

RE-DESIGNING THE CHARACTER of the CARE-ACTOR

Susan Parenti, DMA (doctor of musical arts)

School for Designing a Society, Gesundheit Institute

Background to inquiry: exploring the 'third direction'

Our project: to change from the health care system we've inherited, into health care systems we desire.

We see two directions that dominate the talk around health care systems: that of corporate care, and---challenging this--- that of single payer. We reject the direction of corporate care; we value single-payer and its radical rearrangement of financial incentives that would give all people access to health care; AND we invite people to widen the scope of health care system change beyond the financial aspect. The US health care system is in crisis and it's not only about 'who pays'. We call this widening of scope a 'third direction': a call for a variety of ideas, innovations, models, practices, language, patterns that would constitute structural change in health care system delivery.

In the spirit of this 'third direction', this paper is an inquiry into care-givers and the roles they can play in health care system change.

Re-Designing the Character of the Care-Actor

The care-giving relation is the core of any health care system formed around it. The system itself could be looked at as an 'outside', the care-giving relation its 'inside'.

Most efforts to change the health care system focus on the outside. The fixation in the United States around the financial aspect of the health care system---around the question 'who pays'---attests to this.

While we support these efforts, we also ask ourselves the questions: could significant change happen from that 'inside'---the caregiving relation? Could care-actors and the healing relation be powerful contributors to health care systems change?

Yes. If care is to be the core of a health care system, then we need to re-think our abilities to respond to the variety of situations that the 21st century places us. We care-actors would like to see ourselves as a positive force towards changing the system as we want it to be, not just benchwarmers for the health care system as is.

To emphasize that care is an action (and to enjoy the word play!) we name care givers 'care-actors': people who act so that there's care.

The education of care-actors in nursing/med schools focusses on training their know-how, and forming their character.

In this paper, we focus on character: what people expect of themselves (in addition to know-how) when they enter a care-giving situation--and such that they enter one. 'Character' is a person's resource of a range of personal traits called on again and again so that the person can perform her profession.

Given the contemporary calls on care---crises in the US Health Care System, crises outside on the edge of the medical system, crises in global health--we assert that the character of care-actors is no longer sufficient to meet these calls. There are traits that are endangered; there are traits that are missing.

This paper probes into some of what's endangered and some of what's missing, making proposals for protection and addition. Our probe is incomplete--in some cases we have very few proposals. We welcome contributions to the inquiry.

Our premise: for desirable change of health care system, we need to re-design the character of care-actors.

Some readers may raise the objection: why write about 'character' now, given the urgency of the US health care crisis? If people are dying right now because they can't even get IN the hospital to see a care-actor, shouldn't we concentrate on *access*? Isn't 'character' a luxury consideration?

Others may object: hasn't the 'character of care-actors' *already* been re-designed by means of the corporatization and 'pharma-suiting' of health care? Isn't it too late?

These objections pitch us head-long into the health care system crisis and the basis for this inquiry.

1. PROTECT THE CARING RELATION FROM THE UNCARING SYSTEM

Situation:

I went to an eye clinic to get my eyes checked. The receptionist said the clinic advised an additional exam for glaucoma. I refused, thinking, 'Yeah sure---tack on another expensive test! You guys are only interested in money, or else in making sure I don't sue you'. But I don't know--- maybe I do need that test? I don't know who to trust anymore. (Carol Higgins, teacher)

This story is a familiar one in the contemporary climate of health care systems in the United States. It points to a crucial component in the system: what economist Lane Kentworthy calls the motivation of actors in pursuing transactions with one another.

Care-actors feel that while their work in the health care system is to give care, the system itself is run more as a business than as a caring organization.

Patients feel that the health care system is something to tolerate in order to 'finally get in to see the doctor'. This means that patients distinguish the system (the insurance forms, the complicated billing, the bureaucracy, the waiting, etc) from the healing relation: the moment when the doctor or nurse takes a look at them, listens, gives a context in order to understand what might be happening, holds out hope in terms of medicine or treatment.

Patients trust in this healing relation, and separate it from the system. This is desirable--as the healing relation (and the trust in it) is the core of any health care system. Relation vs. system. As care-actors we need to keep our focus on this core--the healing relation--and daily distinguish it from the system that forms itself around it.

