

## Working at the End of Life: Providing Clinically Based Psychosocial Care

Joan Berzoff

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**Abstract** Social workers who provide end-of-life care do not always see themselves as clinicians. This paper identifies what is clinical in work with the dying. Social workers routinely elicit sources of cultural and psychological ways of coping, tolerate difficult and painful affects, and balance hope with compassion. They work in multidisciplinary teams and on every level (individual, family, and systemically) to avoid splitting or blame. Further, dying is a relational event. Social workers who work with the dying often stand in the most intimate spaces and therefore use themselves intersubjectively. This work requires considerable courage and self-care.

**Keywords** Clinical care of the dying · Intersubjectivity · Self-care

### Introduction

Over the last 7 years, I have taught over 137 post-Masters social workers in an intensive program on end-of-life care. The most recent class consisted of 24 social workers who had an average of eight-and-a-half years of clinical experience. As this group described their work in hospice and palliative care, in medical social work, in home health care, in nursing homes, and in outpatient bereavement, one member of the class said, “I am here to learn how to do

clinical social work.” The desire to learn how to do clinical social work and the disavowal or lack of recognition of the clinical nature of the current work that they were doing has been a theme throughout these 7 years, and one that has left me curious about how these professionals understand and think about their work. Clearly they see the work that they are doing as social care, but not always do they see it as clinically informed psychosocial care.

As always, we went around the room and talked about what each participant did in his or her work. Each of the 24 clinicians described struggling to honor the unique and individual ways their clients were living and dying within high-paced environments that rarely saw their patients as multidimensional or as more than the sum of their illnesses. Most talked about coming from a strengths perspective and helping the client elicit, develop, and maintain strengths as their worlds shrunk to the four walls of a hospital room or a home hospice. Some talked about challenges in containing hope balanced with compassion and reality. Many described practices as offering their presence to the dying and their families. Many talked about helping clients navigate the health care systems, about helping doctors and nurses not to see death as failure, and about the importance of collaboration and communication with the interdisciplinary teams. Others talked about the ways in which they helped families and patients make complex transitions from hospital to hospice or to a nursing home with dignity. Most talked about advocating for patients and families who were disenfranchised by race, class, sexual orientation, or by grief. They described entering work with the dying as a sacred and intimate space. Almost all said that the work continually changed them.

In their musings, it seemed to me that they were describing the essence of clinically based psychosocial care. At the core of work were helping relationships: with

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Author of 3 books: *Living with Dying* (2004); *Inside Out and Outside In* (1996); *Dissociative Identity Disorder* (1995); and many publications. Has presented nationally and internationally.

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J. Berzoff (✉)  
Smith College School for Social Work, Lilly Hall,  
Northampton, MA 01063, USA  
e-mail: jberzoff@email.smith.edu

patients, families, staff, physicians, nurses, chaplains, institutions, and communities. Less processed, however, were their own countertransference reactions to the work, which were often neglected or ignored in light of high expectations for productivity. Without the language to appreciate and value what they were doing, without colleagues with whom they could share the work and the emotional reactions to it, without the legitimacy of mentors and supervisors, they were not seeing themselves as clinicians nor were they appreciating that the holistic ways of approaching clients embodied the best of quality psychosocial care.

### **The Limits of Social Work Education in End of Life Care**

So why did this group of seasoned end-of-life practitioners need to learn “clinical” social work? In part, the answer lies in that none of the 24 “students” in the room had ever had any formal training in end-of-life care during their Masters Programs. Christ and Sormanti (2000) have documented the very limited curricular offerings in end-of-life care in schools of social work. While many schools offer one elective on death, dying, and bereavement, there has been less attention to end-of-life issues. In fact, in a survey of 19,223 pages of content in social work textbooks, Kramer et al. (2003) found that only a little more than 3% of the content addressed the end of life.

Furthermore, according to a report from the Robert Wood Johnson Foundation in (2002), the state of end-of-life care itself has been inadequate at best. About 70% of Americans say that they want to die at home, but only 25% do. Half of all deaths occur in hospitals, but less than 69% of hospitals offer specialized end-of-life care. Most states have only a fair hospice use and only 12–25% of deaths occur in hospices. One-half of all dying people experience severe pain. A study of cancer patients in ICUs found that 75% had pain, discomfort, anxiety, sleep disturbances, and unsatisfied hunger or thirst. Emotional and spiritual care for families and patients that respects cultures and traditions are essential parts of the dying experience, but are not generally available (The Support Study 2002).

