

## BARBARA

### A Story of Loss and Gain

*We sometimes see in our clients, parts of ourselves and want to make the parts available to the other. We have much to learn from each other. This narrative explores my work with Barbara.*

by Joan Beder

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I waited and watched by the window as I had for so many of my clients, to gauge the progress or rather the progression of the disease. In the early stages of cancer, most emerge from their car with a firm step, perhaps aided by the optimism promised by the doctors or before the debilitating effects of the chemotherapy have fully kicked in. As time goes on, for the majority of my clients, the chemo becomes more toxic or the radiation is too intense or the disease is gaining faster than had been predicted and the steps to get out of the car become more halting and painful. The short walk from the street to my door, which at one time would have been effortless, becomes another obstacle to overcome as ordinary things become major efforts.

The bulk of my social work counseling was with cancer patients and their families. I had been hired under a state grant to establish an outpatient community counseling program that offered supportive counseling and individual and group services.

The clients I worked with did not seek counseling in the early stages of their disease while their internal lines of defense were intact. Usually a client

sought counseling when they had begun to feel the debilitating effects of radiation and/or chemotherapy treatment, and were losing their optimism. As a supporter of the Kubler-Ross (1969) perspective, I acknowledge that coping mechanisms usually proceed in stages: denial and isolation, anger, bargaining, depression and acceptance; although not all clients go through all the stages and the stages are not necessarily followed in strict sequence. In my work, it was rare to see a client who was in the denial stage; it was more usual for a client to seek counsel from a position of anger, bargaining or depression.

The task for the worker, in the early phase of the counseling is to: assess and support the client's strengths, to create an atmosphere in which they are free to express concerns and even lament the situation, and to assess and strengthen the available support systems. For more seriously emotionally and physically compromised clients, additional worker supports are needed to address feelings of depression and anxiety, and to manage the illness. I define my role as a supportive element in the life of the client: sometimes as liaison with the family, as



someone with whom the client can explore the feelings surrounding the illness and offer unconditional support.

Barbara, the client who is the focus of this essay, was 38 years old when she was referred. The referral came to me because of my training in guided imagery. Guided imagery asks the patient to visualize the cancer, and create images to disarm the disease. The technique, as established by Carl and Stephanie Simonton (1977) is thought to be helpful in aiding the patient to direct cognitive energy on her/his own behalf. Although I believe the exercises are beneficial, I question the claims made by the Simontons, that this technique can 'cure' cancer. I was never satisfied by the design of the research which established this as fact. Nonetheless, there is value in supporting a cancer patient to use these techniques for stress reduction and to gain a sense of control. My concern, which I raise with a client, is the 'blame the victim' logic inherent in the technique which asserts that someone who effectively uses guided imagery can make their cancer go away. I reason that if someone has the power to make their cancer go away, did they do something to make it happen in the first place? The potential for a client to deduce a sense of blame from this technique becomes part of my discussion in orienting the client to the exercises.

An additional concern that prevents my wholehearted endorsement of any technique — guided imagery included — relates to the possibility for

despair when the hoped for results of a new intervention are not reached. Typically, a client begins a new or unconventional treatment with optimism, especially when the traditional forms of treatment do not work. When these nontraditional approaches fail, and options are in short supply, clients begin to lose hope. When I was contacted by friends of Barbara asking me to work with her and teach her guided imagery, I assumed that the client was seriously ill, had begun to doubt the efficacy of her current treatment regimen, and probably unable to deny the seriousness of her disease.

From my post at the window, I watched Barbara emerge from her car for our first visit. Wearing a turban to hide and protect her balding head she moved well, but was short of breath when finally seated in my office. I welcomed her and we began by my asking for the history of her illness and a description of how she was managing. The story she told related some of the facts of her life highlighting her recent medical history. A social activist she had been involved in setting up a variety of social programs in the county in which we both lived. Her current work was with a crisis hotline. She was articulate and appeared to have a zest for life. The mother of two sons, aged 10 and 13, she lived with her children as a single parent. She had an extensive network of friends, many people with whom she worked. Eight months before our first meeting, Barbara was diagnosed with Paget's disease, a deadly and

egregious form of breast cancer.