But in 2007 this distinction between relation vs. system is in trouble: consequences of the corporatization and pharma-suiting of care have made it difficult for people to separate out the caring relation from the uncaring system. People are suspecting--and rightly so---that when they 'finally do get in to see the doctor', the system is sticking its nose in there too.

As people sit in the doctor's office, a contemporary cacophony of motivations plays itself out. There's at least two conflicting messages: the message of care and the message of gain/self-protection. Is the doctor representing the patient's best interests--or, its, the systems? is that test necessary for the patient or, for it? Is the doctor's motivation coming from the caring relation, or the uncaring system? Messages are being sent--but who's talking?

This realization underscores the need for fundamental change of the US health care system. A system's job is to support and protect the core relations around which it is organized--not contradict and weaken that core relation.

But if care-actors already realize the system needs to change, and yet are still working within the system as it is--what can they do?

Calls on care: Expanding the Character of the Care-Actor

Someone might answer: "Isn't doing my job, enough? (isn't my know-how enough?) If I go about my work competently (monitoring technology, drawing blood, updating readings, etc) then wouldn't that restore trust in the health care relation?"

No. Competent performance of know-how is important, but competent know-how alone cannot restore trust. Further, competent know-how in the 21st

century has been reduced to efficient performance around technology, to the exclusion of loving performance around patients.

Remember, there's a daily cacophony of messages being sent in the US health care system--messages from the system, messages from the care-givers---and the care-actor needs to be proactive in separating out the intended messages of care-giving from the messages from the system. Competent performance of one's job, while important, is not sufficient.

For example, if a patient is made to wait a half hour in a treatment room before a nurse arrives to draw blood--is that half hour wait an intentional message of the nurse in her healing relation? No--it's a consequence of the system. So no matter how well that nurse draws blood, the message from the system has already been sent.

What to do, if professional know-how is not enough?

Here is where the character of care-actors in the 21st century steps in.

Care-actors need to add a voice in their head which persistently reminds them to scan istheir daily interactions in order to redress the lack-of-trust situation at every opportunity. We need to restore trust in the healing relation, and distinguish the caring relation from the uncaring system.

Presentation of Self in Everyday Life

The idea of presentation of self in everyday life here plays an important role. The way a person decides to present herself--her language, her gestures, her dress, her behaviors-- is a form of design. By that we mean that this person's performance of herself can generate a temporary reality--intended by her--in which other participants can live and benefit.

I work in a very busy hospital, with long waiting times. I make a practice of sticking my head into the rooms where people are waiting to apologize to them for the wait. It's a small thing, but when people hear a doctor acknowledge their wait, they feel included in the situation. By the time I get to them, they're cooperative even if they've had a long wait. It makes my work as a doctor much easier--patients understand that I don't like the situation any more than they do, and they feel we're together in this thing. (Dipesh Navsaria MD, September 2007)

The care-actor's presentation of self can substantially alter a situation.

When a doctor presents himself to his patients as friendly, attentive, and concerned by how long they've had to wait, then this presentation of self gives

those attitudes a value, a life. In this doctor's presence we feel befriended (with friendship a value), attended to (with attentivity a value), and feel that our anger about the wait is something he shares. Even if he cannot change it, at least he doesn't intend it.

This doctor's presentation of self generates a temporary reality in which the relation between himself and his patients is affirmed; it's a temporary enclave of care in the uncaring system. Solidarity between patient and healer is established.

Solidarity is an under-appreciated value in North America.

Solidarity is when someone gives a support to other people that cuts across the usual social power lines. In the United States today, the usual social power lines easily connect the interests of doctors with the interests of the health care system--aren't both making LOTS of money, and at the expense of the patient?

THE ROLE OF SOLIDARITY BETWEEN HEALER AND PATIENT IN THE 21st Century

Care-actors can use their presentation of self to establish a solidarity with themselves and their patients, indicating an alliance with the patient, not with the system.

How I set up my chiropractic office is from how things are communicated. Though it might seem like a small thing, I'm very careful with how we speak. When I meet my patients the first time round, we have a special place to meet where we have a conversation about what we're doing, and why. I tell them I'm not here 'cause I want your money. I'm here because I want to help you.

We have the "new patient promise" which we both sign. I make a commitment to work with them towards their health, whether they can pay for it or not. They make a commitment to ask themselves the question: who can I collaborate with so that I can achieve my maximum health?

