes my internal sense of justice and makes my desire for revenge against my enemies seem less base.

Dale Weaver
(Dr. Weaver is Assistant Professor, California State University, Los Angeles.)

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Dear Editor,

I find it difficult to consider forgiving people who commit heinous crimes such as murder, "gross disfigurement, and permanent psychological damage of loved ones due to acts of random violence; politically initiated or politically condoned acts of cultural/racial genocide, terrorism and the use of weapons of mass destruction" as stated in John Oliver's article in the Fall 1998 issue [*Reflections* Vol. 4, No. 4, page 4].

John E. Tropman started "I do not forgive and I do not forget." In some situations I cannot forgive; I cannot forget. However, I can live with "unfairness, serious slights, large inappropriateness, and the like, to me or others" though I may not like it. I, too, hold on to things—objects, possessions, as well as feelings, as Tropman notes. The issue, in my case, is an inability and unwillingness to let go. Further, Tropman says "unforgiveness may act as an energy source and hence have positive elements." I agree.

Micheal Andes writes about a client upset over his wife's drinking. Powerless to help her, he kept his feelings inside and displaced those feelings, eventually slapping his daughter, resulting in criminal charges. Though he deserved punishment for his behavior, I think it was excessive. In any event, although he sought treatment, he was unwilling to forgive his wife.

We all bear scars from experiences we have lived through. I am glad that Paul Ephross was able to write about his experience with Norman Goroff and has done some healing from his disappointment in himself. I agree with the following: "So, I need to forgive myself for not having been able to do something which I was not able to do and perhaps no one would have been able to do at that time."

In an experience that I had, I was able to forgive the perpetrator because he did not deliberately frighten me (he had emotional problems) and was responding to an inner urge at the moment. I survived the experience without any physical harm and only temporary psychological distress.

On Labor Day 1996 there was a male client in my office, located in a building away from the main agency building. He was studying a puzzle map of the U.S. with me when he turned and asked if I was married. When I replied (in the affirmative), he stood up, faced me, unzipped his fly, and exposed himself. I was so shocked I lost my balance and fell to the floor. I picked myself right up and told him to zip up his pants which he did. He opened the door, walked out of the office, headed towards the Boys' lounge and went inside. At that moment the supervisor saw me and I told him what had happened. An ambulance was called and the client was taken to the hospital.

I was given the next few days off and I was interviewed soon after in my home by a police officer, in the presence of my husband. Administrative staff asked me to press charges but I refused to because I was not injured physically and was attempting to heal emotionally by sharing my experience with family, friends, staff and other social work professional. I made reference to the incident at an American Association for Social Work for Groups meeting where the discussion was on the murder of three engineering professors at San Diego State University by a disgruntled student. Though I considered seeking professional counseling, I never did. I had such a good support system and felt that I was not harmed irreparably and the young man was getting appropriate treatment.

As a result of this experience, the agency passed a rule that no social worker in the facility could counsel a resident alone in a private office.

Last, but not least, I wish to express my admiration and affection for Peter and Linda Biehl. They take solace from the thought that "a death in vain is much more terrible than a death that led to a community resolving its problems." May they continue to heal from the loss of their dear daughter, Amy.

Jeanne A. Gill, LCSW

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Transitional

First he said:
It is the woman in us
That makes us write--
Let us aknowledge it--
Men would be silent
We are not men
Therefore we can speak
And be concious
(of the two sides)
Unbent by the sensual
As befits accuracy.

I then said:
Dare you make this
Your propaganda?

And he answered:
Am I not I--here?

-William Carlos Williams

The *Morality* Play's the Thing...

by Paul Abels

A recent film, *The Truman Show*, is the story of a young man who discovers his entire life has been staged with him as the central figure in a three decade long television show. Truman is a True-Man, in that he is unaware of the way he is being used. He is not a True-man because all of the experiences he faces are "set ups," seemingly real, but artificial experiences, with primed people/actors, who follow a script, not their own direction. He, alone, is doing what is natural, of course natural within the limits being set by a conspiracy of actions. All of his problems are resolved, worked out for him by others. But of course his problems are also created by others; they are scripted. Persons grow through the ability to work on the problems they face, and so he must face problems, and of course this gives tension to his life, which is much appreciated by the millions who watch the program. Truman is not permitted to search out his own solutions to problems. When things get too rough, a new character is introduced into the scenario. His wishes to leave town, to search out a long lost teen-age sweetheart, an actress who abandoned her written lines and tried to warn Truman that he was really on T.V. Unknown to him, his desires and plans are all deliberately thwarted, and he is forced to live the life others provide for him.

A series of technical errors alerts him to the fact that he is not in control of his life. Ultimately, and against great odds, he breaks out of the life-long narrative that has been selected for him, out to the world, "less safe" perhaps, but a world in which he will have the right to his own self fulfillment, and be able to make his own moral decisions. As the movie closes we see his once teen-age love, running to meet him. As he walks out of the dome in which his life was shaped, the scene shifts to T.V. audiences all over the world cheering. It is a like a universal morality play, and True-Man, "Everyman," has chosen freedom. The confused, but enthralled world which has enjoyed his enslavement and their own, by the way, for almost thirty years, glories in his freedom, not realizing their own conspiratorial guilt or personal enslavement. One might hope that his experience was a lesson learned, but in the closing scene, with *The Truman Show* off the air, the viewers just switch a channel to another program.

Like the television audience in *The Truman Show*, the helping professions may, though unaware of it, be unaware performers in processes controlled by some prime movers in our society whose orientation toward human needs is self centered and manipulative, and who often lack the "empa-

thy" that Goleman speaks to in his work on Emotional Intelligence.* This unawareness on our part is often at a cost to the clients and perhaps to ourselves as well.

For the healing professions, those concerned with social justice, empathy is a given and we know that all decisions that we make related to our clients are moral decisions., that is, we are always trying to decide on what is the right thing to do. We are always actors in a morality play. The things we do or don't do make a difference in people's lives. The narratives in this issue reflect that idea. Our morality play's actors, the physicians, social workers, mental health professionals, and teachers, reveal their inner thoughts about their moral dilemmas, many which are created by the restrictions placed on them by powerful interests that can set the conditions for their practice. Dissatisfaction with some HMOs which have curtailed physicians ability to serve has created a growing protest from patients, to a movement by doctors to turn to unions, in an attempt to counteract the controls being placed on their ability to give needed service. Limiting service is seen by these doctors as a moral issue, particularly when the laws on the issues are illusive or enhanced by contracts they are committed to sign. All of us, physicians and patients alike are captive to the morality of the organization. We have seen traditional public services made private, and some organizations' policies change from caring to "privateering."

Morality and politics nowadays may seem like an oxymoron. The impeachment hearings have illustrated that moral decisions are contaminated by political influences, resulting in outcomes which ignore the public interest. Television has brought the morality play from the middle-ages into the modern age, and into public dialogue. There's something about a play that grabs our attention. Shakespeare's Hamlet proclaims, "The play's the thing wherein I'll catch the conscience of the king." Morality plays may not have been the rage during the middle ages, but they did draw crowds and "Everyman" was a hit in its day. It played out the story of humanity's battle with, and conquest over, evil. It was meant to muster our awareness and give rise to our "higher," more moral attributes. The hero need not be perfect, but close to it. It was often the person's temptations, and the inner struggles that helped point out the importance of the conquest.

The people who shape our lives are both moral and immoral, and at times both. Not that they would have us do immoral things, but like Truman, the consequences of their actions us as, persons, diminishes our autonomy and diminishes our ability to serve. The solution is to become aware of the forces impinging on us, and to raise the awareness of those we work with as well. The morality play is played out everyday in our offices, the classroom, and our organizations. We are "everybody." □

(I would like to dedicate this editorial to Iris Murdock, whose writings are often wonderfully moral. She died on Feb 8,1999. I particularly liked *The Nice and the Good* in which all the characters are treated in a moral way including the villains. You might also want to read *Elegy for Iris* a book written this year by her husband John Bayley, about their love, her Alzheimer's, and their life together during her illness. It illustrates, powerfully, the relationship between love and morality.)

*Goleman, D. (1998). *Working with Emotional Intelligence.* N.Y. Bantam Books

Re-Imagining Primary Care

by Martin Kohn, Ph.D.

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I have had the privilege of knowing and working with numerous physician-writers for nearly the past two decades of my life in medical education. They have taught me that it is possible to simultaneously maintain both a scientific and a humanistic stance in the world of clinical practice—whether as physician, as nurse, or as social worker or other health care professional.

Their perspective on the place of the humanities and the arts in the medical school curriculum and in our lives is captured well by some lines from the poem "Gaudeamus Igitur" by physician-poet, John Stone (1983):

For there will be the arts
and some will call them
soft data
whereas in fact they are the hard data
by which our lives are lived
For everyone comes to the arts too late
For you can be trained to listen only for the oboe
out of the whole orchestra
For you may need to strain to hear the voice of the
patient
in the thin reed of his crying.

Jack Coulehan, also a physician-poet, answered my call for a reflective essay. He is an important person in my life for a number of reasons. He has been an invaluable source of guidance to the Center for Literature, Medicine, and the Health Care Professions, which we at Northeastern Ohio Universities College of Medicine (NEOUCOM) operate jointly with Hiram College; and he has mentored me in my struggles as a teacher-poet.

I turned to Jack a number of months ago to help with my perceived need to re-imagine primary care. I called on him not only because of his writing skills, but also because of his breadth of knowledge and experience as a generalist physician. I called on him because I had become worried about who were serving as the mentors or action guides for physicians of the 21st century, physicians who I hope will "hear the voice of the patient in the thin reed of his crying." I present as evidence of my concern the following scenario: At a recent class presentation I was giving on death and dying, I asked our first-year students if they knew of Elizabeth Kubler-Ross's work. Only eight of one hundred or so hands rose in response. Perhaps ten of those in attendance knew who Albert Schweitzer was. I asked about Schweitzer because it was his life work that propelled Kubler-Ross into medicine.

Which heroes are our students calling upon? Probably not Schweitzer. More likely they are motivated by the chest thumping and number shouting heroes of the television show *ER*. Or perhaps their role models have the initials "M.B.A." after their names. So I grow more vexed about who our medical students are becoming and how the social forces of professional schooling and the health care delivery system may be turning

them into persons they had not intended to become. Recent scholarly work has convinced me that the situation is becoming dire. For example, MacPherson (1997) uses the metaphor of a "speeding bullet" to describe the pace of the changeover to a for-profit health system. Not only does this analogy imply the temporal aspects of this transition, but it also signifies the potential danger in trying to challenge it. Woolhandler and Himmelstein (1997), longtime champions of a single payer health care system, also have recently thrown down the gauntlet against for-profit care. While leading physicians, nurses, and students in a demonstration against profit-based health care, they warned that "today's medical market displaces patients and caregivers from center stage, elbowing aside the human relationship and cultural crux of care" (p. 6). In a chapter appropriately titled "Imagining Unmanaging Health Care" in his recently published book, physician-writer and recent graduate Raphael Campo (1997) also has eloquently addressed the issue of loss of ideals and the obliteration of the images of caring that had sustained him:

> *I once dreamed of learning how to become more empathic, not more productive; even if seduced in part by the prestige of medicine, I have never wished to be a mere cog in a new system whose sole purpose is to profit by its efficiency. Need, the oceanic depth of it, defies even the most eloquent of poems to articulate it, so how can a single telephone line to an HMO's surly triage nurse suffice? The monumental impassivity of the burgeoning managed-health care system, as it collides with this tidal wave of suffering, seems more likely to produce a disaster than a workable solution.* (p. 203)

Thus, the challenge to my colleague was to take seriously the influence imagination has on our everyday lives and the critical decisions we make. In particular I asked him to reflect on the decision to accept the calling to generalist medical practice and how one who is called to primary care lives up to the expectations of the mentors or heroes who influenced that calling.

I also suggested to Jack that in constructing his essay he should consider the following additional questions:

> Who have I become in comparison to who I thought I was when I began my medical career? What images have influenced and continue to influence me? What are the origins of those images?
>
> Did (and do) the images or persons I call upon express or reinforce dominant ideologies within our society and, in particular, within the traditional medical establishment? Have I consciously sought non-traditional sources of iconic inspiration?
>
> What images would I want the generalists we seem so desperately to want more of to incorporate into their imaginations, individually and communally?

I realize that there is no such thing as an innocent or a pure image or story. Reality is socially constructed and influenced by social values and ideological forces. I must take care not to foist Kubler-Ross (a questionable role model) or even Schweitzer on my medical students. And who says they can't be influenced positively by the doctors on TV. I just hope that they also take the time to listen to or read the work of physicians like Jack Coulehan as well. □

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Albert Schweitzer, William Carlos Williams, and Managed Care

In this narrative I try to describe the influences, such as Albert Schweitzer, William Carlos Williams, Harold Johnson, and others, that shaped my medical career, my thinking, my poetry—and my perspective on primary care and medical education. The central themes of my narrative reflect on the importance of scientific thinking, patient-physician relationships, and empathy, gentleness and self effacement as core values in medicine, both in caring for patients and promoting a collegial work environment. The narrative examines my understanding of the current cynicism about the future of medical virtue; and I hypothesize that the rapid changes in the medical system within the 1990's in the long run may be beneficial for the future of generalist practice and human values in medicine.

by
Jack Coulehan, MD, MPH

Jack Coulehan,MD, MPH, Director and Professor, Institute for Medicine in Contemporary Society; Staff, Health Sciences Center, State University of New York at Stonybrook, Stonybrook, NY.

Martin Kohn asked me, first, to identify the persons and situations that influenced me to become a physician and, in particular, to choose a generalist career. Secondly, he asked me to consider whether (and in what ways) these action-guides might be relevant to today's medical students and young physicians. The project also required me to attempt, at least, to avoid nostalgia, a difficult task because epidemic nostalgia is sweeping American medicine. We are being devastated by an especially virulent form of nostalgia that attacks physicians of all ages, rather than just the old and infirm. The clinical syndrome includes an almost irresistible desire to romanticize the past while complaining about the rapid changes in health care that threaten to destroy our profession. Therefore, be cautious. If you encounter even a suggestion of nostalgia in the following pages, proceed at your own risk.

Albert Schweitzer

Reminiscence

I find it easy to identify action-guides from medical training and later (although they don't necessarily point toward generalist practice), but it is much more difficult to pinpoint how I wound up on the doorstep of medical school in the first place. My childhood and adolescence are notable for the lack of any personal experience with physician role models. I completed college without ever having volunteered in an emergency room or hospital. As far as I'm aware, I never had a sustained conversation with a physician about anything. Given that record, a medical school admissions committee today would almost certainly question my motivation and maturity, no matter what my grades were. Since I loved literature, and wrote and published poetry in college, a hypothetical career counselor would

likely have pegged me for graduate study in English.

How then did I choose medicine? As far as I can tell, my first role model was Albert Schweitzer, who entered my adolescence via books and television. In the late 1950's Schweitzer was the Grand Old Humanitarian of the world. He immediately appealed to me because he was a Renaissance man, a man who had the energy and creativity to excel in a multitude of fields—philosopher, theologian, musician, musicologist, physician, and humanitarian. As a teenager in Uniontown, Pennsylvania, I visualized myself by day working at Schweitzer's side in the jungles of Gabon and, in the evening, listening to him play Bach chorales under the African sky. I was infatuated with the romance and intensity of his life. I remember reading (although, in retrospect, with virtually no understanding) his early theological masterpiece, *The Quest for the Historical Jesus*, and struggling with his concept of "reverence for life" in *Civilization and Ethics*. Schweitzer's work ranged from the theoretical to the practical, from the abstract world of ideas to the concrete world of human suffering, from the security of church and university to the risky life of a missionary doctor.

Later, in college I learned about existentialism and read the novels of Camus and Sartre. Dr. Bernard Rieux in Camus' *The Plague* provided a second powerful medical image for me. Here was another man who devoted himself to duty in the face of insuperable odds, who was a humanitarian as well as a physician. Like Schweitzer, he practiced in a distant, mysterious place. Unlike Schweitzer, however, Rieux struggled to affirm life in the context of a chaotic, meaningless world, rather than as a corollary to religious faith. As a young man in the early 1960's, I was keen on creating meaning out of meaninglessness.

In the fourth year of medical school, I spent several months in Jamaica working with Harold Johnston, an elderly Jamaican physician who, in his retirement, had started a new career as the public health officer for his home parish. In his earlier life, Dr. Johnston had been a university physician who spearheaded the campaign to eradicate yaws, a spirochetal disease related to syphilis, from the Caribbean region. This was an accomplishment for which Queen Elizabeth awarded him the Order of the British Empire. Harold Johnston was also a preacher in the Seventh Day Adventist church, a vegetarian, and, most provocatively, a man with a mysterious past. In the long (and very boring) Jamaican evenings we spent at Dr. Johnston's house, my wife and I would construct romantic stories to explain how he came to have a distinctly non-religious tattoo on his right forearm. We imagined our mentor's days as a Jamaican medical student in Edinburgh and, even earlier, his entirely fictional life as a hard-drinking sailor.

My feelings of love and admiration for Dr. Johnston were mingled with more ambiguous feelings—frustration, impatience, anger, and a deep sense of inadequacy. Living and working with such a person was more difficult than I had imagined. I liked to eat meat, for example, and listen to rock-and-roll. I found myself complaining that he was too generous, too uncompromising, and too free with good advice. I was concerned about whether we would get good enough data to warrant publishing a paper, while he seemed to feel that rigorous design was unimportant. Interestingly, Dr. Johnston (like Albert Schweitzer) was a reserved, austere, and rather distant person, a man who in some ways never quite "fit" into the community he served.

Another important influence was the atmosphere of social activism in the late 1960's and early 1970's. I attended college and medical school during the peak of the American Civil Rights Movement, which later blended into the anti-Vietnam War Movement during my clinical years and post-graduate training. Annually at the University of Pittsburgh the fourth year medical class put on a musical satire, which in my year was called *Medic Hair* after the popular Broadway musical *Hair*. We were convinced that the Age of Aquarius had begun and we were about to remedy poverty, racism, and poor access to health care in America. We were imbued with a sense of energy, commitment, and "can do."

While our parents had failed the poor and become addicted to materialism, we were not going to follow in their example. While they had started the war in Vietnam, we were going to stop it.

The social activism of those years also contained the seed that grew into the "personal fulfillment" movement. Flower children throughout the country were dropping out, smoking dope, using acid, and experimenting with various peace-and-love lifestyles. During my internship at the University of Pennsylvania, some close friends decided to leave their university jobs and join a commune in Colorado. I remember feeling a bit ashamed (and definitely defensive) when I explained to them that, instead of joining a commune, I was planning to study public health and then practice medicine on an Indian reservation in the United States Public Health Service. They told me that by working for the government I would be compromising my principles and selling out. They were convinced that any attempt to "do good" within the system was bound to fail. Their solution was to seek personal growth and fulfillment as part of a small community of like-minded people. For some time I questioned whether my decision not to drop out was really in the service of some ideal, or simply represented a lack of courage.

I also encountered another, less idealistic, set of influences in medical training. At the University of Pittsburgh there was little or no exposure to primary care or generalist role models. Family medicine was in its infancy and not yet represented in Pittsburgh. The faculty was hostile to general practice, which it considered to be an inferior craft, lacking dignity and intellectual bite. Internal medicine held sway as the sine qua non of the medical profession; it still seemed possible to become a "compleat physician" in the image and likeness of Sir William Osler. However, it seemed that academic physicians had in-

terpreted the generalist dictum of "treating the whole patient" to mean understanding how all the organ systems function together, rather than approaching patient care from a biopsychosocial perspective. In Pittsburgh Dr. Jack Myers, the Chief of Medicine, exemplified this approach. To me Myers was a frightening man—sharp, arrogant, insensitive, but awesome in his knowledge of pathophysiology and differential diagnosis. Known throughout the country as "Black Jack" because he so often flunked candidates in their oral Board examinations, Myers was truly a master of his profession. That profession, however, was definitely not the day-to-day work of caring for patients. Nor was it necessarily the work of nourishing medical trainees. Jack Myers frequently intimidated and humiliated his students and house officers. Yet, to have a good recommendation from him might well serve as a ticket of admission to the best residencies in the United States.

Perhaps because I was so timid myself, I found this man's supreme self-confidence tantalizing. I went to him with my professional quandary: Should I proceed to become a public health physician? Or should I go into psychiatry, a course that also held a somewhat hypnotic attraction for me? (I was an avid reader of Freud and his followers as well as of Schweitzer.) In any case, "Black Jack" convinced me to finesse the quandary by applying for a residency in internal medicine. He told me internal medicine would be the best basic training, given the uncertain direction of my future plans. Since he considered me bright enough to join the "club," he cautioned me to apply only to highly rated university residencies.

At the Hospital of the University of Pennsylvania where I was an intern the following year, fascinomas like Churg-Straus syndrome and Goodpasture's disease were the stuff of everyday practice. Primary care was performed by "local medical doctors," a strange breed of wannabes who lived outside the walls of the hospital and constantly made mistakes. My colleagues at Penn were mostly "Young Turks," anxious to become a new breed of scientific specialists. Many of them have subsequently become re-

spected figures in American medicine. While I enjoyed caring for my patients in the hospital, I never waxed romantic (then or now) about the long hours, low pay, and barbarous working conditions. In fact, during much of that internship year the most exquisite part of my day was the 14-block walk from my apartment to the hospital, during which I fantasized escaping from Philadelphia with my wife and journeying together in exotic countries.

I was so conflicted and uncomfortable at Penn that I chose to leave before completing the standard three-year residency. This required taking a stand before an incredulous residency director, a younger, smoother version of "Black Jack," who told me I was making a serious mistake. They were unlikely to take me back, he said, when I finally realized the error of my ways. With this encouragement, I went on to study at the School of Public Health in Pittsburgh. There I met plenty of epidemiologists and planners, but again, no generalist physicians. After another two years, though, and in the absence of real-life role models, I found myself practicing primary care at the Public Health Service Clinic on the Navajo Reservation at Lower Greasewood, Arizona.

Let me skip ahead about twelve years to identify two additional action-guides. By this time I was a faculty member at the University of Pittsburgh, facing the personal and professional conflicts that often arise when you reach your early 40's. My interest in creative writing, especially poetry, had never disappeared, but had long lain dormant. The most I ever did was compose a snappy verse for a friend's birthday or to cheer up my wife when she had her wisdom teeth extracted. I also found myself progressively depressed.

One of my patients at the time was a poet named Rosaly Roffman. Through a mutual friend, she learned that I once wrote poetry; each time Rosaly came to my office, she asked to see some of my old poems. Each time, I declined because I was convinced that it would be unprofessional to share something so personal with a patient. Nonetheless, it was tempting. Inexplicably, after a few months, I took the risk of acting on my feelings and showed her a stack of old poems. This was the beginning of a mentoring relationship that lasted several years. Rosaly and I developed a kind of quid pro quo arrangement in which I provided medical care ("professional courtesy") in exchange for her services as a teacher. She gave me assignments—for example, Write a poem about the brother you never had—and then we would meet to critique my work. For me these were extremely painful sessions. How dare she trash my wonderful lines! Doesn't she realize how good this is? But the discipline and pain released a flood of creative energy. The stuff really was bad, but her gentle prodding drove me to make it better. Under Rosaly's tutelage, I became a working poet.

Many of the poems gave voice to a dimension in patient care that I had felt for some time but could never articulate. I felt that being a poet made me a better doctor. My model for this point of view was William Carlos Williams, who said that for him poetry and medical practice were inextricably linked. I read Williams' poetry, but found only a portion of it to my taste. Many other modern poets were more compelling. But Williams' life was another matter. I romanticized it, not only the synergism between medicine and poetry, but also the theme of under-appreciation. Williams had little time to spend on the literary scene because of his busy medical practice. His poetry sold poorly (even for poetry!) and was unappreciated by most critics. Yet, he continued to plug along until eventually he won renown as one of the leading poets of his generation. If this happened to Williams, my romantic fantasy went, perhaps it could also happen to me.

Reflection

Now I need to consider what value, if any, these action-guides could have for today's medical students or young physicians. In thinking about this, I run into considerable resistance. First of all, there is the general problem of drawing morals or lessons from past experience—the lessons are often boring and self-important. My tendency is also to present romantic "takes" on some of them—Albert

Schweitzer, Harold Johnston, and William Carlos Williams, for example—and to minimize the complexities of their lives and influence. As a writer, I suspect the most interesting approach would be simply to tell more stories about them and let the reader do the reflecting.

The second problem has to do with the recent revolution in how medicine is practiced in this country, which leads to the managed care objection. By the "managed care objection" I mean the current cynicism about the future of medical virtue and the belief that human values in medicine have succumbed, or soon will succumb, to corporate greed. Nowadays, physicians tend to argue that patient-physician communication and relationships were relatively good until a few short years ago when corporate scoundrels invaded medicine and started to squeeze the humanity out of our profession.

That is simply not the case. In fact, if you consider patient-physician relationships the heart of medicine, our health care system has been suffering from progressive heart failure for more than a generation. The changes in the structure and function of medical schools that began in the 1950's with the establishment of the National Institutes of Health and the growth of medical schools as research institutions led, as night follows day, to the contemporary landscape of fragmented, sub-specialty practice. The decline of primary care and, with it, the general deterioration of the physician-patient relationship as a therapeutic tool were unintended consequences of these developments. Long before today's managed care mania, physicians were already spending too little time with their patients, the public was already dissatisfied with medical care, and levels of trust and cooperation were already low. These features, combined with skyrocketing costs (another unintended consequence of subspecialization), led to the demand for dramatic changes in health care delivery.

To counter the managed care objection, I'll go out on a limb and say that the rapid changes we are experiencing in the 1990's may in the long run be beneficial for the future of generalist practice and human values in medicine. In fact, I think shock therapy was necessary. Many features of current for-profit managed care pose serious challenges to the ethical practice of medicine, challenges that will be difficult to resolve, but medicine's need to address these problems may also provide the impetus to refurbish professional values. In the hope that it does so, I want to argue that Schweitzer and the others have something important to say to 21st century physicians.

I would definitely not recommend that future physicians neglect, as I did, getting hands-on experience of medical practice before applying to medical school, nor that future generalists embark on their careers without having good generalist role models. There are also other ways in which my career departs from the "normal range." Over the years my professional interests have developed, partly by accretion and partly by substitution, from public health to epidemiological research, from medical pedagogy to clinical ethics, from patient-physician communication to confessional poetry. Nevertheless, I tend to view all these interests as relevant to my career as a primary care physician. Most academicians would call this variety a terminal lack of focus. I choose to see it as a voyage of self-discovery, but there is no question that embracing so many fields has academic and emotional drawbacks. If I were counseling a young academic generalist, I would encourage her to follow her interests, but caution her against being too diverse. I'm convinced that part of my field hopping resulted from a failure to recognize (or to act upon) what I later realized were passionate beliefs about the relationship of healing, empathy, and poetry. I would try to help the young generalist to be more reflective earlier in her career and perhaps more courageous in acting on her intuitions.

I'm delighted that Albert Schweitzer was the first action-guide who came into my mind.

Although I hadn't thought specifically about him for years, he quickly emerged as the prime candidate for Ur-role model. I've more often reflected and written about Harold Johnston, whom I still consider the "saint" of my early life. Likewise, for better or for worse, Jack Myers is burned into my consciousness as the archetype of the Chief of Medicine. William Carlos Williams has the distinction of being the only one of these action-guides whom I actively sought out; the others simply appeared. These men shared certain qualities. They were strong and fiercely independent. They were steadfastly committed to their distinctive visions. They set their sights on higher goals than "money practice," to use an interesting term Williams coins in his autobiography. Each in his own way was an imaginative and creative person.

One characteristic shared by Schweitzer, Johnston, and the activist milieu of my early medical experience was that a life in medicine could make a difference. By "difference" I don't mean the obvious fact that a physician will help his or her patients get well, but rather that a life's work in medicine may ultimately contribute to the improvement of the community and society in general. They believed that medicine could facilitate social justice and that physicians had a duty to devote themselves to that project. Since the 1960's, the growth of medicine as a "money profession" and our general loss of faith in social action have tended to suppress such beliefs. Perhaps many physicians today would like to speak up for their patients or to work toward making medical care more equitable, but they feel helpless. They see themselves as caught in a web of managed care bureaucracies over which they have little or no control. Other physicians have their activism stunted or blocked by the sense of entitlement they developed in the culture of the 1970's and '80s. Unfortunately, persons who entered the profession during the last 20 years, no matter what their initial motivation was, have practiced medicine only in a high income-low risk environment.

The Schweitzer-Johnston ethic presents a challenge for young physicians entering today's managed care environment. What would either of these men do if faced with the realities of contemporary American medicine? I am absolutely sure that they would not feel helpless. On the contrary, they would pursue courses of moral activism, although it would be risky and uncomfortable to do so.

Nowadays we have grown leery of virtue. Not long ago I was discussing Albert Schweitzer with a physician friend in Kansas City. He immediately threw up his hands and his face turned sour. "Why that man was a total fraud," he exclaimed. "You wouldn't believe how dirty his hospital was. He didn't even believe in germs."

He went on to tell me what a racist Schweitzer was. Granted, Schweitzer's hospital was not the most antiseptic place in the world. This was partly because of his "reverence for life" philosophy and aversion to unnecessary killing, even of insects. It is also true that he was sometimes a distant, irascible, and paternalistic man. I think these features reveal the complexity of his character and make him more interesting. They may puncture a hole in his sainthood, but they certainly don't make the man a fraud. Schweitzer's virtues are no less worthy of emulation just because he also had weaknesses. I suspect our passion to discover everyone's innermost weakness is simply a defense mechanism to avoid feeling like we ought to emulate his or her virtues.

