

Palliative Care of Vulnerable Populations: Maintaining Dignity and Improving Quality of Life

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Appreciations

- Thirty one patients who shared their life stories for this research
- Funding provided by:
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 - ONS Doctoral Scholarship
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Objectives

- Identify sociocultural characteristics that influence palliative care for vulnerable populations.
- Analyze meanings of dignity and quality of life.

What do you believe? What do you value?

- What characteristics define vulnerable communities or populations in San Mateo county in need of palliative care?



- How do you define dignity?
- What factors influence dignity at the end of life ?
- How often do you hear patients or others talk about dignity?

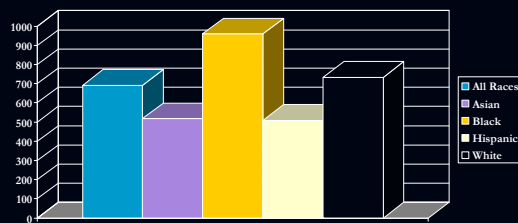


- How do you define quality of life ?
- What factors influence quality of life ?
- How often do your patients discuss QOL?

Vulnerable Population

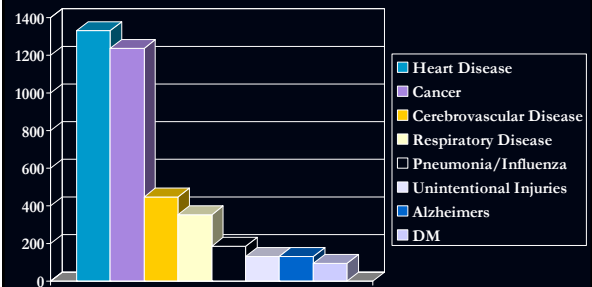
- Community Health Perspective
 - Groups at greater risk for adverse health outcomes, health disparities, increased morbidity & premature mortality, decreased quality of life (QOL). (Aday, 2001)
 - Root cause typically socioeconomic status and access to resources/capital (Flaskerud & Winslow, 1998)
- Research Perspective
 - Groups at greater risk for harm from human subjects research.

1997-01 Mortality by Race in SM County (per 100,000)



http://www.co.sanmateo.ca.us/vgn/images/portal/cit_609/0/52/109260084Mortality.pdf

2001 Leading Causes of Death in SM



http://www.co.sanmateo.ca.us/vgn/images/portal/cit_609/0/52/109260084Mortality.pdf

Dignity

- Term used in human rights, codes of ethics, assisted suicide, disability rights, care of older adults, the dying, and more recently in the human genome.
- Despite its ubiquitous use, the definition of dignity at the end of life is assumed and not consensual (Street and Kissane, 2001).
- Macklin (2003) declared dignity was a useless concept and nothing more than a slogan for personhood (what it means to be a human being) and autonomy (self-determination or control).

Chochinov's Dignity Model

Illness Related Concerns	Dignity Conserving Repertoire	Social Dignity Inventory
<p><u>Level of Independence</u></p> <ul style="list-style-type: none"> • Cognitive Acuity • Functional Capacity <p><u>Symptom Distress</u></p> <ul style="list-style-type: none"> • Physical Distress • Psychological Distress <ul style="list-style-type: none"> ▪ Medical Uncertainty ▪ Death Anxiety 	<p><u>Dignity Conserving Perspectives</u></p> <ul style="list-style-type: none"> • Continuity of self • Role preservation • Generativity/legacy • Maintenance of pride • Hopefulness • Autonomy/control • Acceptance • Resilience/fighting spirit <p><u>Dignity Conserving Practices</u></p> <ul style="list-style-type: none"> • Living in the moment • Maintaining normalcy • Seeking spiritual comfort 	<ul style="list-style-type: none"> • Privacy boundaries • Social support • Care tenor • Burden to others • Aftermath concerns <p>(Chochinov, et al, 2002)</p>

Quality of Life (QOL)

“..the concept of health-related quality of life (HrQOL) refers to a person or group's perceived physical and mental health over time...HrQOL is used to measure the effects of chronic illness ...to better understand how an illness interferes with a person's day-to-day life.”

