



process, to facilitate psychological health during this tumultuous time, with their assessment, training, empathy, and communication skills (DeAngelis, 2002). There is a growing involvement of therapists in the end-of-life process (DeAngelis, 2002).

Many therapists who choose to do therapy with terminally ill patients are drawn to humanistic, client-centered, and existential therapies (Baum & Gallagher, 1987; Spira, 1997). Because of the emphasis on empowering clients in their own growth, client-centered therapy can produce particularly difficult ethical conflicts when the client is in a controlled environment, such as a prison. More specifically, these conflicts can arise when the institution uses the therapist. This conflict can be described as that of a dual role. On the one hand, the role of the therapist is to aid the client. On the other hand, the employment of the therapist requires that strict protocol and rules be followed to ensure the safety of the prison, and society at large. It is very important that therapists are clear concerning who the client is. "Individual and, increasingly, group therapeutic practice often occurs in a larger context of therapist, client, and an array of third parties including family members, employers, insurers, courts, and government agencies" (Smith-Bell & Winslade, 1999, p. 152). Outside of the prison environment, end-of-life care includes medical professionals, clergy, family, social workers, and attorneys. The unique setting of a prison creates an even larger number of individuals, including security staff, prison administrators, and (at times) even the governor. All of these individuals may have different beliefs about the end-of-life process and may control decisions made about the inmates' life. Mistrust is common on the part of the confined inmate, and also on the part of the security and health care staff. This mistrust leads to escalating difficulties on both sides, including depression and helplessness in a terminally ill inmate and anger and burn-out in staff members. In this milieu of mistrust, a therapist must be clear and honest with everyone she works with, and explain her role.

The American Psychological Association (APA) Code of Ethics (1992) stated:

Principle B: Integrity . . . Psychologists strive to be aware of their own belief systems, values, needs, and limitations and the effect of these on their work. To the extent feasible, they attempt to clarify for relevant parties the roles they are performing and to function appropriately in accordance with those roles. (p. 1599)

The APA Code further indicated:

1.21 Third-Party Requests for Services.

- a) When a psychologist agrees to provide services to a person or entity at the request of a third party, the psychologist clarifies to the extent feasible, at the outset of the service, the nature of the relationship with each party. This clarification includes the role of the psychologist (such as therapist, organizational consultant, diagnostician, or expert witness), the probable uses of the services provided or the information obtained and the fact that there may be limits to confidentiality.
- b) If there is a foreseeable risk of the psychologist's being called upon to perform conflicting roles because of the involvement of a third party, the psychologist clarifies the nature and direction of his or her responsibilities, keeps all parties appropriately informed as matters develop, and resolves the situation in accordance with this Ethics Code. (p. 1603)

In other professional codes of ethics, the arrangement with third parties is also clearly described. The American Counseling Association (1995) stated:

D.1. Relationships With Employers and Employees

a. Role Definition. Counselors define and describe for their employers and employees the parameters and levels of their professional roles.

D.4. Subcontractor Arrangements

When counselors work as subcontractors for counseling services for a third party, they have a duty to inform clients of the limitations of confidentiality that the organization may place on counselors in providing counseling services to clients. (p. 11)

The National Association of Social Workers (NASW; 1999) also considers the commitment to employers and its ethical implications. The NASW states:

3.09 Commitments to Employers

- (a) Social workers generally should adhere to commitments made to employers and employing organizations.
- (c) Social workers should take reasonable steps to ensure that employers are aware of social workers' ethical obligations as set forth in the NASW Code of Ethics and of the implications of those obligations for social work practice.
- (d) Social workers should not allow an employing organization's policies, procedures, regulations, or administrative orders to interfere with their ethical practice of social work. Social workers should take reasonable steps to ensure that their employing organizations' practices are consistent with the NASW Code of Ethics. (p. 41)

The following case study explores some of the ethical issues that arose during the treatment of a terminally ill inmate, and how those ethical issues were resolved in a manner congruent with both concern for the mental health of the inmate, and the appropriate adherence to Department of Corrections protocol.

### **Case Study**

W.<sup>1</sup> was an inmate serving a life sentence. When I began working with him, he had already been diagnosed with end-stage cancer, yet had survived for some years since the diagnosis. He lived for another six months and we met every one to two weeks. My approach was experiential, although we also discussed cognitive-behavioral strategies for handling specific problems, from anxiety to interacting with medical staff.