(Paula Murphy, DC)

Paula Murphy's chiropractic office set-up is a small scale system built in order to protect and support the healing relation:

1. The office is not just constructed around efficient delivery of know-how, but rather "from how things are communicated".
2. Paula's presentation of self emphasizes the importance of the healing relation, juxtaposing it with the system

3. The inherent drama of the new patient interview is used to reframe the motivations for what's happening. and establish solidarity .(Notice---she not only makes a commitment to the patient's health, she also asks them to make a commitment back).

MEDICAL SYSTEM UNDER CONSTRUCTION:
WE'RE SORRY FOR ANY INCONVENIENCE THE MEDICAL SYSTEM IS CAUSING YOU.
THIS IS NOT HOW WE WANT IT TO BE .
WERE TRYNG TO CHANGE IT . PLEASE HELP.

signed,

your nurses, lab technicians, receptionists, doctors

2. Contemporary Calls on Care: 'Outside' the System, Health Care as a Human Right?

Situation:

*All the sick people who can't get into the medical system . . .
Y 'know,doctors and nurses don't care, 'cause if they did,
they'd come out to help us. (John Rebutti, uninsured house painter)*

The same forces at work INSIDE the medical system, are also at work OUTSIDE the system. INSIDE, conditions for care are eroded; OUTSIDE, people are prevented from access.

Doctors and nurses are trained on the assumption that they can get IN the medical system. As a matter of fact, where they are, is 'in'. They're in. They're the 'in' that we're all trying to get to.

But what's the care actor's relationship to those who are OUT? To those unable to get into the medical system? and to that medical system, itself? A moral objection? A personal frustration? a professional one?

In a conversation with Carla Rafferty, UIUC med student, she said she doesn't feel especially empowered as a future medical professional to influence the system. Rather, she feels she has the same ability to change that system as any other voter. (If we substitute her word 'ability' with the word 'inability', we can feel the mood of her statement).

Paul Farmer, physician, anthropologist, and activist, writes:

We are now faced with a 21st century decision--where will healers stand in the struggle for health care as a human right? There is, in the global era, no hiding from the question--or from the imperative to respond.

Health care as a human right, nurse? Health care as a human right, doctor?

The question crouches by each health care provider, tapping lightly on her shoulders, on his arm, trying to get attention.

Health care as a human right, care-actor?

If a physician is uninformed about current medical technologies, she would be deemed incompetent in terms know-how; If she lies about test results to a patient, she would be deemed incompetent in terms of professional character.

But if a health care provider doesn't care one way or the other whether health care is treated as a right or a commodity, she is not deemed incompetent, neither in terms of professional know-how or character.

The care-actor may care *as a person*, but not *as a health care professional*.

We call on the character of the care-actor to re-think this. When a person says, "I'm a physician"--shouldn't we then know where this person stands in the struggle for health care as a human right? Why relegate that crucial stance to ethical or moral or political domains, and not the care-actor's character ?

Here we can see the value of establishing solidarity between healer and patient. This solidarity needs to be seen as a potential character trait of care-actors.

Current strategies supporting health care as a human right enlist the language and legal powers of the civil rights and human rights movements. Jay Bhatt public health medical student and past president of AMSA, writes that "the right for healthcare is the Civil Rights issue of the 21st century". Paul Farmer and Partners in Health turn to human rights language and legislation.

We join these attempts. Still, is it from resignation with the unchangeability of the health care profession, that our activism doesn't go to the core and insist that health care as a human right is part of the character of the care-actor?

This is a missing trait in the character of care-actors.

One Strategy to Add Compassion and Service to the Care Actor's Character
Towards this end, Jay Bhatt proposes a change in medical school admissions evaluations:

If you look at med school requirements and admissions evaluations, they will all say that they value the person's character and integrity and compassion etc, but I can't tell if they actually do. The current state of health care---where public trust in physicians is declining, where more physicians are concerned about reimbursement rates than access to care, where there is still a culture of non-disclosure over errors---necessitates revisiting what we value in entering medical students.

I have always wondered what would happen if you stripped away applicants' MCAT scores and GPA - if you just ranked based on the applicant's compassion and morality. Then, add the scores and see whether your rankings change or not. If not, then great, you have solid candidates who have displayed both the academic prowess and social character to join this intensely personal and powerful profession. If the rankings change, I would like to see which factors admissions committees chose to prioritize.

