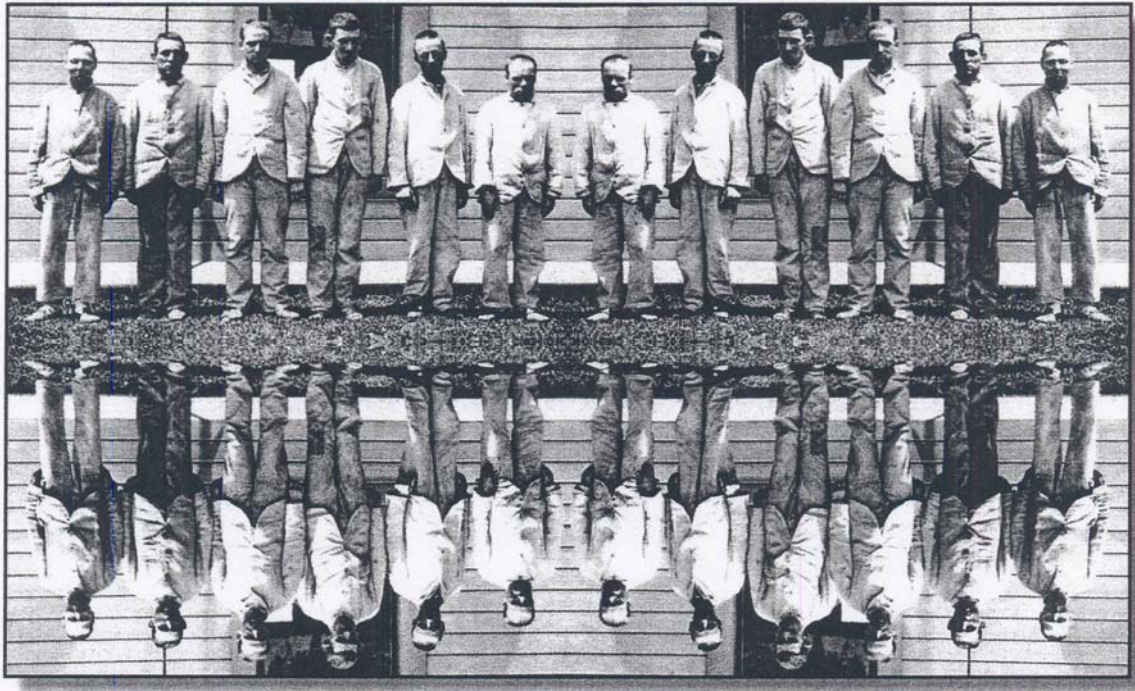


DYING RETARDED



The Emergence of the Hospice Patient with Intellectual Disabilities

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DYING RETARDED

While I am delighted to be here and that my being here is indeed noteworthy there are two things that are worth noting. For one thing the title of my talk, DYING RETARDED has provoked some interest, especially in my own field, the field of developmental disabilities. Some of my colleagues were appalled at my use of "retarded" in the title, DYING RETARDED. And while I'm not necessarily a bandwagoner when it comes to political correctness, I understand the move towards substituting intellectual disabilities for the term "mental retardation." Even the Presidents committee for Mental Retardation, started by JFK in the 1960's has adopted their new moniker and is now known as the Presidents committee for People with Intellectual disabilities. But I thought you; members of the hospice community would be more familiar with retarded as are most of the healthcare community outside of the "intellectual disabilities" arena. And in addition the idea, the concept of DYING RETARDED did it for me, it seemed to have captured what this is all about. For people with mental retardation who are dying, will die and do die it must seem to them to be COMPLETELY RETARDED. I want to return to that shortly.

The other noteworthy thing about my being here is that I'm here period. I could give you an argument for wondering why there had and it is long overdue - why there had to be a session on hospice care for people with mental retardation. Hey what's the big deal here? There aren't any sessions for hospice care for patients named Bob, or a session on hospice

DYING RETARDED

care for ex- all state quarterbacks or a session on hospice care for women who felt trapped in a man's body. Isn't it enough that the body of knowledge about death, dying and palliative care should be, and needs to be applied to everyone. And of course the answer is YES and of course the answer is NO. Yes because people with mental retardation, neurodevelopmental disabilities have died long before the identification of any deleted gene or trisomic condition had been detected; and long before there were state institutions. And No because in many ways as much as they are alike they are different, or at least our notion of them puts them there.