Given these findings and the limitations in curriculum in end-of-life care, it is worth noting that only two schools (Smith College and NYU Schools of Social Work) offer Post-Masters Certificate Programs in End-of-Life Care. It is no wonder that these social workers had a hard time valuing their knowledge and expertise, and identifying the work as truly clinical and psychosocial. Furthermore, it should be noted that end-of-life care does not just take place in palliative care, hospices, nursing homes, and on medical floors. All clinical social workers encounter death,

dying, and bereavement wherever they work: in schools, prisons, in wartime combat, in mental health settings, hospitals, child welfare, substance abuse, inpatient units, or any other realm where people live. Many clients come to agencies for reasons other than a dying relative, but death in the family then emerges as an issue. The one indisputable fact is that all of us will die. We may die young or old, or from a dreaded disease or accident, or from a chronic condition or by an act of violence by another or against the self. Yet how to work psychosocially with the dying has been relegated to on-the-job training. Many social workers in end-of-life care describe “learning on the fly” or teaching themselves. Without Masters or post-Masters training that identifies their native knowledge and grounds it in clinical theories that are narrative, psychodynamic, existential, systems oriented, and spiritual, many social workers and health care professionals do not see what they do as legitimate and valuable (Barnard 1995).

### **Goals**

In this paper, then, I will consider what is psychosocial about end-of-life care. I will discuss how social workers who work with the dying elicit a terminally ill person’s and family’s sources of strength, joy, their cultural and psychological ways of coping. I will maintain that working with multidisciplinary teams requires a high level of clinical skill. I will consider how clinicians create transitional spaces and holding environments. I will address how social workers in end-of-life care have to be able to tolerate difficult and contradictory affects—containing hope, bearing uncertainty, tolerating ambiguity, and avoiding splitting or blame. I will talk about how dying is always a relational event and how the practitioner is always changed by it. I will suggest that end-of-life care requires considerable self-knowledge and self-awareness. Finally, I will address the needs for the clinician’s self-care, which includes on-going training and renewal as essential to providing care to the dying.

### **The Personal is the Professional**

Social workers tend to be drawn to work with the dying out of their own loss experiences. There is a considerable literature on the “wounded healer” (Nouwen 1979) where the practitioner is portrayed as reworking past experiences in the present with new outcomes. However, to my mind, the concept of a “wounded” healer pathologizes the clinician who works with the dying. Dying is not a pathological event, just an inevitable one. Those who choose to work with the dying have stories about how they came to the

work. Sometimes they say that the work chose them. Often they say that loss experiences changed them and that they needed to give something back. Many felt disenfranchised in grief. Some lost children, husbands, parents, or siblings, and work with the dying offers meaning to one's own losses.

Almost every “student” (and by this I mean social work professional) with whom I have worked has noted the centrality of the relationship to the work. Being able to tolerate a client's or family's suffering in the face of a terminal illness, being present after an unexpected or violent death, being with a family facing the loss of a child, helping a family to decide to withdraw life supports when a parent of young children is dying in the ICU, helping a family make the decision to go to a nursing home, working with adolescents who are dying, all require a particular kind of presence. Facing death can be terrifying and disorganizing. Work with the dying revives the clinician's past losses and fears of future losses (Cincotta 2004). Being present means tolerating one's own anxiety about death (Rando 1984) in order to be able to help clients and families to tolerate their own. Psychosocial work with the dying, then, requires being in a relationship with a client and family, located within their culture, religion and beliefs, in which the clinician is able to tolerate a range of affects, including her own anxiety. This work is not for the faint of heart.