There had been many medical consultations and second and third opinions but this type of breast cancer is virulent and once it begins, is very difficult, if not impossible to stop. A mastectomy was not performed. She was advised to have aggressive chemotherapy which she had been under-going. She had lost her hair and some of her stamina to the chemotherapy. Emotionally she claimed that she was holding up. Her support system was fully mobilized, and provided care for her through most of the rough spots. Neither optimistic nor pessimistic she acknowledged that she was becoming worn down by the chemotherapy and its potent side effects. In response to my question — what she was most concerned about — her greatest fear was for her children in the event that she would not be 'able to beat this'. The hint of doubt usually signals the breakdown of denial, expressed through concern for her children. She did not dwell on her own fears, the weakening of her strength, or the difficulty with the side effects of the chemotherapy.

My approach when a client may not be grappling with or even fully aware of the severity of their condition is to support the client's denial as long as he/she was not neglecting the vital aspects of self-care. The assessment of the client's degree of 'grappling' is done through open-ended questions in which I ask the client what they think is 'really happening' to them. I urge them to report what the doctor told them and



note the types of questions that were asked. For example, I asked Barbara why she thought that a mastectomy had not been performed, she was not sure, and thought that it was not a good sign. Had she probed would have told me that she was ready to hear the answer: she would have known that it was too late for a mastectomy and the spread of disease was too great. I chose, based on the desire to support some degree of denial, not to push for further information. Barbara was following the doctor's orders and while aware of the seriousness of her situation, she had not allowed herself to think that the disease would kill her.

When I first began to work with this population, I was unclear how to use myself most effectively. I wondered what separated me, the social worker, from a close friend or family member who was there to offer support? I soon realized that the social work's unique function, was that the worker did not need to be protected from the client's emotional content. A client could rage, bemoan her/his fate, wail, express anger at those around them who were healthy, and the worker could receive this content without the client feeling that they were becoming a burden. The theme of being dependent and seen as a burden is a central emotional struggle for most seriously ill persons.

With this understanding, I often comment to a new client that they don't have to take care of me which has the effect of freeing the person to risk saying

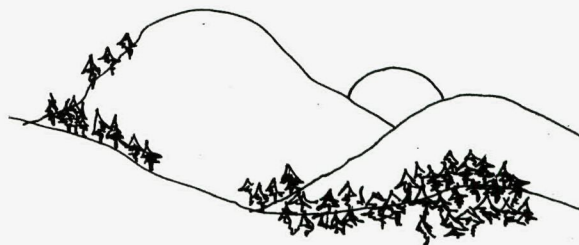
the unsayable. While this is liberating to the client, the effect on the worker can indeed be powerful as we struggle with the projected feelings of rage, frustration and despair. Barbara was very angry, lamented that she was beginning to feel cheated and fearful of facing her future. She worried that she was going to overtax her friends — her primary caregivers — there were no family members nearby. She did not want to upset her sons with her fear and dependency. Encouraged to speak about this she felt some relief from her emotional overload.

By the end of the first few sessions together, I had strong feelings about Barbara, concern, admiration and closeness. With many of my clients I was able to 'professionalize' the relationship and see them with a managed level of emotional connection. They are clients who are ill and while I care about them and work toward their welfare, I do not necessarily carry them with me. A protective distance insulates me from serious personal anguish, which in time would make continued work with this population impossible. It was difficult for me to establish a protective distance with Barbara. Perhaps there was too much overlap for me to be fully defended against my growing anxiety and sorrow over her situation. Our ages were within a year of each other, I had two sons, close in age to hers, and supported some of the causes Barbara championed — for me

to be fully defended against my growing anxiety and sorrow over her situation.

She wanted to put the imagery and relaxation exercises on hold, feeling that she would need to use them later on if her condition worsened. When I am able to reinforce a the client's decision I will. I did not feel that by delaying guided imagery she was neglecting an aspect of her care. Barbara stated that she was managing her emotional reactions, in some part because of our relationship, but more likely because she was between chemotherapies and had gained back a measure of inner strength.

