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The Appreciative Pedagogy of Palliative Care: Arts-Based or Evidence-Based?

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Introduction

It is difficult
To get the news from poems
Yet men die miserably every day
for lack of what is found there.
- William Carlos Williams

This is from the lyrical poem, "Asphodel, that Greeny Flower," written late in the author's life (Williams, 1955). The Academy of American Poets calls Williams's work "a singularly American poetic, whose subject matter was centered on the everyday circumstances of life and the lives of common people" (www.poets.org). When we typed in this last sentence on Google Scholar, seven of the first ten hits came from peer-reviewed healthcare journals.

Prompted by a pediatrician-poet's visionary leadership, especially his direction toward poetry as an exemplar of palliative care (PC), we describe a self study that sets out to advance the role of art in this medical discipline. We build on Dorothy's earlier collaborative self-study (see Lander, Napier, Fry, Brander & Acton, 2006) of the interplay between dichotomies — grief and joy, hope and fear, impotence and autonomy — that emerge from the use of art with the very ill. In the spirit of autobiography, we use our first names throughout — Dorothy (adult educator and researcher and family caregiver) and John (PC and arts-medicine physician and poet). We draw on our own and others' PC experiences, using the arts-based action research methodology, Appreciative Inquiry (AI) and its teaching application, Appreciative Pedagogy (AP), to show the relevance and value of these methodologies to PC research, education, and clinical practice.

AI was conceived in organizational and academic contexts in the 1980s as a participatory, solution-oriented approach to illuminating, affirming, and transforming the subject being studied (Cooperrider & Srivastva, 1987). Its educational outgrowth, AP, is used to deepen and extend the qualitative learning experience (Yballe & O'Connor, 2000). In health care, AI and AP intersect with the discipline of arts-based medicine (ABM), which explores the multifaceted applications of the creative arts to health. All three fit into the overarching framework of affirmative, transforming approaches to research, pedagogy and practice known as Positive Organizational Scholarship (POS: see Fineman, 2006; Roberts, 2006). For this essay we have explored several crosscutting research and pedagogical disciplines that seem to be relevant and serve PC's goal.

Background and Rationale.

PC's one-point goal is to give very ill people comfort and freedom from suffering. At its heart, it is a holistic, community-based philosophy that integrates science and art in optimal ways in its clinical, research, and pedagogical approach. Its special appeal to us as researchers, teachers and practitioners is embedded in our professional and personal stories; hence our choice of the dialogical method of self-study, which we hope makes our experience resonate with others. (see Loughran, 2004, p. 214.) Because readers may be unfamiliar with several relevant terms, we offer working definitions in this table.

Table 1: Glossary of Terms

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Glossary of Terms

Action Research: The systematic development of knowing and knowledge that has practical value in action for human flourishing.

Appreciative Inquiry (AI): A five-step (5-D) participatory, solution-oriented, action research methodology that illuminates, enables, and transforms the subject under study:
   Define: Establish a conceptual and contextual frame, using an unconditional positive question; *Discover:* Value the best of what is; *Dream:* Envision what might be; *Design:* Dialogue what should be; *Destiny:* Innovate what will be.

Appreciative Pedagogy (AP): AI applied to teaching and learning, through vision, dialogue, and transformation based on narrated personal experiences.

Arts-Based Medicine (ABM): A broad clinical, pedagogical and research discipline based on the multifaceted dimensions of the creative arts.

Arts-Based Practice (ABP): The clinical application of ABM to patient care.

Evidence-Based Medicine (EBM): The systematic accumulation of scientific medical research evidence and its application to medical practice.

Evidence-Based Practice (EBP): The clinical application of EBM to patient care.

Narrative-Based Medicine: An aspect of ABM and Medical Humanities based specifically on the narrative-interpretative paradigm of spoken or written patient stories.

Palliative Care (PC): Medical care of very ill patients and their loved ones that focuses on offering them comfort and relieving their experience of suffering.