Let me move on to "Black Jack" Myers. I can frame his influence on me in positive ways; for example, he was a champion of clear thinking in medical decision making. Early in the era of multiple and excessive diagnostic testing, Dr. Myers was a strong spokesman for clinical reasoning based on observation and logic. In light of what has happened to medicine in the ensuing 25 years, I can fully appreciate his distinction between true scientific thinking and the mere application of technology, which, even in the late 1960's, he claimed was damaging the quality of medical care. Long before the term "Evidence Based Medicine" was

coined, Jack Myers insisted upon it. He was also a champion of the general internist, as modeled along the lines of Sir William Osler. Had physicians through out the country adopted Myersian logic, subspecialization and the costs of health care would have increased much less rapidly. Another positive influence was the power of his role as teacher. It's quite possible that Jack Myers' teaching skill made me realize how much influence a teacher could have and may be responsible in part for my choosing academic medicine as a career. His uncompromising adherence to his own vision of medicine was another admirable trait.

What fascinates me more, however, is Jack Myers' counter-influence, specifically my strong conviction—perhaps formed by reputation even before I met the man—that the way he behaved with students and staff was unacceptable. I could never really believe that he cared about the whole patient when he seemed to care so little about the whole student. Paradoxically, my time with "Black Jack" served as an important background to my thinking as I came to see that empathy, gentleness, and self-effacement were core values in medicine, both in caring for patients and in promoting a collegial work environment. Later, as a young faculty member at the University of Pittsburgh, I went to Jack Myers to ask if he would present several sessions in the new Clinical Skills course that I was directing. By that time he had retired from the Chairmanship of Medicine to work on an artificial intelligence system, a powerful aide to diagnostic reasoning which he hoped would ultimately cover all of internal medicine. He was gracious and helpful and, of course, wonderfully impressive in his lectures. Nonetheless, my 1968 image of "Black Jack" humiliating his medical students remained. I can sum up his influence in three words: logic, discipline, and distance. I have tried to embrace the first two and reject the third.

What can I make of William Carlos Williams and Rosaly Roffman as influences in my professional life? One simplistic way of looking at this is to draw a lesson about cultivating interests outside of medicine by stating that physicians should be humanistic and well rounded. However, "interests" is a weak word, which does not capture the importance (to me and potentially to others) of the Roffman-Williams phenomenon. It is not a question of simply diversifying your interests, or of finding alternative ways to let off steam. Nor is the subject important—I can imagine another physician getting turned on by a jazz musician, carpenter, or priest.

The important issue is that I was a 40-plus year old man who unexpectedly experienced a new direction in life. The new direction asserted itself against considerable resistance. (Otherwise, it would have probably arrived a lot earlier.) Like most physicians, I value being in control—being on top of situations, minimizing risk, maximizing efficiency. This style promotes organization and detachment, which in many ways are valuable traits but are not particularly helpful for personal growth. I can't articulate why I was finally able to let down my defenses when Rosaly Roffman pestered me about showing her my work. In retrospect, it seems clear that the desire to make poems is a part of me that should not have been suppressed. Poetry became an avenue of self-discovery. In fact for me, writing poems is a type of centering or meditation. I'm grateful that poetry opened new horizons for me. Others will find their avenue to self-discovery elsewhere.

I'm not sure what will happen to medicine in the next 25 years, but I think the profession will look a lot different than it did circa 1980 or 1990. To me this isn't a dire prediction because many of the virtues we associate with medicine—compassion, integrity, courage, and fidelity, to name a few—are currently practiced more in word than in deed. We have compassionate and courageous physicians, but not enough of them. The profession as a whole these days seems (at least to the public) less than compassionate, less than courageous. Clearly, we are going to need a new breed of doctor. Strange though it may seem, as a result of today's health care revolution, stories like those of Albert Schweitzer, Harold Johnston, Jack Myers, and William Carlos Williams may end up having more, rather than less, relevance to young physicians than they did a generation ago. □

The Patient "Failed" or Did She? How a Transplantation Patient and a Donor's Unmet Psychosocial Needs Became the Catalyst for Change

In 1995, my beloved sister, a social worker, died from complications after two bone marrow transplants. This narrative addresses the absence of needed psychosocial services before, during, and after transplantation for my sister and for me, her donor. While these unmet needs were disempowering at the time, subsequently I have become a policy advocate for psychosocial services for bone marrow transplant patients and their families. The narrative describes the events as they occurred my sister, the patient, and to me, her donor before, during, and after the process of transplantation.

by Joan Berzoff

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Two years ago, I donated my bone marrow for my sister with myelodysplastic syndrome. She was among the one percent of patients whose leukemia had been caused by the chemotherapy she had received a number of years before for breast cancer. The breast cancer was cured, but the treatment was going to kill her.

My sister, like me, was a social worker. A mother of three children, she was beautiful, bright, vibrant. Forty-seven years old, she walked five miles a day, had wild frizzy hair, wore purple scarves around her shoulders, big earrings, long skirts, big coats. She lived vigorously and generously. In one hand, she held the hands of her three children; the other hand balanced bundles of groceries and a briefcase, metaphors for the multiple demands in her life. This was a woman who loved the outdoors. She planted a garden every spring which blossomed pink, fuchsia, and red, defying the concrete and rock pavement which dominated the uninviting urban landscape where she lived. Her family, like that garden, grew similarly. Despite their many difficulties, her children leaned toward her as if she were their bright and sustaining sunshine. She had a spirit, a vibrancy, and an empathy which was magnetic. Unlike me, she radiated a contentment and peace with her life and its fortunes.

The oncologist who had been following her for her breast cancer was unable to convey to my sister that her deadly diagnosis had resulted from the chemotherapy which she had administered. Rather, for two years, her doctor used euphemisms. Shaking her head, she would lament that my sister's "bloods were bad," with vague reference to some indefinite future time in which a bone marrow transplantation might be necessary. Perhaps because the doctor and patient were so close in age, in life stage, and in social roles, coupled with my sister's fears of knowing, her physician did not reveal the obvious and very painful truth between them: that my sister had a fatal illness and the only hope of survival would be through a bone marrow transplant. When my sister finally developed a cough which persisted, she consulted my physician who bluntly gave her his diagnosis and prognosis.

When she was given her deadly diagnosis, her reaction was absolute and fatalistic. She was sure that she would die and equally sure that the recommended bone marrow transplant would kill her sooner were she to undertake it immediately. She understood that she probably had no more than two years to live, but wanted to see her daughter bat mitzvahed, to be able to choose an appropriate school for her son, and to be alive to see her other daughter graduate from high school. She was clear that she wanted to seek every and all alternative treatments first. She was absolutely clear that she did not want to become a cog in the wheel of a major teaching and research hospital where she, as a person, would not be treated well.

With her fatal diagnosis now manifestly clear, my sister and I drove directly to the city where her oncologist practiced. In our three-hour car ride, we faced the ending of her life and the almost infinite losses which lay before us. Between the folk songs of freedom we sang on that journey, we tried to name the losses: of her children, for her children, for me my dearest friend, for both of us our shared history. Singing love songs and lullabies, belting out songs of freedom, we drove on.

Her oncologist made time to see us but conveyed that there was only one treatment now and it must be done immediately. Since I had earlier been tested and found to be a perfect match, she instructed my sister to check into the cancer center in her city and begin the process leading to transplantation. When my sister made it clear that she was not ready, her oncologist suggested that her own capacity to be helpful was over.

My sister embarked on a combination of experimental chemotherapy and Eastern medicine, and her own resolve did keep her alive long enough to choose a school for her son, see her daughter bat mitzvahed, and see her other daughter graduate. But over the next two years, her friends, family, and physicians, knowing that there was no other hope for her long-term survival, mounted increasing pressure for her to undergo the bone marrow transplantation. Despite her clarity that this was both a procedure and a process which would rob her of any choice about the way she would die, she became increasingly isolated in not wanting to die a high tech death. At the end of two years, feeling trapped, hopeless, and even suicidal, she reluctantly agreed to the procedure, knowing that the legacy of having not tried to save her own life would have been equally damaging to her family.

The Pre-Transplantation Experience

My sister entered a highly prestigious, world-renowned cancer center in the spring of 1995. There was as thorough and rigorous an examination of her disease process as was possible. But noticeable by its absence was any evaluation of the patient's dread and fear. When she signed an informed consent cataloguing almost every catastrophic event which might befall her, both her doctors and the bone marrow coordinator seemed oblivious to the terror which accompanied hearing about potential outcomes of the transplantation itself: graft vs. host disease, the destruction of her organs—liver, heart, reproductive, or brain. In fact, when she met with the bone marrow transplantation surgeon and expressed some of her negative feelings, he became furious with her, clearly unappreciative of the profound ambivalence which had brought her to this place.

Why was she so ambivalent? Had one inquired, this was a woman on whom many depended. Her marriage to an attorney was in disarray. A self-preoccupied man, her husband had been chronically unable to care for himself or for others outside of the office setting. He did not know how to warm his food in the microwave, take out the garbage, open the mail, or pay a bill, and depended upon his wife to execute every one of life's details. Now feeling abandoned, he railed increasingly at my ill sister for her insufficient

care of him. He put ads in magazines seeking a new romantic partner to replace her. Sometimes he would not come home at night. Her 14-year-old daughter, sensing that the control and organization which had bound their family was now imperiled, began to over control her eating, becoming anorexic, frail, and weak, like her mother. Her eldest daughter, 17 years old, acted out and smoked cigarettes in places where she was sure to be caught, unconsciously perhaps hoping to rally her mother as she had so many times before. My sister, who had previously met the needs and demands of her family so thoroughly, simply could not meet them now, nor could she envision becoming a dependent herself.

Why else was my sister so fatalistic and seemingly unable to maintain hope? In fact, she was about to turn 49, the very age that our grandfather had died of tuberculosis and the same age that our father had died of sarcolymphoma. Ironically, my sister's children were exactly the ages that we, as children, had been at the time of our father's death. What was the meaning of having a fatal illness, when, at the same age as her eldest daughter, she too had lost a parent in the family where the center could not hold? Was some of her pessimism still bound up with the helplessness and hopelessness from so many years back when her own sense of security and well being had been shattered by loss? Sadly, these questions were not asked nor their answers solicited as she entered into the cancer care center's system.

A deadly diagnosis is traumatic to any individual. Being offered a treatment which in itself may be deadly is especially so. But transplantation does not just deplete the emotions. It also threatens to deplete other resources—both economic and social. For example, bone marrow transplantation is financially costly. By the time my sister died, we calculated that her hospital bill came to over one million, two hundred thousand dollars. She was lucky. Her insurance paid the bill, and she was allowed to die with needed inpatient medical services. Yet, at no time prior to her transplantation was the trauma of the procedure nor the depletion of her resources addressed or acknowledged.

The Process of Transplantation

I had been, not surprisingly, a perfect bone marrow match for my sister: our sensibilities and bodies uncannily twin-like. She chose to undergo the procedure in the summer, coinciding with the opening of the Clinical Doctoral Program which I co-direct: a rigorous academic experience of ten weeks for which students gather from all over the country to study residentially. As both a co-director of the Program and a teacher of three courses, it is normally a very stressful time.

My sister elected to have her transplant in the city in which she lived, a three-hour drive from my home. When I met with the head of her transplant team (for whom I waited over three hours), I asked him, as I had the bone marrow coordinator, about the reality of managing the demands of my career, my two children, and the commute to donate for my sister. He ignored my questions and answered me in a language replete with medical jargon with which I was unfamiliar. There was no literature to translate what he had said, nor to help me to anticipate the process. No one prepared me for the physical pain. No one talked with me about the side effects: anemia, exhaustion, difficulty with my own bones. The donors whom I located myself to talk with were a pessimistic lot. In my small sample of five, each had had a sibling die during the process of transplantation. None had felt that, were they to make the choice again, they would recommend a bone marrow transplant for their sibling. This message was disheartening.

My donation to my sister was done on an outpatient basis because her insurer did not cover a stay overnight. It might have been reasonable for the hospital to have offered overnight care to an out-of-town donor. Despite my having asked for an antiemetic, the request was forgotten, and I spent a sleepless night in a hotel, vomiting and in pain. But my school was beginning, and by the next day, I was driven three hours to my home. Within that day, however, my sister had her first crisis, and I was called to return to her city to give platelets. Since

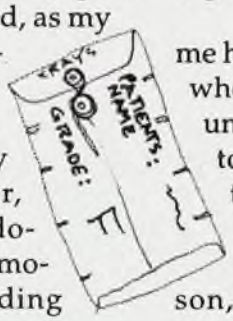
I could not drive, I needed to identify someone to do so, another hotel to stay in, and a way to try to recover so that I could return to teach. Of course, had I known that this might be a scene which was to be reenacted 16 times in the ensuing weeks and months, I might have made very different choices regarding my own life and career that summer. Sixteen hotels, two thousand dollars: what happens to those donors whose financial resources are such that they cannot manage such accommodations?

My sister's first trip to ICU, only a day after the donation, came after her having bled into her lungs. She remained on a ventilator for ten days. Her second trip to the ICU, somewhere in the middle of the summer, was the result of a pneumonia; her third and last trip to the ICU was the result of a stroke.

Halfway into the summer, I was called to do a second bone marrow donation. The first had not taken. I was tired, worn, anxious, and desperate to do anything that might reverse what had now become a nightmare course. My own body ached, as did hers, but neither she nor I experienced an acknowledgment of our difficulties—emotional, financial, or physical—and the ways in which they intersected. This was a time when the emotional aspects of transplantation needed to be addressed for both my sister and her family, and me, her donor, and my family.

After the second donation, I was to stay in a hotel across the street from her hospital. Physically unable to get across the street, I sat on the curb, wondering how, and why, as a donor, a simple wheelchair or nurse were not available. As my own psychological needs to plan and anticipate had been ignored, so too were the simple meeting of physical needs. Like the patient, I had become an organ, but not a person with an organ.

By now, my own two children, then five and nine, were angry at my many absences. I was, myself, quite overwhelmed. Indeed, as my sister began to decline, so too did her family's functioning. Still there was no way to address—for her, her family, or her donor—the very real emotional events unfolding before us.



The inpatient nurses during my sister's five months were both present and caring. But her isolation was profound. Family and friends were masked, gloved, and gowned, stripping them of their identities in order to keep her room germ free. The result of wearing a mask is that it covers up the subtleties of a smile, a frown, a grimace. It masks the feelings. My sister had no access to other patients, no closed circuit TV in which to share this experience with patients also enduring it. How shortsighted and ultimately costly it seemed not to provide forms of human relatedness during transplantation which might have offered some hope, lessened her loneliness, and decreased her helplessness!

By the end of almost five months, this vibrant, beautiful woman, had had a stroke. The hematologist thought the high doses of cyclosporin were to blame. The transplant surgeon thought the patient's first lung bleed had been the original cause of her "failure." Now she was paralyzed and cognitively impaired, her worst fears realized, her worst nightmare actualized. She had become the very mass of non-responsive flesh she had most dreaded becoming.

She had, early on, named me her health care proxy, and so when the next medical disaster unfolded, I made the decision to make no further interventions. She went into a coma and died along with the summer, her favorite season, and the frost of the fall upon us.

Following her death, as prior to her transplantation, there was no follow up for her family or her donor. In the lexicon of medicine, "The patient had failed."

Post Transplantation: From Victim to Advocate

After my sister's death, I received a condolence card from the hematologist and one from the bone marrow coordinator. No one called her family. As there had been no intervention in the crisis facing her husband and three children, there was no follow up help to deal with the aftermath. To my knowledge, the psychosocial aspects of the case were never reviewed.

There was no opportunity to ask what could have been done, how it might it have been better. The case was closed.

For many months after my sister's death, I struggled with the need to express the ways in which her physical needs had been attended to brilliantly but her psychological and social needs had been largely ignored. Should I write an editorial, a letter to her cancer care center, meet with her physicians or with the social work service?

Returning from a conference on the West Coast, I was randomly seated next to a traveler reading *The National Bone Marrow Register*. Since this is unlikely reading for any passenger, and given that we were in for a long flight, I asked whether she or a loved one was about to undergo a bone marrow transplant. In fact, as it turned out, she was the coordinator for the Department of Health and Human Services Division on Transplantation returning from a meeting in which the unmet psychological and social needs of transplantation patients had been the topic.

Six hours later, and many miles traveled, my story and my sister's had become a coherent one in which the absolute need for psychosocial services for donor and patient became clear. I found myself advocating for psychosocial assessment of every patient, family, and donor the need for training of physicians and other personnel regarding the range of feeling encountered and the provision of services—physical, emotional, and economic—for patients and their families.

One week later, my fellow passenger invited me to participate in the first two-day National Policy Forum on Bone Marrow Transplantation in Washington, DC. Without hesitation, and despite another academic summer just beginning, I was glad to participate.

About 150 invited attendees were assembled, many of whom were surgeons, oncologists, ethicists, lawyers, historians, anthropologists, sociologists, and survivors. I was the only bone marrow donor represented. By the end of two intense days working on the psychosocial needs for bone marrow donors and recipients, our small working group made policy recommendations for the psychosocial assessment and intervention for every patient and donor in all three stages of the transplantation process. The formerly unmetabolized experiences of my sister's illness and death were becoming crystallized into national protocol.

Following that meeting, I was invited to give the keynote address to the first collaborative meeting between the Directors of Managed Care and the Directors of Transplantation in the nation's capitol. Again, my story was now taking new meaning and form again. Our seemingly private struggle to deal with overwhelming psychic pain had now become public: a powerful tool to effect change. Soon thereafter, I shared the podium at the tenth anniversary of The National Marrow Donor Network in Minneapolis, Minnesota, where I lectured along with an articulate bone marrow survivor who, like me, told a story of the absolute need for psychosocial assessment and interventions before, during, and after transplantation. While our stories were different in outcome, our processes were hauntingly similar. Every possible physical pathology had been fully attended to, but in each of our cases the patient and donor were left out of the process.

I continue to speak out as an advocate for changing national protocol in marrow transplantation, at professional meetings and on boards, and each time that I invoke my sister's and my own isolation, ambivalence, fear, hopelessness, and dread, I recognize again that I am the living member of the family who can tell her story. It is not, as her doctor suggested, that the patient "failed," but that her experiences succeeded in beginning to secure for others what she could not have for herself. □

Health Care Left and Right

Experiencing and witnessing the health care system over a 24-hour period led me to treasure social work's commitments to confidentiality and to question how the medical profession deals with it. As I witnessed blunders in the medical care of the poor and the rich I felt even more strongly about the need for professionals to advocate for more adequate resources, greater accountability, and enforcement of standards. It also made me think more about the profound changes that have taken place that cry out for a system of universal health insurance.

by
Norma Kolko Phillips, D. S. W.

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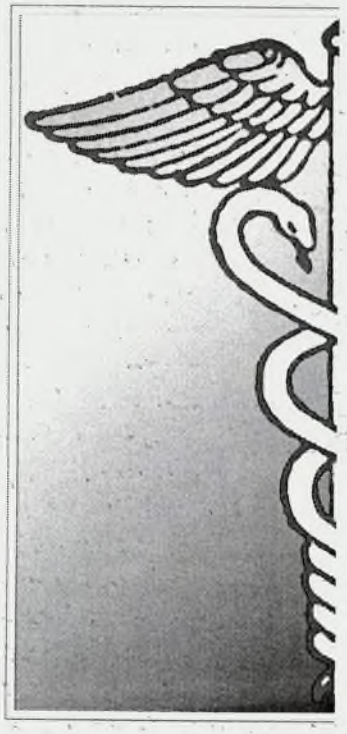
How much more mundane can we get than a nosebleed? It began at 10:45 at night as I was preparing for the morning when I was to meet my friend at 7:30 across town at the hospital where her husband—I'll call him Bob—was having life-threatening abdominal surgery. They both had put on a stoical front, but I knew there was hidden turmoil and I told my friend I would stay with her during the surgery. By 11:15 I had to admit to myself that the nosebleed was out of hand and that I would need to get help to stop it. I decided to go to the nearest hospital, which was just seven blocks away. I grabbed a blazer which I figured would cover at least some of the stains on my clothing, a small towel which I was holding up to my nose along with a wad of tissues, a backpack with more tissues in it, and my pocketbook. Fortunately I found a cab quickly and although I had some difficulty talking because of the dripping into the back into my throat, the driver and I agreed on the nearest hospital. He refused to turn onto the street to the emergency room entrance; he thought it was a one-way street. I was having too much difficulty talking and was not about to argue.



I was immediately greeted by a guard at the door. He summed up the situation quickly, said "nosebleed," I nodded, and he motioned me to a window. Behind the window was a male triage nurse interviewing a patient who was sitting next to him on a small chair on wheels. The nurse did not look up until the guard came over and called to him. They quickly agreed that I should come into the room behind the window and wait there for my interview. The guard showed me the way and motioned me to another small chair on wheels.

A Challenge to Confidentiality

Being interviewed was a large, disoriented man. He announced to the interviewer that he was "a junkie." He seemed to take pride in this, and went on to say heroin, which he articulated very slowly, almost lovingly, as though he were saying "sweeet as huunneeey." He gave his name, explaining the significance of his middle name; the whole process was very slow. He interspersed his answers with long and repeated demonstrations and reports, not complaints, of swelling on his leg and arm.

Why was I hearing the intimacies of this man's story? I felt like an intruder overhearing a private conversation. I have been teaching social work students for many years and in our Program we talk about confidentiality in every course. We take it seriously and we want our students to take it seriously. We find situations where confidentiality is challenged and try to figure out the best way to handle them. Some situations are baffling, but we think of confidentiality as one of the cornerstones of the profession (Goldmeier, 1984). I wondered whether we were alone in this thinking. Why wasn't anyone concerned about it?

The bleeding was not letting up and during a lull between repetitions I asked the nurse for some tissues. He quickly got up to give me a gauze pad. The interview with the man continued; the nurse continued to listen patiently and respectfully to the repetitious statements. Only when he was sure there was nothing else to add did he take his blood pressure using a blue plastic sleeve and also his temperature. The interviewer then pushed some papers to an opening in the wall leading to the next office and told the patient to wait in the waiting room.

Several people were sitting in the waiting room. A little girl of about three years in a pretty pink dress was dancing around. While the interview with the man was still going on a young woman came in holding a washcloth to her left eye. She, too, stood at the window for quite a while, as I had, until the guard came over and called the nurse's attention to her. What happened, the nurse asked. I was fixing a fan with a stick and the stick got pushed into my eye. The same question was asked several times, with the same answer. Are you taking any medications? She answered, I just had an abortion and I'm taking some antibiotic. What kind, he asked. I don't know, she said, and repeated that she had just had an abortion. Let me see it, he said. She removed the washcloth revealing a huge tear on the eyelid. All right, sit down, he said kindly, motioning her to the seats in the waiting room.

Here, too, I came back to think about confidentiality. Standing on the other side of the glass window she had to tell her story to everyone in the waiting room, as well as the three of us in the room. Surely the medical professions accept confidentiality as a value—but a value is only as good as its implementation and it seemed to have the lowest priority.

Dying to Get Through the Paperwork

The nurse then motioned me to the chair for my interview. We talked about how and when the nosebleed started; he asked few but relevant questions. He helped me get one arm out of my jacket sleeve so he could take my blood pressure. The blue plastic blood pressure sleeve that he had used on the previous patient was filled with air and would not stay on my arm. Several times he removed it and punched it but the air remained. Grumbling, he went to the back of the room, returning after a few moments with another. He continued to grumble that this was supposed to take just a few seconds. Some minutes later, when the blood pressure and temperature were done, he took my papers and pushed them to the same opening. I asked if I could see a doctor and he said first we had to do the chart. He motioned me to return to my first chair to wait there, and replaced my gauze pad. My voice was leaving me as I started choking and coughing from the blood dripping into

my throat. Several minutes later the door to the adjoining office opened and a man sitting at a desk took my papers and started asking me the expected questions. I told him I couldn't talk loud and rolled my chair closer. Name, address, phone number, insurance cards, the works. By now I was sweating and beginning to feel very sick. He wanted to know who to contact in case of an emergency. I told him I wasn't feeling well, but we continued until we were finished.

Can Anybody Help

Finally the triage nurse led me into the emergency room. It was not frantic like the TV programs, but it was busy, with many patients in small cubicles and lots of staff clustered around the center of the room. He helped me get off the rest of the jacket, which he put on the bottom of a large plastic bag, and then put in the backpack and then my pocketbook, and placed the bag on the bed with me. I thanked him and told him he was very kind.

I had expected to see a doctor as soon as I actually got into the emergency room but I was mistaken. Feeling extremely sick, with no improvement, and coughing and choking more, I began to worry about fainting or bleeding too much and wondered why I had come here. Only the triage nurse came by to say that they were very busy. Later I called out in whatever voice I had left, "Can anybody help me." I did this several times, and finally caught the eye of a young man who might have been a resident. I motioned to him with a slight wave. He came over and told me to squeeze my nose, which of course I had been doing for well over an hour. I told him it wasn't helping and he showed me how to do it—under the bone at the top of the nose, not at the bottom. He told me to continue doing this for 20 minutes. I had to hold it like that for over two hours before it stopped but during that time it started to get better.

I called out to a nurse's aide who was walking with great energy, asking if I could get a glass of water. She questioned another woman who shrugged and said why not. The first woman got a foam cup and returned to a desk to continue the work she was doing. Disappointed and uncomfortable, I waited, not with patience but hope. Finally she brought it over—not only were there ice cubes in the water, but she also gave me a box of gauze pads. I realized how small kindnesses could go such a long way.

Drugs Left and Right

The resident came back. The bleeding had subsided a lot by now but I was fearful that it would start again, especially if I breathed through my nose. I was still coughing a great deal because of the drip. He said I could stop squeezing it now, that it looked red, like it was about to fall off. I could take a joke. Then he told me that they wanted to put cocaine in my nose. I was sure this was a joke, or I heard it wrong. Did you say cocaine, I asked, and he shook his head and smiled a bit. The irony of it, I thought. For the past six months one of my major activities was work on a grant our Program had received to expand the substance abuse content in the baccalaureate Social Work Program. For much of our winter break the faculty had been writing curriculum and searching for materials for classes. Days were spent together screening videos to show in classes on the use and abuse of alcohol and other drugs. We struggled with how to infuse the content into the program so that every student would be exposed to the material. We organized a conference to learn more about what social workers needed to know in order to work effectively in agencies with drug abusers and others affected by them. We gave pre-and post-tests to students to see what they had learned. Now we were writing the final report on the project. And here I was being instructed to put cocaine into my nose.

"Certainly not," I said. I wanted to tell him about the work we had been doing at school but I didn't think he would be interested. The nostril is directly connected to the

brain, I told him, and why would he want to use cocaine, of all things. I was also worrying about being able to get across town to meet my friend and wondered if I could be of any help to her. He told me that cocaine has lots of medicinal uses and is used frequently in the hospital. "Uh-uh," I said. It will constrict the blood vessels and will also anesthetize the area so he could look at it better and maybe cauterize it, he told me. "Why don't we just put ice on it," I said, "that will constrict it." He laughed and said no, they had to look in it. "What can you see? It's all clogged. Anyway, no cocaine." You think about it, he said, and left.

I wondered what would happen if this were offered to someone in recovery. Or someone flirting with using drugs. I thought about my friend and Bob. Were they sleeping now? Were they crazed with hidden anxiety—how could they not be. I was supposed to be the strong one, and here I was in the middle of the night having an outrageous discussion about cocaine. Little did I know that 24 hours later on the other side of town Bob would fall victim to a similar abuse.

I watched as the self-proclaimed junkie was rolled by my cubicle. He was admitted to the hospital looking quite peaceful. Attention was paid to the woman who had the abortion and the injury from the fan. I heard them say her vision was okay but I could not see whether or not she was admitted. The triage nurse came by again and told me I would be all right.

I was happy to stay put, partly because I was afraid the bleeding would start up again, partly because by now it was so late I wasn't sure there would be any cabs cruising the streets—the early morning hour might be better than the late night. But mostly I wanted to stay because the scene in the emergency room was so absorbing.

A middle-aged man with graying hair was being wheeled into a cubicle directly across from mine. There was an immediate flurry of activity around him and the monitors were turned on. It looked like an emergency room response to a heart attack but I thought he looked too good as he came in to be having a heart attack—his eyes were bright and his complexion was rosy.

To my left was a man with gray-black skin who looked very ill. He was taken out of the emergency room in a hospital gown and then came back, probably from x-ray. Four doctors clustered together in the center of the room the entire time I was there looking at his x-ray and debating his condition. They kept referring to him as the man with the glass eye. But that was not the problem. His stomach was in the wrong place, they said. They couldn't figure out what the condition was and thought they will have to puncture the stomach. Finally one of the doctors went to talk to the patient. He was articulate and explained that he had had an operation to repair an ulcer. He also said he was beginning to feel less pain. By the time I left they concluded that he was constipated. I wondered why they waited so long to talk to him. And again I wondered about confidentiality. I was able to overhear the entire discussion of the doctors.

They took the rosy-cheeked man out; by now he was in a hospital gown and probably going to x-ray; a woman who was with another patient kept walking back and forth, looking at me each time, as she did with all the patients; I found it intrusive.

I decided to treat myself, surreptitiously removing a small ice cube from the foam cup, wrapping it in a corner of a gauze pad, and sneakily holding it against my nose, hoping it would constrict the blood vessels so we could end the struggle over the cocaine. I felt foolish, a little like a naughty child. I asked for more water, but this time the person who heard me call out said I shouldn't be having water. Puzzling to me—I was thirsty, choking, and most of all, running out of ice.

Now there were intermittent visits from the resident. He put the flashlight into my nose, peered into my throat, and told me he ordered "the tray" with the cocaine and I should wait and see. I agreed only to wait. He asked me when I had my last tetanus shot; I couldn't remember, it was a long, long time ago. He told me that they give tetanus shots with nose-

bleeds and I said fine. I was getting tired but it was too uncomfortable to lie down and I didn't want to miss anything.

The man in the cubicle across from me was brought back from x-ray, still looking good. A nicely dressed woman, probably in her 40s, was brought in with a bandage on the side of her forehead. She was wearing a business suit with a short skirt and high heels; she had a big smile that never left her. From time to time she walked back to the nursing station, questioning when she would see a doctor. They told her they had a lot of emergencies.