Several group therapies have developed for terminally ill persons, drawing on the insights of existential therapy (Greenstein & Breitbart, 2000; Spira, 1997; for reviews, see Baum & Gallagher, 1987; Richman, 1995). These therapies attempt to help terminally ill individuals recognize what is meaningful about their experiences. By determining what is meaningful to them, they are therefore able to decide what they value and how to prioritize goals in their current lives. In order to clarify how W. understood his illness in our first session, I asked him to explain the cause of his illness. He explained:

It's like my friend who just died last week. I told him he made me sick and turned away from him because he would not even try, he would just lay there and cry like little baby and blame every one else for his sickness. No one gave him the cancer, he got it from smoking. It's like me. If I really wanted to I could sue the health service because I kept telling them for over one year that something was wrong and they would tell me nothing was wrong, to go back and shut up and stop bothering them. So finally when someone did listen to me it was too late and they could not cure me or even help me. What's so funny is they had already taken our smokes from us 5 months before the cancer started. But then I knew what I was up against by smoking, so it's still my own fault this happened. And I will not go easy, that's for sure, and not before my time. They all tell me, "How are you still alive?"

<sup>1</sup>The name and some details have been changed in order to maintain confidentiality of the client.

The personal meaning for the cause of the terminal illness was important to W. He vacillated between blaming the system in which he was imprisoned and his own behavior. Blaming oneself can be easier than allowing others to have responsibility for events, or acknowledging that events can be random, because it gives a sense of control (Janoff-Bulman, 1992). At the beginning of therapy, W. was very angry and depressed. Blaming himself or the environment led to more anger. Focusing on the loss of control over his health led to more depression.

In the book *Man's Search for Meaning* (Frankl, 1939/1963), Victor Frankl wrote of the horrors of life imprisoned and the clarification of what was meaningful for himself and his fellow prisoners.

A man who let himself decline because he could not see any future goal found himself occupied with retrospective thoughts. In a different connection, we have already spoken of the tendency there was to look into the past, to help make the present, with all its horrors, less real. But in robbing the present of its reality there lay a certain danger. It became easy to overlook the opportunities to make something positive of camp life, opportunities which really did exist. Regarding our "provisional existence" as unreal was in itself an important factor in causing the prisoners to lose their hold on life; everything in a way became pointless. Such people forgot that often it is in just such an exceptionally difficult external situation which gives man the opportunity to grow spiritually beyond himself. Instead of taking the camp's difficulties as a test of their inner strength, they did not take their life seriously and despised it as something of no consequence. They preferred to close their eyes and to live in the past. Life for such people became meaningless. (p. 113)

Similarly one goal of terminally ill inmates may be to find meaning in their lives, and mental health professionals are in a unique position to facilitate this search. In the sessions with W., we focused on the small goals over which he did have control and enjoying the life he had left. The anger he felt gave him a great deal of perseverance, as indicated by his statement "I will not go easy, and not before my time." When directed, it was this perseverance that allowed him to find and pursue his goals.

### *Pain Management*

W. exemplified the effect of attitude on mental and physical health. Most meaningful to him was being released from prison, and toward this end he wanted to survive as long as possible. When I asked him what he needed most, he responded:

It's like this. When someone is dying they really need to have someone who will listen to them because we become very lonely and full of questions. Like what if, how you think I will die, how long do you think I have? The least little thing happens to you, you start letting yourself think, "This is it!!" I do not want to die here in prison.

His desire and firm belief that he would be released motivated every part of every day. W. had very clear ideas about how to improve his survival. For him, survival was more important than outward signs of a good quality of life. His emphasis on this portion of the trade-off was because he believed that the length of time he survived increased the likelihood of his release, his primary goal.

A surprising interaction of the incarceration environment and W.'s experience was the connection that he, like many of the inmates, felt to their physical bodies. In an environment with so few resources, having control over one's body has profound meanings attached. Many of the inmates had special meditation or exercise routines, and this proved very beneficial in dealing with pain and bodily changes. W. had been a competitive athlete for most of his life and was very skilled at perceiving his particular level of tolerance. He was able to describe changes to his body in incredible detail, and he often chose to tolerate pain.