My notion has been that we should review current admissions criteria and improve them to create a new model... The model criteria would place tangible value on experiences to work with diverse populations ,i.e.,if an applicant had done volunteer work or research with homeless folks or substance abusers. That should have a tangible value as she is evaluated, some proportional value that is just as important as her MCAT or her GPW or her research results...

With all the lip service that every school plays to compassion and holistic medicine and the highly ethical profession of medicine, we should ask them to put their money (or rather, their admissions criteria) where their mouth is (or rather, in front of their admissions committee).

3. Contemporary Cares on Call--The Tyranny of 'Burden'

Situation:

*Some of the staff here are nice, some aren't,
but everyone is in a hurry. My children and grandchildren
lead busy lives. I just feel.... I'm a burden.
(nursing home resident describing her life)*

What is the name of the character-trait that enables us to *not* think that a person needing care is a 'burden'?

What is the character-trait that enables us to *yes* think that caring for someone is a privilege and a delight, a situation we long for, we rush back to?

I don't know that name of that trait; I would like to know its name. We need that character trait; we need the conditions that enable and support it.

But even the best conditions could not cause ('enable') that character trait---it needs to be a premise deliberately stipulated by the care-actor.

Why do we say this?

The tyranny of burden permeates all language and behavior around care. It's assumed, it's part of the old history, the old paradigm of care. Any person who cannot take care of herself is assumed to be a 'burden'. Well-meaning book after well-meaning book asks how can we deal with the "burden of care", "who shall have the responsibility for care?", "how can we pay people enough to take on the

burden of care?".

In our desirable world, the character of a care-giver insists that when she cares, she is not caring for a 'burden'. She intentionally avoids any construction in language and behavior that constitutes the cared-for person as a 'burden' (felt so either by the caregiver or the patient himself).

How can she do this? Are there any ideas that come to her aid?

Supporting idea 1: Bi-Directional Care

The care-giver looks at care situations as potentially bi-directional, not only uni-directional.

In present day society, care is perceived as something that is uni-directional---it moves in one direction. The care-actor gives care, the patient (the receiver) takes. The care-actor is help-ful, the receiver is help-less. The care actor is mobile, the receiver is stationary. The care actor is objective and cheerful, the receiver is subjective and weak.

It doesn't take much to go a stretch and notice how patient---the 'takers'---are structurally constituted as burdens. For after all, states present-day society, what are they doing but *taking* and taking?

In bi-directional care, care is perceived as moving in two directions: while the caregiver offers something to the patient, the patient is offering something to the caregiver. What the patient gives the care-actor is not the same as what the care-actor gives the patient. But something can emerge from the side of the patient, and move towards the care-giver: what we call (in purposefully non-technical language) a "sweet". The sweet of care.

Supporting idea 2: the Need to Give Care

It's no controversy that 'care' is a human need. But we entertain the possibility that there are actually TWO needs in relation to care: people need to receive care, AND, people need to give care.

The (well-known) need to *receive* care dominates the care landscape. Hospitals are there to 'get the patients the care they need to receive'.

But could hospitals also be places that 'get the care-actors the care they need to give'? What would those hospitals look like, that satisfy the less known need to *give* care?

Herbert Brün speaks of care as happening "when I temporarily become part of another person's structure". To be able to traverse from one's own structure and cross into another person's---is that not a need?

Time: enabling bi-directionality

Patch Adams of Gesundheit Institute speaks of how taking time with a patient is one of the demonstrations of care. His initial interviews with patients are three hours long.

Why is time necessary? Amongst other things, so that bi-directionality can emerge. Initially, a care-situation is uni-directional: the patient seeks out the healer, not the other way around. But with time, bi-directionality can emerge, coupled with the satisfaction of the need to give care.

Without time, care collapses into a burdened uni-directional universe, where the only need satisfied is the need to receive care. The care situation then closely resembles a commercial transaction in a very busy store: the patients (all those shoppers, so demanding!) needs something, the care-actor (the store clerk) rushes around to supply it.

We say that care is a situation of two-overlapping stories: the story of the need to give care, and the story of the need to receive care. The story of the need to *receive* care has upstaged the space where the second story--the need to *give* care---could emerge.

Supporting idea 3: roaming the terrain between the unique and the standard

The care relation is asymmetrical in the following way: for the patient, her illness and the care she receives are unique dramatic experiences; for the care-actor, they're standard day-to-day experiences.

These two experiences--one, of the patient, the other, of the care-actor--are asymmetrical in significance though they happen simultaneously. For the patient, the experience is one out of one; for the care-actor, it is one out of many. We consider this asymmetry a constraint that requires the art of care.