It was probably an hour later that the tray arrived, a large tray wrapped in more blue plastic. The resident brought it over and unwrapped it near me, revealing numerous items. I thought again about the Social Work Program at school, about the struggles we were having with substance abuse education and the difficulties some students had in talking about abuse in classes. I thought about the mixed messages we give and get—drugs are bad for you, they're illegal, say no. And then drugs are good for you, they're legal, agree to the treatment. I said absolutely not. He insisted that he had to look in my nose, and I reminded him that he had been doing that. When he returned the next time he said that they had to do something for me because I couldn't remain there so long; it would get busy again in the morning and they would need the space. If I don't want the cocaine, he said, then they would use something else. What is it? He mentioned a drug and said that it had epinephrine in it. I wondered why he had not suggested this in the first place. But I am allergic to epinephrine, and I told him I wasn't trying to be difficult, but when I go to the dentist I can't take long-lasting Novocaine. He said he never heard of that. I wanted to tell him that he should have, but instead I told him he is not a dentist.

He disappeared again, and came back with another doctor—one of the four who were still discussing the man with the stomach in the wrong place. She peered into the nose and told him to go ahead and cauterize it. I thought he might have done that five hours ago. He hesitatingly said that I wouldn't be anesthetized. She said that if I didn't want to take drugs, then to go ahead and do it anyway. She never spoke to me. He followed her away and talked to her again.

Who Pays For Education?

Later he returned with two slender wooden sticks, about the size of incense sticks, with some brown stuff on the ends. I was enormously relieved; I thought cauterization required a mini-torch. "Will it hurt?" I asked more for his sake then for mine. He said just a little. I asked how long it would take and he said 30 seconds; I suggested he make it a little less. I asked why he needed two sticks, and he said he always brings two. Okay.

He was holding one of the sticks and a flashlight and kept shifting each from the left hand to the right hand, from the right hand to the left. He seemed reluctant and could not position himself. I knew this was a teaching hospital and I felt respectful and patient with that, particularly as I knew that my troubles were trivial related to almost anything at all. I asked if he had done this many times before and he assured me. Finally I asked if he wanted me to hold the flashlight for him and he said no, the problem was that he didn't have the right tool. "Why don't you get it?" I asked encouragingly. He said he would and left.

I thought about our social work students as they begin in field placement. Surely this is how some of their clients feel. I didn't think much damage could be done here so I didn't worry about it too much. But what if it were something serious, the way students work with clients who have serious problems. Are the supervisors always available? How do clients feel when they experience the students' insecurities and blunders?

He returned with a tool that looked like a guide for the stick. Now he was holding three items, the stick, the flashlight, and the new tool, and again he juggled them, moving them from hand to hand, left to right, right to left, two in one hand,

two in the other. In the end he asked me to hold the flashlight which I happily did as I was sure it would distract me from whatever pain there might be. He finally began the procedure and made it clear to me that he was not at all sure he was on the right spot. It felt to me that he was and I told him that, but just in case he wasn't I counted to 30 very rapidly and when I was at 28 I told him okay, he had his 30 seconds and he took it out. It didn't hurt much and I wondered again why he had made such a big deal about the cocaine.

Near the nursing station there was a discussion about the need for tetanus shots with nosebleeds. I overheard someone say, "why would you do that?" and my doctor's response was that you were supposed to. This one I could stay out of—I didn't care. I assumed it was off, but soon a nurse came with the shot for me.

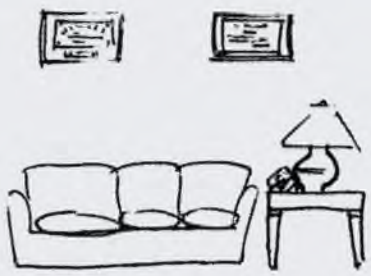
Before I left, the man across the way emerged from his cubicle dressed, looking as healthy as he did when he came in, and walked out. The woman with the patch on her forehead went back to the nursing station to tell them she was leaving. She was told she needed to have stitches, to wait, and she went back, still smiling.

It was five a.m., and I asked an aide if I could wash up before leaving. Again I experienced the vast pleasure of small kindnesses when she brought over several towels and a washcloth. I went over to the triage nurse to say thanks and he told me someone else had just come in with a nosebleed. I thought that if the same resident will treat that patient then he will have done it at least once before. I wondered what that patient would do with the cocaine.

Across Town:
Medicine for the Rich

At 7:30 in the morning, with one restless hour of sleep, I left home to meet my friend in the hospital across town. Like the hospital I had been at, this one was also voluntary. But the one I was headed for is one of the most sophisticated medical centers in the world: large, organized, well-planned; well-endowed; a leader in medical science, they say.

The Family Waiting Room was perfectly designed with nice sofas you could almost stretch out on, cozy chairs and roomy tables, a staffed desk to transfer messages to the waiting families, telephones for in-hospital connections. It had the



needs and comfort of the patients' families in mind; nobody had to sit on small chairs on wheels. There were lots of plaques on the walls honoring the philanthropists. And the layout offered some privacy for family members to talk and to talk to the doctors when they came after the surgeries. Maybe social workers also came but I didn't see any. There also was a conference room with a door where one could anticipate full privacy when talking to the staff.

Stories about my night's adventure provided some distraction during the otherwise tense three and one-half hour wait. We ate breakfast and returned to the comfy room where we snoozed and talked. Finally the doctors arrived—the second surgeon and the cardiologist who also was present during the operation. This was a very complicated medical situation—they probably don't get much more complicated or risky—and on top of it all Bob had long-standing problems with his heart. In addition, while Bob was having this most drastic surgery, he was also scheduled to have a routine but much needed procedure—a simple hernia repair.

Blunders on Both Sides

The surgeon wore his operating room garb including the booties over his shoes, the cardiologist was in a fashionable suit. They looked as finished as the room we were in. They remained standing throughout the conference. After a lengthy and informative discussion about the abdominal surgery, which reportedly had gone very well, my friend asked about the her-

nia surgery. Both doctors looked puzzled and there was silence. Oh yes, well, uh, they're doing that now. They left immediately, with the agreement that the chief surgeon would be down very shortly when all was completed. We were both convinced that the hernia surgery had not been done as planned.

An hour and a half went by, with several phone calls by my friend to the doctor's office on the in-hospital phone. It was a worried and impatient time. The woman at the waiting room staff desk was as helpful as she could be. Finally the chief doctor arrived, still in scrubs. He too remained standing. Yes, he said, the hernia surgery was being completed "as we speak." But they told us an hour and a half ago that it was being done then. Oh, it is a whole other surgery, blah, blah, blah, blah, he went on with so many reasons why it took this long. My friend and I were stunned. It was crystal clear that in spite of all the amenities of this famous hospital with its beautiful appearance, and in spite of fact that the doctors were the most prestigious, they had forgotten to do the surgery and it took this much time to get him back to the operating room. This too was a teaching hospital, but these arrangements had been made with the staff, not a groping student. In fact they were made with the chief of the service.

The next day I heard that during the night Bob had a heart attack. Bob had several organs removed and he also had a morphine pump so he could self-administer the drug for post-operative pain. Without those organs the morphine affected his heart, particularly as he already had serious heart problems. He was treated and was okay. The doctor acknowledged that it was an oversight.

All's Well for Now, or Is It?

In spite of the incompetence and mistakes, both Bob and I are well. Ten days after this incident, mercifully after my college graduation was over, I came down with a raging infection which may or may not have come from the ER; in any event I recovered. Bob was back at work and on the golf course within a few weeks—a remarkable recovery under any circumstances.

But what about the problems that were so obvious in just 14 hours of observation. I had witnessed violations of confidentiality without anyone even acknowledging that there was a problem, an understaffed emergency room with patients neglected, abuse of drugs by the medical care system, incompetent and unsupervised treatment by a resident, and incompetent treatment by a chief of service. And within another twelve hours Bob had a heart attack as a result of further errors in medical care.

Whether on the left side of town or the right side, whether on the political left or right, the need for competent health care that is accessible to all remains the single most important item on today's national agenda. Lack of such care results in physical harm; demoralization of patients, their families, and communities; and emotional harm to poor and rich alike, to savvy people and innocents, to individuals, family groups, communities, and societies.

We have passed the time when medical services could be made available for particular groups—the rich, the elderly, some of the poor. Baffling medical conditions such as TB, dementia, Alzheimer's, HIV/AIDS, substance abuse, mental illness, and the elusive killer viruses, are not diseases of one group. We are at the point that any plan for health care for one group will not be acceptable politically or socially, let alone morally—for the reason that the need is now more recognizably universal. It is no longer a matter of a benevolent society, but a shared effort for survival. Also affecting every income group is the higher cost of care, the need for long-term care, and the absence of medical insurance to pay for it. These medical conditions know no economic or cultural boundaries. These are health problems that touch every person and every family and community, the privileged ones and the disenfranchised.

That Medicare and Medicaid have resulted in a narrowing of the gap between medicine for the rich and medicine for the poor is not surprising. With universal need there must be universal solutions. While we cannot mandate integrity, as a society and a profession we can insist on adequate resources, accountability, and enforcement

of standards (Atherton, 1990; Van Soest, 1994).

The need goes far beyond the furniture in the waiting room, whether in the emergency room, which generally is used by the poor, or in the decorated waiting rooms of the well-dressed hospitals. In both hospitals the staff and patients represented the diversity of the city and I noted no biased behavior in either. For the poorest of the poor the night before there had been endless acts of kindness and respect as well as troubles with equipment, understaffing, lack of supervision, and disregard for confidentiality. Cocaine as a treatment of choice, particularly when it was clearly not needed, must be questioned. For the rich the doctor still got it wrong during the surgery, and the doctor and staff missed the danger of self-controlled morphine intake. These issues affect everyone in every medical setting. We are left with the need for advocacy on the part of all helping professions so we can get it right. □

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A Support Group For Alzheimer's Caregivers: A View from the Inside Out and From the Outside In

The Native American admonition, "Do not criticize a person until you have walked a mile in his moccasins," addresses a profound and never-ending challenge to a professional helping person. We social workers must strive always to understand, comprehend, perceive what is going on in the minds and hearts of our clients without having experienced their experiences. As professionals we listen carefully and knowledgeably. We question informally and formally. We research quantitatively and qualitatively. We develop skill in communicating empathetically so that our clients can try to tell us. However within our clients, "inside the skin" that separates them from us, in the innermost self of each, there is always something more—a special and totally unique process of the self that is always changing and happening as the person moves through the helping experience.

by
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It is a personal journey in the context of a professional life that I am sharing, trusting that it will be of some use to social workers who work with groups. Indeed, the sharing will be clarifying to my own perception of what I have experienced in seeking and using help in a very painful period of my life.

The Native American admonition, "Do not criticize a person until you have walked a mile in his moccasins," addresses a profound and never-ending challenge to a professional helping person. We social workers must strive always to understand, comprehend, perceive what is going on in the minds and hearts of our clients without having experienced their experiences. As professionals, we listen carefully and knowledgeably. We question informally and formally. We research quantitatively and qualitatively. We develop skill in communicating empathically so that our clients can try to tell us. However within our clients, "inside the skin" that separates them from us—in the innermost self of each—there is always something more, a special and totally unique process of the self that is always changing and happening as the person moves through the helping experience.

As professional leaders of many kinds of support groups, made up of persons with realities in their lives that make profound and painful demands on their abilities to cope, we attend carefully to each person and to the growth of an interactional process with ourselves as workers and among the members. Using our knowledge and intervention skills, we watch for norms, bonds, roles and goals to emerge that will tell us that a collection of persons suffering with similar *tsouris* in their lives have created a group.

I will try to share with you, from the inside out, something of what transpires in the mind and life of a person who walks "in the moccasins" of a caregiver, who is a member of a support group for caregivers of Alzheimer's patients. This is the

journey of one who— along with the knowledge, experience, and skills of a group worker form the outside in— has been, and is there now, from the inside out as a member of a group.

Role Confusion: Professional Worker and Group Member

This has been an experience in role confusion. As a member of the group instead of the professional worker, this was a very personal dilemma. The special professional self which I kept private from the group rendered me feeling apart from the membership role. I had introduced myself as a retired social worker but not as one whose strong identity was teaching and writing about social group work. It was the group work connection that seemed to be the source of my uneasiness.

I told myself that I must move through the approach/avoidance dilemma relating to these strangers as my personal self without benefit of my professional mantle, which after fifty years of professional experience, is very much a part of my being. The common experience of having a loved one with Alzheimer's Disease, which I knew I shared with the others, was clouded in the beginning by my "secret" and very powerful other identity, that of knowing quite a bit about the professional role in such a group.

With my ethical head I determined not to compete with the worker and not to allow myself to get stuck in "assessing" her way of functioning as group leader. Rather I was determined to experience the pain and possibilities of group life from the other side. But it was difficult to know what to do, how to be me, how much to share my fears for the future, my anger at my husband for having gotten this illness that was destroying his brain, my confusion, uncertainty, and ignorance about what was happening to me and my loved one. One of the group members told me several sessions later that she had thought I would not return! How I communicated my anxiety, I do not know, except that I said that my husband does not have Alzheimer's but Multi Infarc Dementia, undoubtedly denying the need to be there! I do know that somehow the social worker, with competence and clarity about her role, seemed not to be troubled by my uncertainty and helped me to be comfortable as a new member.

Despite the early experience, I did go back to struggle with the role confusion issues and all that I shared with the other members. We were all caregivers—as well as wives or husbands, daughters or sons, daughters-in-law, sons-in-law and all the possible kinship connections that are affected by this terrible disease that destroys the brain. That was the "commonality" which every group must have. It was a commonality which gave us all immense pain and made it possible for us to bond with each other. It also provided for each of us a rich source of knowledge about this dreadful disease.

I began to find myself experiencing that which I had learned often happens to new members of support groups. I experienced shock with the breadth and depth of the problem of being a caregiver of a patient with Alzheimer's Disease. I did not want to hear about it from so many dimensions. I remembered how social workers who do not understand group life use this as a reason for not advocating for group practice. This is one of the first lessons a group worker must be aware of when a new member joins a support group... and I was experiencing it! I was frightened by what I was hearing. I began, however, to find that learning about so many aspects of Alzheimer's Disease and about what is ahead for both my husband and me, though painful, was also helpful. The worker, an experienced professional, always seemed to notice unusual concern of any one of us and helped us to share our distress in order to neutralize the pain a bit. My courage was bolstered as I listened to others and others listened to me.

I found myself over-involved with some of the members and their problems. Again the professional self was awakened. For instance, I recognized the intensity of Marian's guilt about a nursing home solution to her impossible situation. Her

husband was removing the knobs off the doors and damaging the house in unbelievable ways in the unintentionality of his deteriorating mind. I participated with my whole self—professional and member—as we tried to help her work out a plan. I felt that this was a turning point for me since I no longer felt constrained to withhold my thoughts that had roots in my professional life.

The management of boundaries was an important experience for me. In a new way, I had to discipline myself to heed the worker's gentle admonition to all of us to speak for ourselves, take responsibility for our own thoughts and feelings, and be wary of telling others how they ought to feel. This was clearly one of the norms of the group to which I too must yield.

The group is open-ended. Members leave as their loved one dies or they no longer feel the need of the group. Attending a funeral helps to bring sad and relieved closure and we as members have shared the closure tenderly. There is something indeed profound in attending a funeral with fellow support group members.

When a new member was brought into the group, we, the members, reached out to whoever it might be. I found that I was no longer concerned with what the worker had done to prepare the newcomer. It was we, the members, who were very sensitive in assuming responsibility to welcome the newcomer, to share ourselves, and to help him/her to feel comfortable in sharing with us. This was also a norm of the group. Thus, as members, we moved quickly to sustain the reality of the group.

Later on there were shared member situations that left me overwhelmed with the intensity of the group's experience. I found myself thinking "I am not certain that I would be able to handle this" and I was glad—and honored—that I was a group member and that we could share so much with each other.

I discovered a tremendous sense of respect and dependence on the worker. When we did, indeed, express and share profound and painful feelings in the group, we seemed to be safe. I often thought "How

can she bear so much pain that is being expressed? Each of us can defend ourselves in our own ways: denial, dissociation, etc. But she cannot. She must go on hearing the pain and helping us. She needs time off and a vacation from us!" Now I was detaching my professional self and allowing myself to thoroughly experience membership in this support group.

By acknowledging need, I was finally able to find my own personal way of relating to others in the group. My caring started slowly and grew. At one point the part of my self that does not like to admit frailty was in trouble. My own health, in struggle with the stress in my life as caregiver, was at stake, and I apparently shared that I was ill. One member who was a nurse—and the worker—made certain that I would get to a doctor, even going with me if necessary. It was a profoundly important moment of dependence for me. With the proffered help, I was quickly able to return to my own level of involvement and independence and distance. I experienced in my self how a group member can play out his/her own psychological reality, psychic needs and patterns. For me it was also a moment of new level of recognition of how a worker and members can perceive one's internal issues—can tap into them—and help one to gain new awareness of self and new insight. I felt that it was really understood how difficult it was for me to ask for help, and I understood it better myself. Somehow, without really intending to do so, I had given some cues. Allowing myself to be a member, I had begun to participate in the group with needs as well as the ability to help others.

How does a professional use knowledge in the total reality of the self? One does not package up one's knowledge, tie it up with ribbons, and label the boxes (or bags!). In truth, our knowledge becomes a part of ourselves and we draw upon it always. Actually as I found myself relating to my friends and sharing my needs, I no longer debated the role "expectations."

I was a member with my whole self. Membership expectations were dominant. I no longer was trying to separate myself from my knowledge that comes from my profession—and age!

As an aside, at this point in my life, I know that a truly good professional will have integrated the professional self into the whole self. Professional role expectation contains the self—even as life continues to reveal and enlarge both the role and the self. This is the concept that is so familiar to social workers: "the use of the self" for helping. It is also the concept that is embedded in issues of self-disclosure and the professional ethic. Through membership in an Alzheimer's support group, I had experienced both professional growth and personal growth in a new degree.

Role Confusion: Alzheimer's Caregiver and Self

This was a personal struggle with professional self as member of a support group. But what about the commonality that I shared with all the members of the group? I was a caregiver of a beloved person whose brilliant brain was dying, causing loss of his memory, confusion in his behavior (for example, trying to eat his meal with his knife), helplessness (for example, incontinence), disinhibition. As knowledge of the disease of Alzheimer's became more understandable to me, I could share and clarify and cope.

An earliest struggle was with anger. Peace had to be made with the reality that it was not his fault—nor my fault. We could not possibly have prepared for this illness in this stage of our life together. However, the behavior of an Alzheimer's patient is very hard to bear. One does not understand what is happening to one's partner and there is the progressive nature of the illness that one neither recognizes nor expects. I found myself so very angry all the time—until I finally could face the reality of Alzheimer's, both in his life and in mine.

The proverbial self debate that is present in most lasting marriages (ours lasted fifty-six years), an occasional wondering how one got oneself into this, was no longer relevant. There was no abandoning. This was my life. This was our life, even with the terrible frustration and loss for both of us. It was not Benj's fault that I was so angry.

One day a group member, whose husband also is in a nursing home, mentioned to me that she has found spending time with her husband in the nursing home to be more loving because she is free of the impatience and anger of the caretaking days at home. That idea has been very important to me and I have passed it along to others whenever the moment seemed right. It has helped me to treasure the little time each day that I have spent with Benj—with greater acceptance of our predicament.

A next struggle seemed to be with the seductiveness of the illness—looking constantly for evidence that it is not what it really is. In the nursing home, I was continually looking for evidence that he could be on a higher functioning floor, that he would not need the skilled nursing care. I kept looking for others on the ward who might be healthier, expecting confidently that he would be able to relate. The adjustment to the nursing home was long and slow—but longer and slower for me. I cringed from the realization that he was adjusting to being there and that he could not socialize. When friends asked how Benj is doing, I would draw back from answering. Then I might say, "He is adjusting very well to the nursing home and that is good but bitter," and then change the subject.

Of course there was the struggle with guilt. This played out early on around hiring nursing aides so he would not be home alone. Guilt arose when I went away and left him with aides. It was difficult to allow myself to need assistance in the caregiving. Were the professional parts of my life and all my interests so important? Why should I not become the full-time caregiver like those gallant souls about whom I occasionally heard? Was it so important for me to rescue myself from the selfishness of that role? Some people continue to adjust to the care of their loved one, why shouldn't I? My support group friends kept re-

minding me of The 36 Hour Day (Mace and Rabins, 1984), and the fact that one person cannot do it alone.

Guilt took on new and intense colors as the nursing home decision was slowly worked on. It was my own feelings of vulnerability that made the decision bearable. I could die before Benj does. Then who would take care of him? There was the guilt of having "done it to him" since the illness rendered him unable to participate in the nursing home plan or in the execution of it. I had to work out the plan, without his agreement and without his knowing what was happening to him. (I was blessed by the presence and support of our grown children—and the Agency—and my group.)

There was the guilt of leaving him there each day. In order to leave, I found myself always saying "I'll see you tomorrow." Even after three years that feeling remains...

The impact of the finality of the nursing home move was overwhelming for me. I was leaving my husband there for life! He would not be getting well. How long it would be I could not know. Alzheimer's disease is not a killer. It simply steadily and persistently destroys the quality of life until death can rescue him and/or me.

Death is an issue that the members of the support group have been able to talk about, cautiously but honestly, because of the trust of each other and the strength of the group worker. I think I may have been the member of the group who finally was able to say it. I do not remember what I said but I recall the emotional impact of that session and the importance to me of finally addressing it.

In Conclusion

Stress and illness, loss without death, loss with death, and the emotions of anger, denial and guilt—these are powerful, human issues for a caregiver whose loved one has Alzheimer's Disease. Without a support group with whom to share the experience, it would have been and still would be very difficult for me. The group has made it possible for me to cope with my reality, to reflect without too much rage or panic or despair, and to use these years of my life experience for learning and growth, rather than being destroyed by the pain. I have learned anew the power of the group through being a member.

My life long love affair with the human group has been reinforced by this new and unpredicted and unwanted experience. I have learned also in an unexpected way how precious is the role of the professional group worker—though never easy. The helping component in a group is elusive and can be released through the skills of the worker.

I opened this paper with a proverb from Native American Indians. Let me close with another one that has meaning for me and my fellow group members:

"The soul would have no rainbows if the eyes had no tears." □

Benjamin M. Papell AB, JD
(1916-1998)

REFERENCE

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A Researcher's Reactions to an Atypical Respondent[1]

The writer was involved in a qualitative research project of mostly female older caregivers who were caring for persons with symptomatic HIV disease. Nineteen of the respondents were mothers and grandmothers who were taking care of close relatives. The sole male interviewee ("Billy," a 51-year-old unemployed African American man) was atypical in many respects and could not easily be included in presentations of themes and patterns which emerged from the data; he was helping out with a neighbor whom he knew only casually. Nevertheless, the researcher was impressed with this man's understanding of HIV-related stigma,[2] which was one of the primary foci of the study, and was impressed with his attitudes toward persons with HIV. The interviewer felt that Billy's powerful narrative illustrated well the power of the HIV experience in the inner city and was moved by this man's insight and courage. This article reports Billy's story and the author's reactions to it.

by
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At the time of the research project in which Billy participated, Dr. Poindexter was a doctoral student at the Jane Addams College of Social Work, University of Illinois at Chicago.

In 1996 I was a research assistant and doctoral student at the Jane Addams College of Social Work at the University of Illinois at Chicago. I was at that time involved in a qualitative research study of 20 minority HIV-affected caregivers. My dissertation data came from this project and focused primarily on the respondents' experiences with and perceptions of HIV-related stigma. Nineteen of the interviewees were mothers and/or grandmothers who had been taking care of sons, daughters, and/or grandchildren who were very ill with end-stage HIV disease. Stigma was a big theme for these women, many of whom had not told their informal support networks that they had a family member with AIDS. In addition, the majority of the interviewees were quite tearful as they talked about their strong reciprocal relationships with adult children or minor grandchildren who were seriously ill or who had died from AIDS.

As I discussed in a previous *Reflections* article (Poindexter, 1998), interviewing older African-American women who had decided to provide personal care and emotional support to their loved ones with HIV was an emotional experience for me. The research was intellectually interesting to me, of course, but mostly I felt sad, angry, and incredibly honored that these strangers were freely sharing their pain and grief with me. I loved sitting down at kitchen tables with these caregivers and facilitating their moving narratives, but I often felt discouraged, depressed, and drained with the subject matter. The research triggered many of my own memories and feelings as a caregiver for a loved one who had died from HIV, and it was often quite disturbing to receive the enormous sadness of moms and grandmoms who felt

[1]This article was part of a research project which was funded by the Center for Health Interventions with Minority Elderly (CHIME) at the School of Public Health at the University of Illinois at Chicago (UIC) through the National Institute on Aging (Grant #HHS-AG 12042-03).

[2] Herek and Glunt (1988) coined the phrase "AIDS-related stigma" to designate a level of discrimination and prejudice which is deeper than that experienced by persons with other types of illnesses or conditions; this particular type of stigma sometimes makes obtaining social support and assistance more difficult for persons with HIV and their caregivers.

isolated and alone as they watched their young folks die.

Only one of the research respondents was a man. His interview was very uplifting to me because his attitudes about HIV were progressive and accepting. "Billy" was a 51-year-old African-American man from the west side of Chicago who was unemployed at the time that he spoke with me in the summer of 1996. Billy was not similar to the other research respondents, not only because he was the only male interviewee, but because he had not been deeply connected over a long time to the HIV-positive person, "Renee," whom he was helping. Renee was his neighbor, not a relative, which was another way in which his situation was different from the others. The interview itself was unique in this sample due to the absence of strong emotion such as grief or love for the care recipient.

Billy had been living in the same apartment building with Renee and her husband for the past five years and had been only casually acquainted with them over that period of time. Because of Renee's changing appearance and frequent visits from Renee's mother, Billy had recently surmised that Renee had AIDS and offered to help out during her mother's temporary absence while she visited relatives in the Philippines. Renee accepted Billy's offer of help and acknowledged her AIDS diagnosis to him. At the time of the interview, Billy had been providing companionship and transportation to Renee for approximately a month.

Although Billy was unlike the other 19 participants, he had the most to say about HIV-related stigma in his community. I was impressed with his awareness of the effects of HIV-related stigma, his wisdom about what perpetuated it, and his courage in facing HIV as a social problem which had relevance in his life. During the interview, I was very moved by Billy's narrative style, his sensitivity to the general climate of discrimination, and his willingness to support a casual acquaintance who was HIV-positive. I had the sense that not only was he unique in this study, he was fairly unusual in his responses to HIV.

Over a year's time, as I was analyzing the data and struggling with writing up the results, I was repeatedly frustrated at not being able to include Billy in conference presentations and articles. Each time that my dissertation chair or I wrote about or talked about the study, we realized that Billy "didn't fit" any of the patterns and we ended up leaving him out. I see his story as an important illustration of how disclosure decisions and stigma management can have an intense impact on people, and in the 18 months since I met him, I have not been able get his comments out of my mind. I have been able to find several outlets for showcasing the powerful stories of the 19 women, such as my dissertation, several presentations and papers, and poetry (see Poindexter, 1998). I remain frustrated, however, at not being able to voice what I learned from Billy. In this article I attempt to do so. I want people to hear his passion, his ability to "tell it like it is," and his view of urban life and of persons with HIV. I also think that African-American inner-city men are rarely heard from in our literature, especially on the subject of AIDS.

I did not interview Billy in his home, as I did most of the research participants. He wanted to meet with me in my office at the University of Illinois, which was in the building next door to the place where Renee was getting medical care. Billy was bringing Renee in for a check-up and wanted to speak with me while he was waiting for her. He called me from the Infectious Disease clinic, and I went over to get him. On the phone he told me, "I'll be the one in the Bulls cap." I said "That doesn't help; everyone nowadays wears a Bulls cap." He laughed and said that he'd wait in the hall by the elevators. He saw me approaching him and walked forward to meet me. I saw that he was a casually dressed, young looking, heavy-set dark-skinned man who was missing some teeth in the front of his mouth. We shook hands, and I walked him back to my office through a back hall so that we did not pass any of my coworkers. I set the tape recorder on my desk, sat in my desk chair, and motioned for Billy to sit in a chair in the corner near my chair. Throughout the interview he was upbeat and animated. He would periodically look around my office and interrupt his narrative to comment on posters, photographs, or personal items. He even made two

attempts to flirt with me. In the following excerpts from the interview, Billy's remarkable story emerges.

Billy's caregiving activities were both concrete and emotional; he offered instrumental support and tried to encourage Renee:

"Well, I take her....to the grocery store, and I usually take her out and about,...take her shopping and stuff....she want to go somewhere, I go with her...I usually keep her company. I try to keep her spirits up... And I try to keep her calm, you know? She just seems worried, and she misses her mother... But when she don't eat and stuff, I say, "how you gonna be if you don't eat? You know you gotta eat."

As demonstrated by the quotes which follow, Billy's reasons to offer help to Renee were closely connected to his awareness that persons with HIV are not treated well in his west side Chicago neighborhood, as well as his sense of fairness and his empathy for what persons with HIV might feel and need. He demonstrated an intense dislike of what he perceived to be the usual attitude toward persons with HIV and wanted to be different from his neighbors and buddies. Billy talked in this way about the unfriendly climate of his neighborhood regarding persons with HIV:

...they whisperin' and [makes whispering sounds]....and spread rumors about what they don't know nothin' about. I tell 'um, you want to know somethin', just ask me, I'm serious, you know, but don't spread rumors. You know, that's bad. That's very bad....so they spread rumors....they just be gossipin'. Gossip, gossip, gossip, gossip, gossip. There don't be nothin' to gossip about; they don't have nothin' to say. You know what I'm sayin'?

Billy thought that people in the neighborhood bad mouthed people with HIV because of ignorance: "People are always afraid of somethin' that they don't know anything about." He said that persons with HIV are just like other people and need to know that someone cares. When I reflected, "it sounds like you don't have a problem being with people who have HIV," he responded:

No, well, you know people are people....and you just have to be educated about what's happening... and they need to be, they need to know somebody cares. Just like you or I. Who's to say? It's way out.