Toward the end of the first month of our twice weekly meetings, I received a call from Barbara that she had been admitted to the hospital for chemo treatment because of her low blood count. I arranged to meet her at the hospital rather than miss our usual time. The hospital visit was a turning point for both of us. Since our meeting of a week before Barbara physically had lost ground, she had lost weight, was pale, weak and walked unsteadily. She looked 'sickly' and regrettably I noted her frailty and vulnerability. She spoke of weariness and growing sense of doom. During the meeting my own denial, which has sustained me





through many difficult situations, began to give way forcing the powerful recognition that Barbara was dying.

With those clients that I develop a bond and identify with, this moment of recognition is difficult. I struggle with impending loss, with existential and literal concerns about dying and losing people I care about, and the impotence of being unable to effect the outcome. Feelings of impotence are my way of recognizing my anger at the disease. Cancer robs those it touches of their well-being, vitality, dignity and often life. The recognition of its potential to rob, often guides my interventions toward empowerment. With the recognition of Barbara's terminal state, I had to try to consider, anew, where to professionally position myself in the life and dying of this client. Underlying the question of professional position, is the 'acceptance' that I am unable to stop what is happening, that it is going to progress no matter what I do. As Barbara's social worker, what could be my contribution to this inexorable reality? Should I help Barbara maintain optimism and hope or help her to face the reality of impending death? What did 'facing impending death' mean and entail, for Barbara and for me?

For Barbara, I was to learn, it was a time to solidify final plans and say good-bye. While for some clients it means planning and saying farewell, for others sinking into depression and withdrawing from life as life withdraws from them. For those

clients, the worker and others are often shut out. Our role is to remain in the client's life, by continuing to visit, retaining the position of confidante and recipient of emotional content; and engaging in difficult discussions on an emotional level.

When Barbara returned home from the hospital, she was seriously compromised. She needed home care and was unable to manage alone. Confined to bed, she was unable to care for herself or her children. The most recent chemo treatment had been totally ineffective in stopping the cancer. The support team of friends was fully operational to provide care for her and the children. I spoke with Barbara soon after her return and arranged a meeting at her home.

A friend met me at the front door and escorted me upstairs to Barbara's bedroom. It was early spring and the windows were open, the sun was streaming into the room. The change in Barbara was dramatic. She was in bed because she had to be; she was weak and hardly able to sit up. While she had lost a few more pounds, the more serious loss was of her spirit. The spark was gone and, with it, the ability to fight. Upon seeing her, my inscrutable demeanor sustained me from a more overt reaction while internally, I was deeply upset and horrified by the change. How could someone become so sick, so quickly? I asked how she was managing. She quickly indicated the agenda for our time together. "I want two things from you today" she began. "I want to learn a relaxation exercise to get me

through the very difficult periods of sleeplessness and fear and I want you to plan my memorial service with me." All pretense was gone. At her initiation, we spoke of the changes in her, of her fears for herself and her children. We discussed her memorial service, what she wanted read and by whom, the tone she wanted and the details of where it would be held. She explained what she had in mind and wanted to be certain that I would be there. She had shared some of these details with close friends but wanted me to have the full outline.

Taking my cues from her, I got into the details of the memorial service without exploring the emotional side. When we had finished planning, I asked her how she was managing emotionally. She said that she was exhausted, knew that the end was near and was afraid and relieved at the same time. She was comforted that we had arranged everything and could let go of all the details. I was starting to become overwhelmed and confused. The request to be involved in her memorial moved me beyond the role of support and counselor into new territory. This was unfamiliar terrain.

It was an odd feeling and yet one that relieved me. I had been given a niche in the dying process. I was the resource person with the overview. This was a first for me. I had been with many clients in their final weeks but never to this level of involvement. When a person is dying, they are either heavily medicated or in such a compromised situation, that they



are unable to relate as clearly as Barbara. Most of the time, I would continue to visit a client in the hospital or their home and would get a phone call from a family member informing me of the client's death. I had never been with someone when they died. I came to understand that in Barbara's case, I had become the surrogate family member, there were no others. While there were many close people in her life, none had assumed that position.