But it's not a flaw--this asymmetry is an indispensable part of the structure of care.

An ill person purposefully seeks care-actors for whom her illness is one out of many. Illness makes us move from the unique to the standard. When we arrive in the hospital with our bad heart, we want to be treated by people who "know what they're doing"--meaning, someone who has seen HUNDREDS of bad hearts. The care-actor is sought out just because she can situate within a larger sample our uniqueness.

Even so, our experience is unique. And for the care-actor, it's standard.

The care-actor *as we want her to be* is aware of this structural constraint in care. Both her character and know-how enable her to roam the unmapped terrain between the standard and the unique: medical treatments as usual, and the patient as unique. She 'has the patients' interests at heart'; she 'takes the situation in hand'.

Not only is the patient's mental experience of illness and care unique, the patient's physiological path to her wellness, is also unique. We consider a person's wellness something uniquely her own, constructed by her.

In conversations with medical students at Gesundheit's Health Care System Design rotation (taught by Bonnie Gifford MD) I asked, "Is working with a patient towards her wellness considered a standard procedure or a unique one?"

The medical students answered that their training teaches them to identify in a patient a 'standard' disease, which then will mandate standard treatments, unless there are 'complications'. Both healer and patient *wish* for the treatments to work in a standard and predictable way, with a standard and predictable wellness as the outcome.

But between this *wish* and the actuality of it happening, is a series of unpredictable events that we call the patient's 'path to wellness'. Treatments may be standard, a patient is unique. (That the medical community calls this uniqueness a 'complication' indicates the profession's bias towards the standard). The care-actor *as we want her to be* is witness and advocate for this uniqueness, considering it the domain in which she practices the art of healing.

Ironically, it's often medical and nursing students who are best at "roaming the unmapped terrain between the standard and the unique". For these students--- who are beginning to learn what's standard, but who haven't yet unlearned what's unique---they experience the medical interaction from both sides. They feel, afresh, the patient's fright of sickness and of treatments; they hope, afresh, in the effectiveness of treatments and medicine.

Standing at the patient's bedside while the attending physician talks to a trembling family member, they whisper helpful explanations about what the physician's medical jargon means. When they see the patient's family in the lobby, they go up and say encouraging remarks, almost as much to encourage themselves as to encourage the family.

The art of medicine, the art of healing, hasn't yet *decayed* for them.

Supporting idea four: Retarding the Decay

In the 21st century, the future of the care relation is at a tipping point. Not only do care-actors inherit the past paradigm of 'burden', they also face the contemporary effects of the corporatization and pharma-pursuing on care.

Earlier in this section we wrote:

What are the character-traits that enable us to think that caring for someone is a privilege and a delight, a situation we long for?

We've made proposals towards answering that question.

We offer one more trait to add to the character of care-actors: retardation of decay.

'Retarding decay' is a strategy towards keeping up enthusiasm and interest in the face of knowing that projects and relationships tend to lose significance over time(they 'decay'). We 'retard the decay' by finding and inventing ways to counteract that loss of significance.

When we look at projects and relationships from the point of view of time, we see a recurrent pattern. In the beginning of a project, things are fresh, interesting, uncertain(even confusing), full of possibilities and information. Over time, as we become familiar, things become well known, habitual, predictable---even tiresome and boring.

We call this recurrent pattern of decline the decay of information.

But we humans are not helplessly delivered to this decay.

We can 'slow down' the decline by finding and inventing ways to add something new to the picture. When we sense a decline of our interest in a project, we can of course abandon that project and move on to something else.

But we can also bring something new to the project thus enlivening our interest once again.

The care-giving situation almost mandates retardation of decay: we cannot abandon our patients when we lose interest, and move on to something else. Rather, we need to invent and find ways to maintain interest and freshness under recurrent situations: the art of healing.

4. Clowning, Play, Humor

Expanding the Character of the Care-Actor

Situation:

My mother has Alzheimer's. In the beginning, we took her to all sorts of doctors; they gave her tests, then each told us 'there's nothing we can do'. Just because they didn't have a cure for her disease, they kind of washed their hands of her as a person. Nothing?, really 'nothing'?

Since then, we've been taking care of her at home for the past 8 years. There's been PLENTY of things to do, everyday, such that many of her/our days have been great.