Further explaining his disagreement with the way persons with HIV are treated in his neighborhood, he spoke of his sense of how people with HIV want to be treated and his own commitment to treat them well:

And that's not fair....because you have to put yourself in their position, you know? How would you want to be treated? And you would want to be hugged and touched, you know. It's way out. It take all types of people to make the world go round....I ain't gonna stoop that low. I mean, I'm gonna try to keep it focused. It's hard, but I keep tryin'.

Billy was aware that his attitude toward persons with HIV was unusual among the group with whom he hung out. In the following interchange, he spoke about why and how his own accepting attitude toward persons with HIV differed from most of his neighbors:

Billy: I always been different from a lot of the people in my neighborhood. [Chuckles]...I went to school with a lot of Black people, White people, Puerto Rican people,...a lot of different people,...I know people. A lot of different people....so I don't have....if I have prejudices,...I guess everybody do, to a certain degree, but that's [HIV] not one a 'um....I try to keep a open mind... You're nice to me, I'm gonna be nice to you. If you aren't nice to me, I might not be nice to you. Somethin' like that... A lot of people, they just nasty. [Chuckles]...they just nasty, period.

Cynthia: And sometimes they get nasty to people with HIV?

Billy: Yeah, real nasty.

In the next excerpt, Billy elaborates on how he is governed by his own sense of right and wrong, not by the opinions and actions of his peers:

It's hard....but a lot of people want to go with the majority. And I never liked to go with the majority, so it's kinda easy for me....I know what's right and what ain't. If it ain't right, it ain't right. [Laughs] And that's what time THAT is.

I asked Billy how he had come to be so knowledgeable about the disease. He replied that he had sought educational resources so that he could be more informed about HIV:

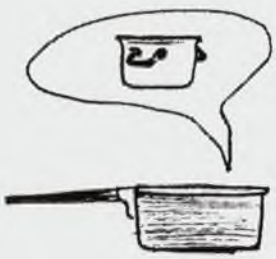
Just....listening and knowing.... and everywhere they had an opportunity to study or talk, I went....and listened to it and participated. You ain't gonna learn nothin' if you go through with blinders on. You know, ain't no tellin' what might happen tomorrow.

Billy had previous experience with friends and acquaintances who had HIV and this seemed to influence his thoughts about the illness:

I know some guys, I know some chicks. And I know some white ones, I know some Black ones, I know some Puerto Rican ones, some Jews... It's an equal opportunity disease. You know? And it doesn't discriminate.

Billy explained that his determination not to mistreat or ignore persons with HIV stemmed from his sense that he was fortunate not to have been infected with HIV himself. His empathy seems to be closely linked to that awareness:

So I just got lucky. I'm serious. It could have been me. And.... how would I have felt? As far as people and friends turnin' their back on me? I wouldn't like that very much.



Billy also believed that his perceived good luck (which had enabled him to not die and not be in jail) was connected to God's having a purpose for him which he had not yet discovered:

Billy: I just came to the conclusion, I say, Man, listen. All these people I know, they dead or in the penitentiary.... and I've been lucky so far, so man, He must have put me here for somethin' other than what I'm doing. I have to find out what the Hell it is.
Cynthia: God has some purpose for you?
Billy: Yeah, you know. People ask me, I say I feel like I'm gonna be a preacher or somethin' [laughs]. And they laugh, you know. But the Man got somethin' for me to do! This ain't it! So, I say, let me check it out. So...I'm tryin' to get ready for to check it out, see what's happenin'... I need to do somethin' other than what I'm doin'. I ain't doin' nothin'.

When he was telling me his ideas about why people hide the fact that they have HIV disease, Billy related (with a mixture of bewilderment, sadness, and amusement) the story of a friend who was very ill from AIDS, but who had been one of those who had speculated aloud about Renee's HIV status:

Billy: And then I got another friend a mine, talkin' about he got cirrhosis of the liver, he drink every day. He used to get high, and then he quit gettin' high, and now he drinkin' every day, but he done had two or three ladies that have the HIV virus, and he don't wanna admit that he got it. And I think he gonna drink himself to death to keep people from knowing that he got the virus. That's dumb. I mean,...That's what he thinks.
Cynthia: Did he tell you that he had AIDS?
Billy: No, he didn't have to tell me. I know the background. Ain't no way he can not have it.
Cynthia: People are real secretive sometimes. They don't want to say they have AIDS.
Billy: Yeah, but it's the same guy that's spreading rumors about Renee! Yeah, he's one of them, he's one of them. The pot talkin' about the kettle... And he started that last year. And, you know, I don't understand. I quit tryin' to figure that out. It's the same guy that was talkin' about her, and now people talkin' about him, and

he can't stand it. And when she [Renee] found out he was in the hospital, I told her, and she went to see him, and he almost jumped out the window [laughs heartily]... He wasn't expectin' to see her.

Billy described Renee's concern with hiding her HIV diagnosis and said that he had encouraged her not to bother with what others thought:

It's way out. I say [to Renee] 'don't let that worry you, man.' That's so...all the folks outside, she be worried about some would treat her like that. I wouldn't even let that worry me, but she does.

Given Billy's advice to Renee not to let the opinion of others worry her, I was curious about how that had played out in his life. Ironically, Billy had not told anyone that he was involved with anyone with HIV. Referring to his decision not to disclose the fact that he had a relationship with an HIV-positive neighbor, he described his secrecy as a sense of privacy:

Cynthia: Is there anybody in your life who knows that you are friends with Renee and that she has AIDS?
Billy: No... I don't think it's anybody's business, myself. But if, you know, if somebody was to ask me....and I thought it was important, I wouldn't deny it, [but] I wouldn't talk either. But it all depends. I don't really think it's anybody's business... I treat it like that.

Billy had not disclosed the situation with Renee to the family members whom he described as the most significant to him, because he anticipated that they would judge him harshly for providing care to someone with AIDS:

Cynthia: Do your mom and grandmom know that you have friends with AIDS, and you're taking care of Renee?
Billy: I think they do. I'm quite sure they do.
Cynthia: But you haven't said it out loud?
Billy: Uh-huh [no]. But I know that, they nosey, nosey, nosey... Nosey. Yeah, man, they run around [makes whispering sounds]. My grandmother, she sets out front of my house and [speaks as his grandmother] 'what are you goin' up there for?'... They all in my business....I know them. They done figured it out [about helping someone with AIDS].
Cynthia: What do you that think they would think about you having friends with AIDS?
Billy: Uh, I don't know. They probably wouldn't care for that.
Cynthia: They wouldn't like it?
Billy: No, I don't think so. They kinda stuck in the 50's. Narrow minded. They really narrow minded. They don't have nothin' good to say about nothin'... I don't want, I don't even like to talk to them about certain things. I know what the answer gonna be before I even....before I say it... I know how they are. I just can't, I have to realize and understand that nothin's gonna change....they got their opinion and I got mine. It's a question of what matters, theirs or mine. And I think mine does. So, I don't even worry about it. I don't even discuss it... I used to value they opinions, but it really doesn't matter. Whatever what was going to happen was going to happen. So I changed. And I quit worrying about it.

When I asked what people like him might need in order to make it easier to take care of someone with HIV, Billy stated that HIV caregivers should not focus on the judgements of others:

Cynthia: What are you thinking that people need when they take care of people with HIV?
Billy: Well, they need to try and stay focused and they need to not look to what other people say so much. And to try to use their own judgment and don't depend on what other people say so much....if you know it ain't right, it ain't right. Don't be so judgmental and don't let your mind be so easily swayed. That's what I think... 'Cause if I know in my heart that it's right, ain't nothin' you can do to make it not be right... If I know that it's supposed to be up here [points to his head] then I know it's supposed to be in here [points to his heart].

Researcher Reactions

I think that Billy's experiences and observations about HIV-related stigma can help us understand AIDS-related discrimination and attitudes in urban areas where the residents are predominantly members of minority groups. The first lesson that Billy's narrative taught me is that HIV-related stigma is salient and powerful in his world. His recounting of the hiding of the HIV diagnosis by Renee and by the man in the hospital illustrates the continued fear which some persons with AIDS have concerning disclosure of the diagnosis. In addition, Billy's description of his relatives' negative views, should they learn of his having friends with AIDS, and his sense of the prejudice in his neighborhood against persons with HIV seem to point to the existence of HIV-related stigma, both experienced and anticipated.

Another thing that Billy highlighted for me is the need for continued public education about HIV. Billy said that people in his neighborhood were still ignorant about HIV and needed to be educated. Billy sought information about HIV himself because he wanted to know what was up and was able, in that way, to respond to an HIV-positive neighbor who needed support.

I also think that Billy's eloquence concerning striving for congruence between his head and heart is an example of the integrity that he demonstrated regarding doing the right thing for persons with HIV who need understanding, compassion, and/or assistance. He told me that many of his neighbors suspect that Renee has AIDS, but they choose only to gossip. Billy guessed that she has AIDS and decided to offer his help. I find that remarkable. He is certainly not the only person who has come forward to assist fellow human beings who have HIV; this pandemic has obviously had countless heroes and heroines who have provided care despite feeling isolated and stigmatized. However, I think that his reaction as a neighbor and casual acquaintance is rather rare, and his empathic insights and altruistic motivations should be noted and appreciated. He seemed to have an attitude of "there but for the grace of God go I," which inspired him to treat others as he would want to be treated.

I disagree with Billy on one point, however. Billy said that he thought that HIV-affected caregivers should not mind so much what others say about persons with AIDS and their caregivers. While that may indeed be good advice, it does not go very far toward ameliorating the problem of HIV-related discrimination and stigma. It seems to me that societal attitudes must move more toward compassion and helpful action if persons with HIV and their caregivers are going to feel safe in disclosing the presence of HIV and asking for help. Then perhaps it will be more likely that neighbors will care for neighbors. □

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Breast Cancer: A Personal and Professional Crisis

My own experience with a diagnosis and treatment of breast cancer has given new meaning to my capacity for change and reshaped my professional role as group facilitator and teacher

by
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I thought I was an expert in working with women diagnosed with breast cancer. Not a modest statement, but I have been doing it for almost 20 years. This narrative about my experience with breast cancer describes a journey which affected me personally and professionally.

I am a single, 51-year-old woman with three grown children. Social work was the career choice I made as an undergraduate and continued on through graduate school. I have been employed full time in the field since my youngest child was a baby and have struggled with such typical issues of balancing family with career responsibilities. Proud of my accomplishments, I enjoy this stage of my life as it gives me more time to focus on my own personal interests. I have had many different social work positions since my first post-MSW job on the oncology unit of an acute hospital but continue to work part time with women diagnosed with breast cancer.

Frequently I wonder what drew me to work with cancer patients. It is a difficult question. It is a population clearly in need of social work services on many levels: the overwhelming sense of loss; pain and suffering; body image issues; financial issues. Cancer's impact on an individual and a family has been addressed *ad infinitum*. I do know that my work with cancer patients has been satisfying and meaningful, even though I have had my share of "burn-out," wondering if it is time to move on. Those are the times I catch myself using "pat" phrases, responding too quickly, not listening or tuning in. Yet I really want to continue. Often I am able to recognize my feelings, re-focus, and continue to find satisfaction in the work I do. The feedback from clients that I have made a difference in their lives makes me feel valued and important.

Most women diagnosed with breast cancer react to the news with considerable shock. This is the most predominant feeling, despite the fact that the national incidence of breast cancer has increased to 1 in 8 women, and information about detection, early cure, and new treatments is constantly in the news. Women often say to me, "I always knew it could happen to me; I just never really believed that it would." Listening to women struggle with making decisions about surgery and treatment, I wondered what I would do. Would I opt for a mastectomy? Could I cope with the possibility of recurrence? How would I handle the loss of my breast? I don't think any female social worker can work with this population without having these thoughts. Have I ever wondered that I might be

diagnosed with breast cancer? Absolutely! Have I ever thought it would happen to me? No. I have a lot of experience counseling individuals diagnosed with all types of cancer, from the initial pre-diagnosis period to hospitalization and surgery, treatment, and the post treatment fear of recurrence.

My Personal Experience

A year ago, I was diagnosed with breast cancer. The diagnosis was made following a mammogram that showed "micro-calcifications," and a surgical biopsy which confirmed the malignancy. The mammogram, which I normally have once a year, was done six months late. I was "too busy" to get around to it (an indication of my naiveté and denial that breast cancer was something that I might have to deal with). My personal physician is the physician with whom I work, and whose women patients I counsel both individually and in a group. The physician's nurse specialist is also a close personal friend. I knew that she would receive the results of the biopsy before I did. We discussed how she should handle this difficult position or, more accurately, how I wanted her to handle it.

I knew all too well how this is normally handled in the office. Following a biopsy which is positive for malignancy, women are scheduled for a follow-up visit, with the tactful suggestion they bring someone with them to the appointment. At the appointment, they are ushered into a well-decorated conference room. The surgeon and the nurse (my close friend) then tell the patient the results of the biopsy and discuss options for treatment.

Obviously, calling me into the office in this manner without sharing the news on the phone would not work for me. Instantly I would know the news was not good. I told my friend, "Just call me and tell me in a straight-forward manner." Later I wondered how she felt about my request. How did she feel about having to be the person to tell me I had cancer? Anxiously I waited. I called the day the results were expected, and there was no news. By the next day, my anxiety was at an all-time high, and I was avoiding another phone call to the physician's office. One of my colleagues at work encouraged me to get it over with and make the call. I closed the door of my office and called. My friend was straight-forward and to the point. "The results are what we were suspicious of. The biopsy was positive for malignancy. Even though it is a very early cancer, it is the more aggressive type. The doctor needs to talk to you about further surgery or treatment." I sat and cried. "You knew it was likely," she softly replied. I responded, "I know. I guess I didn't really believe it."

My cancer experience is not unlike the experiences of the women I have worked with over the years. And, I realize I am not the first woman to be diagnosed with the same illness as her/his clients. The experience of dealing on a personal level with a crisis that one has been such an expert on professionally is complicated. As with many women, my initial reaction to the diagnosis was shock, followed by periods of denial and a "blunting of feelings." Is this kind of reaction unusual for me? Not really. My therapist reminds me that I am much more skilled at tuning into others' feelings than I am at recognizing my own.

I opted for a mastectomy after researching all of my options and had two weeks before my surgery. I wanted to use the time to deal with my feelings in preparation for my surgery. This is what I focus on with those women I meet prior to their surgery. If they can express their feelings, they seem to approach their surgery with the reassurance that their feelings are normal. What I actually did was to avoid my feelings as much as possible! I spent the time with my partner, who was concerned about my emotional state and I think decided that his job was to keep me as busy. His concern and attention were reassuring and comforting. We shopped. We saw every newly released high-action movie we could. We talked a lot, but not about my diagnosis or upcoming surgery. I felt he was watching over me, and he seemed to be my buffer against the outside world. I would check in with myself. I wondered what I was feeling and found I wasn't feeling much.

As I awaited the mastectomy, I began to feel a "heaviness" that was with me all the time. I did all my normal activi-

ties with the constant awareness that something within me had changed. In groups of people I wondered if I looked "different." I wavered between wanting to tell everyone, "Hey, I've got cancer," and avoiding people—wanting to be alone. The tears, the anger, and the upset came later.

I have had my share of caring professionals, and those oblivious to the impact their callousness has on persons who just received the news that they have a life-threatening disease. Extremely angry at some of them, I wondered if I was overreacting or displacing my anger. Early on, when I went to the hospital for my pre-operative lab work, I filled out the paper work and was asked to have a seat. The receptionist then called out across the room, "What kind of surgery did you say you were having?" I was appalled. I quickly went up to the desk and whispered, "I am scheduled for a mastectomy." I did not share with her the horror I felt—exposing to all in the waiting area this very personal information.

While awaiting surgery, I often felt and acted helpless, and sometimes passive, which is unusual for me. I consider myself assertive and I was surprised with some of my reactions. I would go to the doctor's appointments and "forget" to ask important questions. Or, the doctor would make decisions that upset me, and I would say nothing. It is ironic because I practice assertiveness and encourage it in the women I counsel. I began to realize how difficult assertiveness is when one is feeling vulnerable, helpless, and powerless.

Fortunately, I do practice what I preach—eventually. After enough of such encounters with medical staff, I absolutely forced myself to schedule another appointment "just to talk." During one visit with the plastic surgeon who was doing the reconstruction of my breast, the nurse asked me to browse through a copy of *Playboy*, and to choose the model who had breasts that I wanted the surgeon to strive for. I felt as if I was given a catalog of clothing to look at and pick from. But, this was my body! I just wanted to look normal again, and wondered if this was even possible. I felt humiliated and depressed. I had heard similar stories from women who described some of their doctors as detached and insensitive. Here I was after my mastectomy and in the middle of reconstruction, losing a breast due to a life-threatening disease, and being treated casually by the doctor, as if this was a cosmetic procedure I had asked for. Hadn't this doctor learned anything from me as a professional? After choosing, I said nothing, left the appointment, went home, and cried.

I have professionally worked with these doctors , and they have excellent reputations for their medical skills and their relationships with their patients. I was surprised at my passivity with them: I have had no difficulty advocating for my clients. After much encouragement from friends, I met with the plastic surgeon and told him my feelings. The doctor's reaction surprised me. A kind and considerate man, he listened carefully. He then asked me if I thought I might be projecting my anger related to my diagnosis to the incident with the magazine. After all, he said, none of his other patients had ever reacted negatively to looking through the magazine. I was angry. Did he really know anything about psychological defenses? He did give me some food for thought, though. I told him he could be partially correct but that I did indeed find the experience upsetting and wanted him to know about it. I hadn't been aware of how angry I was about my diagnosis of cancer; maybe this was a safe place to allow the anger to surface. I left the appointment still depressed, but at least I stopped "obsessing" about the incident. I was glad that I had the meeting. I could see firsthand the benefit of confronting the issue for myself, but also saw that I was in an important position professionally to share how I felt with my doctors in order to sensitize them to how other women might feel in similar situations.

Facilitating the Breast Cancer Support Group

I run a monthly support group for such women, and my first challenge professionally was whether or not to share my diagnosis in the group and, if so, how much. My biggest concern was deciding what was appropriate and helpful; and about my own feelings and reactions. Would I be able to keep the focus outside of myself? It was clear to me that to not tell them would be dishonest. I was a patient in the same office as many of these women, and very likely they would learn of my diagnosis anyway. If this were to happen, I feared this would damage the trust and closeness that had been established. Conversely, I knew that at some level, sharing my experience might benefit some of the women and add credibility to my knowledge about the emotional aspects of breast cancer.

To keep my feelings from interfering with the group's process, I needed to be aware of what those feelings were. I never realized how difficult this could be! I found it hard to focus on my feelings when my general reaction to the crisis was shock and denial. Before facilitating the first support group, I had several therapy sessions focused mostly on my anxiety about the next group session. At that first meeting, I shared the news of my diagnosis with the other women. I began the group and stated that I had something personal to tell them. "After having a routine mammogram, I had a biopsy that is positive for a malignancy, and am scheduled for a mastectomy in two weeks. As I spoke, I focused on the group and their reactions. The members expressed shock at my news. "I just can't believe that this has happened to you of all people." Their response was disconcerting; why would they be surprised when this diagnosis can happen to anyone, and in fact happened to them? It caught me off guard, and I struggled with an answer. "It was a shock to me as it was to many of you when you were diagnosed," I responded. Later, when I had a chance to think more clinically about their reaction, it made more sense to me. I was their group leader, there to help them with their crises, not to have my own. In their eyes, I was "immune" to cancer! I realized that I missed an opportunity to explore this with them—to help them express their feelings. They were very interested in my experience, and it was difficult to refocus the group away from me. First they asked many factual questions, which was a relief to me. It was so much easier to talk about facts than to answer questions about my emotional state. I was afraid that if I focused too much on my emotions, I would lose control and cry. Eventually, one member asked (mirroring my own words to them in the past!), "So, how are you holding up?" I have known this particular woman for a long time. She is a ten- year breast cancer survivor and has been in one of my groups since her original diagnosis. She is cancer free and active in the national breast cancer organization that sponsors our support group. She comes to the groups to comfort other women and to receive support for herself. I felt awkward, but shared a little more about how I felt on an emotional level. "I am feeling somewhat numb, depressed at times, much like you have described," I stated. They nodded in agreement. I felt a warmth and closeness to these women that I hadn't felt before. I realized after the meeting that the challenge would be to maintain my role as facilitator without becoming a group member. How would I do this after receiving such welcome support from women who had been there already? I needed to be careful not to use the group to "work" on my issues. It was clear to me that this was the appropriate boundary. If I were to "work" on my issues, I would no longer be the facilitator.

My mastectomy and reconstructive surgeries completed, I continue to facilitate the support group, and talk about my experience. I talk about my feelings related to my appearance, how painful some of the procedures have been, and how the whole experience has been such an intrusion in my life. Just recently I talked about feelings about the one-year anniversary of my diagnosis and initial surgery. I have often told the group that the most meaningful support comes from oth-

ers who experience a similar event. The mere presence of these women in the group gives me support. I have watched the women struggle with many crises—they have been able to cope and it reassures me. Some of the women have had recurrence. Some of their relationships have ended. They have lost jobs. These are scary stories, and yet they find the strength to deal with their fears and losses and continue to lead meaningful and productive lives.

Many of the women have become much more assertive and proactive in their care. One woman I have worked with for several years began with a lot of anxiety. Since her original diagnosis, she has had many rounds of treatment to deal with a number of recurrences. Emotionally, she is almost unrecognizable today compared to the woman I first met. She developed a solid support system that she relies on; she is assertive and makes her own decisions around her treatment. She is a positive role model for the group and for me.

I try to help the women develop strategies to deal with their fear and now see for myself that some of these work! Fear is such a normal part of this experience, and it is helpful to acknowledge it and talk about it. However, I can see that accepting fear as a normal reaction is easier said than done. When some of the women have shared their fears with their friends and family, the response has often been, "I know you are going to be fine," or, "you need to have a positive attitude; being negative may just make you become ill again." As a result, many women have been resistant to discussing their fears. In the group, I try to reframe this. I might ask, "What are you most afraid of?" One of the most common answers is, "I'm afraid the cancer will come back." The threat of recurrence is a real one and has happened to several group members. The discussion about recurrence is painful, but most women tell me they feel much better after the discussion. I feel more genuine in my responses. In the past, I might have said something such as, "Many women diagnosed with cancer have shared with me ....." Now, some of my statements begin with, "I find myself feeling... similar to what many women have shared with me." I am much more patient and understand that coping with cancer is an on-going process. Grieving the loss of a breast, dealing with a new body image, coping with the pain of surgery is very difficult. The grieving process is not accomplished smoothly; feelings surface and disappear in no logical formation. I have known this on a theoretical level, but never so personally.

Teaching At the University

My experience with breast cancer has also had a major impact on my current full-time position as a field coordinator in both the MSW and BASW programs. My responsibilities include teaching small seminars focused on helping students integrate social work theory into their field practice experience. Although the seminar is unstructured in the sense that students function as a group and it is focused on students' issues and concerns, there are several topics that I do cover in depth. Of these topics, self-awareness, self-disclosure, counter transference, and setting appropriate boundaries are among the most critical. As the facilitator, I realize that I am a role model for the students (positively and negatively). I need to model appropriate behavior, and practicing what I teach is important. I have found that one of the earliest challenges for students is self-awareness—to be able to identify one's own feelings. Students seem to have the most difficulty in identifying their own feelings as opposed to those of their clients. I have observed this as students struggle with the dreaded "process-recordings." Many students confuse feelings with thoughts. They discuss their views on the interviewing process, or they focus on what the client was feeling during the interview. When asked directly, "What were you feeling during the interview?" many students respond, "I don't know," or, "I wasn't feeling anything." I admit, I find this very frustrating! I believe that my cancer experience has taught me just how difficult it can be to "get in touch with one's feelings."

My initial diagnosis of breast cancer and surgeries have occurred during university sessions, and I missed several class sessions. Because the surgeries were planned ahead of time, the

students knew that I would not be in class. But, what was I to share with them? Normally, I disclose little about my personal life with students, again trying to be a positive role model and to share what I think will be a good learning experience. If I am to miss a seminar, I normally share just that, and no more. Was this an opportunity to model appropriate self-disclosure? I had several weeks to struggle with this issue, and decided to give some details of my upcoming surgery. I came to this decision because I thought it might be difficult to keep this a secret and that the way I told them might provide important learning for the students.

Briefly I told them about what was happening to me and let them know in general how I was doing. The students were incredibly empathic. They wanted to know how I was feeling. Some of the students talked about people they knew who had a similar experience and had done quite well. They tried to be very reassuring. I told them that I would continue to let them know how I was doing but would not generally talk a lot about the experience. This was the boundary I set. Was this boundary too rigid? I never really explored with my students their feelings and reactions to my diagnosis. I have no idea if my experience resulted in feelings of fear or reminded them of similar personal experiences. This might have been a meaningful discussion to have but one that I did not initiate and hence, another opportunity missed. Throughout the semester, students continued to ask how I was, but respected my privacy. They continued to write wonderful notes of encouragement and support.

Reshaping My Thoughts: New Questions and Challenges

The morning I turned 50 I woke up tearful. I continued to sob throughout the day. Was I crying because of my age? I wasn't aware of being particularly depressed about turning 50. I was, however, in the middle of my reconstruction. I was uncomfortable; I hated the way I looked. It had been a rough several months for me physically, and I realized I was depressed and angry. Was I finally reacting and having a good cry? As I review my cancer experience, I realize several things. It is embarrassing to admit that as a professional in the social work field and one who has focused on the emotional experience of breast cancer, I initially believed that I would handle this experience somehow better than the women I had worked with, that because of my knowledge of what to expect, I would cope "better." I also expected the physicians that I worked with professionally and who became my personal physicians to treat me deferentially as a colleague with more respect and patience. It is not that I thought I deserved better treatment, but that surely they would remember some of what I had shared with them about treating women with respect and dignity. The reality was that I struggled as most women do and that I was treated by my physicians as any other woman. It has been an important humbling learning experience for me, one which I hope will continue to enhance my skills with clients and students.

I have set some rather definite boundaries in my professional roles. Were these boundaries too rigid? I realize that at times I set them with my own comfort in mind, rather than what would be most beneficial for my clients or for my students. I have tried to be less rigid in my support group by sharing more of myself. In some ways, my role has become blurred. I am the facilitator and a group member at times. I wonder if this dual role is appropriate. I have no answer at this point but will continue to struggle with setting boundaries and expect that I will continue to find this difficult. In my role with students, I understand more keenly that learning is a process and that self awareness, self-disclosure, and setting boundaries are difficult concepts to put into practice. I am more humble and patient. I realize that even the very experienced social worker can find that practicing appropriate social work skills is an incredible challenge. □

On the Receiving End of Social Work Services

This narrative chronicles a family tragedy which served to transform my understanding of social work. My years of experience as a social work practitioner and educator failed to prepare me to be a recipient of service. I never knew what it felt like to be a client until my father committed suicide.

by
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Overture

Some months ago I had a painful but profound experience. Painful because it involved the untimely death of my father. Profound because it gave me a significantly deeper and more intuitive understanding of social work.

One Thursday morning in January, I received a phone call from my step-mother, Peg, informing me that my father had jumped ten stories from the balcony of their New York City apartment to the sidewalk below. Miraculously, he had survived the fall, which had been partially broken by the branches of a tree. My father had been rushed by ambulance to the emergency room at Mercy Hospital, just several blocks away. He was in the process of being admitted. Peg was calling his three children, as well her own daughter Eleanor, so that we could come to New York as soon as possible.

By the time I got to New York (the cab ride from LaGuardia Airport predictably taking longer than the plane ride from Maine), it was almost evening. I went straight to the hospital where my father had finally been admitted to the intensive care unit. Apparently everyone—from the police, paramedics, and ambulance drivers to the nurses and doctors—was amazed that a 74-year-old man could have survived such a fall. The news was far from good, however. My father's body was badly broken; he had sustained multiple, severe injuries and was paralyzed from the chest down. During his brief periods of consciousness, he had begged and pleaded with the paramedics, the nurses, the doctors, his wife to allow him to die.

My father, a retired professor of some renown, had a long history of depression. Most of his life the depression was in remission, never really interfering with his professional career. Although earlier depressive episodes had consistently failed to responded to medication, they had always been vanquished by electro-convulsive therapy (ECT). This most recent episode had been different. My father had been severely depressed for well over a year, increasingly unable to speak on the phone, read, or even concentrate on television. All of the myriad new anti-depressant medications that had become available since his previous depressions had been tried. None had any impact on his deepening despair. Finally, the doctors again resorted to ECT. This time, however, my father's depression proved more powerful than electro-shock.

There was no improvement. By year's end, there seemed little reason for optimism. He had clearly given up.

First Movement

When I arrived at the ICU, I saw my own fears and sense of horror reflected on the faces of my family members. The patient in the bed was unrecognizable. He was barely conscious, heavily sedated, and bandaged up to the neck. He was attached to a respirator. A monitor displayed his vital signs in neon purple, yellow, red, and blue. Tubes were taking liquids out of his body. Other tubes were putting different liquids in. I had worked as a hospital social worker for many years. The various technological paraphernalia, their constantly shifting lines and periodic beeps, did not really faze me. My father's appearance did. I was told that the attending physician was expected shortly.

The doctor, a Jewish man in his mid-sixties, was brusque and authoritative. He directed most of his comments to my father's wife, despite her stated preference that he speak with all of us. The bottom line was that my father was lucky (!). He would most likely survive his "fall," albeit as a permanent quadriplegic. I thought to myself, "This is the ultimate nightmare, to be severely depressed and want only to die but without the physical ability to make it happen." A glance of understanding passed between my sister, Sara, and me. I think this was the moment where we both stopped hoping for my father's recovery.

The doctor was still issuing pronouncements. My father would be scheduled for a major surgical procedure to stabilize his back, probably the following week. This surgery would not improve his overall condition but it would enable him to be sat up and fed, making it possible for him to be cared for at home with around the clock help. We were told that the surgeon would meet with us the next day to further discuss the surgery. We raised the question of whether surgery so soon was really such a good idea, but the doctor merely repeated his statement that the surgeon would be speaking with us. Having had little input into that consultation, we sought out the chief resident, an Asian woman in her twenties. Her demeanor was considerably more empathic than the attending physician's. She seemed to understand our growing confusion about the efforts to save my father's life, given his condition, when he had been so specific about his desire to end it. Despite her apparent understanding, there seemed to be nothing she was willing or able to do to intervene. She repeated the mantra that the surgeon would stop by tomorrow afternoon to answer our questions.