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AI's primary tool is the sharing of personal stories by people alone or in groups, which become building blocks for the systematic 5-D step model — DEFINE, DISCOVER, DREAM, DESIGN, DESTINY — to shape preferred futures. (See Table 1). DEFINE establishes the context by introducing the "unconditional positive question," which always directs the inquiry to bring out the best in human potential (See Whitney, Cooperrider, Garrison & Moore, 2002.); DISCOVER engages participants in telling their stories of "the best of what is" from their current experience; DREAM engages them in envisioning "the best of what could be"; DESIGN is a dialogue of "what should be"; and DESTINY is innovating and sustaining "what shall be." AI's arts-based approach is echoed in the medical context by ABM's narrative-interpretive use of patient stories in research, pedagogy and clinical service (See Graham-Pole, 2000; Lander, 2005; Lander et al., 2006.) The most systematic application of arts-based methodologies to medicine is narrative-based (see Greenhalgh & Hurwitz, 1998), but over the past two decades the Society for the Arts in Healthcare (www.thesah.org) has overseen a much broader dissemination of the creative arts in all healthcare settings.

Self-Study Examples of AI/AP in Practice, Pedagogy, and Research
(a) Professional practice and development.

Our collaboration began in July 2005 when Dorothy enrolled in the Summer Intensive ABM course of the University of Florida (UF)'s Center for Arts in Healthcare, Research and Education (see www.arts.ufl.edu/CAHRE/) as professional development for her emerging research. CAHRE is the university's outgrowth of the hospital-based Shands Arts in Medicine (see www.shands.org/AIM/); both organizations recognize art

and narrative as integral to PC. Dorothy's husband Patrick had died nine months earlier, and the solitude of a 2000-mile car journey from Nova Scotia was as much a quest for meaning as for a professional research agenda.

During the 3-week program, she shadowed the Shands Hospital artists-in-residence. She had used art as a family caregiver with her husband (see Lander et al., 2006), but shadowing John on PC bedside rounds with three other artists was her first encounter with ABM being practiced at the hospital bedside. This extraordinary experience for Dorothy was for John everyday practice. It was not until she spotlighted the many exemplars of healing art in these patient encounters that he saw its qualitative research potential. She pointed out that his professional affirmation of arts-based and holistic remedies for these very ill patients was entirely consistent with AI's methodology. Here is a poetic description of one of these PC encounters (Graham-Pole, in press).

Signing

Isolde lies inert, the morphine still on her,
as the doctor introduces us. We're gathered
at her bedside in Intensive Care, we four:
painter, poet, singer-dancer, recorder.
Isolde's glazed eyes slide over us. In the six weeks
since they cut off her foot to arrest the gangrene,
this fourteen-year-old's cursed each nurse, each
resident who seeks to help, cursed father, mother,
mother's lovers (two women from her divorce group),
even herself, to death. It's the physical therapist's
turn to bear the expletives' brunt, at work on
the remaining leg. It has at least the effect of
stirring her to wave the foot in the air over the pulley
to rid herself of this importunate adult.

Susan, the artist, seizes the moment, asks her:
Isolde, what will you do when you're grown?
Unhesitant, improbable, she flashes: *Help people;*

be a nurse. Susan presses: *And if not a nurse,*
what then? The further astonishing response:
A dancer. She twitches the leg at her a little.
Then Paulie, the singer-dancer, jumps in:
Then a dancer you'll be. She has her rotate her leg
in the tempo the therapist has taught her, choreographs
a dance of hoops. Isolde's agog, animated by Paulie's
sounding out the dance. *I can sign too,* she declares,
adds: *my boyfriend's deaf.* Tim McGraw:
 "Live like you were dying." I can sign that.
Dorothy, the recorder, asks her: *Can you sign*
"I love you." Isolde points at her mouth: *"I"*
folds her hands over her heart: *"love"*
extends her arms in embrace of us all: *"you."*

We sign the words back to her, then to each other,
pick up the cadence as Isolde conducts her orchestra.

This poem is at once a piece of art, a description of bedside clinical care, and a self-evident healing experience for a patient, and perhaps for her caregivers.