I want to first say that despite this being a meeting addressing the clinical considerations of care for hospice and palliative care professionals I am glad that the "clinical" pillar has been fortified with science, skills and soul. This triumvirate constitutes the whole enchilada; and I see myself providing more of the "soul" than the science and skills. Since both of those emanate from the "soul" of the work you do and not vice versa I see that as my trump card. You won't get eureka's into titrations schedules or galvanic skin response of people with Down syndrome as the last gasp approaches - the clinical pearls and perhaps this is a pearl itself - that you already harvest are all applicable to people with intellectual disabilities. And before you get up and leave thinking well that's not really helpful to me and my team back at the East Overshoe Hospice Center.

DYING RETARDED

Here's another challenge for you: how do you present the end of life for someone who may not fully understand the end of the week or even the end of their nose? And while you think what a cognitive limiting reference that is and it's virtually impossible you might want to recall that in many primitive societies, or at least what we call primitive the notion of the end of the week doesn't exist indeed the notion of the week doesn't exist and yet they have stable cultures that are sustainable and self plenishing. So maybe we need to rethink the value of being able to understand and appreciate the end of the week, the end of our nose or indeed the end of anything. So my contribution to you in providing or trying to provide the "soul" part of science, skills and soul might simply be to challenge your own beliefs, which of course provide the framework for how and why you provide hospice and palliative care.

Let me try to help you get your arms around the legacy of how we care and how we have cared for people with developmental and intellectual disabilities, people with mental retardation.

Three things should be included in a brief survey of how we got to where we are today. One is where we put, or where we kept, people with mental retardation. After that we should look at how we kept them. From an appreciation of both the where and how the realization that how they died will be fairly evident.

DYING RETARDED

Firstly many children born with deformities and abnormalities didn't survive or were helped along with not surviving. This wasn't done with a nod or the quiet order to a nurse that went, "Nurse I assume you know what to do with the Simpson's son." In many circles this was considered the best practices. Those who survived were kept at home, often in locked back rooms, basements, out buildings; and although they were loved they weren't nurtured. The medical model evolved and the great places on the hill, out of the way were erected. The institutions were designed as they were intended to be, fortresses to keep society free from the perils of having these so called people with criminal tendencies mixed in with society. The mandate was to keep them fed, dry and occupied; we did a lackluster job on all three accounts. When they died, either from complications of their innate conditions or from medical care that was intended more as record keepers than interventionalists they were buried, often in unmarked graves in cemeteries situated right on the grounds of the asylums as they were known.

Our beliefs, references and ideas about them were molded to fortify our fears and need to isolate them.

These perceptions provided the groundwork for our practices. There are seven roles as described by Wolf Wolfensberger.

DYING RETARDED

One of the most prominent role perceptions of the retarded individual has been that of the SICK PERSON. With this view the medical model goes full bore. The residence is called a hospital, residents are referred to as patients, their condition is identified as being a disease, case records are referred to as charts and hospital routines prevail.

The Retarded Person as a Subhuman Organism. From subhuman it's only a hop skip and jump to referring to them as "animal-like" or even "vegetables" or "vegetative." The Nazi focused on this perception when they introduced their "final solution." Subhuman organisms were provided subhuman conditions and subhuman expectations as well.

The Retarded Person as a Menace. The concept of the menace allowed for segregation from society, segregation between the sexes. With any perceived menace there is the condition of vindictiveness and persecution.

The Retarded Person as an Object of Pity. The retarded person was seen as "suffering." It was believed he was unaware of his deviancy. He was seen as an eternal child who never grows. He was held blameless for his condition; the person is seen as not accountable for his behavior. The retarded person is viewed with a "there but for the grace of God go I" attitude. The pity image allowed a paternalistic environment to be created; the institution sheltered the resident against injury and risk and made few demands for growth, development and personal responsibility.

The Retarded Person as a Burden of Charity. This was similar to the Victorian age image of orphans. This led to a natural response to deformity that was more contempt than sympathy. Charity clients were seen as entitled to food and shelter and little more.

The Retarded Person as a Holy Innocent. This put the retarded person as being perceived as the special children of God. As such they are usually seen as incapable of committing evil voluntarily, and consequently may be considered to be living saints. It may also be believed that they have been sent by God for some special purpose.

The Retarded Person as a Developing Individual. This takes an optimistic view of the modifiability of behavior, and usually it does not invest the differentness of the retarded person with strong negative value. This was the perception that promoted a resident-oriented atmosphere; this is the perception that announced a return to the community.

Other roles that citizens with developmental disabilities have played included the village idiot, court fools and jesters. They were objects of ridicule and merriment.