But that attitude of the medical profession---there's nothing they can do---wasn't good for us. Initially it made us feel there was nothing WE could do---which wasn't true at all. (Karen Parenti, about Jo Parenti's care)

Our organization, the Gesundheit Institute, has been associated in the medical profession with clowning, humor, and play. Rightly so: it's by design. For 30 years our global outreach work has happened--intentionally--within the framework of clown trips (visiting orphanages, refugee camps, hospitals all over the world, bringing play and medical supplies, building clinics and schools). We could have chosen a different framework---medical missions, for example---but instead, we intentionally chose to nest our global work in the framework of clowning, play, humor.

Why? Especially as these traits seem antithetical to the seriousness of the medical profession? Everything in a clinical setting shouts its solemn-ness, its fearfulness: "we're not playing around here" "these are life and death-situations here". Maybe jokes, yes, to relieve the tension, but as one cardiologist told me, "Say what you like, no one wants a clown in the operating room."

Why then, clowning, play, humor? Simply answered: these traits expand(add alternatives to) the character of the care-actor. The clown and the play-mate expand the range of care character for the healer. Allowing the clown in is a major shift in expansion.

If care is to be the core of a health care system, we need to develop the ability to respond to the contemporary variety of situations that care places us.

In the present-day health care system, the character traits of the care-actor have been shaped by situations that seem to require professional distance and efficiency, as well as mastery of medical technology. Corporatization and pharmapursuing of care have also made their mark on the situation: care-actors are required to do large amounts of paper work, and make do with short amounts of patient-healer time.

Thus, care-actors give off the attitude of people who are 'going about their business'--they're busy, detached, serious, efficient, in a hurry.

In many situations this may be what's needed.

But these situations are a subset of a far larger set where this character and know-how is insufficient.

We think of situations of people with chronic illnesses, or mental illnesses; of situations of people who are handicapped, aged, dying, housebound.

How to be a care-actor in these situations? Act competently, efficiently, be professionally distant, master technology, do paperwork? What does that offer a person bewildered by Alzheimers?

If care-actors are seen as 'going about their business', then what exactly is their business when faced with these situations of care? If there is no machine to tend, or diagnostic reading to take, does the nurse then back out of the room saying 'there is nothing we can do'?

Nothing? really, 'nothing'?

If there is no hope of cure, does that mean there's no hope of care? Have we mis-named the health care system all these years? Should it have been called the health cure system?

Clowning, humor, play: we offer these traits as additions, not substitutions. We value seriousness in some medical situations; we value the purposeful dedication of health care providers taking matters in hand. We don't want to lose that. But we do want to add. Clowning, humor, and play are additional resources to meet the calls on care.

On our clown trips, the clown walks into a room and faces the same group as the health care provider does: very sick people, chronically ill people, poor people, dying people, people locked in or locked out, the families of these people, the staff, the nurses and the floor cleaners.

The clown, like the doctor and nurse, walks towards suffering.

But here the clown, unlike the doctor, has no higher rank than the patient. (On the contrary, people tend to feel a bit superior to the clown, the fool, greeting with a grin the clowns' ambling up to their bedside). Here, the clown can't 'hide' behind technology or tests, is not busy doing 'medical procedures', as the health care professional is. Here the clown doesn't assuage suffering with drugs; there is no pharmapursuing of care.

Health care, in its indispensable minimum, consists of a healer, a patient, some tools, and time. But in the current disease bureaucracy system, that relationship has become complicated, segmented, huge, expensive.

The clown, like the doctor and nurse, walks towards suffering---but the clown pares the relationship down again to its minimal indispensables: there's the clown, there's the patient, there may be some toys, there's time.

And why the clown is there---the over-riding attempt---is to make human connection. John Glick MD, friend and colleague at the Gesundheit Institute says " the goal is not to make a smile but to make a connection, which can be a smile or a 'leave me alone' or quiet hand holding; anything where the patient has the freedom to decide whether to play or not, and, if not, to have control over their environment."

Patch Adams calls clowning a trick to bring love close. (Professional distance, good-bye!)

In the following essay, John Glick describes clowning as 'playful attentiveness'. In medicine we have diagnostic attentiveness; we have commiserating attentiveness; we have technical attentiveness. The health care system adds bureaucratic attentiveness, and gain attentiveness. What about playful attentiveness, to add to the traits of a care-actor?