- National Center for Chronic Disease Prevention and Health Promotion Health-Related Quality of Life (CDC) <http://www.cdc.gov/hrqol/>



Study Purpose

To understand the meaning and experience of dignity to the urban poor with advanced disease.

Mixed Methods

Interpretive Phenomenology (Qualitative)

- Primary approach for this study
- Seeks first person accounts of meaning and experiences.
- Interview transcripts, field notes were the primary data sources

Survey (Quantitative)

- Designed to evaluate Chochinov's dignity model in this more marginalized and vulnerable population.
- Administered one time after in-depth interview

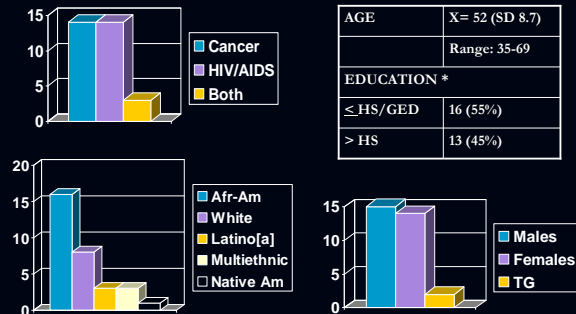
Sample Interview Questions

- Can you tell me a story of a time when you felt you were treated well or felt cared for?
 - What happened? Who was there? What about the story made you feel like you were treated well?
- For some people, it is important to be treated with dignity, have you ever thought about that?
- How does (being a patient in a nursing home/hospital) affect
 - Your illness?
 - Your treatment?
 - How you think about yourself?

Survey Content

Dignity Items	32 items	Developed for this study to measure Chochinov and other theoretical issues	Psychometrics not established
Loss of Dignity (Wilson, 2000)	Single item	7-point, no loss of dignity to extreme (cut off $\geq 3 = fx$)	Intraclass correlation $r = .92$
Symptom Distress Scale (Mc Corkle, Young, 1978)	13 items (13 - 65)	5-point likert Lower total score= lower distress	Reliability in cancer patients $\alpha = .79-.89$
Control Preference (Degner, 1997)	5 preference styles	Inductively derived, individual cards with style with cartoon depiction.	.66 reliability in hypothesized dimension
QUAL-E (Steinhauser, 2002)	26 item (26 - 130)	5- point likert Inductively derived measure of QOL at EOL.	$\alpha = .83$ (5 domains) Factors $\alpha = .60-.84$
Enforced Social Dependency Scale (Benoliel, McCorkle, 1980)	10 items, scored by investigator	Measures capacities for performance of adult role, i.e. self-care, mobility and social competency. Higher score-more dependency	Reliability coefficients in patients with advanced disease was $\alpha = .90$

Sample (n=31)*



Selected Qualitative and Quantitative Results



Sally's Story

“What does dignity mean? I got to know what it means before I can answer the questions?”

Sally, 55 yo white widow with Stage IV Ovarian Cancer, who lives in an SRO

Stories of Indignity

- Most vividly told stories were difficulties encountered with health care providers and systems.
- Perhaps it is easier to recognize when dignity has been violated, threatened or withheld, than when taken-for-granted dignity is experienced.

“Then ..when I had .. diarrhea and everything .. I tell her [nurse], “You know what? I’m shitting on myself.” (she says) “Oh, I’ll be with you in five minutes.” Five minutes go- a long way, a long way. Five minutes go by. 30 minutes go by. An hour go by.

I say, “Nurse, I (messed) in the bed” and (nurse said), “Oh, well... I’ll get to you uh, next.” When... the nurse tell me that, she’s nowhere around. All she’s doing is being out in the hallway lollygagging. And I told a couple of the man doctors about this here. “Oh, I will talk to the nurses about that.” I don’t think any of them said anything to them about that, period.”

