on the other side of hope:

PALLIATIVE CARE IN SPIRITUAL PERSPECTIVE ---------- ELLIOTT #2094

In some human activities you have the comfort and joy of knowing you've won, you're "in," before you start. The opposite is true of palliative care: you know, before you start, that you've lost: death will be the winner, you and your patient losers. This Thinksheet is about the spirituality of PALLIATIVE SPACE in between two other spaces, viz (1) health, everyday wellness, in the glow of which death is in oblivion, and (2) therapy, the process whose existence = the intention to defeat illness and death. Indirectly, this Thinksheet is a celebration of HOSPICE, the most sophisticated occupant of this interstitial space between health and therapy, an institution and movement uniquely coalescing intelligence and compassion face-to-face with the fact that none of us is going to get out of this (ie, earthly life) alive.

1. HOSPICE is a fresh challenge to medicine (which aims at healing) and religion (which aims at hope). It takes up where both medicine and religion must leave off in defeat (though, in self defense, medicine can extend its model of therapy to include nonphysical healing, and religion can extend its model to include an afterlife). My point here is that Hospice is in a unique position (1) to present us all with fresh dying-death-grief data and so (2) to enrich the ministrations of both medicine and religion. To state the matter actionally, both medicine and religion are, vis-a-vis Hospice experience, first of all in the listening position. As a biblical theologian, I accordingly see myself first of all as listener--primarily to my wife, whose work and ministry are primarily in Hospice (so I was with her today, 17Sept86, at Cape Cod Hospital for a clergy group discussion of a Hospice case led by Loree's boss, Hospice of Cape Cod's director Mary McCarthy, a charismatic leader in the field, and current pres. of Mass. Hospice--"Pain-Assessment and -Management").

2. Let's look at the three occupation areas under the aspect of concealment: (1) Medicine tries to conceal death by defeating it; (2) Religion tries to conceal doubt by overwhelming it with trust-faith; (3) Hospice tries to conceal pain by abating it. All three have their bright, angelic side: (1) Medicine is right in its warfare against death; (2) Religion is right in helping people to life-affirmation in the teeth of the world's and the soul's attacks on hope and the will to live; and (3) Hospice is right in pain-assessment and -control to the extent that particular pain--physical, emotional, psychological, social, spiritual--is hindering, by attention-absorption, other at least equally human business. But all three have also their dark, demonic side: (1) Medicine falls easily into the self-seductive moralism of sanctifying life as "good" in itself and denigrating death as "bad" in itself--so that heroic, aggressive measures, no matter at what cost to patient and family and society, are viewed as automatically "indicated"; (2) Religion moralizes faith as automatically "good" and doubt as automatically "bad," even in face of the evidence that spiritual growth requires doubting your faith (as one foot's step) and going on to doubt your doubt into a more mature faith (as the other foot's step); and (3) Hospice has its own self-made moralistic trap, the temptation to mindless negation of pain as "bad" and, the flip side, mindless affirmation of pain abatement as "good," within the too-limited objective of "making the patient as comfortable as possible" without addressing the pain's potential for good.

3. NOTE on "palliative" to describe the care given a patient the physician has given up on, ie, stopped therapeutic measures on, ceased "therapeutic" care of. Setting aside for now the question of the best antonym for "therapeutic," let's have a lexical look at "palliative."

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The concealment notion is in the etymon: the word's for the Latin for a cover-up (!), a cloak ("pallium"). In this root sense, palliative care "covers up" whatever's causing the patient discomfort in his/r last days. (Sure that's an unfair description of how Hospice actually intends to work, but it's unfortunately close to the bone as to how it actually does often work: "making the patient as comfortable as possible" = "death with dignity" understood largely under the aspect of a Stoic negative, viz placidity.) (Brain physiology provides us with a parallel irony: the "pallium" is the cerebral cortex--the "rational" brain--which covers up the nonrational, socalled "earlier" brains. THIS type of cover-up is more apt to be used by medicine and religion than by Hospice!)

But how is the word itself used? (1) "To reduce the violence of: ABATE" (the meaning in the word's Hospice use), and (2) "To cover by excuses and apologies: EXCUSE." (All God's chillun get good at this second activity by age 5, and it pollutes all occupations.)