(b) *University teaching.*

We gave a seminar to the UF College of Medicine 3rd year medical student class in which we were asked to address both arts-based and palliative pedagogy. We decided to explore these medical paradigms together through the lens of AI's 5-D model, although, in the time allotted, we could only engage the students in the first three steps. For the DEFINE step, we settled on the unconditional positive question (see Ludema, Cooperrider & Barrett, 2001) related to personal loss as something they would address often in their professional lives. We asked them: "Can you think of a time in the past 24 hours when you experienced a personal loss from which you learned something of value to your future practice?" We wanted their everyday losses to challenge them to think about how they might equip them for "larger" losses they would later face. For the valuing DISCOVER step, we asked them to write for ten minutes addressing our

unconditional positive question. To give them a context, John offered this poem: a

morning walk that would never quite happen this way again.

> *February*
>
> We mourn
> the passing of a morning
> that had held such expectation
> in the mist light of its peach-streaked sky,
> reaching its hand through
> the bedroom window to bestow
> gifts yet unwrapped.
>
> Back at the house
> we say goodbye to the walk
> on the blunt frost-rimmed grass
> where the rocks slept and the dark oaks
> dreamt beneath two flirtatious buzzards
> intent upon their circle dance.
>
> Knowing we would not pass
> quite this way again,
> we saluted you, shortlived friend of
> a journey: without whose loss
> nothing, not even this walk in first light,
> holds grace.

This abstract but everyday loss helped the students contemplate their own

ordinary losses — concrete (keys, cell phone) or abstract (opportunity, sleep — a

ubiquitous experience for them). Several volunteered to share their stories. Brad told how

at 2 a.m. his pregnant wife had had a craving for ice cream, but he was too tired to get it

and she was mad with him at breakfast. Reflecting on this, he saw the loss of this chance

to show his love for her as a prompt to attend to simple requests — the "stuff" of doctor-

patient care — then and there. Maria told of planning to go running at 5 p.m., but having

to abort when called into the Emergency Room. She saw the value of this in teaching her

the need to let go of resentment when forced to put her own plans on hold, so she could

attend well to her patients — something she knew would be a common challenge. Danny told of losing sleep and study time to the Winter Olympics, by getting caught up in the beauty of the dance skating on TV. He reflected that taking time for play, recreation, and appreciation of beauty is not something to feel guilty about, but a vital way to balance personal and professional life.

Collectively, the students came to see these everyday, mostly abstract, losses as valuable learning tools for their inevitable presence in their professional lives. In later teaching sessions, we will continue this AI pedagogy through the remaining DESIGN and DESTINY components. We are beginning an AI study with professional caregivers and their students, to learn how their stories of loss have taught them new affirmative approaches to their work.

(c) *PC research.*

We led a workshop at the 2006 Association for Death Education and Counseling conference, in which we used an AI inquiry with PC researchers and practitioners to frame their experience of best PC practices. We asked them this unconditional positive question: "Can you think of a best PC practice you have experienced or witnessed that inspired you or taught you something?" To jog their right brains, and reinforce the arts-based nature of AI, we asked them to focus on three images: What *animal* (or bird or insect), what c*olor*, and what g*esture* come to mind?" We stressed "first image" — what struck their minds/bodies first — and gave them colored pastels to create picture*s* rather than written stories.

All three images came easily to the participants. For her *animal* image, psychotherapist Anna depicted a doe emerging from the forest; the *color* pink in her picture represented caregiving, and hands dropping to the side with palms extended a *gesture* of letting go. She then told of witnessing a burly working man, cast unwillingly into the role of caregiver for his dying wife, but moved from anger and helplessness to something akin to mother-love by marking their anniversary with a giant pink sequined card.

Dorothy's own first image was of a *gesture* of cupped hands around a downy penguin chick — her *animal* image. Her *colors* were red rays on pale yellow, reminiscent of chicks incubating under infrared light on her family farm. She then spoke of watching the film, *The March of the Penguins*, in which both parents care for the egg and the newborn chicks in the face of great adversity and often death. She saw these images as closely linked to her experience of caring for her husband, Patrick. After taking early retirement while she pursued her academic career, Patrick had given her constant loving care as both house husband and loving partner, almost as a parent does a child. The reversal of their caregiving roles was gradual in the early days of his colon cancer, but mounting tenderness marked her experience as she grew into end-of-life caregiver. Although never a birth mother, she likened this to mothering a perfect newborn baby. Seeing this connection let her freely express her grief.