Ozzy, 55 year old Af Am, divorced vet, met colorectal CA, lived in supported SRO hotel

“You need somebody ... If you get your (call) light on, pay attention to the light and come in and check on who it is. You never know, that person might be having a heart attack. Like I had a friend ... she was.. right next to me, and I kept calling for the nurses to come in ..to check on her. You know? And they took their wise merry time coming in there. And then- by the time it was too late. She had already hit the point where she was gonna die. You know, they come in there with the machine and she’s already dead.”

Rita, 37 yo African American woman, AIDS and ESRD, on CAPD

Dignity and Respect

Martha: "... That's what I said, respect."

Bill: "That's all we ask for, give me respect. That's all we asking is, "Can you give me respect?" ... Respect me...If you got something to say, listen. Don't jump to conclusions. If you don't know what that person's saying, don't say something that make me look bad. That's what dignity means. I read it in the dictionary."

(Martha, 51 yo African American woman with AIDS, s/p CVA
Bill, 41 yo African American man with AIDS, s/p SCI)

Dignity and Respect

"Well - you begin with yourself. And it's self-respect to have dignity. And once you have that, the other (respect from others) will fall in place."

Issac, 51 yo Filipino/Mexican man with HIV

Dignity and Respect

"Basically..- my dignity is not about how much money I have ...- or where I'm from, (but) what I do...Just by making me the person that I am. I respect others. I give respect. I demand respect."

Matthew, 36 yo African American with HIV

Measuring Dignity Model:

Illness Related Concerns

<u>My Sample (n=29)</u>	<u>%</u>	<u>%</u>	<u>Chochinov's Sample (n=211)</u>
Being able to think clearly	86.2	77.3	Not being able to think clearly
Physical symptoms or emotional upset can affect dignity	82.7	53.1	Experiencing distressing symptoms
Knowing what to expect with illness in future	75.8	59.2	Uncertainty regarding illness
How body has changed as result of illness	75.0	66.4	Changes in physical appearance

Dignity Conserving Repertoire

<u>My Sample (n=29)</u>	<u>%</u>	<u>%</u>	<u>Chochinov's Sample (n=211)</u>
Having a fighting spirit	93.1	74.5	Not being able to mentally fight
Having a life worth living	92.9	75.1	Feeling life no longer has meaning or purpose
Comfort received from your faith or spiritual beliefs	89.3	73.7	Not having a meaningful spiritual life
Being able to fulfill responsibilities to family, friends and other	88.9	78.5	Not being able to carry out important roles
Accepting what life brings	85.7	71.6	Not being able to accept things the way they are
Having control	75.8	83.7	Feeling you do not have control over your life
Keeping your normal day to day routines	75	74.9	Not being able to continue with usual routines

Social Dignity Inventory

<u>My Sample (n=29)</u>	<u>%</u>	<u>%</u>	<u>Chochinov's Sample (n=211)</u>
Being treated with respect	89.6	87.1	Not being treated with respect or understanding
Treated like a person	86.2	81.4	Not feeling worthwhile or valued
Feeling like a burden on others	78.5	87.1	Feeling like a burden to others
How important to sense of dignity is privacy	72.4	65.9	Feeling your privacy has been reduced

Severe Loss of Dignity Single Item

Since you have been sick have you ever felt a loss of dignity and if so, how severe? Before you were sick had you ever.... how severe?

1. Never felt loss of dignity
2. Minimum loss of dignity
3. Mild
4. **Moderate**
5. **Strong**
6. **Severe**
7. **Extreme loss of dignity**

Responses of moderate or greater coded as severe or fractured dignity

Measuring Loss of Dignity

	Yes	No	Pearson R	Sig.
Illness-related Loss of Dignity	16	13	.111	NS
Loss of Dignity Prior to Illness	15	14		

Illness-related Loss of Dignity	N	%	Sig.
My sample (n=29)	16	55%	p-value <.001
Chochinov sample (n=211)	11	5.3%	



Quality of Life

“And we did that (chemotherapy) from January all the way through July - and my quality of life was really lousy. I mean, just.. the accumulation of it. I was not able to go to the yoga classes anymore. I was just tired all the time. I was just not feeling well. I was just egh!... My aunt asked me today. She said, “Well, what do you understand on the quality of life?” And I said, “You know, if a friend says, ‘Come over and look at my new house,’ I like to go- sit in the car and go... I like to go do something once in a while and not be at home all the time. I mean, that to me is quality of life.”