The nursing staff was concerned that W.'s refusal of increased pain medication during some episodes was because of denial that he was terminally ill. They wanted him to go to an off-site hospital for pain medication that they could not provide at the prison because of its classification as a controlled substance. The nurses suggested to me that my role was to get him to accept his terminal status, and then he would accept more pain medication. They felt that as a prison employee, I should be able to convince him to comply with their level of medical treatment.

It was not immediately clear to me that this issue was an ethical dilemma. It was common for me to teach inmates improved communication skills to behave appropriately and/or assertively in eliciting the health care they needed. However, I came to realize that the nurses had placed W. in the category of "denial". Many terminally ill persons use denial to protect others and preserve relationships (Connor, 1992). Once the nurses believed he was "in denial", his behavior was interpreted in light of this category.

As a fellow healthcare worker, I was expected to coerce him into changing his behavior, and accepting the level of pain medication. I

knew that it had become an ethical conflict when I found that I had trouble proceeding in my session with W. I felt an obligation to the prison staff and the pain protocols that the nurses followed. However, I felt an obligation to the goals of my client. I was caught in a dual role.

It has been shown that the meaning of the pain to the patient is a strong predictor of how much pain is subjectively experienced (Barkwell, 1991). For me, questioning W. further clarified the situation:

They want me to go to the hospital for pain control. But I am not going. I would rather stay here. Up there they just leave you chained to a bed and forget about you. It's [the pain episode] only happened 3 times so far and it only lasts for about 30 minutes. Most of it is my ear. It is swollen shut. Well, I am not trying to put off the dying part but I am trying to live what is left the best I can. But running to the hospital is not going to help any at all.

For W., the increase in medication or transport to the hospital for pain control indicated a loss of control. Like many terminally ill patients, W. was afraid of being over-medicated. He preferred his alert mental status to reduced pain. An alert mental status meant he was progressing toward his goal (survival until release). Despite some physical pain, the goal-directed behavior induced a more positive emotional state. Through clarification we were able to come to a compromise. The nurses agreed to rely on W.'s subjective pain reports. W. agreed to the following protocol:

Just give me the Tylenol-3 and let me out to move around and I will work it out. The pain on my temple becomes more than what I can handle all at once . . . When it becomes more than what I can deal with then I will say, "Let's go to the hospital."

This situation brought to light several ethical issues with regard to patients' rights when the patient is incarcerated. Clarifying the therapist's role to the staff (i.e., valuing the goals of the client) and clarifying the therapist's role to the client (i.e., adhering to a pain management protocol) was vital to the solution of this dilemma. In addition, empathy for the inmate and for the nurses allowed the underlying meaning of the proposed actions (e.g., increased pain medication or transport to the hospital) to be discovered. W. saw increased medication as thwarting his goal of an alert mental status, and he was willing to tolerate subjectively minor increases in pain. The nurses perceived W.'s outward signs of pain as an indication that they needed to increase medication in accordance with their pain management protocol. Although pain reduction was an admirable goal, the breakdown of communication

prevented W's true motivation to be included. An ethical compromise was achieved that upheld responsibilities both to the client and the institution.

### *Compassionate Release*

Clarifying what is meaningful to an individual puts into relief what goals the individual values and prioritizes. Because of the nature of limited time and energy in the latter stages of a terminal illness, the importance of those goals may become greater each day. But how do we handle the situation when the goals of a terminally ill inmate and the goals of the institution may conflict? On the one hand, mental health and quality of life can be greatly improved by goal-directed activity (Fawzy, Hyun, & Wheeler, 1997). On the other hand, the goals of inmates often include control over one's medical care or release from prison and these goals are often disallowed because of imprisonment. The National Institute of Corrections (Anno, 2001) stated:

Biomedical ethics is based on patient choice because the patient has the overwhelming moral authority in matters affecting his or her body and mind. But the very foundation of correctional philosophy is that someone other than the inmate has the ultimate say over his or her behavior, movement, and personal decisions. (p. 70)

The motivating goal for W. was compassionate release. The most important daily task for W. was survival, because survival meant a chance of release. Consequently, the effort to control his physical body was enormous. He asked constantly for information about his physical status, as a kind of biofeedback. This type of monitoring has been documented as a way that persons with late-stage cancer exert control over their situation (Lewis, Haberman, & Wallhagen, 1987). When I asked him what advice he would give to others who were terminally ill, he replied:

Everybody has to find what works for them. But first you have to have the want to live to put the time into it. It's like I have to make myself eat. They told me when my vitals started to go then I would know it's close to my time. Well, that started 2 weeks ago so I asked what makes each one so I can put a game plan together and each time bring [my vital signs] back to normal, or close. In the morning it is a little low so in the afternoon when they do it again I will have it back to normal. Lack of water will bring it down so I add a little more. Getting excited or thinking too hard about something not good will make it high. So when you find out, stop and then think what you were doing so you do not do it



again. It's mainly self control. Being aware of what you want in life and how bad you want it.

Accepting and supporting W.'s goal of compassionate release was my primary focus in our first sessions. In a client-centered approach, it is important to accept how the client views his situation. Seeing through the client's lens is vital, even while seeing a future for the client when he may have a different perspective. I knew that goals change frequently, almost weekly, when physical health is declining. I tried to remain very rooted in the present in our sessions, and discussed his current state and the meaning of his current goals. Because he had come to trust that I was supportive of his goals, he paradoxically was able to discuss other possibilities when the likelihood of release dwindled. In the second of his six months, he stated:

It does not look like they're going to let me out and I still have one year for a work furlough, two years for parole . . . I already told them that when it's time to just leave me alone, do not try to save me or any machine . . . My vitals are still perfect . . . Thank you for coming and I will see you next time, so take care, because I still have a lot of fight left in me. One way or another I will still be here, and up and around.

As the months passed, there was no response to his petition for compassionate release. W. held onto every shred of hope, through comments of correctional officers and administrators. He became convinced that the Lord had already granted his goal of release, and this idea brought him a great deal of peace. In one of the first sessions that he mentioned this spiritual aspect, he reported:

Friday I talked to a guy . . . and he said first thing Monday he would get started on trying to get me out. But I am not looking to that. The Lord will send me home—free. He will touch everyone involved's heart to let me out this time.

Because of the nature of the crime W. had committed, it was never clear that he would be granted a compassionate release. Inmates in some systems are able to apply for compassionate release when they are determined to be terminally ill. However, there are many hurdles before that application is granted. The National Institute of Corrections (Anno, 2001) indicates that the use of compassionate release is complicated:

Many judges and state officials are reluctant to release inmates until it is clear that their physical disabilities will preclude their return to antisocial behavior.

Often, by the time that marker is reached, inmates may be too sick to benefit from their release. (p. 77)

Although I had to decide for myself about the societal implications of compassionate release, I deemed this irrelevant to working with W. therapeutically. In client-centered therapy, therapists strive to keep their own personal values separate from supporting clients in their own growth. I knew, however, that the chances of his release were slim at best. Although I supported him in his pursuit of the goal of release, I was simultaneously able to reinforce the real possibility that he would not be released.

The goal of release had many underlying meanings for W., but it was wrapped into a single, identifiable event. By discussing what he would do after his release, we were also discussing what was important for him to complete prior to his death, without regard to where he was when his death took place. W. often had vivid images, and he summarized one this way:

The main thing is to try and live as long as I can. I can feel it coming though, and it's not far away . . . Like that doctor said . . . I had from 1–10 days to live . . . Then he said a month at the most and that's more like it . . . I believe in my heart the Lord will get me out. I will find my family even though they all know and said, "So what." I will find them and tell them that I am not mad after all. I am the one who got into trouble so I will still ask for forgiveness and then it's on them.

We discussed the possibility of writing to his family, or working with his family to have them visit him inside. For him, these possibilities were not the same as seeing them in person when he had been released. The goal of making things right with other people came to mean something different when it appeared that he was not going to get to see his family. Then the other inmates and staff became more meaningful to him, and resolution concerned his attitude toward people in general. One day I asked him how he would like to be remembered. He responded:

I would like to show people how to be strong inside and never give up, no matter how it looks. Most of all put your love and trust in the Lord for he will never let you down or hurt you as long as you believe with all your heart and keep your faith and good things will come your way.