Sometimes, providing end-of-life care is also narrative work. Often very sick patients or their families need to tell their stories, sometimes again and again, in order to make meaning out of their circumstances (Browning 2004; Neimeyer 2002). As is true in working with clients who are traumatized, the clinician who works with the dying may be vicariously traumatized by the cumulative losses that are part of the work. Often the clinician becomes the container for the fear or helplessness that clients cannot bear (Ogden 1996). Professionals who work with the dying may experience countertransference feelings such as aversion, shame, anger, sorrow, and the wish for those feelings to go away (Arora et al. 2006). These countertransference reactions must be surfaced. Often they provide an empathic window into the client and family's experience of shame, dread, or aversion. Often they inhibit the work and lead to the clinician's unconscious withdrawal or anger. Yet if these countertransference responses can be shared, in supervision or in peer led groups, the fears, anxieties, dread, and hate can be demystified, tolerated, and held, and the clinician can return to the work, less burdened and with less compassion fatigue. The work requires staying present and tolerating suffering. Staying in the work, which can happen when countertransference reactions are made conscious, can limit distancing or dissociating. In order to stay with the client's narrative, the social worker needs to find

some coherent meaning in the story and allow it to become a part of a larger narrative of the social worker's professional experience. Working in isolation, without supervision or peers with whom to share countertransference reactions, can undermine any grounded sense of the work and makes it easy to become overwhelmed or disorganized by the stories.

### **What Do Clinicians Need to Know to Provide the Best Psychosocial Care?**

Clinicians in end-of-life care need to be well versed in biopsychosocial assessment. They need to be able to assess ego functions, defenses, judgment, reality testing, mastery, depression, anxiety, trauma, and underlying mental illnesses. They need to know the courses of their clients' illnesses and the effects of medication. They need to be able to examine how the dying person and family adapt to their environments, be they hospitals or hospices, home care or nursing homes, and the degree to which the environment does or does not adapt to them (Hartmann 1939). Often the work requires mobilizing resources on behalf of a patient or family. Sometimes the work is helping patients and families mobilize on their own behalf. For example, Foster and Mendel (1979) wrote about initiating self-help groups for patients with COPD in a VA hospital. The groups had two functions: one was to provide coping and support to patients who were experiencing the same frightening and debilitating illnesses; the other was to change the institution in which the patients were suffering. The goals of mobilizing individual resources and collective resources, of course, activated a sense of mastery and competence (White 1971) in the group's patients and led to institutional changes.

### **System(s) of Care**

Clinicians who work with dying are always working in systems: family systems, institutional systems, cultural, and spiritual systems. Sometimes the work is facilitative: helping a team to hear a patient; enlisting the help of families in end-of-life care decision making; helping patients, families, and staff to concur around discharge planning; and including patients in team meetings. In medical settings that are more hierarchical, the work is often slightly more subversive. In such settings, social workers may engage family members as co-teachers and co-learners, thus helping them to deconstruct the authoritarian medical model so that they can be a part of shared decision making (Browning and Solomon 2006).

Whether a social worker works with pediatric palliative care or with the frail elderly, he or she needs to be flexible and fluid, able to maintain boundaries and able to suspend them.

Danielle was 57 years old and dying of renal failure. Her twenty-two-year-old daughter was about to be married. Danielle wanted desperately to see her daughter launched, so she and her social worker planned the wedding, the menu, the flowers, and the guest list, and the social worker arranged to have it take place at her bedside. Danielle's close family was present for the wedding and Danielle died the next day, having been able to participate in a life transition that held meaning to her and her family.

The social worker also needs to be able to facilitate difficult conversations between physicians and patients. Not every patient is ready to know his or her prognosis. Some patients and families fear the palliative care team or hospice as the end, as giving up hope, or as the death squad. Helping staff take the family's cue and assessing patient and family readiness are essential to good psychosocial care.

## Ethics

Social workers in palliative care often face complex ethical conflicts. Some patients want the most aggressive treatment despite a terminal prognosis, and the social worker must advocate for their wishes. This is often in conflict, however, with palliative care, and the organizational culture of hospitals to move patients out (E. Chachkes, personal communication, March 3, 2007).

In interdisciplinary teamwork, ethical dilemmas abound. There may be issues of a client's right to choose a self-determined death, which may conflict with a family's needs or values to prolong life. There may be ethical dilemmas in the decision to remove life supports, which a hospital may support, but a family may not. Social workers often take up the central role of mediator. The following example illustrates one of these ethical considerations—the need to weigh patient self-determination with cultural values.

Alvin, a five-month old African American boy was diagnosed with AML (acute myelogenous leukemia) and was hospitalized on a pediatric medical floor. His parents had no sources of income or social support, as both had quit their jobs to take care of their child. Once diagnosed, the family consented to treatment, but two weeks into treatment, the parents brought him home against medical advice. A week later, he arrived at the Pediatric ICU intubated and with

multiple organ failure accompanied by necrosis (the rotting) of his feet.