Second Movement

Friday morning found Sara, my half-brother, Simon, and me having breakfast at the coffee shop near the hospital. Peg and my step-sister, Eleanor, were at my father's bedside, maintaining the vigil. For the first time, my father's three children gave voice to the unspeakable: Should my father be kept alive when he wanted so much to die? Shouldn't we , who knew better than anyone never to cross him, respect his final wishes? The doctors and nurses were mobilizing all their efforts toward keeping my father alive. Was this what we wanted, or should we persuade them to allow him to die? Couldn't we, as his family, refuse medical treatment on his behalf? Otherwise, what kind of a miserable life sentence were Peg and my father in store for?

We knew we had to talk all this over with Peg as soon as possible, to let her know what we were thinking and gauge her reaction. We needed to include Eleanor in the discussion as well. The topic of allowing my father to die felt scary just to talk about, even among the three of us. We had initially experienced an enormous sense of relief upon learning that his suicide attempt had been unsuccessful. Our first reactions were similar, "Oh please, let him survive this!" It seemed as though many days had passed since we had first received the shocking news...

actually, it had been about 24 hours. I awaited the discussion with Peg with considerable trepidation.

We spent the rest of the morning in the hospital, watching the respirator breathe for my father. At lunchtime, we went back to the apartment. I don't remember which one of us first broached the subject of allowing my father to die. Neither Peg nor Eleanor seemed shocked that we had been discussing this. Perhaps they had had a similar conversation. Peg took seriously my father's wish to end his life, although she was clearly uncomfortable talking about hastening his death. She said, in a strained voice, "You all have to remember, I am the one who will have to live with this decision on a daily basis. I need time to think it over, and I need to talk to him about it." She also wanted to discuss the situation with an old and trusted family friend, a physician who had been my father's closest friend since childhood.

We returned to the hospital after lunch and met with the surgeon, another aging white man. At one point in the discussion, Peg interrupted the doctor's detailed description of the planned surgical procedure and questioned its necessity. She explained that her husband had been so depressed and so determined to end his life that she was beginning to question the elaborate efforts to keep him alive. The surgeon acknowledged that he would probably be asking the same questions if this was his family member but that the hospital had legal and ethical obligations to keep my father alive. He did mention several possible courses of action for her to consider and clarified that either her or my father's consent would have to be obtained before any surgical procedure could be done.

Friday evening, Peg called my father's childhood friend and filled him in on what was transpiring. He strongly supported the idea of allowing my father to die. He urged Peg to act immediately in informing the hospital staff of the family's preferences, warning her that they would initiate all kinds of heroic measures if she did not. He assured her that this was the right thing, the caring thing to do for my father.

Peg returned from the phone call galvanized. It seemed as though she had wanted to make this decision all along but had needed support and encouragement from several quarters to convince herself that it was the right decision, motivated solely by concern for her husband. She still wanted to talk to him, if possible, and make sure he had not changed his mind, but she acknowledged that he had made his preferences very clear. The rest of us were relieved, if a bit stunned by the rapidity of her decision. We agreed to persuade the hospital staff to cease their efforts to "save" my father. For the first time in 36 hours we had a plan, a purpose. We knew that we would get resistance from Mercy Hospital and its staff, but we would proceed as a united front.

Things were moving so quickly, I felt dizzy and faintly nauseated. I walked out onto the balcony from which my father had jumped, a place I had been consciously avoiding. I needed to be alone with my thoughts for a little while. I felt strangely close to my father standing out on the balcony, still very sad but calmer than I had felt all day. I marveled at my family's uncharacteristic unity; it was extremely reassuring. I felt convinced we had made a good decision, we were doing the right thing. After a while, the frigid January air sent me shivering back into the warmth of the living room.

Third Movement

Early Saturday morning, we went, en masse, to the hospital. My father was still heavily sedated and seemed unaware of our presence. We asked that the attending physician be paged. Fortunately, he was already in the hospital and came within the hour. Peg spoke firmly of our resolve to allow my father to die and detailed our family friend's specific instructions (including canceling the surgery, removing the respirator, and signing a "Do

Not Resuscitate" order). The doctor became annoyed, said he could not remove the respirator until my father could breathe on his own, and indicated that he would have to consult the hospital's attorneys and medical ethics board before considering our requests further. He left the room abruptly. Peg looked deflated. Nothing would or could happen until after the weekend. Ethics boards? Lawyers? This was all getting much too complicated and we had no one in our corner. I suggested we contact the social work department first thing Monday morning. My family agreed.

Needing an excuse to leave the hospital, I volunteered to go to the supermarket to replenish our supplies. When I returned to the hospital, my family was gathered around yet another physician, a white-coated, Caucasian woman in her early forties. Her demeanor, affect, and communication seemed completely different from that of the other doctors. She was commenting on how much strength it must have taken for us to come to our decision, how much we clearly supported each other and wanted what was best for the patient. She concluded the discussion by saying that she would try to help us get through to the attendant or find other members of the medical staff who would be more sympathetic to our position. She left, saying she would be in the hospital and reachable by page all day. I stood just outside their circle, amazed. When she left I exclaimed "That doctor was wonderful, who was she?" Sara replied "She isn't a doctor, she's the social worker." Recognition dawned. The white coat and Saturday work schedule had obscured what now seemed obvious to me. Of course she was a social worker!

Crescendo

I raced down the hall and caught up with the worker, introducing myself and my social work credentials. She identified herself as Diane Rivers, a worker at Mercy Hospital for six years. We chatted a bit. She spoke openly about Mercy Hospital's squeamishness about my father's case. Apparently, there was already much concern among the lawyers and higher level administrators. I expressed surprised that they even knew about the situation so soon. She explained that the phones had been humming all morning; this was apparently a very new situation for this Catholic hospital. She saw the hospital as having a long way to go in understanding the many meanings of mercy.

Diane asked me a few questions about my family, reiterating her earlier comments about our strengths. She shared her observation that from our appearances, my siblings and I were presumably the progeny of several marriages. I briefly described our family structure and its complexities. I shared my realization of the previous evening that the current crisis seemed to be bringing us closer together than we had ever been. She told me she often saw that happen in medical emergencies, that this could be something important to build on. The conversation turned to the problem at hand, the resistance of the hospital system to carrying out our wishes. Diane told me that a psychiatric consult had been ordered to determine my father's competency to refuse medical intervention and gave me the name of the psychiatric resident she thought would be most sympathetic to our plight. She said she would try to arrange to have this resident assigned to my father's case. She also repeated some of the suggestions she had made to my family in terms of overall strategy and renewed her commitment to advocate for us. She handed me her card, looked me in the eye, and left.

I sat down, letting waves of intense feeling wash over me. I felt understood, appreciated, and valued. I also felt bolstered, respected, and acknowledged as an individual and as a member of a viable, self-determining family unit. I felt joined in the battle against the bureaucracy. Finally, someone shared our perception of the situation and was on our side. Moreover, this was not just anyone; this was someone with perceptivity, training, experience, and knowledge of the hospital system, someone with some clout. I returned to my father's bedside, feeling clearer and stronger.

Finale

Events followed quickly. The psychiatric resident appeared but was unable to rouse my father. She took the family into a private room and interviewed us at length. Seemingly convinced of our unity and our desire to do what was best, she recommended that the attendant place a "Do Not Resuscitate" order in the chart. The attendant was paged and conferred privately with the psychiatric resident. The attendant apparently was still uncomfortable acting solely on the family's wishes. He wanted to again try communicating with my father, who had not had any pain medication for a while. He shook and shouted at my father and finally managed to rouse him. My father briefly opened his eyes. The attendant ascertained that my father seemed to know where he was and why. He asked my father to blink once if he wanted medical care withheld, if he did not want help to remain alive. My father blinked once, unmistakably. I felt the tension ease out of my shoulders. There was no further productive communication but the attendant seemed satisfied. He explained to us and to the psychiatric resident that he just had to be absolutely certain before he could withhold medical treatment since that went so deeply against the grain of his training and experience.

The attendant wrote orders for my father to be weaned from the respirator and for a "Do Not Resuscitate" order to be placed in the chart. There would be no surgery. Other minor procedures that had been ordered were cancelled. My father would be given nourishment, hydration, and pain medication, nothing else. The doctor warned us that he might continue to live like this for several weeks. Once off the respirator, he would be moved out of the Intensive Care Unit.

Diane stopped by before leaving the hospital for the day to see if we needed anything. We discussed the day's events. She let us know that this had been a pretty big deal for the hospital, that they had been concerned not just about medical ethics but also about potential lawsuits from one or more family members should we come to regret our decision and blame each other and the hospital. We had apparently impressed the psychiatric resident and the attendant as to our unity and resolution. My father's ability to communicate his wishes directly to the attendant had, of course, been pivotal. Diane suggested that we remember this if we should ever question our own decision making, since the final decision had indeed been his. We thanked her for all of her help during this very difficult and exhausting day.

The next day, Sunday, my father was weaned from the respirator. The "Do Not Resuscitate" order was placed prominently in his chart. Sunday afternoon, he was moved to a semi-private room where he was kept heavily sedated on pain medication, which had the side effect of suppressing his respiration. Monday night, my father experienced severe respiratory distress and died.

Coda

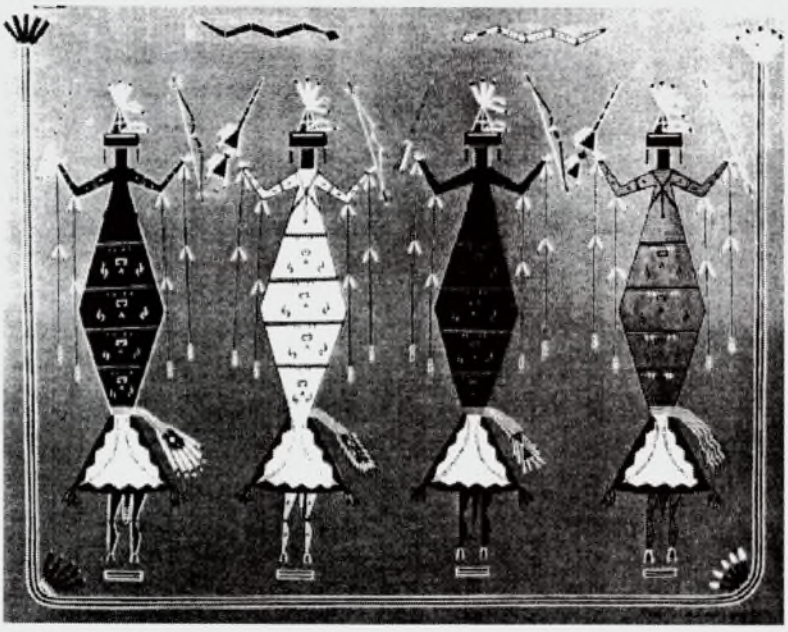
One of the few positive aspects of this terrible ordeal was my experience as a social work client. Why did this very brief encounter with the hospital social worker feel so powerful? She was highly competent but really not all that unusual. I had utilized similar skills in my own practice with clients and I had taught hundreds of students to practice, as she did, from an empowerment-oriented perspective. Diane embodied the social work values and skills I had been teaching and preaching for many years: tuning in, starting where the client is, conveying empathy, identifying and working with strengths, providing information, mobilizing resources, and offering to intervene on the client's behalf while acknowledging and building on the expertise of the client system. She moved easily between the roles of supporter, clarifier, educator, advocate, and change agent.

As client, I experienced these skills and attributes in a profoundly different way than I ever had as practitioner, teacher, or researcher. What had previously been a series of concepts and constructs became a lifeline, a source of help, a promise of partnership. I gained a very special understanding that weekend of what social work could be.

Some time after my father's death I wrote a letter to Mercy Hospital's Director of Social Work. It read, in part, as follows:

...those days were among the most difficult my family has ever faced. Trying to advocate for my father and for ourselves with various medical personnel proved enormously difficult at a time when we were feeling vulnerable and in need of no additional challenges. We were confused, overwhelmed, and frightened.

In the middle of this nightmare, Diane Rivers appeared. The rapidity and accuracy with which she assessed the situation, grasped the complexities of our family composition and dynamics, and tuned into our needs was breathtaking. She understood that we needed support rather than clinical intervention, information rather than answers. She heard our frustration, respected our concerns, and advocated for us with the staff. She also provided us with the necessary knowledge in order to advocate more effectively on our own behalf. In short, Diane's skilled interventions made an unbearable situation significantly more endurable. We finally had someone who was on our side, who understood what we were going through, and whom we could trust...After a quarter of a century as a social work practitioner and academic, I thought I understood social work practice as well as anyone, but I had never before been on the receiving end. I now realize how different experiencing social work is from that vantage point. Diane helped me to see social work from a wholly new perspective that I cannot adequately put into words. It has to do with the incredible relief and groundedness you feel when your whole world has suddenly turned upside down and you finally discover someone who understands and is on your side, someone who respects what you want and is able to help... □



Family Unity Camping Weekend: Dreams Come True for HIV-Affected Families

Anyone who has spent time working with HIV-affected families has stories to tell about the families' courageous efforts to stay the course while confronting a stigmatized, life-threatening illness in one or more family members. While HIV disease is becoming a chronic disease as a result of medical breakthroughs, many families are still experiencing catastrophic loss due to HIV. These ongoing, multiple losses are difficult for families and providers alike. This narrative is about a family camping experience for HIV-affected families. This experience provided family members and the professionals working with them a renewed zest for the challenges of living with HIV and an impetus to seize the moment.

by
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The Experience

In 1986 when I first became involved with HIV/AIDS, little did I imagine that I would dedicate the majority of my career to this arena. Over a decade later, my clinical work, research, and teaching all center on the impact of HIV on families and our communities. The reality of having to say good-bye to so many who have left us prematurely is not easy; but working with parents to ensure that their children have a bright future is the most rewarding aspect of my career. This weekend underscored just how important it is to join with families confronting HIV/AIDS and revitalized my commitment to staying the course with families living with HIV/AIDS.

Only 72 hours prior, 56 family members and 28 staff members came together at the Double "H" Hole in the Woods Camp to participate in Family Unity, an opportunity for HIV-affected families to have a carefree weekend. For Labor Day weekend, we joined together to celebrate life and to explore the meaning of being a family living with HIV/AIDS. All of us returned home with a deeper appreciation for the meaning of a caring community.

Family empowerment means that families know what is in their best interest and that professionals, by relinquishing the "expert" role, join with families to achieve family goals. From planning the weekend to cooking food to helping with the horses or cleaning up, the boundaries between family campers and staff blurred as we came together to form a community. Women living with HIV who either did not have children or whose children were grown helped plan the weekend and participated as staff. Syracuse University School of Social Work undergraduate and graduate students, faculty, along with alumni, joined with Double "H" staff to create a weekend of fun, relaxation, memories, and a chance to reflect on living with HIV. Horseback riding, swimming, boating, bonfires, arts and crafts were balanced with rap groups, the wish-boat ceremony, and a reflection service. Let me share a few of the more poignant moments.

Family Unity was "born" two years earlier when a member of our support group for HIV+ women questioned:

"Why can't families go camping? Don't get me wrong, I'm glad my kids are going next week, but, what we need is a break from this damned disease."

She was right. She along with the other parents needed a chance to simply enjoy their time with their children. Equally, I was energized by the chance to work with a fun project versus addressing the psychosocial complexities of HIV disease. Since 1990, we had explored the meaning of HIV in group members' lives. Planning camp was a new challenge on which to focus our energies.

We agreed to work together to make family camp a reality. The Double "H" Hole in the Woods Ranch, co-founded in 1992 by businessman Charles Wood and actor Paul Newman, immediately came to mind as the place to have the camp. Wood and Newman teamed up to deliver unique, fun-filled program services for children. Double "H" provides a camping experience for youngsters with life-threatening illnesses. Children have a chance to just be kids and to enjoy activities that are creative, adventurous, and fun, ranging from a ropes course to pottery to fishing to white water rafting. An onsite Elderhostel involves members over 55 to come and be with the kids.

During the previous summer, I volunteered as a social work consultant at Double "H" to provide psychosocial support to both the children living with HIV and the staff. The camp's commitment to offering fun and growth-producing experiences was a good match for our families' need to experience the same. From that experience, I knew that children thrived in the Double "H" camp setting and felt confident their families would too.

In fact, many of the children who attended the HIV session became part of our family-camping cohort. Max Yurenda,

the director, and his staff were supportive of the idea of developing a family camping experience and we began to plan. From the onset, parents were an integral part of the planning team. We worked to build a sense of community with all of us contributing to the success of the weekend. Affirming the positive aspects of living with HIV was an underlying premise of the weekend as shared in the *Family Camping Newsletter* by LaSharon Haskins, a local activist and member of the planning committee.

As a woman living with HIV, it never ceases to amaze me how very rich my life continues to be with opportunities for life-giving experiences. When I received that positive test result eight and a half years ago I thought, "Oh my God. I'm gonna die." Had I known then what I know now, I would have said, "I've been dead for all these years. Now it's time to live." I'm not saying by any means that I'm glad I've got HIV. I hate this virus and the way it is devastating our race, the human race. What I am saying is that for me HIV has proven to be the perfect opportunity to learn to love and to appreciate life. A day at a time I'm learning to reach within and find God, to reach out and touch somebody's hand and to look up and kiss the sky. Especially in the face of HIV, it is important that I know and believe that I am a wonderful, beautiful and lovable child of God and sister to each and every one of you. Where there is life, there is ALWAYS hope. Where there is hope, there is ALWAYS love. Where there is love, there is ALWAYS God. Love somebody. Start with you...

For more than a year we worked to develop Family Unity and raise the funds needed to pilot the family camping experience. The original weekend was delayed for one year due to insurance problems. Additionally, a number of funding sources, who previously supported services for children, were not interested in supporting a family camping experience. Many were afraid that they would not be healthy enough to come the year later, or worse yet, maybe they would

not be alive in a year. Many times the dream seemed to be slipping away. Finally, Family Unity became a reality Labor Day Weekend 1997.

Imagine moms, dads and children emerging from a coach after a long, tiresome five-hour trip across upstate New York on a holiday weekend. From that moment until Sunday when everyone clamored back on the bus, there was a sense of community. For once, family members could share their experience of living with HIV without worrying whether they would be judged by the person across from them. Family members and staff alike joined together to create positive memories.

Lucinda*, mother of 5, climbed aboard a horse for the trail ride, fulfilling a lifelong dream to ride a horse. She had so much fun that she went on another trail ride in the afternoon. As she urged her horse forward, she said with a laugh, *"Who would have thought this Latina would be riding a horse?"* The Martinez family built a wind chime together for their back porch. All family members helped with meals, the teens taking care of the Saturday evening barbecue.

As the afternoon sunlight filtered through the trees, we sat on the porch overlooking Lake Vanare making life masks, plaster of Paris impressions of each person's face. From our perch, we could see the Double "H" pine tree which is two trees grown together in the form of an H. Ironically, the two trees grew together before the camp was founded. To anyone who knows Double "H", this tree is just part of the magic of Double "H". Today, one tree lives while its counterpart is dead. Double "H" stands for health and happiness which the joined trees embody. As folks were making life masks, we talked about the meaning of the trees. A grandmother shared, "That tree is like life, it's the mix of living while remembering those who have passed before us." We reminisced about Sandy, a founding member of our group.

Remember how Sandy insisted the group start in June and not wait until the fall? She said we didn't have time to wait until the fall. She's with us today, I can feel her.

While making the life masks, each person thought carefully about how to pose. Some smiled, others struck a more somber pose. One father closed his eyes creating a mask that appeared lifeless. His countenance was eerie, cold and death-like. I resisted my urge to coax him to lighten up; it was his mask, not mine. As I continued to build his mask, I asked him what it felt like to have his eyes totally covered. He described a sense of calm and being at peace. All five of the Jones family made masks. They compared their masks, noting how similar their noses were and how strong a nose they shared. They planned to put the masks all together in the family room, a memento of their time together as a family As each mask was peeled from the individual's face, a picture was taken of the mask beside the person's face, creating a vivid contrast of a living with a lifeless image.

Beth had come to camp with her 9-year-old daughter, Samantha, and her mother, Ann, who had flown in from the west coast. On the second day, Beth and Ann asked me to join them for a coffee and to talk. Based upon observing their interactions, I assumed they wanted to talk about how much fun they were having at camp. Both women had been highly involved in the camp activities since their arrival and were clearly enjoying themselves and the others. So I was taken by surprise when, in a halting voice, Ann shared:

We're glad we're here. I've learned so much from Beth. Before this trip, I thought I had to support her and as it turns out, she's teaching me how to live in the face of death. I was just diagnosed with end stage cancer.

Silence and tears followed for all three of us. Beth's guardianship plan to have Ann care for her daughter was called into question by Ann's cancer diagnosis. Both women wanted Samantha's future to be stable, yet the reality was that it was uncertain. As I collected myself, I asked them to share what Ann's diagnosis meant to them. In essence it meant that all life is fragile and none of us has a guarantee on the future. I felt pressure to make things okay, to

* All campers names were changed to protect individual's identities.

help find a solution. I resisted my urge to speak up immediately, to try to make it all right, because no one can make this situation all right. The painful reality is that Samantha will probably lose both her mother and her grandmother during her childhood. I felt powerless. As I reached for their hands I said "How painful." They nodded and both shared their sense of vulnerability and concern for Samantha's future. Beth asked me to look out for Samantha; I reassured her that I would.

In the evening, the boat ceremony embodied hope and healing. Throughout the day, natural materials were collected to make a boat; nothing artificial could be used. So, campers had to figure out how to build the boats without using string, nails or other manufactured materials. Once the boat was complete, builders wrote a wish or a fear on a piece of birch bark which was sent into the lake via the boat. After the sun set, the camp song was sung:

Campers we adore you
Place in our hearts for you
How we love you

The boats were launched from the peninsula. As the current carried them out into the lake, people hugged and watched the boats drift away. Van, 12 years old, was hanging back from the group, observing all that was happening. Two weeks earlier, during the session for children living with HIV, Van had been in the front with tears streaming down his face as he remembered his mother who passed away last year. I had known his mother, so, as he cried, I rubbed his back and shared memories about her. Specifically, I shared her remembrances of Van as a child and how much she loved him. As his crying slowed, one of his favorite counselors invited him back into his group. This time as he stood in the background with his arms tightly wrapped around himself he looked fretful again. I approached him and asked what was up. Van said, "I'm standing here, checking it out so that I won't cry." I sensed he was remembering what had happened at the last campfire and was ready to comment on that intense experience. Instead, I decided to support his holding it together and encouraged him to rejoin us when he was ready. A few minutes later he snuggled next to his adoptive mother. Later he was surrounded by his second family, his sister, their adoptive family of five, and a foster brother. Van felt his Mom's presence and remembered her while surrounded by the love of his second family and everyone there.

Like the boats drifting into the depths of the lake, we found ourselves drifting toward the bonfire, talking about the meaning of the boats' journey to each of us. Slowly we began to sing, "This Little Light of Mine," "I'm Gonna Make It Shine," "Amazing Grace," and others. The youngest children nodded off in their parents' arms or were cuddled by members of the staff whom they hadn't known 24 hours earlier. As the fire began to fade, most of us headed to the cabins. The teens stayed behind for cabin chat—a chance to talk about how HIV affects them or anything on their minds. Haltingly Lamar began to share

"I don't know where I belong any more...it's real hard. All year I lived with grandma in Rochester. On Wednesday she said she couldn't keep me any more and put me on the bus to Syracuse. Friday mom brings me here."

And this six foot-two, fifteen year old began to cry. The counselors and I were taken aback. Lamar suddenly was vulnerable, a striking contrast to the day before when he had intimidated staff based on his physical build and streetwise attitude. Now, he needed solace and comfort. Yet, he was right. He truly didn't belong anywhere and it would not help to falsely reassure him that he did. Instead I focused on what he does for himself and who has helped him get through the tough times of the past year.

Old familial conflicts bubbled to the surface as one divorced couple adjusted to being close together and having to share their son with each other. From the start I had difficulty dealing with the father. As the families got off the bus, the bus driver demanded to speak with me about his problems with Jack. Jack had missed the bus and chased it 60 miles on the Thruway to get on. The driver felt this was dangerous and wanted me to take care of it. Immediately Jack faulted me for not being clear with him about

the time of departure. I felt defensive as I struggled to listen. He also was physically intimidating and was using that intimidating presence purposefully in this situation.

Within an hour, a heated exchange broke out with his ex-wife, Ellen. I stayed at a distance, hoping they'd resolve their issues. As they yelled at each other, their son, Nick, tried to distract them as everyone else became visibly uncomfortable with the argument. I felt I had to intervene and was met with hostility again. Jack made it very clear that no woman director was going to tell him what to do. I felt threatened and tried to diffuse the situation. Neither parent was interested in listening to the other, or to me for that matter. So, mediation was out of the question. We were at an impasse, and I encouraged them to center themselves on the purpose of the weekend, to give their son a family weekend. I debriefed the incident with my administrative staff and shared my concern that the family would not make it through the weekend. We explored the ways to handle it and agreed that future conflict had to be addressed quickly and clearly. We developed a plan that the executive director and I would meet with them jointly. I felt it was important to have a male co-facilitate this with me. We ended the debriefing with the hope that this plan would not be needed.

Less than two hours later, another screaming match erupted in the dining room. When I asked them to leave the dining room and come meet with Max and me, they initially refused and continued fighting. I insisted that we had to meet or they had to leave. Jack accused me of forcing him to meet with us, while Ellen asked me to send Jack home, allowing her to stay with Nick. I refused her request and I reframed the situation by saying they had a choice to meet with us and agree to some ground rules or they would be choosing as a family to leave. Both accused me of ruining their weekend with their son. Max and I repeatedly put the choice back to them while stating that we had to run the camp and ensure the experience was good for all the families. A moment of comic relief came when Jack claimed that I had created all of their problems by delving into their business, and that they could get along very well without me interfering. Max picked up on this and said we were there to help them get along. We reviewed our administrative decision that the ongoing fights were not acceptable, and that all of the family would be asked to leave if the conflict continued. Jack and Ellen left our meeting, stating that we were unreasonable. We asked them to think it over. Shortly, they returned saying they were ready to give their son a special weekend. As we debriefed, we were unsure whether the weekend would work for them. Max and I made a point of reaching out to both parents and talking to each of them at various activities, focusing on how Nick was enjoying himself. Fortunately, both parents were able to put a hold on their discord and gave Nick a memorable weekend. Watching Nick fall asleep in his father's arms, while his mother sat next to them rubbing his back as the campers were singing, created a visual image of the weekend's meaning by symbolizing the ability to work through conflict and connect in a meaningful way. The next morning, this family wrote the following about the weekend experience:

You gave us-
Unity instead of isolation
Hope instead of desperation,
And above all love!

On Sunday morning, some of us participated in a reflection service. As Zach's beautiful guitar melody filled the chapel, we were invited to share what the weekend meant. Near the end, Kathy rose and brought her three-year-old son, BJ, to the front to share:

"I found out my diagnosis when BJ was born. I'm here today because of him. I'm not yet the woman I want to be, but I've come a long way since then."

As she spoke, Alice, also living with HIV, stood behind her rubbing her back. As Kathy cried, Alice gently picked up BJ and hugged him while other parents hugged Kathy and her older daughter.

Twenty minutes before the bus was scheduled to depart for home, the fragility of life for everyone living with HIV/AIDS was underscored when a mom's heart rate became erratic and she appeared to be in congestive heart failure. Nyla hadn't had any of her cardiac medications since Friday afternoon when her prescription ran out. Medicaid doesn't allow patients to fill prescriptions in advance. From her perspective, the choice was go to camp without medications for the weekend or stay home from camp. As we sat in the infirmary, Paul's Body Shop, deliberating whether she needed to be sent to the hospital or was able to return to Rochester, the stark reality of living with HIV hit all of us again. Medically, she needed to go to the local hospital. The nurse practitioner was adamant that Nyla be taken to the hospital and initially refused to even consider Nyla's wishes. Emotionally, Nyla needed to take her four sons home to Rochester and get them settled in before attending to her medical needs; she said, "Sue, I need to go home, my boys need me, I'll be okay." Her choice was clear, the boys needed to go home. I felt torn between her medical and emotional needs and equally torn between Nyla and the nurse. Both had legitimate concerns. I chose to support Nyla's decision and worked with the nurse to explore her discomfort. Both of us worried about the fragility of Nyla's medical status, yet as mothers ourselves, her need to care for her boys resonated with us. Slowly, Nyla climbed onto the bus and headed to the back seat to lie down. Nyla assured us all that she would be okay, an assurance that provided little comfort because we knew she couldn't control the congestive heart failure. While we were deliberating, her sons and some of the other parents had packed up all of her belongings. Bob, the driver, calmly said he would call 911 if Nyla became sicker on the return trip.

As the remaining families loaded the bus, I hugged a dad and said, " I hope you'll join us next year." To which he replied, "I hope I am here next year to be here at Double 'H'." It took me a second to grasp his meaning as we nodded to each other and hugged good-bye.

Later driving down the darkened Thruway with my daughter sleeping next to me, I anxiously awaited reaching the perimeter of Rochester where I could call Nyla on the cellular phone. As I started to press the send button, I hesitated, wondering who, if anyone, would

answer the phone. When Nyla answered, I realized that I was holding my breath. We were lucky this time.

Reflections

Of all the HIV/AIDS clinical work I have provided since 1986, this is the most meaningful. The words in this essay fail to adequately capture the spirit of Family Unity Weekend but hopefully offer a window to the reality of living with HIV and the challenges and rewards for those of us who work with HIV-affected families. The intensity of the work is invigorating. Reflecting upon this description of Family Unity weekend, I am challenged to analyze why this moment of respite from the harsh reality of living with HIV was so meaningful professionally.