4. In 1661 the manometer, which measures the elastic force of gases, was invented. Before and since then, every people-helping occupation has tended to gaseous expansion to fill the whole people-helping space. Partly because of a simple psychology-of-perception fact, viz that what gets your attention subtly suggests that it's all there is that's worth your attention (and so, in my bromide, what gets your attention gets you); and partly because one's ego, in the ego-jostling gaseous medium named "society," tends to puff itself up into self-importance as a mirror image of the importance of one's work. As clergy and a teacher of clergy (in preparation and in ministry), I'm a master of clerical self-puffery and the blindnesses and deafnesses of the bloated ordained ego: it takes one to know one. And I'm pretty good, too, at pricking the ego-gas balloons of other occupations. Indeed, the occupations need each other not just for synergism (teamwork, as in Hospice) but also for mutual balloon-pricking to improve the functioning of each occupation and to protect each occupation's laity (every occupation being a conspiracy against its laity, more or less). Now, since, as Jesus says, the wheat and weeds grow up together, Hospice, as it's been getting older, has increased (like every aging occupation) in both good and evil (or, in my analogy, bloating). One aspect of the evil is the tendency to overclaim--more relative to religion than to medicine.

5. Every occupation (and the academic "discipline" attendant thereto) has the right and duty to claim special knowledge and special skills and should be respected, heard, cooperated with vis-a-vis its specialties--in this case Hospice, with its growing fund of "interdisciplinary" skills and knowledge. But the more "multi-disciplinary" (as the flier of Hospice of Cape Cod), the more an occupation is tempted to overclaim; and the temptation is proportionate to the social standing, the respectability, of the occupational model ("paradigm") whose virtues and values one is tempted to lay strategic though specious claim to. In 1986 USA, the therapeutic paradigm ("medical model") has the highest respectability (even though medics themselves are experiencing increasing public disenchantment); so religion and Hospice are in danger of letting themselves be overinfluenced by the medical/health mind --and Hospice, as closer to the medical occupation, is in great danger of encroaching on, overclaiming in relation to, religion (Kubler-Ross being the most glaring example of the medic overclaiming in religion). One form this Hospice overclaiming takes is the holding of interdisciplinary Hospice conferences (as recently in New Haven) with experts from every relevant field except religion, which thus appears (1) of too small importance to be considered or (2) absorbed (cannibalized!)

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into other disciplines and occupations. I don't want to be too rough on Hospice here: (1) Religion itself is partly to blame, so many religious leaders having so sold out to more respectable disciplines and occupations that the public isn't convinced a religion expert could make a significant contribution in a conference; and (2) Religion as discipline and occupation is so low on the totem pole of respectability in the public eye that conference planners in fields other than religion fear that having a religion expert would (a) cause potentential participants to question the wisdom of the conference planners, (b) lower the conference's quality, and/or (c) introduce an unnecessary "controversial" element to the proceedings.

6. Neither of the above objections, however, are valid given the enormous overlap of concerns: religion and Hospice occupy the common ground of end-of-life issues. Either one without the other impoverishes any situation's care-potential and warps actual care (1) toward itself and (2) against the other. As warpage is more easily seen from outside, and Hospice is more on the inside ("on the scene") than is religion, religion is in a better position to see Hospice impoverishments and distortions vis-a-vis religion than vice versa (though every Hospice worker having done much time can tells stories of horrendous unproductive disturbance of the care situation by heavyhanded, insensitive religious ministry).

7. One thing to be expected with improved Hospice/religion dialog is dogma decrease. Unillumined by actual dying-and-death-care experience except under its own control (ie within the security and comfort of its own paradigm in unchallenged space), religion will control the scene cognitively and ritually (as it has almost everywhere almost always, this being the human situation till very recent times, and still the human situation in most places on earth). Religion functions (1) to render impressive the values a society considers highest, and so (2) to preserve-conserve those values against the challege of foreign or emergent values. That's just an anthropological description of how religion works: no criticism intended. Now notice the parallel: Hopsice, developing its own "head" and "mind" unchallenged from religion, quite naturally evolves its own dogmas (1) to render impressive what it has come to feel is most important and (2) to promote-protect this "paradigm" (as well as its turf!).