His parents' first question to their social workers was "Had she been saved?" to which she answered, "Yes" (wondering to herself: Is a Catholic, saved? but also thinking that she had no chance of developing an alliance otherwise. The family, she quickly learned, had met all of life's challenges with "the will of God.")

After ascertaining that she had been saved, the baby's mother said, "I am this child's mother, just as this is a small child of God. I cannot as a follower of our Lord try to bend His will to suit my own desires and my own needs, no matter how great they are. It will be an abomination to the Lord and all his angels if I do not make sure that this baby, this precious gift from God...if I do not give the Lord time to work His miracles. The Lord works in mysterious and mighty ways, His wonders to perform." (Julie Greathouse, unpublished paper).

The social worker struggled with her own religious beliefs, ethical concerns, and need to try to meet this family within their meaning system. She described her struggle not to judge them but to go where "they were." After an ethics consult, the family was helped to let Alvin suffer less, as this too was the will of God. His parents then took him off the ventilator, still guided by God's will.

This social worker's voice in the team—raising spiritual and racial issues, socioeconomic stressors, and ways to the approach the family—helped the team and family come to an outcome that was acceptable to all.

Psychosocial care with the dying also requires a relationship in which the social worker can accurately assess what the family does and does not want to know in terms of prognosis. Some patients (or families) want to know the truth; others do not. Respecting these differences is crucial. Culture and religion can impact the value assigned to discussing prognosis and end-of-life issues directly and openly. Social workers who work with the dying need to be vigilant about the cultural differences that help clients and families to maintain their dignity and integrity without intrusion.

Yoshi was a 35-year-old high school teacher and the only child of a successful Japanese businessman who, at age 65, was dying of colorectal cancer. The physician was insistent that her father be told the truth as he had treatment decisions that needed to be made. The prognosis was very poor. However, Yoshi did not want the doctor to discuss her father's condition with him. The doctor was annoyed, seeing her as an impediment to her father's care. Only when the social worker explained to the team that in Japanese culture,

truth telling is not appropriate and that Yoshi was behaving in culturally appropriate ways by protecting her elder parent, did the physician find a way to work with Yoshi's father that protected his dignity and treated him with respect.

### A Sacred and Intimate Space

Inevitably, practitioners in end-of-life care speak about the sacred and intimate spaces that are created between themselves and the dying client and family. Winnicott (1958) described the holding environment that is created through the mother's presence to the child. In normal child development, the caregiver's attunement to the child provides the nutrients to help that child develop as long as the caregiver does not impinge upon the child, but allows the child the capacity for solitude and for creativity. When clinicians work with the dying, they often describe offering connections that do not impinge, offering themselves without the goal of having to "fix" the family or patient's experiences. When social work practitioners describe engaging in intimate spaces with the dying, they are, I think, describing holding environments in which sorrow, sadness, anger, love, and hate can be tolerated without retaliation, reaction, or premature action. But the ability to hold the sorrow of others requires being held oneself, and often end-of-life clinicians become burned out and isolated by settings that do not hold them.

Winnicott (1965) also describes the concept of a false self, which may be created when a caregiver is too rigid, demanding, or primarily serving her own needs. When a child is impinged upon, she may lose her authenticity. In work with the dying, many patients or families are forced to comply with the needs of their caregivers, doctors and nurses, or to the norms of the settings in which they are dying. Allowing patients to maintain their true selves can be very challenging, but it is of utmost importance in the provision of excellent social care. Commonly, patients will also try to protect their family, and the family will try to protect the patient—only to find out that they are both thinking and feeling similar things. So bridging that gap and allowing for open communication is an important task for end-of-life caregivers.

Jill was a 49-year-old African American social worker dying of breast cancer in a research hospital. She entered the hospital terrified and anxious. Her own mother had died of breast cancer at the same age as she was now, and her children were the ages she had been when her mother had died. As an African American who carried the legacy of the medical exploitation of Blacks at Tuskegee, she did not trust

that she would receive quality care and was initially reticent to engage with her white social worker about advanced directives. Never one to express her feelings, she hid her terror politely and was designated by nurses and staff as a really "good patient."