As a social work educator, I have committed myself to preparing both graduate and undergraduate students to provide quality services for those living with or affected by HIV. Despite my best efforts in the classroom, over the years many students candidly shared that while being very interested in HIV/AIDS, they were uncomfortable with the prospect of working with these individuals and families. The camping experience offered a chance for me to work with students from the planning phase to the camping experience to the evaluation. In other words, we could transform our discussions of providing strengths-oriented family-centered services into an experiential learning opportunity. I felt challenged to connect my students with the families, some of whom I had worked with since 1990. My hope was that the weekend would create a positive experience for all involved.

Two years ago, when an HIV mother and I discussed the possibility of a camping experience, I naively thought, *What a great idea, shouldn't be hard to do.*

In retrospect, I am glad I was such an optimist; it helped me stay the course through the various challenges those next two years brought us in making this dream a reality. Equally as a researcher, I had learned from families how we were not serving them well. I looked forward to spending the weekend and learning more about the families' concerns to better inform my work.

The difficulty of securing funding was harder than anticipated. As the student members of the Planning Committee sought funds, many HIV-supportive funding sources simply did not reply to our requests. Whereas funding a bus for kids to go to camp was appealing to funders, many balked at the idea—including parents. One source queried, "Why include parents? We like funding the kids, we're not interested in the parents." Understandably, the students were upset by the lack of positive response. Confronting colleagues' anti-parent bias is disquieting, but this created a rich learning opportunity for students. We explored how parents have been negatively portrayed as uncaring, unloving vectors of HIV disease who transmit the illness to their children. Since beginning this work in 1986, I have yet to meet a mother or father who willingly gave this disease to their beloved child. Parents need and deserve support as they cope with the realities of living with HIV.

The students had to problem solve how to present parents positively to funders and found that sharing the stories of parents was an effective approach. While continuing to pursue the necessary funding, we examined how their experiences mirrored those of the families and developed strategies to address the persistent stigma surrounding HIV/AIDS in the community. The stigma of HIV affects social workers working in the field in a parallel process. Frequently, the worker is stigmatized too. Colleagues queried, "How could you do that work? I am too sensitive." As if HIV/AIDS social workers are not. By acknowledging this and supporting each other's efforts, we were able to move forward.

Recruiting volunteer staff highlighted another reality of HIV care—compassion fatigue. Many HIV frontline staffers were simply too tired to volunteer a holiday weekend. Initially, some said yes, only to drop out when the logistics became too demanding, resulting in increased demands for the core volunteer staff. The long hours in preparation, not to mention the weekend itself, gave each of the core team a moment's pause. Yet, they were satisfied by contributing to the success of the weekend. Collectively we were able to help the families and supported the front-line providers. As the population of infected and affected has grown, supporting staff confronted by the challenges of working with people who have a life-threatening disease is becoming increasingly important. This experience is a first step. More needs to be done to renew frontline staff and enable them to continue to provide quality services.

Equally, efforts to involve students and social workers who were not frontliners brought up a sense of personal/professional inadequacy as illustrated by, "I'm not trained enough to do HIV/AIDS work." Social workers need to feel more comfortable responding to the unexpected and unknown. As educators, we need to prepare our students more effectively to address uncertain situations, in large part by reassuring them that they have the requisite skills and to seek consultation as needed. Again, the family camping experience gave them an opportunity to experience this directly in a supportive environment. I met with staff throughout the weekend, and we debriefed the session at the conclusion of the weekend.

This sense of inadequacy was echoed by some of the camp volunteers during the debriefing session. Staff had completed written evaluations and were invited to share their perspective regarding the highs and the lows of the weekend in the group meeting. I set an example by sharing how hard certain moments were for me and by inviting them to help me think how I could have handled it differently. One queried, "Why didn't you tell us the about the kids' (especially the adolescents) histories? They have so

many issues and anger, I didn't feel prepared." I shared that I had elected to not disclose specific aspects of their histories because the written descriptions of some of the campers were so negative that a strengths-oriented perspective would be all but impossible and probably would have kept some of the volunteers from coming. I noted that throughout the weekend, all volunteers had access to consultation services from seasoned HIV staff who helped clarify the issues raised by posing questions such as: Where is the strengths-based approach that we talk about in social work? These adolescents have every right to be angry about the intrusion of HIV into their lives. How would any of us respond to losing one or more members of our family? We focused on how to help them channel that energy in a way that helps them cope more effectively. I was energized by the creativity of the staff. Bearing witness to a person confronting his/her mortality creates anxiety and all too often people turn inward toward their own issues instead of being present for the individual who is struggling with an uncertain future. Our ongoing consultation and debriefing helped us stay present with the families.

I am known for challenging my students to dare to "flub" or experience failure. I firmly believe that some of the best learning happens when we "flub"; yet, I caught myself being afraid to do just that. As I intervened with the divorced couple described earlier, I found myself trying to "settle" their conflict with the hopes of getting the experience back on track for them and the rest of the camp community. As I reflected on my work, I realized they needed to resolve the issue between them and I had to relinquish my perceived control for this to happen. So, during our follow up meeting, I shared with the staff that I had flubbed and we reworked the issue. Admitting a mistake is easier to say than to do. A few of the students were surprised that I shared my mistake with them. We explored different ways the situation could have been handled and speculated about the effectiveness of each.

The potential for human growth is promising when a person feels supported in making changes. I have learned that the reality of HIV may give the gift of reassessing your life and making needed changes in order to make the best of what you have in the face of uncertainty. This conflicts with my MSW training which emphasized the negative consequences of life-threatening illness, the relative inability to change characterological traits, and focused on problems instead of strengths. In all honesty, a significant portion of my professional training would lead me to focus on what the family *could not* do versus acknowledging the changes the family members have made and the resulting growth. It is easy to lose sight of the saying, "Each person is doing the best that s/he can at that moment in time." I have learned to think "outside of the box" and to be willing to approach novel situations with an open mind.

HIV work causes each of us to confront mortality, our clients' and our own. At 43, I have attended far more funerals than I would have if I were not working in HIV/AIDS. For each person who passes, their families, partners, friends, communities, and caregivers are left to incorporate each life and each loss. So many left behind cope in silence with little opportunity to acknowledge the impact of this loss on their lives. I have worked hard to note and honor those losses by the use of rituals and ways of honoring those who have died. At the School, we have a graduation award, named for a student who died of AIDS-related complications. This award is given to a student who excels in either substance abuse or HIV/AIDS work. One of the students from Family Unity will receive this award this year in recognition of the contributions he made to Family Unity.

The reflection service the last morning of camp gave us a chance to remember, to honor, and to renew our commitments to those who have passed, and to help their survivors. The reflection service uncovered the raw pain inherent in lives lost

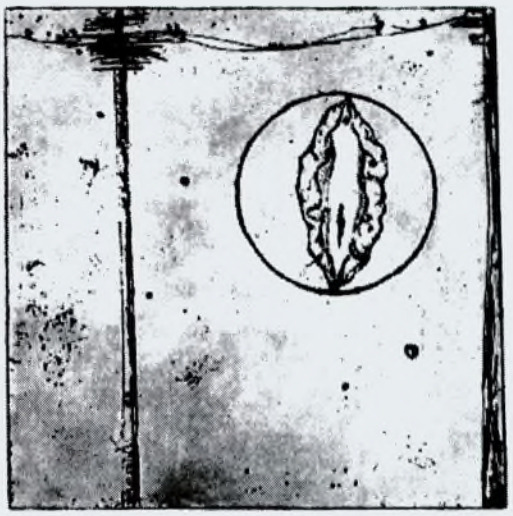
too early. The pain is immense but the sense of community and caring in the chapel helped to buffer that. Many parents turn to us to be sure that their children are cared for in the future; we must honor this. Increasing the bonds among HIV-affected families is one way to help with this by creating a caring community. Watching people embrace each other as memories and dreams were shared was renewing.

We have made a difference in each other's lives. My life has been enriched immeasurably by the opportunity to work with families. On a personal level, I see the benefits for my children who are involved in Family Unity; their belief in a caring community is refreshing and gives hope that our future will be brighter.

While I resist being characterized as an "old timer" in the HIV/AIDS field, I am. Few of us who have been doing HIV/AIDS work for more than a decade remain in the field. This experience gave me an opportunity to reflect on my contributions to the field and to critically assess what contribution I can make as we approach the year 2000.

Shortly before the weekend, I sensed that this would be a turning point, that perhaps I had done all that I could in HIV. I believe that it is important to question where you have been and where you hope to go in the future. HIV/AIDS work is demanding and challenging. At times the conflicts inherent in HIV work and the ongoing challenge of coping with multiple losses has called into question my ability to be effective. AIDS work is a transforming experience in that it permanently alters your world view by simultaneously highlighting the best and the worst aspects of our society. Certainly my role has changed and is evolving in new ways. Family Unity was more than any of us had hoped for; it was an opportunity for growth and connection for all who participated. For me, this experience renewed my sense of optimism and I look forward to Family Unity II this summer.

The gift of HIV/AIDS is that it makes you live in the moment and capture as much life as you can. This is a lesson that all of us should heed. □



A Narrative Interview with Ann Hartman Part Three: Keeping the Social in Social Work

Ann Hartman has been a leader in the social work profession through her practice, administration, scholarship and service to the profession. In this third part of a narrative interview she recalls her tenure as Dean of Smith College School for Social Work, her work as Editor-in-Chief of Social Work, *and her many speaking engagements throughout the country. She describes her teaching and writing projects during her "retirement." She reflects back over her rich and distinguished career and looks ahead to challenges facing the profession.*

by
Joshua Miller, Ph.D.

Joshua Miller,Ph.D., Associate Professor and Chair of the Social Policy Sequence, School for Social Work, Smith College.

Introduction

This final interview with Ann Hartman covers her tenure at Smith College School for Social Work as Dean (from 1986 to 1994), her retirement, and her reflections on her career. Ann also served as Editor-in-Chief of *Social Work* from 1989 to 1994, and in this interview comments on the paradigmatic shifts that occurred during her editorship. During this period Ann also did a great deal of speaking across the country at agencies and at state NASW conferences. She also organized an annual meeting for women deans and directors of social work programs.

Ann describes her teaching and scholarship during her "retirement" as well as her philosophy about letting go and moving on. She reflects back on what has been most meaningful in her career, her many sources of pleasure, and her one regret. She offers some thoughts about managed care, private practice, power and egalitarianism, and future challenges for the social work profession. Ann shares an anecdote about her relationship with Harry Specht that exemplifies her humor, grace, tolerance, and integrity. □

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The Interview

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Joshua Miller: What led you to leave Michigan and go to Smith?

Ann Hartman: Michigan was fine. I didn't leave Michigan because I wanted to leave Michigan. In fact, I found it very hard to leave Michigan and The Ann Arbor Center for the Family. But we really wanted to move back East where we had so many friends.

J: So was it people?

A: People and geography and we just began to think that we would like to move back. I had some inquiries from various schools and then I received a letter from Smith inviting me to apply. Joan [Laird] was on sabbatical and down in Florida writing. We talked back and forth over the phone and it really was not good because we only had these phone conversations while all this was going on. In a funny way, I got swept up into it and it got out of hand

J: Momentum?

A: Momentum. Partly because of the way that they did it – three members of the search committee came to Ann Arbor.

J: Was that unusual?

A: I thought it was pretty unusual. Mary Dunn [the President of Smith College] felt this was an important thing to do. It's a good idea. They sure found out everything about me and they knew exactly what they were getting before I came. They walked around the University of Michigan and talked to people and met with the staff at The Ann Arbor Center for the Family.

J: Did you have to give a release before they could talk to people?

A: No, I knew they were going to and they told me they wanted to do it and I said "o.k.," but what it did was make the whole business public. So I had to tell all of my clients that I was thinking about this and of course everyone at Michigan knew. It almost became *a fait accompli* before I had decided what I wanted to do.

J: You start to look into something and then it is somewhat out of control.

A: I could have said no at any time, but it wouldn't be easy. If Joan had been home we would have talked more about it and we might have realized this move really wasn't good for her: One she was working on her doctorate; two there wasn't anything in Northampton for her in terms of jobs. I am sure that my affection for Smith and my long intergenerational connection with the School was very important in making this decision. Also, it was very advantageous financially—I didn't have that many more years to work and it made an enormous difference in terms of my retirement.

J: Did you actively want to become Dean?

A: No, never. Schools, including Columbia, pursued me. The only reason that I considered this was that it was a small school and in the winter you do other kinds of work. I never wanted to administer a great big place. Smith turned out to be a great big place in terms of the administrative demands, but I wasn't aware of that.

J: Was there something you wanted to avoid or were concerned you would lose by becoming a Dean?

A: Full-time administration was not what I wanted to do. When I came to Smith it was pretty exciting because a lot of people, such as some alumni, were very unhappy about me coming.

J: How did you become aware of this?

A: There were rumblings. I think underneath they thought that I was going to change the School away from being psychodynamic. A close friend of mine was one of the leaders of the fight. We had been good friends but she became very antime and published a letter in the Clinical Society's magazine or newsletter about all I was doing to Smith and I how I was changing the bibliographies.

J: This is when you had already arrived?

A: Yes, I had been there a couple of years. I thought, "can you imagine not changing the bibliographies since 1954?" They knew exactly who I was when they hired me. Everything I thought I had published. A second thing was I had absolutely no desire to undermine their perspective, but I did have a very strong need to put the social back into social work. I told them that—that I was a social worker and I thought the school for social work should not be a training institute for psychotherapy and that I felt the social content was extremely important and that was what I was invested in.

J: You said this when you were being interviewed?

A: Yes, absolutely. And that our historic strength was person-in-situation, people in their environment, and that we simply had to maintain that or we didn't offer anything special as a profession. I had a lot of conviction about that. Some people were afraid that I was going to turn it into a family therapy training institute or something. I simply hoped to strengthen the family and have that as one of the options available to students. But that wasn't my primary goal. I don't believe you can do that to institutions. Institutions aren't like that. Anybody who tries to decide to unilaterally change an institution is going to be in deep trouble. Institutions have a life of their own, and an old venerable, people institution like Smith has a life of its own and any change process is slow and is going to have to involve a lot of people. I think there were a lot of changes made while I was at Smith but they were slow and hard to come by.

J: What was it like being a Dean?

A: I had a good time. I loved the summers—the students and all of the adjunct faculty coming in, the seminars—the whole business.

J: You liked having the students around?

A: Oh, yes. I would have never come to Smith to teach because there was not enough student contact. I never would have been satisfied with it. A few people continued to be very upset but most people in the community, agencies and alumni, were reassured and by the time we had the 75th anniversary celebration things were going very well. We were in very good shape financially and had very high applications. When I think about contributions that I made that I feel good about, one was the whole issue around race. My first year at Smith there were maybe four or five students of color on campus. There was one African American person in the first-year class. I was desperate when I saw that because you cannot have a white school of social work. You can't teach social work in this world in that context.

J: So Michigan was not like that?

A: No. One of the most exciting things that we did at Smith, I think it was my second summer, was invite all of the graduates of color back to campus. I guess because I am a family therapist I thought that for an intervention you bring everybody together, everybody in the family. Harlene Anderson and Harry Golooshian would say everybody who is in conversation about the problem. Well, the people that would be in concerned conversation about this problem would be all of our alums of color, plus all of our faculty. So they came in and it was a watershed. You can't imagine how powerful it was. Sixty-five people, over half, came from all over the country. We brought them to ask for their help and we talked about curriculum and we talked about recruitment. They spent a lot of time with our faculty of color. Without any white faculty they could really talk. It was very intense for them. I don't know the details of the meetings that I didn't go to but I learned from talking to people individu-

ally that people who attended at different periods or from different walks of life had very different experiences at Smith. Some were feeling that they were very privileged and grateful while others felt very resentful about the way they were treated at Smith. I can't remember all the figures but in a couple years we had forty students of color at Smith. Jerry Sachs, new on the faculty, headed admissions and helped tremendously with the recruitment.

I think the other thing I did that had a major impact on the School was strengthening of social content in the curriculum. The racism and socio-cultural concepts courses had all the students in one large lecture section. What it communicated was that this material was less important. I changed both of these courses to small sections, eventually with a bi-racial teaching team in each section of racism. The other thing was that what little social theory there was, was in social policy. So I moved this content over to HBSE and we developed courses and increased the number of requirements.

J: So you had to restructure, change requirements, and actually change the curriculum.

A: Yes. Of course the reaccreditation process was enormously helpful. There was a rumor out on the grapevine that I was using accreditation to change the curriculum and they were absolutely right. Because that is one advantage of the accreditation process—is that it really makes you look at all of these things. The faculty had never been involved in reaccreditation before; previously they had brought in an outside person who wrote the reaccreditation.

J: So you devised a process that brought the faculty in?

A: Absolutely. There was no question about it. We worked hard and had huge committees of students, alums, and field people—everybody was involved. And they knew they had to do it. Joan Laird had taken her previous school through three reaccreditations so she knew the process, knew how to go about this, and I had done the Michigan report. Columbia, BU, a whole bunch of schools were being reaccredited the same year and were put on probation. We came through with a glowing report—not one criticism. We had a tough reaccreditation team and I wanted a tough one, people that would be so respected by the commission that the commission would not challenge their work.

J: It sounds like one of the themes that you kept stressing throughout was ownership at all levels.

A: At all levels and another thing that I was determined to do was rotate the chairs. The custom had developed that chairships belonged to a person for perpetuity and I thought that chairs should rotate and it was in the faculty code that they rotate. I felt it was essential that everybody had an opportunity to occupy some of these positions, but also that people should not be burdened forever with all the administrative work so they could do other things. That was really the biggest battle that I had with the faculty. It took the whole time I was there, but by the time I left everybody had begun to rotate.

J: So these were your major priorities.

A: Another was to develop a closer relationship between the College and the School. I was very active with the College.

J: Why did you feel that it was important to do?

A: I think being the poor stepchild that isn't even invited to the table is not a good place to be in an institution. However, getting too close is risky because if you aren't very careful you give up autonomy. Mary Dunn and I worked very closely together and she used me a great deal in relation to the college. I found that fabulous—one of the things that I enjoyed the most was learning all about how a college runs and being a part of that. It was fascinating and a very close-working group of colleagues. It really was wonderful because otherwise a Dean would be very much alone.

J: It sounds like you systematically dealt with the composition of the student body and the faculty and the staff ; you dealt with the mission, goals, nature of the courses, what was in the courses; looked at the whole administrative structure, who was running it. Did you know that this is what you would end up working on from the beginning?

A: It was doing the job. I didn't have any idea of what I was really walking into. I just had a memory of 35 years ago when I had been a student.

J: How long did it take you to realize what you needed to do?

A: I recognized the situation about the composition of the student body right away. Almost as soon as I walked in and looked around. And then I think you just go slowly, take one thing at a time as it comes. I didn't have some grand plan at all.

J: Did it ever coalesce as a kind of grand vision after you had been there for a few years?

A: No, I don't think I had any grand vision. I work close to the ground, developmentally. My only grand vision was to get the social back into social work, that was my grand vision. And that included more varied agencies available for our student placements. One of the things that some of the alums were upset about was when they heard we had placed a student in a settlement house. They were so upset because "how can students learn treatment in a settlement house?"

There was another thing that I wanted to do. Smith had always been located in Northampton but it wasn't very connected with its local community. I think there was one student placed at Austin Riggs and that was it. People were worried that Smith was too psychodynamic, or whatever, to bother with Ware, Greenfield, and Athol. So that was one of my top agendas, to get connected with our local community. It was good for the College and for the School. The College was delighted to get these connections because the College is always looked to to do community service and we were the obvious people to be doing it. I also had one dream that partially came to fruition and that was bringing in students from Alaska, hopefully Native Alaskans or people working with Native Alaskans, and Native Americans from Albuquerque [where we also opened placements].

J: It sounds as if your wanting the College and the School to be connected to the community was similar to you wanting the School to become connected to the College so the School would be grounded as an institution. What were the things that you found most difficult about being a Dean?

A: I suppose dealing with some of the faculty. I think most of the Deans I know would say the same thing. There were a few people on the faculty that were very unhappy with me and wanted to undermine me. It was foolish on their part because it wasn't going to happen, not as long as Mary Dunn and the trustees were solidly behind me. It caused some pain and made it quite miserable between them and me. But it wasn't as stressful as it could have been because I knew I wasn't going to lose my job, and I didn't care if I did lose my job. I was eligible for Social Security by then. I sometimes think you shouldn't take one of these jobs unless you don't need it. You are absolutely free—there is nothing that anybody can do.

J: Were there things that you wanted to do that you found you couldn't do?

A: Sure, and everything was slower, everything was harder than I wish it could have been, but I'm sure that is always the case.

J: Have you ever run into anything like this in your previous jobs?

A: No—I administered the agency in Long Island as long as I ran Smith, exactly the same number of years [8] and that was a comparative breeze. I think academic situations are fraught with difficulty structurally in terms of peer review, tenure, and competition. I think that all these things structure in painful political realities

that are very destructive to relationships. I also don't think that Smith is a good place for faculty. It is a wonderful place for students but I think the block plan is very hard on faculty. You have this intense period of hard work, when the whole world is on vacation, and then this long winter without students but lots of administrative work. The faculty sort of turned in on itself in a way. That is one reason I put a whole lot of money into faculty travel budgets. Now let me say another thing. I did take advantage of the Smith system by doing a lot of interesting things in the winter. I worked all the time—day and night—but not just on Smith. I didn't find that it was a job that would occupy me all day, every night, every weekend, except in the summer. During this period I was secretary of NASW, then I was head of publications at NASW, and then I was editor of *Social Work* for 4 1/2 years during my tenure at Smith, which was very exciting. I loved it.

J: What did you love about it?

A: Being editor of *Social Work* is such a privilege, to be able to address the profession every two months, to write editorials, say what you think and get it into 160,000 homes. I liked working with the staff at NASW and I liked working with the writers. It was a wonderful job but it meant I read 400-450 articles a year.

J: Did you read all the articles that were submitted?

A: I read an awful lot of them—everything that was accepted. But I also read an awful lot of stuff that was rejected because I was changing the direction of the journal and a lot of stuff that I would want to publish would be rejected.

J: So what direction were you trying to change to?

A: The journal was not supportive of qualitative research. They would not publish case materials. They were really modeling themselves after a hard science journal. I felt that was not the way a social work journal ought to be, so early on I wrote an editorial called "Many ways of knowing," which really encouraged people to send in different kinds of materials. But I had an editorial board that had been appointed during the previous philosophy, so they would reject things in line with the previous policies. Not that they were not honest and thoughtful, but they had a different paradigm and I wouldn't have gotten to publish the kind of thing I wanted to publish. So I had to read the rejections. And then I had to read all of the reviewers' comments.

J: That's a phenomenal amount of things to have to read each year.

A It was enormous but was enjoyable. I wouldn't read every word carefully, but I knew what was in them all. I was driving the staff crazy because I was always behind and then I had to write these editorials. That was an enormous job. I would decide every two months what the topic was going to be and then read in that area, study, and prepare to write. I certainly wasn't an expert on all of the topics I chose.

J: So every time you wrote an essay or editorial you had to do research for it?

A: Sure, there were such a range of topics, often not about social work and not necessarily in my field. I don't think I wrote more than one or two things about an area in which I have expertise. I wrote one on the definition of family after Dan Quayle's Murphy Brown speech.

J: Was this your main writing during that period of time?

A: Yes, it certainly was. I did a lot of writing in social policy, such as a big chapter in Froma Walsh's *Normal Family Processes on Family Policy*. But I think that was probably the main piece of work I did aside from all the writing for NASW.

J: Were you still doing conferences and workshops?

A: Yes a lot. I think I've done a keynote or a conference presentation in almost every state for NASW state conferences.

J: Do you to put a lot of time and effort in preparing for these or is there a kind of template that you use?

A: No, I don't have a template but I do it fairly easily. I will have a speech that I'm working on, like a keynote, and I'll put a day in and the time on the plane and then I will always write things on 5x8 cards, and I'll rethink and change it, add more, subtract something. I never did the same thing twice.

J: Do you find that when you are giving a talk that you do like to have a very careful outline as opposed to speaking off the cuff?

A: Oh, I never speak off the cuff, but I also never read. I have very detailed notes on cards. I loved going around the country. I had lunch and dinner with people and would hear what was going on around the country. I used to do something once or twice a month.

J: So you really must know people from all over the country.

A: The thing I feel so badly about is that I didn't keep a journal. I did so much traveling that I would lose track of people and forget where I'd met them. It began to all go together. You know, if its Tuesday, it must be Belgium.

The other extra-curricular activity that I did that I got a big kick out of was starting a summer camp for women deans.

J: You held this at Smith?

A: We held it at Smith and all the women deans were invited to come.

J: What led you to do that?

A: The National Association of Deans and Directors held meetings twice a year but women were so silenced in those days. I felt we all needed networking and support. We had between 20 and 25 women deans come to summer camp.

J: What were those get-togethers like?

A: They were great. We had no agenda, no plan whatsoever. We developed our agenda out of the group collaboratively at the first meeting. We did it the way women do things. I would have loved to have done that at Smith and very idealistically tried, but it doesn't work. But in this situation it worked. There was no competition; we were just there to help each other. And we would meet the first night when they came in and plan what we were going to do, what we were going to talk about for that next two days. And of course we stayed in the dorms and had a great time together. And we built a meaningful network. We would call each other up—a lot of the women were having very painful times, being challenged. It's very tough for women in positions of authority.

J: What were some of the types of things that came up?

A: Oh, the same kind of things I was going through, and worse. People who had the paint on their cars keyed and nasty telephone calls. I mean I never had anything like that. Really nasty stuff.

J: Was the network of connections the most important outcome of this

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A: Yes, it was the network. It wasn't ideas or initiatives, it was the network and helping each other resolve problems. People would present a problem they were having and we would all share ideas and think about it together.

J: Was it difficult for you when you set up things if they weren't continued?

A: No. When I left Smith, I said I am not going to sit here and agitate about what's going to happen to "my Smith." It's not my Smith anymore. My Smith was for eight years and what happened during those eight years. I graduated probably close to 1,000 students who had a different kind of experience for those years. I could also carry on about is social work looking like I want it to look like. You don't do that. You do what you do and then you say, "that was my turn

and now it's somebody else's turn and I am not going to worry – sufficient unto the day was the contribution thereof."

J: That sounds like a very good philosophy.

A: And I have been able to hang on to it. I've left a lot of things I have built. I built that clinic in Long Island and left it after eight years and just walked out, said "goodbye" and never have been back. And I put my heart in that place. The Ann Arbor Center for the Family, we started that and put our hearts into that for ten years. The same with the curriculum at Michigan. When it's over, it's over.

J: That sounds like it frees you up to do other things.

A: Well, of course it does. It's not generosity on my part, it's survival. You can't let those things drag you down. I want Smith to do well. I care a lot about the institution and I am very pleased with how things are going. I am not going to worry that my imprint gets rubbed out, because it will. Other imprints will be put on. By the way my retirement was absolutely spectacular.

J: Why don't you tell me about that.

A: It was such a nice ending for my time there. People came from all parts of my life. As for the program, I had only two instructions: no asking for money and no memorial service. I didn't want them to get up and talk about me. It was just great, because they had historian Blanche Cook and feminist professor Carolyn Heilbrun do a seminar on writing a woman's life. They had a conversation. It was wonderful. And then this lovely outdoor reception afterwards with all the food and wine and everything and 70 of my closest friends and colleagues went to the President's house for dinner.

J: So that launched you into your so-called retirement.

A: Into my so-called retirement. Which is a laugh.

J: What is it like?

A: Well it's extremely busy. I am working very hard, but I am just doing what I want to do. I love teaching at Fordham. Next to seeing clients I love to teach or they are tied, maybe. I pretty much can develop courses as I want to. I'm having the best teaching experience of my life.

J: Why is this the best?

A: I don't have any other demands (other than some writing and reading) in my work life except teaching those two courses. I really can focus and work on it. I love the Fordham students. They are an interesting New York metropolitan-area group. A lot of people of color, a lot of first generation college students: dads who were policemen and civil servants; firemen; Irish, Italian, Hispanics. And the doctoral students are super—people who have carried a lot of responsibility out in the real world in social work and now they are back getting their doctorate and they bring in so much. And then I go to the opera and the theater. It's the perfect retirement job. It is only in the fall.

J: And then do you travel?

A: A lot of travel and writing. We are working on revising the family book. It's what I am doing now. I also have some chapters, three big pieces of writing to do. Then we have a contract, Joan and I together, to write a first-year practice book after we finish the family book. I could write full time, all the time. I try to say no, but I still have too much to do.

J: Tell me about your travel plans?

A: We are traveling to Sidney for a few days and then to Adelaide, Australia, where Michael White's family therapy center, the Dulwich Center, is having a narrative family conference. Joan and I will be doing a one day workshop on the social construction of gender and sexuality before the conference and then repeating an abbreviated version of this at the conference. We are also leading a brief discussion with other educators and

supervisors on the pros and cons of the teacher in the classroom adopting a transparent position. After that we are going to Kangaroo Island for three days and then we will be in a one-week, intensive small group with Michael White.

J: What do you find meaningful about your work with Michael White?

A: He certainly has been the person in family therapy who has been most influential for me in the last six or seven years. I think the depathologizing, empowerment, and respect for clients, and the recognition of their truths—all of these things are very congruent with my values and very exciting in terms of working with people. I have already been to three workshops with him in Cambridge and we have gotten to be quite good friends, so I really look forward to spending some time with him. And he is a social worker.

J: Do you really think you are less active than you were before? I mean, it sounds to me like you are doing a full-time job.

A: No. I am less active now. But I am still active. I regularly baby-sit the grandchildren. Last year it was two afternoons a week; this year it's just one because we are trying to get the book out. I wear blue jeans all the time. There is a lot I don't have to do because I don't go to work, except for the two days in New York.

J: That's what I am hearing is the major difference—that you are only doing what you want to do.

A: Only doing what I want to do.

J: Aren't you part of some on-going groups?

A: Yes. One group is the Fortune Cookies. And that group has been going about nine or ten years. We meet once a month on Saturday afternoon and are all family therapists, women of varied age and ethnicity. We all share an interest in women issues and in family therapy and family issues. And then the other group we just started is a reading group—not reading social work, they are not social workers—reading for pleasure. I love to read. Now this is going to make me read novels. So it will be good.