Discussion

AI as a self-study methodology in palliative care

Self-study is a process of personal reflection and development, which becomes research and pedagogy when offered to others to evaluate, and perhaps integrate into,

their own practices. Our exemplars intersect practice, pedagogy, and research in accord with Hamilton and Pinnegar's (1998) description of the self-study methodology, in which researchers and practitioners "use whatever methods will provide the needed evidence and context for understanding their practice" (p. 240). The unconditional positive question that initiates AI studies asks participants to let go of "givens" and journey into the unknown with an openness to learn, so they "become curious rather than contentious, listeners rather than insisters, and co-creators rather than naysayers" (Whitney. Cooperrider, Garrison & Moore, 2001, p. 179).

We have applied our AI self-study to the nuance and complexity implied in Stanworth's (2004) definition of PC: "An approach that improves the quality of life of patients and their families/significant others facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, assessment, and treatment of pain and other problems: physical, psychosocial, and spiritual. (p xvi)." The values summarized by the Canadian Hospice Palliative Care Association (www.chpca.ca) suggest many possibilities for AI to activate the interplay between positive and negative states. Examples are the value of life, the natural process of death, the intrinsic value of each autonomous individual, the opportunities for self-actualization, and the need to address patients' and families' suffering, expectations, needs, hopes and fears (p. 7). Kuhl's (2002) deficit-oriented study of what dying people want, on the other hand, reveals that insensitive communication by physicians often engender more suffering than the illness itself, or the awareness that the condition is terminal. Because further research into experiences between patients and

their caregivers may improve communication practices, we have begun a systematic multicultural AI study based on the stories of loss of professional caregivers and students.

Evidence: a false dichotomy.

Qualitative methodologies are more and more accepted as complementing quantitative research with the dying and bereaved. (See Morse, Swanson, & Kuzel, 2001; Strang, 2000.) This is a renaissance of the ancient marriage of science and art: it is no accident we use art to describe both creating works of beauty and offering skilled patient care (Graham-Pole, 2001, p. 165; 2005, p. 21). There is practical value in western healthcare's applying these methodologies to PC, to improve professional development, funding, and public acceptance.

In focusing on potentially oppressive situations, our study suggests the possibility of collapsing the seeming dichotomies of positive and negative, quantitative and qualitative, art and science. "Positive states are not merely the opposite of negative states, and positive dynamics will not emerge by simply reversing negative dynamics" (Roberts, 2006, p. 295). AP, the adaptation of AI to teaching and learning, collapses the dichotomy of didactic and experiential when it "trusts in, celebrates, and deliberately seeks out [learners'] experiences of success and moments of high energy and great pride." (See Yballe & O'Connor, 2000).

Our self-study also suggests a false dichotomy between "evidence-based" (EBM) and "arts-based" (ABM) research. At its simplest, science is knowledge; Parker (2005) points outs that in Classical Greece, art referred to anything that could be taught and learned. John's poem, "Signing," not only represents his story of bedside caregiving, but also suggests art as a form of EBM — the accumulation of clinical evidence applied to

medical practice. Qualitative research may seem to be an "orphan field" of EBM, but the bedside practice of every physician is founded in observations — *clinical signs* — that have been gathered over several hundred years and systematically recorded for every medical student's classroom.

The concept of EBM has emanated from the increasingly specialized focus of medical scientists (Rousseau, 2006) and has come to see quantitative evidence, especially the randomized clinical trial, as its gold standard. But in trying to eliminate confounds and observer bias, it discounts a wealth of psychosocial, arts-based, and spiritual experience. (See Stanworth, 2004; White 2000.) Qualitative research assumes that the research participants bring these socially and culturally determined biases and positions to meaning-making (Parker, 2005).