Jump cut to the so called developmental and then the community model. Following the many exposes of the inhumane criminal conditions in the state institutions we saw the movement to repatriate citizens with developmental

disabilities back to their communities. To small group homes and habilitation programs tailored to meet their individual needs and goals.

As a result of this migration and the then unknown life enhancing psychoneuroimmunological effects of social affiliation, self determination, health promotion, connectivity and activity engagement they fooled us and stopped dying. At least they stopped dying in their teens and twenties. And so we saw, okay so stymied and mystified are better descriptives, we saw their survival and longevity start to jump off the charts.

It's important for the hospice community to at least appreciate certain aspects about the lives, conditions and profiles of people with mental retardation in order to make accommodations, modify existing protocols or even to step back when appropriate. I want to provide some global considerations for your perusal since we couldn't do justice to a comprehensive survey here.

- People with intellectual disabilities constitute a heterogeneous population. The "two group" model is an attempt to point out that people with mild cognitive impairment may have different etiologies and clinical issues than people with more severe cognitive who may be more likely to have associated syndromic conditions and other developmental disabilities.

- As more people with intellectual disabilities attain older age, it is important to note that excess functional impairment, morbidity, and even mortality can result from the consequences of early age-onset conditions, through their long-term progression or their interactions with older age-onset conditions. An example of the potential consequences of long-term progression is the high incidence of esophageal reflux in children with cerebral palsy and severe motoric compromise. An example of the interaction of early-age onset and later age onset conditions is, in persons with down syndrome, the superimposition of adult-onset sensorineural hearing loss on childhood acquired conductive hearing loss resulting from inadequately treated middle ear infections. The long term consequences of therapeutic interventions also need to be considered – examples are movement disorders that may result from the prolonged use of neuroleptic medications and bone mineralization disease that may occur . secondary to the chronic use of certain anticonvulsants.
- Research indicates that specific populations of people with intellectual disabilities have particular health risks. These populations may be defined by the presence of specific syndromes or by the extent of the central nervous system compromise that has caused the intellectual disability. The increased longevity of persons with intellectual disabilities leads to the definition of populations by chronological older age

and a subsequent increased risk of acquiring adult and older age associated conditions.

- Throughout the lifespan, persons with Down Syndrome manifest higher risks for specific endocrinological, especially hypothyroidism, infections, dermatologic, oral health, cardiac, musculoskeletal and other organ system disorders. In addition, they exhibit high rates of disorders of the special senses of vision and hearing. Older adults with Down syndrome have an increased risk of the early development of age-related risk of the early development of age-related visual and hearing disorders, epilepsy and dementia. Adults with Down syndrome have decreased longevity compared to the general population of people with intellectual disabilities. The average life expectancy for someone with Down syndrome in the US is now 55; however for African Americans with Down syndrome that span is halved. Even in developmental disabilities we are not immune to the great gaps of health care disparities.
- Fragile X syndrome is the most common inherited disorder associated with an intellectual disability. People with Fragile X syndrome exhibit relatively high rates of mitral valve prolapse, musculoskeletal disorders, early female menopause, epilepsy and visual impairments.

Knowledge of the specific age-related health risk factors associated with specific syndromes might be of value in providing comprehensive palliative and hospice care,

DYING RETARDED

although this knowledge is most beneficial to increasing life expectancy. In conditions like autism, a knowledge and appreciation of the significant sensory integrative challenges would prove beneficial to modulate, enhance or provide special sensory environments would be a great boost for hospice scenarios.

While most of the research and experience has addressed life fortifying measures for people with developmental disabilities there is a fertile opportunity for you to contribute to the body of knowledge of hospice care for this marginalized population.

One of the problems which perhaps will be dumped on you is the fact that there is an inadequate cadre of adult primary care physicians caring for people in the community with developmental disabilities. There is no formal training, few fellowships and incentives for family practice and internists to be attracted to this population. As a result the care matrix is suboptimal, lacking coordination, collaboration, continuity and cultural competence. When the patient is referred to hospice it is often difficult for the hospice team to get a sense of "who is this person" and what are their special needs. There is probably no other patient population that is more in need of a biopsychosocial approach and who gets it less. Very often the records, files and charts are disability related and compartmentalized into vocational narratives, behavior plans, residential situations, critical incidents, disease management and other disjointed

DYING RETARDED

components; the language is full of idiomatic expressions from independent support plans that focus on what levels of support are required and is often confusing to professionals outside the field. End of life issues have only recently been put on the "needs" list and programs like Last Passages are only now being introduced to the field that supports citizens with disabilities.

