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Aiding AIDS Through Writing: A Study and Bibliography

Cover Page Footnote

Emily Nye is an assistant professor of English at the New Mexico Institute of Mining and Technology and heads the university 's writing center.

Aiding AIDS Through Writing: A Study and Bibliography

Emily Nye

Narrative writing, according to Jerome Bruner's (1984) often-quoted passage, joins the writer to "possible worlds that provide the landscape for thinking about the human condition" (p. 128). Expressivist pedagogy stresses writing toward self-discovery, while a Freirean view emphasizes not just self-awareness but a "critical consciousness" of self and society. Such consciousness empowers individuals and groups to improve their situation. Nel Noddings (1984) also focusses on awareness, change, and growth as a result of caring relationships between teachers and students. Noddings' theory of care simply states that every human encounter is a potential occasion for caring. The connections between writing and healing are evident in the work of theorists' in composition studies and education (Campbell, 1994; Moffett, 1981; Rico, 1991). But it is a scholar from another discipline, nursing, who brings together self-awareness, change, and growth as healing. Jean Watson's idea of human care in nursing asserts that patients and nurses together are partners in the healing process. Their relationship is mutually transformative; it is fostered by understanding, love, and concern. This is particularly important in nursing, because caring is necessary when curing has failed. No cure is known for AIDS, but healing is still possible.

At an AIDS clinic called the Nursing Project in Human Caring (also known as the Caring Center) in Denver, Watson's ideas were put into practice. Patients received one-on-one nursing care and engaged in traditional and nontraditional therapies, including *reiki* massage, *tai kwando*, and rafting and hiking trips.

While volunteering at the Caring Center, my proposal to run a six-week writing group was welcomed as an expressive activity that would constitute a caring occasion. Eight people attended, six men and two women, including me. The group spanned ages 20+ to about 60 years. Half the writers were homosexual and half were heterosexual. Over the next six weeks, four writers stayed with the group and a few others dropped in.

I filled two spiral notebooks with field notes and collected more than 200 pages of the participants' writings. I also conducted in-depth interviews with each writer as well as with the director of the Caring Center, its personnel, and others involved in the AIDS community. I later analyzed the data to learn more about the healing that took place when these individuals wrote.

As I collected the group members' writings and other materials, I followed a qualitative research method based in sociology called Grounded Theory which enabled me to analyze the writing and the interviews and to distinguish impor-

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tant themes in the narratives (Glaser & Strauss, 1967; Strauss & Corbin, 1990). This method allows theory to emerge from the data collected: writing samples, interview notes, and other materials like local publications and brochures. I kept track of my own reactions to the phenomena observed and experienced through a research journal. I combed the data, taking apart each observation sentence by sentence. I coded the ideas described with a name or conceptual label. In order to see connections among ideas, I studied the concepts in relation to each other (in Grounded Theory terminology this is called *constant comparison*). Once I identified these categories, I grouped them together and consolidated them. More than two dozen categories became evident. These included themes like: Family/Support, Making Sense of Life, Anger, Guilt, Humor, Survival Tips, Regrets, and Pride.

An Emerging Taxonomy

Story-telling or narratives surfaced repeatedly in the data. Four particular kinds became apparent, each with a different healing function. These functions included making sense of life, in general; teaching others about AIDS; helping others with AIDS and generating a community of support; and gaining control and empowerment by claiming one's own experience and survival.