Figure 1: Appreciative Pedagogy of Palliative Care
(Adapted from Ludema, Cooperrider & Barrett, 2001)
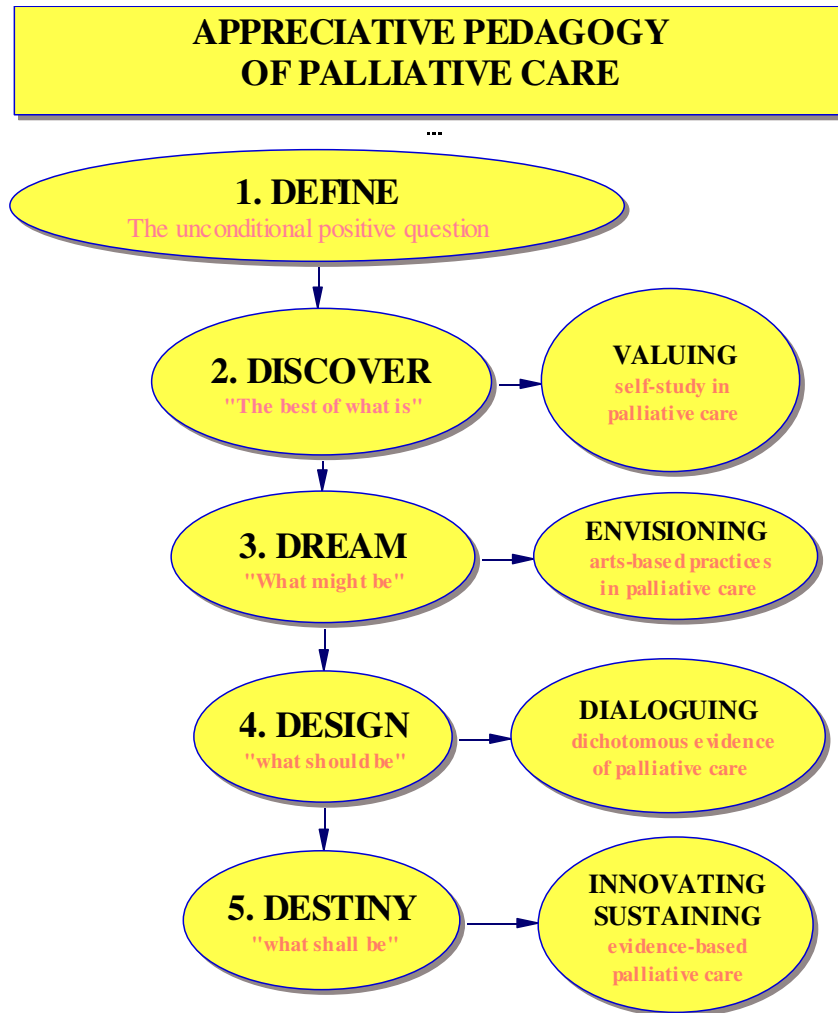
Inconclusive Reflections

Figure 1 is our attempt to organize the ideas suggested by our self-study. We have depicted it as an AI methodology and pedagogy that points the way toward integrating ABM and EBM, art and science — two facets of the same diamond of human knowledge.

Rainer Maria Rilke (1934) urged us to "be patient…. and try to love the questions themselves… perhaps you will then gradually, without noticing it, live along some distant day into the answer" (p. 35). Another poet, the 13th-century mystic, Rumi, exemplified arts-based self-study in his affirmations of human loss: "There is a shredding that's healing, that makes us more alive, a grieving required to enter the region of unconditional love" (Barks, 2002, p. 174). "Some grieve by donning battle armor, some satin clothing. Others, like me, love the word bunches called poetry" (p. 175). After Rumi's first wife died, he married again, raising four children; thus, his grief poetry was a very earthbound testimony to his lived experience, akin to the narrative evidence of AI. Barks's translation of Rumi's poem affirming grief as blessing merges the earthly and the ecstatic.

> *I saw grief drinking a cup of sorrow*
> *And called out, 'It tastes sweet, does it not?'*
> *'You've caught me,' grief answered, 'and*
> *you've ruined my business. How can I*
> *sell sorrow, when you know it's a blessing?'*

As our self-study reflects, AI and AP are life-affirming methodologies that, in the context of the professional practice, teaching, and research that make up PC, stress the value of "living our dying"' over quantifiable facts, including the value of the dark side of experience. Is it pie-in-the-sky to imagine a day when the doctor performs her objective "history and physical exam," then creates a poem to capture her patient's

subjective experience, setting the two side-by-side on the medical chart (see Graham-Pole, 2005)?

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