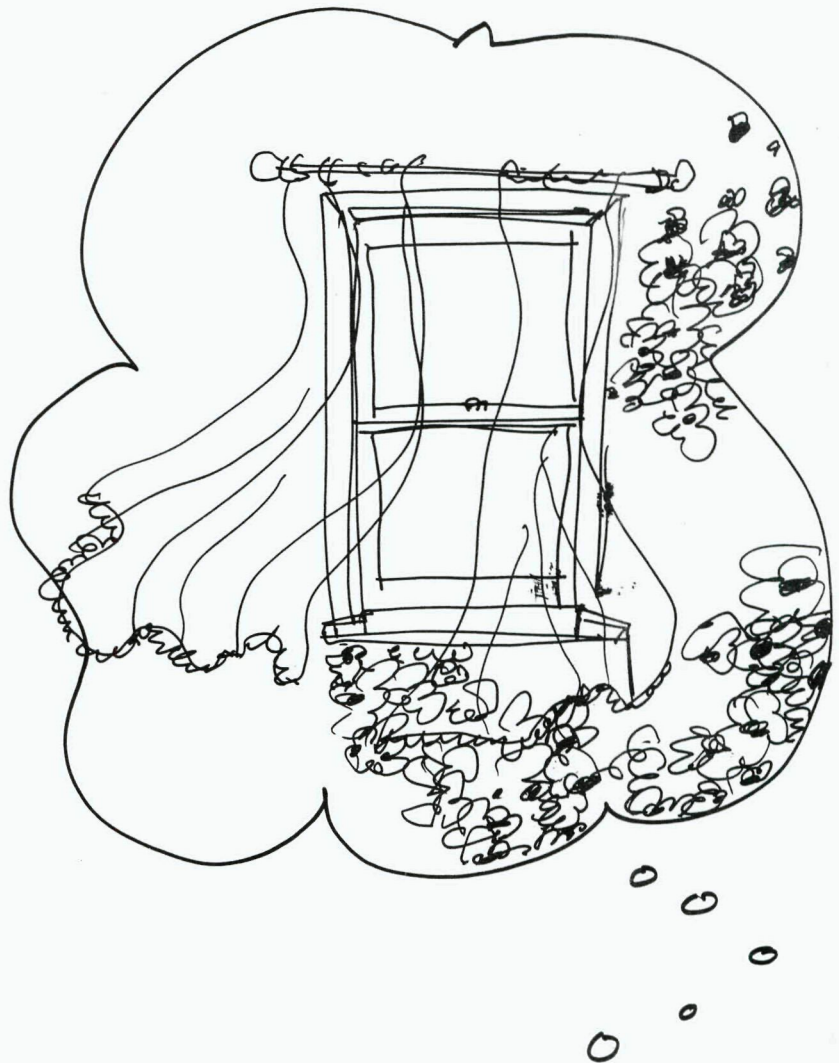
During this final home visit, we discussed relaxation and imagery exercises. She spoke of her fear and sleeplessness and I spoke of what could realistically be expected from a relaxation/imagery exercise. In the exercise, the individual imagines a scene which can produce a feeling of being relaxed as images are conjured. For many people, the imagined scene has a beach, water, mountains, a peaceful setting. I asked Barbara to describe a setting in which she felt safe, comfortable and relaxed. The setting would be the scene which she or I could 'place her' to begin the relaxation process. Barbara's imagery setting was the room in which we were sitting, it was warm with a cool breeze rustling the mauve curtains. The next detail of the setting asks the client to describe themselves within the scene. Barbara wanted to picture herself well and fit, on vacation, reading in her bed. The image of home was what she wanted and what she anticipated could relax her during a stressful time. In theory, once having the scene in

mind, the client or the worker in a soothing voice evokes the setting, places the individual in it and suggests a slow muscle relaxation. In some ways, it is mildly hypnotic as the person settles into this place of imagined well-being.

We tried the exercise and with her eyes closed, I described her scene and gently suggested that various tense points in her shoulders and neck should become relaxed and stress-free. She lay still for several minutes and as she opened her eyes, she said that she felt calmer than she had for some time. She said

that she planned to do this relaxation on her own, that she had felt it to be helpful. We arranged another home visit although that visit never took place. I left her home, sad and heavy hearted.