J: Do you still do a lot of professional reading?

A: In the context of projects I do all the time. As soon as I retired, the first thing I did was this monograph for the National Center on Social Welfare Policy and the Law which was to counter Gingrich's recommendations about putting kids in orphanages. So I had to get into that literature and all the research about what has happened to kids in congregate care and then write it all up.

J: Do you have any future projects that are in different directions from what you have already done?

A: One of the things I think about is doing a history of the Smith School of Social Work. I could do it up to my deanship, maybe. The other thing I thought about doing is putting together this course I'm teaching at Fordham in a book.

J: And what is the nature of the course?

A: It's really what Carel Germain and I had a contract for writing a book: the development of social work practice theory from day one until today. I have these two volumes of readings for the students—they read all original sources, things like the correspondence of Mary Richmond.

J: You have had such a rich, long, and varied career. When you look back over it, which parts stand out for you as having been the most meaningful?

A: I think working with clients. And I think the second thing is starting things. Like starting the Southeast Nassau Guidance Center, the Ann Arbor Center for the Family, the National Child Welfare Training Center. And the students. And I loved scholarly work. So I don't know, I liked it all. I even liked administration....

J: It sounds like even though you integrated it all, that these things drew on different parts of yourself.

A: I don't experience moving from one realm to another; it's always me.

J: You are saying that these are all connected.

A: Yes. For example, we did a family book and I was seeing families and I was teaching the material in my family classes at Michigan—total feedback loops.

J; I guess one of the reasons I am asking you this is that so many people don't do it all. Many people are really good teachers or really good clinicians, but they aren't writing. Or people who are writing have stopped practicing and are less invested in their teaching. And I am just trying to get a sense of how come you were able to do all of these things with such energy.

A: I think it's the energy and also, I liked variety. I liked to be active.

J: It seems that you had positive feedback and you got satisfaction.

A: Absolutely, all the time. I've had and enjoyed all of it. I couldn't complain for a minute about my career. How could I? If anyone could describe it, it's like a perfect career. What else could I have wanted to have happen?

J: Do you ever have any regrets? Any thing that you wish you had done differently?

A: Well, Joan's experience was very difficult at Smith. The one thing I regret, from that perspective, is our move to Western Massachusetts, although we love the area and are delighted to be retiring here. But it was not good for her and I'm regretful of that.

J: So, if you were talking to someone starting out in social work right now, what advice would you give them about entering the profession and pursuing a career?

A: Well, I would say to them, "if you are thinking about opening up an office and doing psychotherapy, or going into some clinic and doing psychotherapy, forget it—if you want to be a social worker, come on in." There is an enormous need for social work, as there will continue to be in protective services or child welfare, as well as in the development of programs in schools and our aging population... we are going to need more and more. I mean, it's just endless. But the flight of our profession into entrepreneurial psychotherapy, I think, is over.

J: Do you echo what Harry Specht said in his book *Unfaithful Angels*?

A: No. I don't think we were unfaithful at all. I don't feel at all critical of that route we took. People can use the training that we gave in schools of social work to do all kinds of things. And I am not going to say they shouldn't have done what they were doing. But I am just saying it isn't going to be possible anymore with managed care; the world has changed. And I always say that one of the reasons that people went into private practice was to be able to do the kind of work they wanted to do. That's why I started the Ann Arbor Center for the Family. Not to make money, I had a job, I didn't need the money. I think many people go into private practice because they want to do the kind of work they want to do. They want to see clients and they want to be able to see them the way they want to see them. So I am not critical of people that went into private practice, because many of them went in to be able to be of more service than they were able to be in agencies, where they felt so frustrated and controlled. So I don't feel like Harry Specht at all.

I had a funny experience with Harry Specht on this very topic. He was a reviewer for *Social Work* and there was an article that was very psychodynamic and he rejected it. I thought it was very well done, and I wrote my comment to the staff, "Harry wouldn't accept a psychodynamic article if it was written by Freud himself." It was supposed to go to the office but they made

a mistake and Xeroxed it and sent it to Harry. So he was furious and he called the President of NASW. Then I wrote him a very apologetic letter and he was very sweet afterwards. He came off it right away and was very gracious. I really agree with Harry and his colleagues in lots of ways about where we ought to go, but I don't feel negative about people when they take another route. That's their route.

And they made a contribution too. The one thing about private practice that I loved is it's your client and you had a deal and they paid the bill, and if you weren't giving the service they weren't going to pay their bill and they walked out. It was much more egalitarian, in a sense, and accountability was clear. I loved my practice and I didn't charge much, but I was being hired by people to give them a service and I liked that relationship. Agencies tended to be where people got lost in bureaucracies. Remember, Bertha Reynolds went to the Maritime Workers Union so she would be hired by and accountable to her clients.

J: So it sounds like you would encourage someone to consider social work as a career.

A: Sure, but they would have to think about what its going to be like.

J: And I guess the other side of this question is if you were advising our professional organizations about what social work should be doing and what it will look like, what might you say to people at NASW or CSWE or any of our major professional organizations?

A: Stay close to the ground. I think NASW has had to fight for our place among the helping professions and I think it's terribly important for them to fight for us. I just think we have to keep our ear very close to the ground. We have to maintain our historic values and our historical focus on social function and people and their environments. And all those old terms we have always used. But, be more and more sophisticated about the meaning of those environments. The last few years I've been very interested in social constructionism, which is just another layer of understanding the meaning of the environment. So I think we have to maintain our stance and be very alert to see where we can move to be of service, but not relinquish our stance in order to do that, because we would lose out in the long run.

J: It sounds like enrich our stance or retain our stance but also not just keep it as it is.

A: Oh yes, never. We have to keep responding to the need out there and also to new ways of thinking. I am very interested in social constructionism and in different ideas about our political relationships with our clients.

J: It sounds like almost an elliptical quality, doing something and then coming back.

A: Oh, I keep re-visiting. I keep re-visiting the social issue, what is the nature of the social reality and its impact on people? I have been revisiting that from Mary Richmond to Michael Foucault. And the other thing I keep re-visiting is, fundamentally, the political nature of our work. And I really mean our relationship with power. I've always had the ideal of establishing relationships that were egalitarian with clients—a truly level playing field. Very hard to do. How to divest ourselves of power. Because I don't think we can empower clients as long as we are in the position of powerful professionals. I'm an old radical.

J: A radical. I wouldn't say old.

A: Yes, I am. I am just as radical as Harry Specht, probably in some ways more so, but I just don't have such strong feelings about what other people are doing. □

This was the last of a three part series.

"A Narrative Interview with Ann Hartman"

Part One: Becoming a Social Worker- Vol. 4, No. 3 Summer 1998

Part Two: The Importance of Context- Vol. 4, No. 4 Fall 1998

Using Narrative Assignments in the Classroom: Teacher and Student Reflections

This article reports on the experience of using narrative assignments in graduate education. A teacher (John Kayser) and three students—two from social work (Laura Buchanan and Lynn Halfmann) and one from education (Michele Coates)—share their narratives and reflections on the opportunities and limitations the assignment afforded in their learning and subsequent professional development. Sharing this work may be helpful to others seeking to incorporate narratives into the classroom. Boundary roles and confidentiality issues this type of assignment raises are examined.

by
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"The experiences of the first three years of life are almost entirely lost to us, and when we attempt to enter a small child's world, we come as foreigners who have forgotten the landscape and no longer speak the native tongue."

—Selma Fraiberg

Teacher's Reflections: Purpose and Structure of the Assignment

For the past several years, I have included a narrative assignment in a graduate social work course on the assessment and interventions with children. The assignment originated as a brief in-class exercise done near the start of the course. Students were asked to bring an artifact or memory from childhood to share and compare their experiences with a small group of classmates as part of an effort to build a community of learners (Kayser, 1995). Subsequently, the assignment evolved and became more formal and lengthy. Students were asked to write a mid-term, first-person childhood narrative of a meaningful event, experience, or formative period in their development. The purpose was to share something about their childhood that they valued and treasured now, and which they can draw on in understanding their *current* work with children. There are several underlying benefits of this type of narrative assignment:

First, narratives help students decenter from their own culturally and cognitively bound experience as adults. How adults view children is decidedly different from how children view themselves and/or us—the adult world. Adultcentrism (Petr, 1992; Tyson, 1995) is a concept which suggests that adults working with children often fail to recognize that we are viewing them from our adult perspective—the perspective of our big adult shoes, clumping around noisily, intruding in their world, probably trampling on things precious to them. Adultcentrism represents all those things about childhood that we were taught to "grow out of" in our hurried march towards the promised land of adult privileges and responsibilities. Unless students work to obtain a *passport* (Anthony, 1964) allowing them to

travel respectfully and humbly in children's world (as good travelers do in unfamiliar lands), they are unlikely to be effective.

Second, narratives help students recapture and reconnect to a source of expertise they bring to this course—their own experience of childhood. Often, however, in the haste or necessity to grow up, many of us have forgotten our own best source of wisdom—the language, culture, and lived experience of childhood. Thus, the narrative assignment reflects a central premise in my approach to teaching this course—to be an effective worker with children one must reconnect to personal childhood experiences (Gardner, 1975) as a means of preparing ourselves to see the world of our current child clients from *their* perspectives. Then we can integrate this with adult knowledge about children (i.e., theories about child development, knowledge of child behavioral disorders, child and family counseling techniques) into a more effective whole.

Third, narratives help students gain an appreciation for the storied nature of human experience and the value of stories as a therapeutic medium through which to do child work. (In addition to the narrative assignments, I incorporate children's literature, stories, and biblio-therapy approaches into the course on a regular basis.) While the course also stresses the importance of mastering other types of professional writing, such as the objectively written comprehensive assessment or intervention report, I believe exposure to the first-person written narrative is important in direct work with children. Learning the importance of time, context, characters, and plot in constructing their own narratives helps students in using the narrative metaphor in their direct practice (Zimmerman & Dickerson, 1994). In addition, narratives help students become more sensitive in examining the meta-level stories of race, class, and gender through which individual life stories are lived (Laird, 1998).

Because students often are unfamiliar with and/or uncertain about using the narrative genre in academic papers, the assignment is structured in several ways. I begin by providing a handout with several quotations from a cross-section of writers (encompassing the fields of biography, fiction, psychological theory and research, child development, and child therapy) offering diverse perspectives on children, the experiences of childhood, and the use of narratives. I hope this handout will serve as a nutriment or catalyst for their own reflections. A sample of quotations is as follows:

1. The child psychoanalyst, Bruno Bettelheim, says that the single most important quality a helping adult must have in working with troubled children is the capacity to empathically be in touch with the experience of his/her own childhood. In his book, *The Empty Fortress* (1967), he states: "Much of modern psychology seeks to know about others; too much of it, in my opinion, without an equal commitment to knowing the self. But I believe that knowing the other—which is different from knowing about the other—can only be a function of knowing oneself."

2. "The more time you spend with children, the more you notice how they explore the world and the acuteness with which they think about the most subtle things—things which escape materiality, easy recognition, definite forms, the laws of invariance—things one can touch but can't touch, that brush against the real and the imaginary, that have something of the mysterious about them and provide wide margins for interpretation." (Guido Petter's *The Hundred Languages of Children, 1998*).

3. "What sets one Southern town apart from another, or from a Northern town or hamlet, or city high-rise? The answer must be the experience between the unknowing majority (it) and the knowing minority (you). All of childhood's unanswered questions must finally be passed back to the town and answered there. Heroes and bogey men, values and dislikes, are first encountered and labeled in that early environment. In later years, they change

faces, places, and maybe races, tactics, intensities, and goals, but beneath those penetrable masks they wear forever the stocking capped faces of childhood" (Maya Angelou's *I Know Why the Caged Bird Sings*, 1969).

4. "But people are always speculating—why am I as I am? To understand that of any person, his whole life, from birth, must be reviewed. All of our experiences fuse into our personality. Everything that ever happened to us is an ingredient" (Alex Haley's *The Autobiography of Malcom X*, 1964).

5. "Recent work following girls into adolescence has explained. . . that girls move from a rich relational world of childhood in which it is possible to express the full range of human feelings, into a culture of constraining conventions of femininity that pressures girls to narrow their feelings and to modulate their voices. Young children tell psychologically astute stories of human relationships, rending in exquisite detail their connections with themselves and with others. A struggle breaks out at the edge of adolescence, however, when these same girls are encouraged to disconnect from their knowledge, to see and hear the world largely as it has been seen and spoken about by men. What girls knew in childhood seems as if it cannot be known, and what girls want to say suddenly seems unspeakable. . . .Many girls struggle to remain connected to their childhood knowledge, actively resisting repressive conventions of femininity and fighting openly for authentic relationships" (Annie Rogers, Lyn Brown, & Mark Tappan's "Interpreting Loss in Ego Development in Girls: Regression or Resistance," in *The Narrative Study of Lives: Exploring Identity and Gender, vol. 3*, 1994).

6. "The therapist must have the capacity to project himself into the child's situation, to see the world through the child's eyes—and probably to feel the way the child feels. . . .We use such terms as sympathy and empathy in our feeble attempts to describe this quality, but we still have much to learn about it. . . Does an accurate memory of one's own childhood play a role in this capacity? I think so, but as far as I know this has not been tested. . . Egocentrism may inhibit this quality. . . The therapist who lacks this quality to a significant degree is ill equipped to help his patient. If he cannot see the world through his patient's eyes (not necessarily agree with the patient, however) then he is handicapped in helping him" (From Richard Gardner's *Psychotherapeutic Approaches to the Resistant Child*, 1975).

After allowing a few moments for students to read the handout, I outline the parameters of the assignment. I stress that students should share only what they feel comfortable with others knowing. I acknowledge that some students come from difficult childhood experiences, and that the assignment is not meant to force unplanned disclosure of painful material. What students choose to share is honored and treated confidentially, to be read only by me. In addition, I state that the grading of the narrative is not based on the content of the life experience being shared, but on their ability to construct a narrative addressing questions such as: "Do your recollections shape or inform your understanding of yourself?" "Do they help you understand others?" "Can you draw on these recollections in understanding your current work with children?"

Finally, I read students an excerpt from a first-person childhood narrative constructed by a student from a previous section of the course. (This sample is drawn from Michele Coates' childhood narrative which is contained in the student narrative section below). The excerpt is offered as an example and model of the type of learning I hope the narrative assignment will facilitate for them. After reading the excerpt, students discuss their reactions to the assignment, which helps to air any remaining anxieties or concerns they may have about completing the assignment. Then, they have about three weeks to write the assignment.

As course instructor, I have found the results of this assignment to be very gratifying. Students have described an incredible variety of childhood experiences—some growing up in apartments in large urban areas, some in mid-western rural settings, some in small towns on the coast, some on western cattle ranches, some in international settings. In the section which follows, three students have agreed to share their narratives. At the time of this writing, Laura Buchanan and Lynn Halfmann are second-year masters students in the University of Denver Graduate School of Social Work. Michele Coates graduated in 1996 from the Child and Family Studies Program (College of Education), and currently is working as an early childhood intervention and community coordinator with families in Denver for the Colorado State Department of Education.

These particular stories were selected because they embody a number of exemplary narrative elements. The stories are beautifully written—evocatively and creatively recalling the perceptions, experiences, and reminiscences students had during childhood. In addition, the three narratives describe a wide range of childhood experiences: narratives of exuberance and happy growth; narratives of challenges and obstacles; narratives of oppression and resilience; narratives of stability; narratives of displacement and transition. Further, the narratives are sensitive to the impact of race, gender, and class on the individual life experience, providing a transparent window through which the working of these forces momentarily can be observed. Finally, each narrative shows how the students related their childhood experience to present work with children in social work or education. The narratives offer original insights on working with children in a variety of practice settings.

Student Narratives

Laura Buchanan—
"My Experience of Childhood"

I am one of those lucky people who can say that I had a wonderful childhood. To this day, my memories are a comfort to me, and unfortunately it seems like everything was better when I was kid. When I was a child, I was more free to fully experience my emotions, and everything had a dreamy, magic quality to it. I didn't really know pain or regret, and there never seemed to be any real responsibilities. Playing was my number one priority, and this was encouraged by adults. Perhaps the only damaging thing that I was exposed to were sexist stereotypes and gender roles. Still, my memories of childhood are very positive, and gave me a foundation for viewing the world as a generally safe and fair place where most people can be trusted.

I can remember thinking of my parents as the greatest people in the world. They were infallible. My mom was the most loving and beautiful person in the world, and my dad was strong, hard-working, and handsome. I thought that they were happily married (they divorced when I was 17), and my brother and I were well provided for. Whenever my parents got mad at me, it was like they would become totally different, mean people. This did not fit in with my idealized image of my parents, so I had to have a dichotomy of good parent/bad parent instead of seeing them for who they really were. As I became a teenager, I shed this image very quickly, but it was difficult to lose these perfect people who took care of my every need (almost). My paternal grandparents lived four hours away, but they were close and very involved with my brother and me. It was like I had a second set of parents close by to satisfy me in any area my parents couldn't.

Friendship in childhood is much different than it is now. I would sometimes take baths with close friends, we would sleep over in the same bed, and we would hang out for days until we got sick of each other and separate for a night. Arguments could be very painful, and very petty as well. There was no attempt to be polite, and hurt feelings were not your problem unless an adult guilt-tripped you. The best friends I had as a kid are nothing like adult friendships. They just seemed to happen, and they revolved around fun and games.

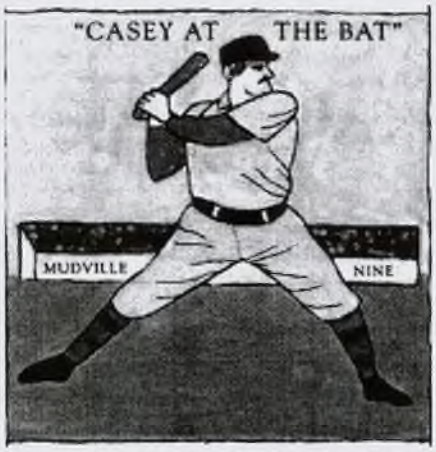
I miss the frequency in which my friends and I would laugh until our stomachs hurt and tears would roll down our checks.

I also remember how impressionable I was as a kid. I would believe anything I was told, including Santa Claus and the stork, and everything was a template for letting my imagination run wild. I remember wishing that I had magical powers, or that I could transform into a cat or a dolphin. I would see a movie, and it would be in my head for days and weeks. This was sometimes a bad thing because a scary movie would keep me up at night and cause me to be afraid of creatures in the closet, underneath the bed, and outside my window at night. I'm glad I have outgrown that childhood feature.

I learned a lot about myself growing up as a girl in Texas. This seemed to determine so much of what I could do and who I could be. Toys, TV shows, shoes, bikes, bedspreads, activities, language, almost everything seemed to designate as either a boy thing or a girl thing. I always thought that girls were being shafted, and hated the toys and clubs that girls were supposed to be involved in. My brother did boy scouts and I tried girl scouts but quit after our camping trip was changed into a downtown shopping spree in Dallas.

The toys I was supposed to play with were Barbie and Strawberry Shortcake, but baking plastic cakes and dressing-up the doll got old really quick. I remember my mom giving me a big Barbie head, so that I could practice putting makeup on it and styling its hair. Somehow this toy wasn't stimulating enough. My brother always had better toys in his room. He had a wind-up Evil Knievil stuntman doll that would go flying around on its motorcycle like a bat out of hell, and he had the Millennium Falcon "Star Wars" spaceship that would make cool noises, flash lights, and open up to carry figurines.

Whenever relatives would come over, they would say something like, "You're gettin' so pretty, we're gonna have to get a stick to chase the boys away." I would just blush and get embarrassed. My brother would get quizzed on sports trivia and be told how smart he was. I never thought that I was smart compared to him, but maybe no one took the time to really notice if I was as smart.



I sometimes wished that I could be a boy, because they seemed to be so much more important. They were always the heroes or main characters in movies, TV, or books. Whenever female characters were represented, they were usually blond and extremely pretty. I grew up thinking that the only way to have power as a woman was to be pretty and to have large breasts. I feared becoming a woman, because I was afraid that I would not grow up to be pretty. I also thought that it would just be a stupid world of hair, make-up, bras, and boyfriends.

Texas is probably not the most empowering place to learn about female gender roles. Dallas as a city seemed so proud of the fact that it had so many blond, leggy, and large breasted women. There were many strip clubs all over the city, beauty pageants were big, and the Dallas Cowboy Cheerleaders were worshipped by all ages. I did not have many strong female role models growing up. The only one I really remember was Olivia Newton-John and her performance in "Grease." In this movie, all she had to do was wear tight leather pants, tease her hair, and start smoking, and John Travolta fell madly in love with her. Maybe this movie wasn't such a good influence.

When I was eleven years-old, our family was transferred to Michigan, and that is where my childhood ended. I was a relatively popular girl in Texas, and I had a pretty healthy self-esteem. The new neighborhood that my family moved to was very wealthy, and I was not well received by my classmates there. I think that they saw me as a Southern hick. I spoke with a Southern drawl, and I wore all of the wrong clothes. My classmates would ask me how many cars our family had, how many bedrooms were in our house, and they would lift up my shirt

to see what kinds of jeans I was wearing. I wasn't ridiculed but I knew I wasn't accepted, and this was deeply painful to me. I remember going home from school, crawling into my bed, and crying. I thought that it would be worth it to give up my leg if I could go back to my friends in Plano, Texas. I became a much more shy and independent person after that, and I began to think that I am somehow different than everyone else. Eventually I made wonderful friends, and now I am thankful that I got out of the South at the age I did.

To this day, I think I have retained a good deal of my childhood creativity and I find that my "right-brain" style comes in handy when relating to children. I seem to have an easy time facilitating play and getting lost in kids' imaginations. Since my childhood was stable and happy, I may have a difficult time knowing what it must be like for a young child to be dealing with loss, trauma, or difficult emotions. I didn't experience any hardships until I became a teenager, so it may be a stretch for me to know how this would impact a child's world. Also, I will always be sensitive to gender roles and their influence on young children, especially girls. Sexism was an issue for me growing up, and I wish I could prevent it from limiting and taking away from girls and boys growing up today. All and all, I see childhood as a happy time, and this may be one reason why I enjoy working with children and letting myself climb back into their world.

Michele Coates—
"Perspectives of a Childhood Journey: Connections and Unwritten Chapters"

I remember the four-hour drive home to the small blue-collar town in southern Colorado where my extended family lived. I know every twist of the highway and each cluster of trees in the Black Forest. I remember the snowstorms on Monument Hill and the summer rain that made the last five miles slippery and endless. I have often done this drive in my sleep seeking out the comfort of my memories. Childhood summers and holidays were divided between my parents' large and boisterous families. Eight blocks apart, they both lived in the lower eastside of a predominantly working class steel town. The orange glow from the graveyard shift at the mill cast strange shadows on a seven-year-old's night-time sky watch. These two families blended together into a crazy whirlwind of aunts, uncles, cousins, and grandparents. I was the first-born grandchild on both sides of the family. My birth was celebrated, they like to tell me, for three days. I was treasured, indulged, and loved throughout my childhood and adolescence. My second home was a rich intermingling of two deeply traditional cultures. My paternal grandparents were first generation Italian-Americans. My maternal grandparents are Hispanic-Americans. At the age of eight I could fluently insult anyone in three languages. I felt connected, surrounded, and completely immersed within a family, a community, and a culture.

My great-aunt Bess lived in the old family farmhouse that had belonged to my Nana (paternal great-grandmother). Each summer, six (of over twenty-five) first cousins and I would plan the great sleep-over. The house, filled with beautiful old furniture, black and white photographs of solemn-faced people, and antique clothes, was like a great imaginary castle through the eyes of a child—with fantastic props ready-made. It would not have been complete without my Aunt's fat wiener dog, Pepe, rock-hard marshmallows, and the ice cream kept in the 1920s freezer. Inevitably, we would feed the dog twenty or so marshmallows just to watch it throw up under the large four-poster brass bed where we all slept. I was the ring-leader, being the oldest, and I often negotiated our way in and out of trouble. Aunt Bess was a retired dietitian from the State Hospital and had what seemed to a seven-year-old hundreds of white uniforms hanging in the damp and very dark cellar of the house. One morning, seven little girls reverently took down a coat from its wire hanger and immediately transformed into Marie Curie. We had the power to change the world and cure the sick with just one tiny sip of our magic potions. If we could only talk Dina (the youngest cousin) into

drinking them, the world would be in our little hands. We systematically waited, like sneak-thieves, until Aunt Bess went outside to water the eggplant and romas (tomatoes). The cousins promptly locked the door and strategically stuffed rocks, juice, milk, kool-aid, marshmallows, paper—everything (and anything) we could find—into the ancient blender and pressure cooker. There was a marvelous array of color, debris, and one extremely angry Italian great-aunt when we had finally finished. My ears still burn with the fluidity and creative twist of Sicilian and English profanity in perfect iambic pentameter.

The Star Bar, a local joint around the corner from my grandparents' house, has the hottest green chili, the cheapest beer, and the best conversation in town. My Grandpa Victor spent every Friday afternoon sampling their offerings. Every other Friday, during the summer when Grandma had church, I would go along. We each had a "slopper" (open-faced hamburger smothered in green chili), a Pepsi in the bottle for me, and a large foamy draft for Grandpa. We would talk about the Broncos, the best fly-fishing spots on the Arkansas River, and tell jokes. My Grandfather repeated the same six jokes over and over. Each time I would laugh like I had never heard it before. Then, after a beer or two, Grandpa would begin to tell the stories. He would weave incredible tales about the Co-Co man, a mythological Spanish bogey-man, who rode empty train cars and liked to eat small children with bad manners. My favorite story was about a crying woman, la Llrona, who had lost her baby to the evil spirits of the Rio-Grande River. She walks up and down the riverbed wailing and looking for her lost child. Grandpa Vic still claims her tears can be tasted, even today, in the fresh flesh of a river trout. We had a ritual for coming home. He would wash my face and hands with a drink napkin, and remind me that the Star Bar was our little secret. We would walk down to the corner market and eat strawberry ice cream cones and drink a glass of warm water. This was important, he said, to keep the stomach from becoming too cold and inviting evil spirits to dance within the body.

Working with children constantly challenges my ability to wonder. It re-attaches the magic of childhood often lost in the adult perspective. My own childhood stories are endless, I draw upon them vigilantly as a constant reminder of what play, imagination, and exploration are really all about. My work within the Head Start agency (parent organization, Child Opportunity Program) has placed, front and center, children with various needs into my care. I assess the developmental process of both the child and the family. I visit children in their home environment and encourage a lasting bond between educator and family of mutual trust and respect. I attempt to educate the parent through the child about the child developmental process, furnish a stimulating and safe environment for these children to grow and experiment, and provide a connection to community resources when needed. I am truly amazed at just how much I enjoy the process. I embrace each family and child's individual experience as part of a continual educational workshop to improve my understanding of human development. What better way to spend the day than dressing up, finger painting, and building great imaginary cities out of blocks, only to knock them down and begin again?

Every August, I sit down to write a short and extremely personal statement concerning my philosophy of child development. I post this on the door to my classroom. I spend an inordinate amount of time reflecting upon my own childhood story. I draw upon several key factors: the stability and security of my environment, cultural and ethnic experiences which augment my connection to community and self-worth, the act of play as a stepping stone for mastery of interpersonal skills, and the sheer joy in exploration. I hope, with this incredibly short statement, to express the validity and importance of protecting the development of each individual child's story. I attempt throughout the course of the school year to actively recruit parents to join the children in the classroom. I ask them to get on their knees and play in the dirt, sand, or soap with their children. I encourage extended family members to have lunch or attend a teddy bear tea party in our land of make-believe. We have guest

story-tellers from the community to share an experience, folktale, or memory. These storytellers are regularly extended family members and community helpers. We create a class journal noting our important discoveries large and small. I frequently send home imagination pamphlets, which stress language development as a motivation for parent-child play interaction. Monthly pot-luck lunches welcome families to bring cultural foods and music into the classroom arena where it has always belonged and is often ignored. In almost every dimension of my work with children and families, I remember the comfort of my childhood home. My objective then becomes a synthesis with the children, their families and needs, and the joint construction of an environment in which they can feel safe to explore, challenge, and create.

The experience of childhood helps pull together an extremely operational format for working with children as an adult educator and facilitator. It reinforces my belief in maintaining a fundamental understanding of where each child begins and an acceptance of their individual journey. It is tremendously exhausting, trying, and emotionally draining to work in an atmosphere where children are often lacking some basic building block like food or shelter. Sometimes my only goal can be to provide a safe haven for these children (food, heat, or love) in four-hour stretches. Five days a week, I can create a tangible place for them, where the magic of the childhood story richly unfolds and travels to unknown and unwritten chapters. Their journey belongs to our future.

Lynn Halfmann—

"Memory One:
Rock-Powder"

Scrape-*scrape*, scrape-*scrape*, scrape-*scrape* is the rhythmic sound of the rock grinding against the square slab of concrete. I kneel with my feet tucked under my rear like an Indian woman grinding corn on her rock. My arms are stiff as they extend to my hands which carefully hold the rock so it glides forcefully, yet smoothly, against the concrete. I am rocking back and forth in a steady motion, applying even pressure to promote the most efficient powder production.

Each rock that I grind is a different color, and has been gathered from various areas of my neighborhood. As I am rocking, I am falling away from the consciousness of the task at hand. I am thinking, daydreaming, unconsciously rotating the rock as not to grind at my fingertips. I do this for hours, stopping only to notice: "Ooh, this is a beautiful color powder, this will do very well in that particular magic potion." I am in my secret hide-out. I don't know who developed it, but it is in the far back left corner of my yard. Someone cleared out a space in the middle of a bunch of bushes and trees. Then they placed seven cinder-sized concrete blocks in a row down the middle. They are perfect for sitting on and having conferences. The slab that I use to grind on is a flat two-foot-by-three-foot slab. It sits right outside the entrance to the hid-out like a pedestal or an alter in a shrine. I love to compare the different softnesses and colors of the rock powders as they fall through my hands like silk. I stick a wet finger into each pile and taste them, expecting to taste a difference. (Yes, I ate rocks as a child.) I sandwich-bag each type separately and seal it with a twist-tie, for use in later potions. The one mixture that I vividly remember making was a "dandelion killer" poison. It contained various items such as dirt, sticks, rock-powder, water, plants, berries, etc. I remember carefully compiling this mixture with a friend of mine in the back yard, as if I really knew what I was doing, and had used it before with great success. Then we ran around the yard pouring just the right amount on each dandelion.