John Glick writes:

I was first a clown, as a child growing up in an unstable and luminous world, tending toward happiness and play, while sensing the seriousness underlying my family's drama. Then I became a doctor, and despite the seriousness of suffering and death, and despite my growing pains as a physician, I was able to laugh and delight in the dynamics of the caring relationship. I learned a lot about what makes a person sick or well, and about the difference between pain and suffering. As a doctor I had many tools and yet I did not fully understand the power for healing inherent in the human dimension of the relationship with my patients. Then I became a clown again, on a trip to Russia in 1993. ..

I've learned much about the incredible power of playful attentiveness, how a clown can calm an agitated fearful person, how a person's physiology changes from stress-based anxiety and arousal to relaxation and fun, and how shared play and laughter decreases suffering, how easily clowning creates a framework for friendship...

The power of direct human contact, in an atmosphere of play, respect and fun has become very clear to me now. People, in their suffering, their fear and loneliness are so often isolated from the mainstream of life, of community. Smiles, touch,

eye contact, music, these are crucial elements of the healing interaction throughout all cultures and all times...

After the Beslan tragedy where 300 children were murdered at school by terrorists, many survivors received medical and psychiatric care in Moscow. 4 clowns visited a unit where 6 young children were housed, and when we began, the children were aggressive, frightened, and agitated. Across their faces played a complex series of expressions signifying echoes of a horrible experience; anguish, anger, fear, confusion, cruelty. Finally, we were sitting at a table, eating cake, when we began a spontaneous game, whereby the boys made ugly faces and sounds at the girls, who made ugly faces and sounds at the boys. Taking turns, we each expressed our maximum silly gross stupid behavior towards the other side, and laughed at and with each other. After this game we were all friends, and the children were relaxed, sitting on our laps, cuddling. We had inadvertently found the path to intimacy and play and trust.

This, really, is clowning for me, bringing peace to those who have lost trust in life's joy and fun. Healing the body, the mind, the spirit, the community, the world.

Pk Bevell, a nursing home activist and director of Second Winds, says that when she makes keynotes to nursing home conference, she tells the people, "If you don't like to play [with the residents of the nursing home] then this is NOT the job for you. Quit this job, and find another one. This is where you get to play!"

Conclusion:

Check-list for Re-Designing the Character of the Care-actor:

We look at the care relation as the core of any health care system formed around it. From that relation--that *inside*--what significant change can the care-actor do?

We assert that if we strengthen that *inside*--the care relation--by both protecting and expanding it, then we have a chance to perturb the *outside*, the system.

What we have going for us, is this: daily, care relations are being established between care-actors and patients. The care-actor/patient relation is the 'frontline' of the health care system. Yes--the system intervenes as a powerful intermediary. Yes, the healer who really wanted to have the initial patient interview last a good hour, is forced by the system to cut it down to an inadequate 10 minutes.

But still--that healer gets the opportunity to present herself, to be with the patient, and to respond to situations of care. Her presence, and her presentation of self, generates a temporary reality. And the patient is seeking

the healer, the care-actor---not the financial people, not the insurance people, not the bureaucrats. These people and the roles they play are fundamentally immaterial to the delivery of care. The patient is seeking the 'sweet' of care; the care-actor is seeking the 'sweet' of care.

We need to protect and expand that sweet of care. By doing so, we create a contrast between the caring relation and the uncaring system large enough to trigger the system to adapt to the caring relation, rather the caring relation eroding and adapting to the uncaring system. The health care system needs to learn from care, rather than teaching the caring relation to not care.

In the service of this aim, this paper has probed into the character care-actors, asking whether these traits are sufficient for the 21st century calls on care.

We have looked into some traits that are endangered, some traits that are missing.

Our check-list is the following. The character of the care-actor:

1. protects the caring relation from the uncaring system
2. establishes solidarity between healer and patient
3. considers the presentation of self a way to substantially alter a situation
4. asserts that health care for all is part of a health provider's professional competence
5. looks for admission standards for med/nursing schools that would reward applicant's experiences of compassion and service
6. refuses to link care with burden, and instead considers care a privilege and delight
7. acknowledges the need to give care, as well as the need to receive it
8. supports conditions such that bi-directionality emerges
9. roams the terrain between the standard and the unique
10. retards the decay of care
11. uses clowning, humor, and play in order to be playfully attentive in the many situations of human suffering

We repeat: our probe is incomplete. We welcome contributions.

October 7, 2007