After her double mastectomy, she seemed profoundly depressed to the nurses, and her social worker began to meet with her. They talked initially about how the clinician might feel if this had happened to her (her own mother had died when she was an adolescent), talked about the loss of Jill's mother in her adolescence, and wondered how Jill's children were managing their anxiety and fears.

The social worker offered her many ways to deal with the anxiety through cognitive behavioral interventions, medication, and meditation. She also talked simply about sitting with terror. Ultimately, the social worker and Jill were able to talk about Jill's own unprocessed grief and her wishes to protect her children. The social worker helped her to also join a group of other mothers with breast cancer so that she felt less alone.

As in psychotherapy, the role of the practitioner in end-of-life care is to open space for reflection and awareness, to understand oneself and one's relationships, and to act from a more conscious place in which change is secondary. For the most part, people who are dying are not dealing with psychological problems (although those who are ill may also carry psychiatric diagnoses), but the majority are making meaning out of a life lived, trying to make plans for the future, struggling with legacy and what will be left behind. Many are in great physical pain and the social worker's role is to assess that pain and see that it is treated (Altilio 2004). Others suffer existentially or spiritually. What may be especially hard for the clinician is to sit with a client in such a spiritual place. This may feel like a slippery slope, and quite isolating, unless there are colleagues or supervisors with whom to share these moments.

Practitioners in end-of-life care also have to tolerate ambiguity in work with the dying, which is often in short supply in medical settings where death is seen as the enemy, and where patients are often blamed for medical failure. For example, it is not uncommon, when a medical procedure fails, for the physician to explain to the family that "the patient failed" (Berzoff 2004). How do social workers who work with interdisciplinary teams help other clinicians to deal with the unmet needs of clients without resorting to anger or blame?

Melanie Klein (1946) describes the depressive position as a developmental achievement that requires the capacity to tolerate love and hate, and to bear intense and contradictory feelings without acting on them. This position is

difficult to maintain, but needs to be cultivated in settings where end-of-life practitioners work. Often in high-tech settings, the care is aggressive, and the patient and family are seen as non-compliant or difficult if they challenge the team. The social worker's ability to work with physicians whose goals may be in conflict with their patient's requires holding contradictory ego states and helping the team, patient, and family to do the same. This is also true in working with contrasting ego states, needs, and expectations between the patient and family members.

Dying is a relational event, and the clinician cannot be neutral, absent, or objective. End-of-life care requires reassuring patients and families that they are not alone. Thus, clinicians who work with the dying are always working intersubjectively, both sharing in suffering and being companions on a journey. The palliative care social worker may arrive in the room during a medical or family crisis. She may hold the patient's hand, read to a dying child or adult, or simply sit in silence or stillness. The practitioner may share tears with a family or patient. Barnard (1995) refers to these as intimate encounters that hold enormous promise for meaning in the face of suffering. They require mutuality and transformation of the caregiver. "Intimacy," he writes, "bursts forth, unbidden, unsought, un-engineered in the midst of our everyday lives and interactions with the power to transform both partners in the relationship" (p. 291). Ehrenberg (1992) writes about the intimate encounters with patients in psychotherapy in which both engage in a relational dance. How much more is this true where the patient is in a bed or in a hospice?

Kirchoff (2003) has written a poignant narrative about her intimate and intersubjective encounter (Aron 1996; Ehrenberg 1992) with a dying client, Milton the cowboy:

An African American homeless man who lived under a bridge in his "cave," Milton had been admitted to the county hospital for radiation and palliative care for terminal lung cancer. When the social worker and palliative care team began to note his disappearance from the radiation sessions, his social worker learned that he was leaving to feed his dog, "Cowgirl." Developing a therapeutic alliance, she offered to feed the dog, which she did daily. She then worked with him to procure safe housing, from which he was evicted continually so that he could return to his cave. She began to visit him there, first to feed his dog, later to meet with him to talk about hospice care, and later to bring medical students and residents to hear his stories of resilience in the face of crushing poverty, oppression, and trauma in the South. In her work with him, Linda tried to reconcile being present to, with loving this man while still maintaining professional boundaries. He would leave her flowers and poems,

singing to her, and she in response, offered comfort, solace, and consistency.