Gretchen, 63 year old white European business woman, divorced, uninsured when dx'd with met breast cancer



Spiritual Wellbeing/QOL: Meditation in Nature

“I always believe that...if you don't just get out and totally be by yourself where your mind could just wander... leave all your stress and everything behind for at least a few hours, that few hours is for you... the rest of the world you just tune out... when you do come back, you seem like you come back more energized... And it works for me ... sometimes I catch a bus and just ride like I'm not paying attention to the street signs or nothing. I'm just sitting there like meditating...sometimes I get off the bus and might be at a park or by the beach and just enjoy the beauty of mother nature.... I wake up in the morning and I just walk out and just look out and say, “Hey God, thank you for letting me see this day.”

Frank, 47 yo. African-American man with AIDS and lung cancer

Spiritual Wellbeing: Community

“I’ve always believed to be myself a spiritual person but not religious. I don’t believe too much in religions... why does it exist (and cause) so many separations from people?..... If there is a God..., He’s the creator of everyone and everything that exists... I do believe, again, that whatever helps you and there’s something really magical about doing something in a group and finding that you’re not the only person that thinks or believe in certain way. And of course you feel the energy from the people around, especially you’re meditating or singing or praying... It feels wonderful that you’re doing it with some other people.”

Moses, 46 yo Latino with AIDS, Kaposi Sarcoma and NHL.

Implications for Practice

- Recognize that hospitalization or NH placement threaten a person’s dignity, regardless of the quality of care or the compassion of the caregivers.
- Promptly respond to patient requests for assistance (call lights) as these as seen as evidence of respect.
 - When there are unavoidable delays, explain the reason in a manner that is affirming and apologetic.
 - Responding promptly is a recognition of the humanity of another, failure to recognize, dehumanizes and increases suffering.
- Focus on the patient exclusively (and supervise others to focus exclusively) when providing care, and not on social or work conversations with others.
 - Focusing on the patient conveys that the person/patient is seen, heard, cared for, & valued.

- Caring relationships that recognize the humanity and uniqueness of the person, not simply ‘the patient,’ preserve dignity of the other.
- For persons with HIV/AIDS, the relationship between stigma and dignity requires further examination.
- Care settings influence patients’ sense of respect –
 - Delays in service, poor staffing, “hoops” to be jumped through, rude or dismissive treatment by front desk staff, arbitrary rules, treated as a number, lack of auditory privacy when discussing sensitive issues, or physical privacy when bodies are exposed.
- Advocate for patients in negotiating systems and providers.

continued

- Inquire about spiritual practices and beliefs to create an opening to uncover the deeper concerns of persons facing the end of their lives.
- Recognize, assess, and manage illness-related symptoms, and treatment side effects.
- Evaluate and enhance coping resources/strengths
 - Housing and access to basic needs
 - Resilience & capacity for survival
 - Adaptive & not so healthy coping strategies
 - Mental health and substance abuse services
 - Social support

Summary

- Patients and caregivers may or may not ascribe similar meanings to dignity and quality of life,
 - appreciating the differences will allow an understanding of patients’ values and beliefs about what makes life worth living and
 - how end of life decisions are considered.
- Palliative care for vulnerable populations not only requires care to bodies, minds, hearts, but also to souls-- which often have been deeply wounded.

“You matter because you are you and you matter to the last moment of your life. We will do all we can do to help you, not only to die peacefully but to live until you die.”



Dame Cecily Saunders, *Nursing Times*, 1974