Three days later, I received a phone call from one of Barbara's close friends at the Hotline. Barbara had been hospitalized early that morning in intense pain, and wanted me to come to the hospital as soon as possible. The admitting doctor spoke in terms of hours, perhaps a day. Her brother had been summoned from Maryland.



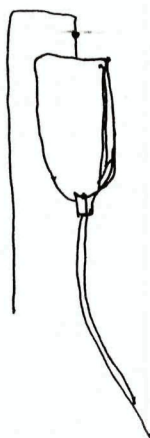


I arrived at the hospital to find a cluster of her friends outside the room. We could all hear her anguished cries and frequent screams as the nurses ministered to 'get her comfortable'. Her dearest friend went into the room. She came out a few moments later and told me to go to Barbara, alone. Despite dulling medication, she was alert and fighting to stay in control. She said "I need you to help me to say goodbye to all these people. I can't do this alone. I want you to help me by relaxing me when I am about to lose it. You know the exercise, with the breeze and the curtains and..." Yes, I knew the imagery but felt overwhelmed by the task Barbara had set for me. She wanted me by her side as she closed out the deepest relationship she had known, to calm and reassure her, to take care of her during this, the final hours. I remember thinking that there was nothing in my experience that prepared me for this task, no amount of schooling or training had readied me to help a person to die. The gamut of my feelings and emotions was extensive. I was frightened, in awe of what lay ahead, overwhelmed as people looked to me for direction and oddly proud of being given this degree of trust and responsibility.

One by one, she summoned her friends to her bedside. Periodically between the goodbyes she would draw me close to her saying "Bring me there, the curtains blowing and the warm breeze." I did as asked, evoking the images which indeed calmed her for the next

person. Many people came and went during those several hours. Barbara dozed for a brief period. I was exhausted by the emotion which I had witnessed and what I knew to be my own emotional overload.

I managed to remain collected until late afternoon when Barbara's children arrived with their father. Before she called in her children to hold them for the last time, she said to me "I don't know how I am going to do this but I must." I was aware that a drama of untold dimension was about to unfold. The goodbyes up to this one had been tearful and poignant and my work with Barbara was to soothe and strengthen her for the next one.



The children were different. She looked to me to give her whatever strength she could borrow to be with her children for the last time. I stroked her brow and reassured her that she could do this and that I would be in the room, by her bedside. I did not know what more to say or do to make this impossible task any easier.

Both boys came in at the same time. They were frightened and began crying as she pulled them to her. She rocked them for several minutes and used her waning energy to hug and kiss them. Few words were said. As Barbara began to fade, she said "I will miss you. I loved being your mother and I will love you forever." A final hug from each and they left the room. My heart still hurts as I recall this moment. The vivid pathos of that scene will remain with me forever. Barbara fell back to her pillow, spent. She reached for my hand and we sat quietly for a long time, both of us crying. She dozed. I was almost to the point of numbness as it was impossible to feel much more than what I had experienced in those moments.

The vigil was coming to an end. Her brother was expected by early evening. She turned to me and said "I have two more goodbyes, you and my brother. I want to thank you for all you have done. I will be able to deal with my brother by myself. You should leave. How do I thank you for giving me strength, for helping me do this?" I thanked her for the honor and teaching me about dignity and commitment. We hugged and I left the room dazed. I had been at the hospital for many hours. I was depleted while knowing that what had happened in those hours was a profound experience.

Barbara had managed to stay alert until her brother arrived and spent some time with him before slipping into a coma and dying several hours



later. The memorial service conducted according to Barbara's wishes, captured her essence and honored her. I cried for her during the service and silently thanked her for the privilege of participating in her life.

The work with Barbara occurred ten years ago. Over these years, I have thought of Barbara frequently and my role in her dying. In evaluating the experience, I think that I over-identified with her because of the similarities in our lives and lost some of my accustomed objectivity in my ability to be effective with her, although I don't know how different I would have been had the identification not been so strong. I know that I liked and respected her and had we met under other circumstances, we would have been fast friends. These are the hardest ones, the cases in which we see in our clients, parts of ourselves and want to make the parts available to the other. We had much to learn from each other. Barbara taught me about courage, I taught Barbara a one-time skill which allowed her to die with dignity and complete closure. My life and practice has been enhanced by having known her. □

## REFERENCES

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