First, people found it psychologically healthful to make sense of their lives. Writing their life stories, particularly key moments and events, helped them to become more aware of their lives and reckon with their past. They developed a sense of the whole of their lives by marking points along the time-line of their existence. Second, teaching others about AIDS posed a different healing function. Teaching requires knowing. Thus, in this narrative posture, writers accept an authorial stance which is adversarial. The writers found it healing to fight back by sharing their stories. The narratives of people with AIDS, similar to those of Holocaust survivors, may shock or frighten outsiders into confronting the reality of the epidemic. Intersubjective connections occurred, as a member told a class of community college students at a speaking engagement: "I'm the other guy. I'm the person who thought it would never happen to him." Such realizations of otherness brought to light their own mortality. As another stated, "AIDS has no boundaries and can enter your [the participants'] lives as easily as it did mine." Finally, sharing information and survival tips among members of the AIDS population strengthened support within the community. In effect, such support nurtured the caring networks. This assertion also brings this article full-circle to Bruner's idea of the centrality of story in our lives. A caveat is, however, in order. Facilitating writing groups is not for everyone. Some who do this work—like me—are skilled, but not credentialed. Others are credentialed, but not skilled. A third group is neither, and, I suppose, a final group is both. It is useful to examine one's own motivation before working with writing groups. For those readers wishing to learn more about this work an annotated bibliography follows.

Annotated Bibliography

References for this Article

Bruner, J. (1986). *Actual minds, possible worlds*. Cambridge, MA: Harvard University Press.

Bruner examines how narratives transform the mind, allowing us to make meaning of our experiences.

Elbow, P. (1986). *Embracing contraries: Explorations in learning and teaching*. Oxford: Oxford University Press.

Elbow's collection of essays describes "the perplexities of learning and teaching." He presents creative and compassionate ideas and exercises for drawing students out and encouraging inner growth in teachers as well.

Freire, P. (1970). *Pedagogy of the oppressed*. New York: Herder & Herder.

The author's classic work professes that people can only change and improve their situations by becoming critically conscious of the world around them and their place in it.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine De Gruyter.

Grounded theory is presented as a systematic way of gathering, coding, and analyzing field notes, interviews, written material, and so on. Rather than proving a hypothesis or testing a theory, themes and theories emerge from the data, effectively closing the gap between theory and research.

Moffett, J. (1981). *Coming on center*. Portsmouth, NH: Boynton/Cook.

This collection of essays and talks (from the 1970s to the 1980s) looks at education in America and suggests ways for teachers—of language arts, in particular—to improve their teaching and curricula. The article, "Writing Inner Speech, and Meditation," examines connections between writing and therapy.

Neil, R. (1994). Authentic caring: The sensible answer for clients and staff dealing with HIV/AIDS. *Nursing Administration Quarterly*, 18, 36–40.

Neil explains Jean Watson's theory of human care and how it is put to practice at the Denver, Colorado Nursing Project in Human Caring.

Noddings, N. (1984). *Caring: A feminist approach to ethics and moral education*. Berkeley: University of California Press.

Noddings proposes a theory of care in education where the one-caring (the teacher) enables the one cared-for (the student) to act freely, to grow, and to learn.

Strauss, A., & Corbin, J. (1990). *Basic qualitative research: Grounded theory, procedures, and techniques*. Newbury Park, CA: Sage.

For an audience of novices this book makes grounded theory methodology accessible to researchers in any field.

Watson, J. (1985). *Nursing: Human science and human care*. Norwalk, CT: Appleton-Century Crofts.

This general nursing textbook applies Watson's theory to the nursing field. Interdisciplinary Readings on Writing as Healing:

Watson, J. (1990). Transpersonal caring: A transcendent view of person, health, and healing. In M. E. Parker (Ed.), *Nursing theories in practice* (pp. 277–288). New York: National League for Nursing.

According to Watson, the nurse is a co-participant in the human care process. Watson's perspective is phenomenological and subjective.

Campbell, R. (1985). Writing groups with the elderly. In M. Sundell, P. Glasser, R. Saari, & R. Vinter (Eds.), *Individual change through small groups* (pp. 546–588). New York: The Free Press.

Campbell describes the therapeutic benefits of senior citizen writing groups that she has facilitated: Participants leave a legacy for family members, record and validate their lives, learn new things about themselves, and make friends.

Gilman, S. (1995). *Picturing health and illness: Images of identity and difference*. Baltimore: The Johns Hopkins University Press.

Gilman looks at the history of our culture's perception that health is beautiful and illness is ugly.

Kelley, P. (Ed.). (1990). *The uses of writing in psychotherapy*. New York: Haworth Press.