"Memory Two:
Breathing in the Spirits"

This is Indian Creek Park. It contains play equipment, tennis courts, baseball diamond, skating rink, woodlands, and the creek with the little arching, brown bridge. The sun is always shinning here and the grass is green and evenly mowed. I often play with friends and my parents at this park, but my favorite times are when I come here alone. Today I begin my journey by

slowly and quietly entering the woodlands or "forest" as I call it. Branches and leaves brush my legs and face as I make my way through the old trails. Looking at the interaction of the light, leaves, dirt, rocks, flowers, and animals that make-up these sacred burial grounds, I am searching for the "Indian burial mound" that I am sure exists here, unknown and uninterrupted. "No, No, not that one, not that one either, I've dug at both these before." I come to a new bulge of dirt. I stand with my eyes closed, as I try to breath in the spirits below the earth. A twinge of fear and excitement rushes through me, beginning in my chest and spreading through my limbs. My lips are cold, my stomach quivers. It must be here. I begin to dig into the loose, damp earth. As I dig, I discover interesting earth creatures, pretty rock specimens, seeds, clay, etc. Much to play with and analyze. But no, not today, I have not found the burial mound. However, several of the stones are shaped like arrowheads, and are a soft shale material. With a little grinding and chipping on the edges I could convince myself—and then my friends—that they are true Indian arrowheads. Next, I head for the cement-basin creek to look for crayfish and the legendary baby octopuses that live there. I swear, once I looked into the creek bed and saw hundreds of miniature animals, with bodies the size of peas, and eight little squiggly legs on them. When I went to look for them the next week they were gone. I don't know if they were a weird form of plant or algae, or some kind-of tad-pole, or what, but I think the memory is real. Once I brought a crayfish home and put it in the water of the deep puddle that forms in our gravel driveway. I thought it would be my pet, but it ran away. This makes me sad, because it can't live without water, and the creek is blocks and blocks away. I feel like I killed it, but I didn't know any better.

"Memory Three:
The Great Black Panther"

We are scouting the area, crouching, running quickly for the cover of each bush and tree. It is hot and muggy, the sun beats through the minimal shelter of the tree tops in this suburban jungle. The buzzing of the electricity in the telephone cords sounds like the hum of exotic jungle tree insects. In our minds we have our khaki's on, and our tranquilizer guns at our sides. We are hunting the Great Black Panther that has been spotted in our neighborhood. I myself have seen it eye-to-eye several times. Its piercing green eyes and frozen stance confront me briefly each time before it slinks powerfully behind a house or garage. I have convinced my neighbor friends that this is a true and worthy cause, to find this animal. And it is. It is exciting. Every second of it.

"Memory Four:
Buried Treasure"

They will find this. Be it one hundred years from now, or thousands of years from now, someone or something will find this. It is my duty to leave behind specimens of my life as a kid in the 1970's, for others to unearth. I don't remember exactly what I included in this buried personal history: some jewels, newspaper clippings, magazine pictures, writings, playing-cards, etc., but somewhere in my backyard there is a treasure buried. It is double-plastic-bagged, placed in a little wooden box, and double-bagged again. I felt it was my duty to leave a record of what things were like during my lifetime, so that future humans, new earth species, or aliens would know long after I was gone.

"Points for Use in Current Work"

As an adolescent I had a lot of trouble and have used many of those experiences to help me understand the adolescents I have worked with in the past. I have never really analyzed my young childhood memories before.

I believe these memories are from when I was between the ages of five and ten. The memories I have described are ones that I cherish as positive, fun, and free. "Memory One, Rock-Powder," helps me see how purposeful, organized, efficient, and creative children can be, even in seemingly simple play. How simple things like color, texture, and taste can be enjoyed as children and over-

looked as adults (although I did end up going to a fine arts college, so I haven't lost it all!). Also, how I used the repetitive motion of grinding as a gateway to meditation, relaxation, and growth. I wonder if I used this an intuitive coping skill to deal with family discord?

"Memory Two, Breathing in the Spirits," reinforces the idea that children can be very creative, and use fantasy both as play themes and growth experiences. I had a deep spiritual connection to the earth and made-up Indian spirits. I was not raised with a religion, and this is how I rationalized my existence and developed my own religion. I think one needs to be careful when working with children who reveal a recognition of spirits, visions, or voices. You need to ask yourself, case by case, if it is just healthy fantasy play, or if it is a culturally and religiously based recognition rather than a sign of mental illness. As far as the baby octopuses—even though I think I saw them—I wonder if some of my memories were embellished and/or made-up. Were they so much fun to believe in and to share with others that they became a reality for me? It reminds me that not everything children say is even close to the truth, even if they think it is. I believe this combines normal cognitive and developmental issues. My tendency to exaggerate was something that I had to confront as a young adult, because it was no longer appropriate, and was seen as lying. Lastly, the fact that I didn't understand the consequences of taking the crayfish from its home can also be seen as normal cognitive and developmental learning.

"Memory Three, The Great Black Panther," further highlights the fabulous skills of fantasy, adventure, creativeness, and purpose that children can have. "Memory 4, Buried Treasure," reminds me to realize how smart and in-touch children can be. I had probably seen a show on archeology or something, and decided that I would bury traces of my culture for future generations. The fact that I understood concepts like life, death, culture, future generations, extinction, future earth species, and aliens astounds me when I think about it now.

I think it is very useful to tap into the fantasy world and creative intelligence of yourself (as a child and as an adult)—and of child clients, in order to do better work with them. For instance, in the video that we saw in class, a boy in therapy talks about getting "new brains" every two years to replace "children's bad brains." This was a very creative and intelligent solution to this child's problems. The therapist skillfully tuned into the underlying messages that accompanied this story in order to pick-up on where the child was coming from, and we were able to infer what some possible causes were for his issues.

Conclusions

In this final section, teacher and student reflect on the opportunities and limitations this assignment afforded.

John Kayser: Balancing Boundaries and Confidentiality

In the narratives above, students share primarily positive experiences of childhood. Their stories are rich in imagination, playfulness, connectedness, resourcefulness, and resilience. The narrative assignment provided Laura, Michele, and Lynn an opportunity to purposefully reflect and connect childhood to their current work with children and families. As an instructor, I find the narratives wonderful to read and easy to grade because they fulfill the learning expectations I hoped this assignment would promote.

With other narratives describing more troubling and troublesome childhood experiences, students have reported that they found it helpful when I commented on the strengths their stories displayed and honored the lessons they learned, meanings made, and/or gains achieved in later years of development. Much more difficult, however, are those students who write narratives of unremitting negative experiences about multiple, unresolved, overwhelming traumas from childhood. Despite the parameters, cautions, and safeguards about confidentiality I have tried to build into this assignment (i.e., to only disclose what

students feel comfortable with the instructor knowing), I continue to get a handful of such narratives each year. As this pattern has continued, I have become uncomfortable and uncertain about the narrative assignment.

On the positive side, the narrative assignment is similar to others used in our graduate school that promote self-reflection, consciousness raising, and values clarification. The vast majority of students who have written childhood narratives seem to have enjoyed and benefited from the opportunity. On the negative side, I struggle with maintaining my role as primarily educational, rather than clinical, in responding appropriately to the small number of childhood narratives recounting unresolved traumatic or tragic experiences. I worry that the assignment creates further stress in the lives of already vulnerable individuals and that the power differential between student and teacher in terms of status and control over grades and academic rewards offsets any confidentiality safeguards I try to employ. On the other hand, these narratives are shared for a reason—perhaps as the proverbial "cry for help." As an educator and gatekeeper to the profession, should my role be to request (insist?) that these students get outside help (i.e., counseling or therapy) to deal with these issues so that their work with clients will not be affected? To do so seems intrusive and may blur the roles of teacher, clinical supervisor, or therapist. Not to do so seems irresponsible, for it puts clients at risk of being harmed by a (potentially) troubled professional.

There is no final answer to this dilemma. I continue to be guided by the principle that it is not the actual lived experience—whether positive or negative—that is of central importance in this assignment. Rather, it is students' work in constructing meaning out of their experiences that is the essential feature of the narrative. If students fail to connect their past experiences to the present, or fail to develop empathy with their child clients, then the assignment has failed to achieve its intended objective.

Presently, I remain committed to incorporating narratives into the course, but am experimenting with different formats that may not require the same depth of personal disclosure. I also am instituting a new safeguard—allowing students to pass on writing a childhood narrative (no questions asked) and to choose, without penalty, an alternative mid-term assignment. While I continue to believe narrative assignments are valuable, readers are invited to respond to this article with comments and suggestions and perhaps narrative accounts of their own experiences. I have also asked Laura, Michele, and Lynn to offer their own final reflections about the opportunities and limitations this type of assignment provided.

Laura Buchanan:
Final Reflections

In my graduate course work, it has often been said that your "Self" is the tool bywhich to help clients. This assignment has allowed me to excavate my childhood self and use her as a translator with my younger clients. The fact that this assignment did not ask that we analyze or apply theory to our recollections seemed to facilitate a more vivid and authentic experience of who I used to be. Besides, aren't all memories embedded in an emotional context? Putting my memories into a narrative helped me to pick up on some of the themes of my childhood, which mostly related to gender roles. My experiences in childhood have turned into values about what constitutes healthy behaviors in individuals and families. By becoming more aware of what my values and assumptions are, I also become more aware of how I may wish to influence my clients. Writing about personal experiences in a narrative form brings back to life memories which may be haunting or blissful. Perhaps it is necessary for all people who wish to work with children to examine their own formative years and become aware of the forces that may guide their interactions with children.

Michele Coates:
Final Reflections

I wrote my childhood narrative nearly three years ago. Those three short years have wrought great change in my life, my family, and my work. Although the exact nature of my work with children and their families has shifted, I find, upon reflection, my childhood journey still has navigated the same basic approach and fundamen-

tal beliefs written above. This assignment, perhaps more so than any of the multitude of others I encountered in graduate school, provided an opportunity to make a meaningful discovery about myself and the work which I have chosen to do.

The narrative assignment was written in a few short hours, although deciding which account to detail and which one to leave out took more time than I expected.

The benefit of this assignment will last even longer. Three years later, I continue to connect my own experiences, values, and beliefs in childhood magic to the every day interactions I have with children and families. It has enriched my ability to be empathetic, to listen, and to learn from them. There are still hundreds of Star Bars yet to visit and many Co-Co men yet to vanquish.

Lynn Halfmann:
Final Reflections

Not only was this childhood narrative assignment useful for future work with children, but it was a fun and creative departure from the standard, labor intensive, graduate papers. I remember feeling a sense of writer's block at first, and then I decided that it would be easier if I tried to relive the experiences as if I were still a child and in the moment. In general, I seem to have trouble remembering things from my earlier childhood, unless I see a photograph of the moment. This experience enabled me to remember memories that contained senses of touch, smell, sight, taste, and emotions that created internal physical responses. It was informative for me to see that my process of developing identity, spirituality, and a need for purpose and creative outlets began very early on. This knowledge will be remembered when working with future child clients. Although I did not choose to write about negative or traumatic childhood memories as other classmates did, I think it would be a useful exploratory and healing tool in such cases. In my opinion it is a therapist's responsibility to work on such personal issues in order to be a more effective, understanding, and true helper. All in all, I am thankful for this opportunity for self-reflection and increased awareness that could benefit children I may work with. □

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Commentary On Commentary On "Who's Teaching Whom"

In an effort to clarify some of the questions Agathi Glezakos raised in her commentary (Reflections. *Summer 1998) on my narrative, "Who's Teaching Whom?"* (Reflections. *Spring 1998), I submit this response . Such a dialogue can only benefit the field.* Reflections *hopes that it fosters this kind of discussion beyond it's pages and strives to be a forum for working on ideas that face professional helpers.*

by
Stacey Peyer

Stacey Peyer, CALSWEC Field Consultant, California State University at Long Beach, Long Beach, CA.

It is a challenge to write this response as I do not want to come across as defensive, but fear this is inevitable. I am grateful for Dr. Glezakos' ideas and excited to be a part of this dialogue. In pursuit of being non-defensive, I'd like to articulate some areas that may have led to Dr. Glezakos' conclusions regarding some aspects of the experience. Clearly we view practice from very different perspectives. Such differences are unavoidable yet necessary components of dynamic social work practice.

Dr. Glezakos categorized her comments under five headings; I do the same for clarity, although the order is changed.

The Relational Goodnes of Fit

In her commentary, Dr. Glezakos indicated that I erroneously matched the intern, Kelley, with the client, Rick, based on the intern's needs and interests as opposed to those of the client.

A field instructor in a social work setting must take many factors into consideration when assigning cases to interns. Of course, clients' needs take precedence over the needs of the intern, but in many cases, the needs of both may be accommodated in the match. Although in the original article I focused on Kelley's interest in working with Rick, this was not meant to imply that I did not consider Rick's needs first and foremost. I believed strongly that working with Kelley would be in his best interest.

Group psychotherapy was the primary component of treatment at the Diane K. Smith Center. The program structure and the court-related job responsibilities assigned to the primary therapist did not allow time for individual psychotherapy. I believed that Rick could have benefited from individual work, and had the verbal ability to participate in psychodynamically focused treatment. Other residents usually had family therapy as an adjunctive component of their program. However Rick, abandoned by his father, had no other adults involved in his life. This was one of the reason that I believed closer mindfulness was appropriate.

In the narrative, Kelley explained that I had asked her to let me know if there were any residents with whom she might be interested in working. Although not stated, I had been considering assigning Rick to her for the reasons noted above.

Dr. Glezakos casts doubt on the assignment by referencing Rick's asking me as to why, given his issues of abandonment, was he assigned an intern. Nearly all residents at The Center confront abandonment issues. Rick questioned his assignment to Kelley because he wished to avoid the pain of separation from her, as it resurfaced his pain over past abandonment. I believe that it is precisely that process of attachment and separation that allows for much of the work that occurs in the treatment.

Lastly, if interns were not assigned residents that had experienced abandonment as a prominent theme, interns would not have received training at The Center. More importantly, residents would not receive on going, individual psychotherapy.

The Client's Role in the Process of Goal Setting

Dr. Glezakos relates the appropriateness of client involvement in goal setting and states that "the supervisor and intern outline his needs...," indicating that we did not allow Rick to be a part of the goal-setting process. It was beyond the scope of the original narrative and therefore I did not include it. Rick was deeply involved in setting goals for his treatment. Despite the involuntary nature of treatment at The Center, I believe that residents have choices in how they participate and that they can be helped to set goals that are meaningful to them, in addition to what the court might have ordered.

The Worker's Degree of Unfulfilled Neeniness and Countertransferen ce

This is perhaps the most sig nificant aspect of my narrative, and of the actual experience between me, Kelley, and Rick. Dr. Glezakos was concerned that the countertransference Kelly experienced was a negative aspect of this case and perhaps a reason for her and Rick to discontinue their work. Dr. Glezakos states that "...the professional's capacity to contain the pain so that it does not interfere with the therapeutic process separate the effective wounded healer from the ineffective one." She seems to imply that we are in disagreement to this idea; we are not. I felt very strongly that Kelley needed to contain her pain and express it in appropriate ways outside of the therapeutic context of her relationship with Rick in order to be effective and certainly not harmful. The fact that there was such strong countertransference is precisely the reason I introduced the "Countertransference Journal" which we used as an aid in supervision. Dr. Glezakos goes on to say that in addition to developing insight into her thoughts and feelings, Kelley "needed guidance about how to make emotionally satisfying contacts outside of the therapeutic relationship." Again, I wholeheartedly agree. I recommended early in the year that Kelley seek out therapy, which she did, and when issues arose in the journal and in supervision that were more appropriate for exploration in her own treatment, I encouraged her to address them there. I did not know this at the time due to the boundaries of the student/ field instructor relationship, but I know now that much of her own therapy that year focused on exactly what Dr. Glezakos' states was necessary.

Kelley feared that at some point Rick's anger might not subside and that he would push her away for good. Dr. Glezakos states that this fear compromised Kelley's competence as a therapist. It is my belief that this fear had the potential to compromise Kelly's effectiveness. The fear itself was not dangerous. The way that Kelley addressed her fear would determine the degree to which it hindered or furthered Rick's treatment. As her field instructor, I worked to normalize her fear as well as Rick's behavior and to help Kelley to understand this behavior in the context of his emotional development. Group supervision was also helpful in this area as some of the other interns struggled with similar issues with their own clients. In addition, I know, based on my experiences as a field instructor and as a field liaison, that the fear of angering the client and thus "losing" the therapeutic relationship is not unusual. It is fairly common. New social workers/students often need to be helped to trust the process and deal with such potential losses. As Kelley did, they need to learn to avoid allowing their

fear to guide their intervention.

This brings me to the statement that "Countertransference can be counter therapeutic." Again, while this statement implies that Dr. Glezakos and I are in disagreement, I believe we are not. Countertransference is potentially dangerous. It is dangerous when it remains unconscious, when the therapist does not work actively in supervision, consultation, therapy, etc., to manage it responsibly and to remain focused on what is in the client's best interest. It is precisely to avoid this danger that I worked diligently with Kelley on increasing her awareness, directing her to her own therapy, and keeping Rick's treatment goals in the forefront.

Thus far, I have tried to clarify points in which I believe some misperceptions led Dr. Glezakos to believe that she and I were in disagreement, when in fact I do not think such disagreement exists. The final two sections, termination and the issue of dual relationships, are areas in which we do clearly have different perspectives.

Termination

Dr. Glezakos states that " In a planned termination, intense emotions from an earlier phase ought to weaken..." I think that Dr. Glezakos and I disagree about what constitutes "normal" attachment and therefore "normal" termination for beginning social workers.

Termination is an emotionally laden topic and significant phase of social work intervention. Some workers believe it to be the most important phase of work. Hepworth, et. al. state that. "the manner in which the helping relationship and process are concluded strongly influences whether clients maintain the progress they have achieved and continue to grow following formal termination" (1997). In Kramer's preface to *Positive Endings in Psychotherapy*, Sheridan states that endings can be difficult and complex for therapist and client alike. Kramer states that terminating a therapeutic relationship can be as difficult, or even more difficult, than ending any other relationship." He goes on to say that "the intricacies of a clinician-client relationship add to the complexities of closure..." Kramer also discusses the countertransference issues that are common for therapists in dealing with termination (1990). Ending long term therapeutic relationships, particularly with clients who have endured multiple abandonment in the past, adds additional challenges to the mix. This was the case with Kelley and Rick. I have spent a lot of time addressing termination in my work with students, both as a field liaison and as a field instructor. As always, we are role models for our students and the way we handle termination with them influences their termination with clients, colleagues, and their own students in years to come.

I do believe that there were some factors during Kelley's internship that served to increase the attachment of interns to the agency and to make the process of letting go more charged for all involved. There were seven interns at The Center that year, and four supervisors/field instructors. We participated in a weekly group supervision process that was rewarding for students and supervisors alike. It was also very challenging and contributed greatly to an increased sense of cohesion. Additionally, about one month before the academic year ended, there was a serious incidence of violence at The Center that affected line staff, interns, and clinical staff. This was a significant crisis which aroused feelings of anger, sadness, hopelessness, and helplessness in everyone. It is well documented that such crises have the potential to increase bonding among families and non-related groups as well, as people attempt to cope with emotional and practical outcomes.

In my years as a field instructor and as a field liaison, I have found that termination is an extremely difficult process for many students. They often do not understand the need for complete and final endings. Struggles are common regarding why they cannot maintain contact after their internship is over. Some students have asked to give clients their address or write to clients. I once had a student who wanted to tell a client a "white lie" regarding the reason they would not be meeting anymore, rather than being forthright about the limits of their professional relationship. Most often, while their questions are general, their desire to

remain in contact is around one "special" client. The fact that Kelley wished that she could continue to "be there" for Rick was not a feeling or wish unique to her. Most students I have worked with have had such an experience.

I agree with Dr. Glezakos that "when mental health practitioners accept their presence in a client's life as a single, purposeful, and time limited incident...terminations are less emotionally charged." However, I see this as a goal for the developing social worker to strive towards and have found it takes time and practice for many beginners. I also believe that the way we respond to terminations continues to be impacted by other events and phases of our lives, and that even seasoned workers revert to earlier responses, as I did during my experience with Kelley and Rick. As always, self-awareness and appropriate supervision and/or consultation is necessary so that the worker can maintain his/her effectiveness.

One final thought in regards to Dr. Glezakos' comments on termination. She stated that when emotions weaken as the relationship moves towards the termination phase, then the worker and client "can part with a sense of accomplishment, rather than with a feeling of loss." However, these are not mutually exclusive and my narrative makes clear that the termination involved both feelings of accomplishment and of loss. When relationships of any kind end, there is often a mixture of feelings evoked. Dr. Glezakos acknowledges this but at the same time expresses concern regarding the feelings of loss present in this situation and appears to negate or minimize the feelings of accomplishment and joy.

The Dual Role of the Supervisor

In my original narrative, I indicated that the style of my supervision with Kelley would be a source of controversy. In Dr. Glezakos response, she acknowledges the difficulty in defining boundaries between educational and therapeutic content in supervision. She states that our use of the countertransference journal introduced therapeutic content into supervision, thus creating a dual relationship. Yet I believe that therapeutic content is present in supervision regardless; the question was only how I would respond to that content. I discussed this in my narrative, referring to literature that supports this point of view while acknowledging the controversy regarding the extent to which such content should be addressed. Burns and Holloway (1989) wrote of the appropriateness of using counseling skills to assist supervisees in understanding their reactions and behaviors to clients, with the goal of enhancing practice effectiveness. Rubinstein again validates this view in her discussion of the parallel process of supervision and therapy. She explains that the differences are mainly those of goals; the goal of supervision being "the enhancement of the client's therapy rather than the supervisee's development as a private person" (1992). I reiterate here, I do not believe that the road I took in supervising Kelley would be right or appropriate or even possible for all supervisors and/or students. In using the countertransference journal, I needed to accept that I would be walking a fine line and to be committed to checking myself to be sure that I focused on the impact of Kelley's responses to her work with Rick in a way that maintained the boundaries of supervision. It also seems relevant to reiterate that I learned about the use of the journal in a training sponsored by The University of Southern California School of Social Work where Kelley was a student.

I agree that dual relationships are treacherous. For that very reason, I was especially cautious in my work with the journal so as to avoid such a relationship. Dr. Glezakos went on to state that because of my own issues, my judgment was colored and that I suggested the journal instead of consulting with colleagues. She also said that if my colleagues were unaware of the journal, then I would have been practicing selective disclosure and would be a poor role model for the students. I did consult with colleagues throughout, and they were aware of my use of the countertransference journal as an aid in Kelley's supervision. It most certainly would have been inappropriate for the journal to be a "secret" in any way. Furthermore, had I expected Kelley to

maintain such a secret, I would have been guilty of a serious exploitation of the power differential between us. This is not what occurred.

I acknowledge that Dr. Glezakos and I have significant differences of opinion regarding what the boundaries are between supervision and therapy and how to maintain them. But we are in full agreement regarding the need for these boundaries. I recently met with Kelley to discuss the commentary, and we discussed ways in which we talked in supervision so as not to cross the line. I always worked to be conscious of how I responded to Kelley, and to keep my supervisory questions and interventions focused on the impact on the client. For example, when Kelley wrote in her journal that she realized that Rick reminded her of some friends she'd known in college, I asked her how that might be impacting her work with him. I did not ask for deeper exploration of the issue of the friends in college, as that would have been clearly outside of the scope of supervision.

Conclusion

As I stated at the outset, Dr. Glezakos and I approach practice from different vantage points in significant ways. I agree that ethics and guidelines are absolutely necessary. Within those boundaries, however, there are many different ways of viewing and approaching practice situations.

Countertransference, an issue that was very present in my work with Kelley and Rick, is inevitable. Consciousness, I believe, is what can prevent countertransference from being harmful. Consciousness, on my part and Kelley's, is what I was after in this case.

On a number of occasions in her response, Dr. Glezakos commented that one issue or another, mine and Kelley's, compromised our competence and/or our objectivity. She seemed to imply that one should or even could be without such personal issues. But this is not possible. The issues that were raised in the original narrative were not unusual to social work students or to seasoned practitioners. What was unique was our willingness to make our experience public. □

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REFLECTIONS: SPECIAL ISSUE
RECOGNIZING DISABILITY AS DIVERSITY
SPECIAL EDITOR: THOMAS BUCARO

A special issue on the experience of "disability" and its recognition as an area of human differences along the axis of ability. The earliest cultural representations associated disability with sin and evil. Later, the representation of disability became associated with illness and deficit and function. This association, based on a medical model, assumed impairment and dominated the representation of disability in the education and training of academics and practitioners. Over recent decades, initiated by persons with disabilities, the cultural shift has been toward a social construction of disability, a minority group model that has in common with other minority collectives, themes of oppression and discrimination. This conceptualization of disability presents new visions for positive identification and opportunities for human actions. Disability as diversity is a cultural transformation not fully understood or accepted by academics and practitioners.

The images of persons with disabilities as social participators challenge long-held assumptions of practitioners. And, as the disabled have found their voice, their call for collaborative partnerships with practitioners and their demand for self determination are just beginning to be heard. In effect, practitioners are "at risk" of exercising acts of oppression and discrimination, even if intended to follow standards of practice or acts of kindness. It is an issue of critical importance for the helping professions as the population becomes aged, technology expands the prolongation of life, and the visibility of persons with disabilities expands as part of a worldwide disability-rights movement. We seek narratives about all levels of practice—service, social change, academics, and research–that helps us to understand, appreciate, and celebrate disability as diversity: Narratives about practice; about experiences that describe work that either failed or succeeded in informing and challenging negative images of the disabled; and existing modes of practice. The recognition of disability as diversity where it intersects with the helping professions brings us to a new level of discourse and the possibilities for narratives seem endless.

NARRATIVES:

- That portray practice (families, groups, communities, program/policy development with or for persons with disabilities).
- About the commonalty/ differences in practice across disabilities; and workers that experience disabilities.
- That show practice at different levels that contribute(d) to one's or to others' understanding of the experiences of discrimination because of disability.
- That focus on working, teaching, organizing, participating in, and collaborating with the disability culture: issues of language, pride and identification, choice and self advocacy.
- Practice narratives that depict experiences associated with "coming out" or "hiding out," and the meaning of the experience for persons with 'invisible' disabilities.
- About practice in affecting environmental and attitudinal barriers faced by persons with disability; their families; and technology that liberates/harms persons with disabilities.
- About direct/indirect practice issues of cumulative discrimination to persons with disabilities and members of other minority groups that portray the complexities that disability bring to families.

It is our belief that the present discourse on disability, as it cuts across all classes, sexes, races and ethnic groups, will serve to alter some of our basic conceptions of human concerns like gender, competency, power, dependency toward better understanding of all human relationships.

Manuscripts due March 31,1999. Send to:
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REFLECTIONS:

NARRATIVES OF PROFESSIONAL HELPING

Reflections: Narratives of Professional Helping (ISSN 1080-0220) is published quarterly by the University Press at California State University, Long Beach under the auspices of the Department of Social Work. Annual Subscription Rate: individuals, $30.00; libraries and institutions, $45.00; outside USA, add $15.00. Single copies: $12.00. Payment: check, money order, or credit card (Visa or MasterCard, please include number and expiration date). Please send to:

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The purpose of ***Reflections*** is to publish narratives, personal accounts that describe and explain the process of helping others and shaping social change over time. The journal seeks to build a literary tradition and a record of wisdom for critical study and fruitful discovery. It encourages stories that convey a sense of immediacy, portray practice across diverse populations and capture the range and variety of strategies and systems within the helping professions. Priority is given to articles that provide a new understanding of practice. The journal publishes stories of professional helpers such as ethicists, psychotherapists, community organizers, case and group workers, policy makers, family and child practitioners, health and mental healthcare providers; educators, researchers, and administrators in the helping professions.

The central theme of **Reflections** is narrative inquiry of professional practice. It publishes personal accounts of professional action designed to aid and support human and social development. The stories have a literary presence, offer new perspectives on practice, and demonstrate the conceit of failure as well as success. The narrator explains the reasons for the action and freely identifies the mistakes make in the practice. The purpose of the narrative is not to demonstrate achievement; rather, it is to capture the experience.

The narrative structure: A narrative is a story worth telling. Narratives are personal stories that give readers a fresh perspective about the practice of change. Written in a temporal sequence and or within a thematic structure; narratives recount the helping process. Narratives are explored within a contextual frame and supply a rich textural description of the experience, taking into account time, place, action, persons, behavior, and interaction. Narratives explain and describe event; results; conflicts; complicating actions; and how, why, and what was done. In narratives, the writer evaluates the experience, whether or not there is resolution, and fully explores the meaning of the experience. Some narratives end with a coda, that is, a perspective on what occured.

Writing Instructions and Submission: Manuscripts are peer reviewed. Articles appropriate to the journal'spurpose are reviewed anonymously by members of the Executive and Editorial Board. Articles are accepted based on their contribution to practice knowledge. Publication decisions require about four months.

1. Authors are expected to use the most recent APA publication format.
2. The manuscript length depends upon the temporal sequence of the event.
3. Include, on a seperate page, a brief abstract written in the same style as the narrative.
4. Place identifying information such as name, affiliation(s), title(s), address(es), phone/fax number(s), and email address(es) only on cover page.
5. Send three (3) printed double spaced hard copies of the manuscript to the editor.

Upon Acceptance of the article for publication, one (1) copy on disk in Microsoft Word or Text format and one (1) additional hard copy will be requested. Submission of narrative poetry, photography, and artwork is strongly encouraged.

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REFLECTIONS: NARRATIVES OF PROFESSIONAL HELPING

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