Many of the myths about people with developmental and intellectual disabilities have permeated into the hospice halls. The myth about their high tolerance for pain – since they couldn't express or at least articulate pain – resulted in generations undergoing dental procedures with little or no analgesia. The myth that they couldn't understand their own demise resulted in no one discussing it. The myth that they were immune from stress, depression or frustration derailed psychosocial intervention. The myth that they never formed connections and thus never grieved loss was also not without its grave consequences. The myth that they had no spiritual connection resulted in their not being exposed to rituals, celebrations and religious affiliation. The fact is that there is no evidence that the architecture of their pain receptors, or their spinothalamic tract is any different should put them all in the cross hairs of pain management teams. They have an intuitive sense about endings that can't often be expressed. The manifestations of their stress and frustration is often translated into what is termed challenging behaviors including head banging, self injurious behavior and skin ripping; these behaviors which have been

DYING RETARDED

misunderstood resulted in strict behavior programs and psychotropic medications. Their style of spirituality is often compared to tribal spiritual beliefs and practices; it is more intuitive with less demands and expectations. While they may not pray they certainly do hope.

Historically citizens with mental retardation would predecease their parents, often to the relief of the parents who dreaded the idea of strangers caring for their children after their death. The cycle has come full circle and older individuals with developmental disabilities may have been cared for by direct support professionals for ten, twenty years or longer. Despite the high turnover rate for caregivers in this field many people with intellectual disabilities have been connected to caregivers for many years and those caregivers constitute their hybrid families. It's important for hospice staff to know what the history is -between the patient and their caregivers. Long lasting and committed direct care staff are often the best, most reliable and dependable information sources for preferences, baselines, defusing techniques, subtle signs of change, discomfort and decompensation. In patients who are nonvocal the direct care staff can be helpful in translating their often confusing, irrational gestures, signs and body announcements.

I usually like to drop some pearls, not a string of them but a few. In order for something to qualify as a pearl it has to be of some utility, but it doesn't necessarily have to tell you how to do something specific. Its value is strictly its

extrapolative value. And if you work in hospice most of the stuff you know, you do, or see is not from some cookie cutter template or boiler plate protocol. Its stuff you have extrapolated, its pearls you have learned from your mistakes, your shortcomings and your worst nightmares. My pearls are intuitive, at least for me, then are more gestalt, but combined with the clinical pearls you're hopefully harvesting at his meeting you will hopefully be able to translate them to a more poetic way of delivering the stuff you do. Some of these pearls will have immediate application to what's waiting for you back at your units, wards, clinics or centers. And maybe if Mrs. Fleischman, or Mr. Carter is still there when you get there you can use them in your caring for them.

- Don't try to orient people with intellectual disabilities, stay in the moment, it's their' world, enjoy being part of it for the moment.
- Appreciate that you are all CRABs, C - R - A - B, an acronym for Currently Regarded as Able Bodied, and that in a nanosec, not wearing your seat belt or having some piece of an arterial wall decide to self dissect or some random length of muscle fiber demylnate for kicks you will be on the receiving end of total, full tilt boogie caregiving. So treat the caregivers, the direct support professionals who escort your patients to see you with kindness and respect. Word will get out; and hey, you never know.

DYING RETARDED

- Forgive yourself the big mistake. It isn't the end of your life. It will not define who you are, unless you stay stuck on it.
- Give the people you love some slack.
- When baking, follow the directions. When cooking, go by your own taste. Next time you're at the bedside try to figure out whether your baking or cooking.
- We're all tourists. It's up to you to decide if you can relate to what you're seeing; and if it's worth staying a little longer.
- If something seems overly difficult, you are probably doing it wrong.
- If someone offers you a breath mint, take it.
- If you find yourself in a hole, the first thing to do is stop digging.
- Expectations are premeditated resentments.
- If a thing goes without saying, let it.
- If you think you shouldn't, don't.
- Never get your heart set on a peanut butter and jelly sandwich until you're sure you have some jelly.

It may be somewhat ironic that of all the human transactions; of all of the societal institutions we may finally experience full and total inclusion for people with intellectual disabilities. The irony of course is that the last frontier for the special needs community is the last frontier for all of us. The frontier that provides the answer to the question of "our own" meaning, an answer that is provided

DYING RETARDED

to all of us, regardless of our intellect, our ability to understand natural phenomenon and to employ logic. The frontier that treats us all as individuals; with our own special needs.

Thank you for the opportunity to leave behind what I hope will be some things for you to consider regarding both the rewards and challenges of providing hospice and palliative care to individuals with intellectual disabilities. We owe it to them. Thank you.