Social work professor Patricia Kelley collected eight articles that show how writing has been used with deaf children, Southeast Asian refugees, the elderly, incest survivors, and individuals with eating disorders.

Klein, A. (1989). *The healing power of humor*. New York: Putnam.

This book explains the importance of humor. It provides techniques for "getting through all that not-so-funny stuff."

Leedy, J. (1985). *Poetry as healer: Mending the troubled mind*. New York: Vanguard Press.

Leedy presents essays by psychiatrists and psychologists who have used poetry with patients in clinical settings.

Scarry, E. (1985). *The body in pain: The making and unmaking of the world*. New York: Oxford University Press.

Using literature, art, medicine, and politics to analyze the subject of pain, Scarry delves into the difficulty of expressing pain and the ability of pain to destroy the sufferer's language and even his or her world. The act of creation—producing cultural artifacts and language—is a "re-making" of the world.

Texts about Narrative and Healing:

Butler, R. (1963). The life review: An interpretation of reminiscence in the aged. *Psychiatry*, 26, 65–76.

Butler describes the importance of self-reflection and reminiscence as a normal part of life. Such life review helps people resolve conflict, make sense of their lives, and prepare for death.

Myerhoff, B. (1992). *Remembered lives: The work of ritual, storytelling, and growing older*. Ann Arbor: University of Michigan Press.

This collection of anthropologist Myerhoff's essays provides insight into the elderly in America and the importance of the stories they tell. This book is especially useful for anyone planning to conduct writing workshops with seniors.

Pennebaker, J. (1990). *Opening up: The healing power of confiding in others*. New York: William Morrow and Company.

A psychology professor at Southern Methodist University, Pennebaker presents the findings of studies that measure the effects on health of disclosure through writing. Written for a lay audience, the book includes citations of studies from the fields of medicine and psychology.

Polkinghorne, D. (1988). *Narrative knowing and the human sciences*. Albany: State University of New York Press.

Polkinghorne writes about psychotherapy as narrative reconstruction. By making patients aware of the structure and role of narrative in their lives, they may reconstruct meaningful interpretations of their past.

Sandelowski, M. (1994). We are the stories we tell: Narrative knowing in nursing practice. *Journal of Holistic Nursing*, 21, 23–33.

Because narratives are expressions of human consciousness, the skills in narrative analysis taught in holistic nursing may benefit patients.

White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. New York: W.W. Norton.

Clinical social workers with specialties in family therapy, the authors examine therapy as a process of "storying" one's life through letters, invitations, certificates, and declarations. Their therapy is based in part on Foucault's theories of power and knowledge.

Texts about AIDS

Boffin, T., & Gupta, S. (Eds.) (1990). *Ecstatic antibodies: Resisting the AIDS mythology*. London: Rivers Oram.

This multi-media book/exhibit casts light on the politics of representing AIDS. Partly sponsored by the Arts Council of Great Britain, the work depicts AIDS through social and political commentary in the form of articles and art work.

Borger, I. (Ed.). (1996). *From a burning house*. New York: Washington Square B.

This collection of creative work by members of the AIDS Project, Los Angeles Writer's Workshop resulted from a group Borger facilitated for several years.

Boudin, K. (1993). Participatory literacy education behind bars: AIDS opens the door. *Harvard Education Review*, 63, 207-232.

Boudin, an inmate as well as a literacy scholar, led a prison reading class based on Freire's idea of empowerment education. Participants developed their own curriculum on the subject of AIDS.

Crimp, D., & Bersani, L. (Eds.). (1988). *AIDS: Cultural analysis/cultural activism*. Cambridge: MIT Press.

This collection of essays considers how culture perceives and deals with AIDS.

Erni Nguyet, J. (1994). *Unstable frontiers: Technomedicine and the cultural politics of curing AIDS*. St. Paul: University of Minnesota Press.

Erni Nguyet uses Foucault's theory of discourse to analyze the power structures and cultural politics surrounding medical treatment in the AIDS crisis.