Eventually a decision was reached regarding W.'s request for compassionate release. His request was denied. Although this decision would

block W. from his ultimate goal, the worst part of the ethical dilemma for me had only begun. I felt a relief that a decision had finally been reached. Although the relief experienced after a decision not in one's favor is not the same as achievement of the goal, the end result may still be the cessation of worry and tension. However, W. was not to be given the same relief. The administration indicated that I was not to tell him about the decision, because they believed that it was wrong to give him bad news. They believed that he would die more peacefully without knowing that his release had been denied.

As an employee of the prison, I was bound to the decisions of the institution. It had been made very clear to me that I was not allowed to tell him. It is vital to the security of a correctional facility that the administration not only control the movement of persons, but also of information. And yet, I knew that W. could not accept his death until he knew the outcome of the request, for better or for worse. He had already proven that he was able to hold on physically far past most human limits. He re-iterated "never give up" in many ways and many times. Seeing him was very conflictual for me, as I felt that I had to be deceitful even with simple evasion. I did see him twice during the time that I knew of the decision but was not able to tell him, but at least my presence was comforting to him (Richman, 1995).

As a therapist I was ethically obligated to help him, and I believed that the waiting was creating more depression than the denial of his request would. He needed the relief that I had been able to experience when the decision was handed down. He needed the information in order to move onto the next goal, the goal of a good death. He reported on one of the occasions that I visited him:

I am just lost with all this waiting. Yesterday they had to leave my door open, even last night they had to leave it open. I was just real depressed. I walked and walked until I could not walk any more, then I finally went to sleep. My vitals is way down again today.

I engaged in a great deal of consultation with other mental health professionals about the constraints and obligations of my role. My deliberation concerned autonomy, or the rights of the individual, and professional responsibility, or fidelity to the institution (American Psychological Association, 1992). As with all ethical dilemmas, two values came into conflict. Both values, autonomy and fidelity, were worthy of upholding. As is the case with any situation where two good

values are in conflict, there are numerous possible solutions. Moral individuals could come out in favor of many of these solutions.

Thus, I also had heartfelt discussions with the administration. I attempted to clarify both the end-of-life process and the meaning of a compassionate release to W. Finally, I was given permission to tell him that his release had been denied. As I had expected, his attitude became one of acceptance. A couple of days after he received the news, he stated:

Well, this morning . . . I went out to smoke and could not smoke. The tumor in my mouth is so big it has my lips turned and my throat is completely closed off so I cannot inhale through my mouth. Nothing is going right at all. I cannot go home, cannot eat, drink, smoke, talk. The only ones that even want to talk to me or listen to me is you and [another staff member]. The others go the other way. I am going to talk to my friend Sunday and decide what to do. I want to let go, but how? I have been a fighter all my life. I feel good, my vitals are all the way back up. I do not want to do anything against the Lord. So what do I do? Wait until the next time I start bleeding and just let it go . . . I sleep at least 18 to 19 hours a day . . . I do not think it's too far anyway . . . This guy that was here when I first got here . . . said it will happen in my sleep . . . I guess all I can do is wait. If something happens while I am awake then I will just let it go that way. They said next time would be it anyway. I sure wanted out.

There was no longer anger or depression in his tone, simply acceptance. Finally, he was able to conceive of what letting go might be like and of how to stop fighting. He had shifted to a place where he could see the advantages to not fighting any longer. W. died very peacefully several days later.

### **Conclusion**

Although ethical conflicts can arise during the psychotherapy of terminally ill inmates, this case study has attempted to illustrate how these conflicts can be resolved in compliance with the APA Code of Ethics, the mental health concerns of the inmate, and the rules and protocols of the prison institution. This conflict can occur when the personal meaning important to an inmate's mental health at the end-of-life is contrary to the necessary rules of safe conduct of the prison environment. Foremost, the clarification of the therapist's role to both the inmate and prison staff is vitally important. In addition, consultation on these (as with all) ethical matters is crucial to creating new and creative solutions. Finally, careful listening and empathy for all parties

involved, an acceptance of both the goals and meaning of a situation, as well as the reality of the rules and procedures, may create new opportunities for solutions or change.

The end of life is a time when very little personal control is available. In a prison environment, there is even less. And yet it is the quest for meaningful existence that allows the terminally ill inmate to fully live out his last days and months. It is the role of the mental health professional to help the inmate find sources of meaning, and accept the anger, depression and grief that he will experience. The value of this difficult, yet rewarding process can be seen in the acceptance and growth demonstrated by both clients and caregivers in coping with the final stages of life.

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