A religion/Hospice dialog would seek, among other things, to identify each other's dogmas. Just quickly, here are a few I've noticed from being on the scene and reading the literature of a number of Hospices:

(1) The anti-punishment dogma. It's partly a hangover from the old Freudian anti-guilt dogma that's pervaded "the healing arts" in America (but not in Europe). Even Hospice workers well trained in listening will sometimes attack the patient who wonders aloud whether "I'm being punished": "Of course you're not being punished! What sort of God would do this to you? Put that nonsense out of your head!"--though usually in more polite language. Observe: (1) The Hospice worker is in no position to know whether the patient is being punished; and (2) Casting his/r situation into the punishment question may be the most creative way of dealing with what's happened. The intensity with which a worker rejects either or both of my observations signals the relative depth of his/r anti-punishment dogma. And the deeper this or any other dogma, the more Hospice training the worker needs for creative caregiving free of the temptation to manacle the captive audience, ie the patient (and others who may have this worldview the worker rejects). ("Pain" and "punishment" have the same etymon, root.)

(2) The pro-dignity dogma. "Death with dignity" is the control

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value in this dogma, and the personal symbol (ie control biography) here is the death of Socrates (as presented in Plato's "Phaedo"). Hospice is so hooked on this dogma that it operates as a potter to shape the patient into a Socrates-like Stoic philosopher. Whether or not this molding is good for the patient and family, it's "good" for the Hospice overall operation because (1) it pacifies the patient and so makes him/her more controlable and (2) it makes the Hospice workers feel good about themselves for successfully using the model and so confirming the skill and knowledge of Hospice as caregiver. Again, anger at my description of this dogma would show the intensity with which a Hospice worker holds it....Note that this kind of "dignity" is drawn from the Greek strand of Western civilization. The Roman, Jewish, and Christian strands would yield otherwise. Irony: Most Hospice workers worship not Socrates but Jesus, whose death was radically different from that of Socrates. Here's just one difference: In dying, Socrates is in control (cf. the Hospice saying "the patient is in control..."): in Jesus' death, God is in control. So in a Jesus'-death-model Hospice, the worker would feel defeated if the patient died without the convictional experience of God as in control. (NOTE! I'm not proposing here a substitute dogma; I'm only exposing the Hospice dogma.) If in defense against my analysis a Hospice worker were to claim that US "pluralism" would rule out a Jesus'-death type of public-sphere Hospice, my response would be that the current Socrates'-death type is under the same burden of the "pluralism" criterion. It's cultural imperialism, and antipluralistic, to see to it than any one model dominates; an open, pluralistic Hospice would not rig dying to conform with any one conception of "death with dignity."

(3) The anti-pain dogma, obviously related to Socrates' painless death and to the narcissistic-hedonistic moralism that mindlessly accounts pleasure "good" and pain "bad." I hasten to applaud Hospice as supreme above all other institutions in the continous and close monitoring of sedation to provide, under the patient's control, the desired balance or trade-off between consciousness-awareness-alertness on the one hand and pain-suppression on the other. One identifying dynamic of Hospice, indeed, is the personal touch: the patient is not treated as an organism that gives the least "trouble" when sedated slightly below the threshold of decisional awareness (as in many a hospital and nursing home). No, the anti-pain dogma is something else, a subtle something I can only point toward by alluding to the attitude that pain is something to be attacked, an enemy, a negation the medical model aims to negate. One is free of this dogma if, instead of only aiming to "keep the patient as comfortable in all respects as possible," one intends sedation in the interest of (as I describe it at the beginning of this Thinksheet) "the spirituality of palliative space"--the human spirit, free and lifted above the flame of attention-absorbing pain, to do the highest work at life's latest and last stage on earth. ....My #2095 explores this analytically and distributively.

8. In London, at the original Hospice, I read this in a work of the founder, Dame Cicely Saunders (C...S..., Shirley duBoulay, Hodder & Stoughton/84), describing the spiritual perspective of that Hospice: I & Hospice are "fully committed to the belief that in Jesus of Nazareth, God knew a human life and the ultimate weakness of life as we know them, and this for all men, whether or not they believe." God "loves (all human beings) and shares all pain from within," so "can still our doubts and questions, not because we understand but because we can trust....The small transformations that we witness continually speak of a Resurrection which will finally redeem and encompass all creation." (158) "If God calls, he also enables." (159) "Death is an outrage.... I'm always seeing the Resurrection." (255) *16Sept86*