Gilman, S. (1988). *Disease and representation: Images of illness from madness to AIDS*. Ithaca, NY: Cornell University Press.

Gilman analyzes the images of disease through history, including the plague and syphilis. His chapter, "Seeing the AIDS Patient," provides an historically grounded view of the media's representation of AIDS that has had harmful effects on patients and the public alike.

Hadas, R. (1991). *Unending dialogue: Voices from an AIDS poetry workshop*. New York: Faber & Faber.

Poet Rachel Hadas facilitated a poetry workshop through the Gay Men's Health Crisis in New York. The book includes poems by AIDS patients as well as the poet's own in response to the experience.

Holleran, A. (1989). *Ground zero*. New York: Morrow.

This collection of essays presents the author's reflections on the AIDS epidemic and his experience as a gay male in New York.

Kubler-Ross, E. (1987). *AIDS: The ultimate challenge*. New York: Collier Books.

Kubler-Ross applies her philosophy of the stages of death, dying, and grief to the AIDS epidemic. She discusses the experience of AIDS among several populations and stresses the importance of creating support communities for AIDS victims and their caregivers.

Lamendola, F., & Newman, M. (1994). The paradox of HIV/AIDS as expanding consciousness. *Advances in Nursing Science*, 16, 13–21.

Interviews with nine gay men showed how self-disclosure about HIV/AIDS was a turning point in their lives, which led to a heightened consciousness and/or more positive outlook.

McMillen, L. (1994 October 19). AIDS as metaphor: The epidemic spawns a growing body of scholarship on its signification. *The Chronicle of Higher Education*, p. A20.

McMillen reviews new scholarship on AIDS within the humanities, political science, sociology, public health, social science, and history.

Monette, P. (1988). *Borrowed time: An AIDS memoir*. New York: Avon.

Chronicling the last months of his lover's life, Monette writes powerfully and memorably as an AIDS insider.

Murphy, T., & Poirier, S. (Eds.). (1993). *Writing AIDS: Gay literature, language, and analysis*. New York: Columbia University Press.

The 14 essays in this collection provide an interdisciplinary examination of AIDS as depicted in literature, journalism, film, gay activism, and the gay culture. An annotated bibliography of AIDS literature from 1982–1991 is provided.

Patton, C. (1990). *Inventing AIDS*. New York: Routledge.

Patton analyzes the complex discourse of AIDS. She challenges the media's treatment of the AIDS epidemic and re-examines science's authority on the epidemic. The author also looks at the political aspects of AIDS activism and AIDS education.

Peabody, B. (1986). *The screaming room*. New York: Avon Books.

This mother's narrative describes her son's death from AIDS as well as her struggles and grief.

Reeves, C. (1996). Language, rhetoric, and AIDS: The attitudes and strategies of key AIDS medical scientists and physicians. *Written Communication*, 13, 130–157.

Taking an interesting twist in AIDS scholarship, Reeves interviews AIDS medical scientists to understand how these persons act as communicators. She analyzes the process of rhetorical negotiation in a medical crisis.

Seidel, G. (1990). Thank God I said no to AIDS: On the changing discourse of AIDS in Uganda. *Discourse and Society*, 1, 61–84.

Seidel presents an intriguing look at how the leading AIDS education agencies in Uganda adapted the rhetoric of their publicity according to the ideological and cultural context of the time.

Shilts, R. (1987). *And the band played on: Politics, people, and the AIDS crisis*. New York: Penguin Books.

Shilts' journalistic chronicle of events surrounding the AIDS epidemic provides much historical and anecdotal material.

Sontag, S. (1988). *AIDS and its metaphors*. New York: Doubleday.

Sontag examines the metaphors used in AIDS discourse: war, plague, end-of-the world rhetoric, and others. She writes about the effect of such metaphors on society's consciousness.

Treichler, P. (1988). AIDS, homophobia and biomedical discourse: An epidemic of signification. In D. Crimp & L. Bersani (Eds.), *AIDS: Cultural analysis/cultural activism* (pp. 31-70). Cambridge: Massachusetts Institute of Technology Press.