In her eulogy for him, she wrote: Milton would tell me his dreams for the future, even though he knew he was dying. "In the spring, Cowgirl and I will move back to the Cave to live," he would say. He taught me about hope. And he taught me about humor in the face of death. Whenever Milton would be discharged, I would ask, "Are you ready to go to a nursing home?" and he would respond, "Not necessarily." And he taught me that if I am really brave, I can learn to love again. Milton loved me and he had a dream that he would get well. Then I couldn't be his social worker anymore and we could be married. Milton's favorite song was "I Could Have Danced All Night." The entire time I knew Milton, dance we did. He would press my limits to see if he could push me away and I didn't leave. My job was to be there for comfort, resources, empowerment, and support. In the course of the work I came to care for him deeply.... My work with Milton, like work with anyone facing the end of life, required my active presence, a kind of love, a willingness to enter in realms of experience such as song and touch that are not always comfortable for social workers. By letting Milton touch my heart, I think I gave something to a man who had known care, hope, and love inconsistently. He certainly gave me hope about the possibilities inherent in living and dying." (p. 476–77)

### Self Care

Work with the dying requires self-care. It is very difficult to stay engaged with those whose existence is threatened, who suffer psychological, spiritual, or physical pain, or who may be depressed or despondent without replenishing the self. Often it is the social worker who is called into "make" the patient or family "behave," be less angry or less difficult. Practitioners describe isolation in this work: the tears shed alone, the lack of interdisciplinary peer supervision, and the difficulty in sitting without doing. It is hard not knowing what to say or do in the face of a parent's unending grief or a child's questions about what will happen when she dies. It is hard to face cumulative grief, day in and day out, and to tolerate suffering without suffering oneself. Figley (1994) calls this compassion fatigue.

Rezenbrink (2004) writes of the need for social workers to engage in "relentless" self-care. This can come in the form of supervision and peer learning; it can come with debriefing and collaboration with chaplains, doctors, and nurses. Practitioners may exercise, meditate,

or practice yoga, as ways of dealing with secondary trauma. Good colleagues with whom they can share their countertransference responses help them to use themselves more consciously and, with this, more flexibly. As a result, they feel more empowered and this leads back to better psychosocial care.

We have certainly learned that our training program in end-of-life care provides a form of self-care. Here, students are able to express their feelings and have them validated by others doing similar work. They engage in experiential and relational learning where they talk about countertransference responses, ethical dilemmas, spiritual issues, advanced care planning, cross-cultural and cross-racial dilemmas, legal issues, pain, and suffering. In the context of consulting with one another and learning from each other, they validate what each knows and share strategies of working with families, patients, and teams. By talking about countertransference, they are much more actively aware of how they use themselves, and tend to feel less oppressed and isolated by the work. There is always a great deal of humor in these intensive trainings, which also helps practitioners to feel less alone. By giving name to countertransference reactions, they come to see those responses as inevitable and even guiding their work by mirroring what the clients and families are encountering. In sharing the ways that they have learned to assess clients and families as well as the institutions and organizations in which they are working, practitioners can develop plans to initiate changes in their settings. By empowering themselves, they often come to see themselves as leaders. Many post-Masters practitioners have gone on to give presentations, write grants, develop programs, consult, teach, supervise, and publish. These forms of renewal are essential to preventing burnout.

The work of end-of-life care, then, requires standing in the intimate spaces, alleviating pain, tolerating suffering, responding to psychological, spiritual, and cultural needs. It requires being open to colleagues, and being willing to challenge the status quo. It requires assessment and intervention at all levels—individual, couple, family, institutional, and community—and this demands a high level of psychological and social skills. It requires creating networks with other professionals, offering teaching and supervision, and accepting the responsibility for leadership. End-of-life care takes curiosity, awareness of one's feelings, and being able to be changed by the work. It takes humility, commitment, connection, and the capacity to live with uncertainty. It takes the willingness to help patients and families make meaning out of misfortune, and the capacity to see every experience as “intercultural” (W. McCluney, personal communication, January 20, 2007). It

takes considerable common sense and the capacity to face the unknown. And most of all, this work takes courage.

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#### Author Biography

**Dr. Joan Berzoff** co-directs The Doctoral program and directs The End of life Certificate program at the Smith College School For social work. She is in private practice in Northampton, MA, USA.