Treichler follows feminist theories of language and Foucault's discourse theory to examine the social constructions of AIDS and its influence on public perception and the authority of medical science.

Verghese, A. (1994). *My own country*. New York: Simon & Schuster.

Verghese, a physician, writes about his work in a small community in Tennessee and his growing compassion and respect for the AIDS population that he encountered there.

Weir, J. (1985). AIDS stories. *Harpers*, 273, 22.

Weir's haunting one-page essay provides a snapshot of men in an AIDS writing group and their stories.

Weitz, R. (1991). *Living with AIDS*. New Brunswick, NJ: Rutgers University Press.

Rose Weitz interviewed 37 people in Arizona who had HIV disease, describing their lives and the phases of the disease. She addresses the social construction of the disease and how HIV affects the body, relationships, and doctors' perspectives.

Related Texts in Composition

Bishop, W. (1993). Writing is/and therapy? Raising questions about writing classrooms and writing program administration. *Journal of Advanced Composition*, 13, 503-516.

The author encourages teachers to acknowledge and explore writing as a healing process in the classroom. Bishop provides thoughtful arguments for both sides of the personal writing question. Colleagues in school writing centers and counseling offices may profit from this piece.

Brand, A. (1989). *The psychology of writing: The affective experience*. Westport, CT: Greenwood Press.

Brand examines how emotions change when writers write. She surveyed five different populations of writers (from students to professionals) on a

scale of 20 emotions. She concludes that positive emotions intensify during writing, negative passive emotions weaken, and certain levels of anxiety are helpful in writing.

Brand, A. (1980). *Therapy in writing*. Lexington, MA: Lexington Books.

Brand conducted a study of 16 secondary school students to examine the possibilities of developing a writing program for personal growth. She found that students came to grips with personal problems when they wrote and also showed improved self-concept.

Brand, A. & Graves, R. (Eds.). (1994). *Presence of mind: Writing and the domain beyond the cognitive*. Portsmouth, NH: Boynton-Cook/Heinemann.

The 21 essays featured in this collection examine alternative aspects of writing, including writing as healing, writing and meditation, writing and its relationship to emotions, and writing about archetypes and the unconscious.

Campbell, J. (1994). Writing to heal: Using meditation in the writing process. *College Composition and Communication*, 45, 246–251.

Campbell teaches students to meditate in order to help them generate images and details in their writing and, in some cases, help dissolve writer's block.

Coles, R. (1989). *The call of stories*. Boston: Houghton Mifflin.

A psychiatrist and teacher of literature, Coles looks at the relationship between literature and the human self and spirit. Each essay in this collection illustrates Coles' philosophy that every person has a story to tell, "and we owe it to each other to respect our stories and learn from them."

Daniell, B. (1994). Composing (as) power. *College Composition and Communication*, 44, 238–246.

Daniell suggests the need for language that allows descriptions of its spiritual and emotional aspects in addition to those that are cognitive, intellectual, social, and political.

hooks, b. (1988). *Talking back: Thinking feminist, thinking black*. Boston: South End Press.

hooks traces her evolution as a black feminist scholar. Speaking out, according to hooks, is a move toward empowerment. Finding one's voice is essential in one's struggle against oppression and toward liberation.

Kirsch, G., & Sullivan, P. (Eds.). (1992). *Methods and methodology in composition research*. Carbondale: South Illinois University Press.

This collection of 14 articles presents research methodologies used in composition, including teacher-research, ethnography, and textual analysis. The essays also discuss the philosophical issues of epistemology and the politics of knowledge.

Morrow, D. (1991). Tutoring writing: Healing, or what? *College Composition and Communication*, 42, 218-229.

A former physician-turned-writing-coach, Morrow explores the metaphorical connections between writing and healing, envisioning revising as the healing process in writing.

Murphy, R. (1990). Anorexia: The cheating disorder. *College English*, 52, 898-903.

Murphy examines the pedagogical questions involved when teachers mis-read student work.

Nye, E. (1996). *The more I tell my story: Writing as healing at an AIDS clinic*. Unpublished doctoral dissertation, University of Michigan, Ann Arbor.

This study contains an extensive literature review in her examination of several AIDS writing groups.

O'Reilley, M. (1993). *The peaceable classroom*. Portsmouth, New Hampshire: Boynton/Cook.

In this compassionate and insightful collection, O'Reilley recounts her evolution as a teacher, scholar, and peace worker.

Swartzlander, S., Pace, D., & Stamler, V. L. (1993, February 17). The ethics of requiring students to write about their personal lives. *The Chronicle of Higher Education*, p. B1.

The authors question the fairness of both disclosing and grading personal writing. They offer instructors such helpful tips as maintaining a student's confidentiality and using the school counseling center as a resource to sensitize teachers to the "implications of forced revelations."

Witherell, C., & Noddings, N. (Eds.). (1991). *Stories lives tell: Narrative and dialogue in education*. New York: Teachers College Press.

This collection focusses on the power of narrative to teach students about the world and about themselves. Included are exercise and readings.

Adams, K. (1990). *Journal to the self*. New York: Warner Books.

Adams develops a series of short journal-writing exercises from list-writing, to letters, to detailed accounts of memories or dreams. A workbook is available.

Cousins, N. (1979). *Anatomy of an illness*. New York: Bantam Books.

Cousins uses humor and a positive attitude to fight a serious degenerative disease of the connective tissue.

Dunning, S., & Stafford, W. (1992). *Getting the knack: 20 poetry writing exercises*. Urbana, IL: The National Council of Teachers of English.

This is a wonderfully accessible guide to writing poetry with children or adults.

Goldberg, N. (1986). *Writing down the bones*. Boston: Shambhala.

A decade has passed since this book was published and it is still a favorite writing exercise book: accessible, simple, humorous, "zen." Her second book, *Wild Mind*, is also noteworthy.

John-Roger, & McWilliams, P. (1991). *Focus on the positive: The workbook*. Los Angeles: Prelude Press.

This activity book addresses the problem of negative thinking, listing no fewer than 100 writing exercises.

Koch, K. (1977). *I never told anybody: Teaching poetry writing in a nursing home*. New York: Random House.

Poet Kenneth Koch describes teaching poetry writing at a nursing home in New York City. Included are exercise ideas as well as participants' writing samples. Koch's *Wishes, Lies, and Dreams*, directed at teaching poetry to children, is also recommended.

Metzger, D. (1992). *Writing for your life*. San Francisco: Harper.

Metzger shows how writing and storytelling can be spiritual acts, capable of shedding light on archetypes, fairy tales, and myths.

Ostaseski, F. (1994). Stories of lives lived and now ending. *Inquiring Mind*, 10, 14-29.

Ostaseski, Founding Director of the Zen Hospice Project, explains that hospice workers need to cultivate a "listening mind" to hear the stories that dying people tell.

Ouwehand, T. (1995). *Writing your way to wholeness: Creative exercises for personal growth*. San Jose: Resource.

This activity book is divided into four categories: Uncovery, Discovery, Recovery, and Reading, containing more than 70 writing exercises.

Progoff, I. (1975). *At a journal workshop: The basic text and guide for using the intensive journal*. New York: Dialogue House.

Psychologist Progoff pioneered a journal-writing technique that helps people explore their families, work, dreams, and spirituality.

Rico, G. (1991). *Pain and possibility: Writing your way through personal crisis*. Los Angeles: Jeremy P. Tarcher.

This book provides writing and drawing exercises that help readers understand and work through emotional pain.

Schneider, P. (1994). *The writer as an artist: A new approach to writing alone and with others*. Los Angeles: Lowell House.

Apart from listing 50 exercises, Schneider discusses her work as a writer. A powerful documentary, *Tell Me Something I Can't Forget*, has been made about her work with women writers in a Massachusetts housing project. ☺

