

Suffering Apart: Invisibility of the Mexican American Caregiver

Patricia Bradley, DNS, RN
Jo Nell Wells, PhD, RN
Carolyn Spence Cagle, PhD, RNC
Donelle Barnes, PhD, RN

*R15 NR0085 10-01A1
Harris College of Nursing & Health Sciences
Texas Christian University, Ft. Worth, TX*

Aims of Presentation

Describe:

- “Suffering Apart”
- “Mirroring”
- Impact of “Suffering Apart”
- Implications for health care

Aims of the Overall Study

- Develop a Grounded Theory of Mexican American (MA) female family caregivers caring for persons with cancer
- Examine associations among acculturation, perceived health status, mood state and burden in MA female family caregivers.

Data Collection

- First Interview
 - Demographic Data
 - A Short Acculturation Scale for Hispanics
- Second Interview
 - Qualitative Data
 - Quantitative Data
 - Short Profile of Mood States (POMS)
 - SF-12 Health Survey
 - Burden Interview

Tools

- POMS - examines the general psychological distress using 30 items rated 0-5 (Cella et al., 1987)
- SF-12- assesses physical and mental health from the subject's point of view, 12- items (McDowell & Newell, 1996)
- ASASH – 12 item questionnaire examining language preference and preferred ethnicity (Marin, Sabogal, Marin, Otero-Sabogal, & Perez- Stable, 1987)

The Power of Caregiving

Demographic Findings (n=34)

	Range	Mean	Standard Deviation
Age	21 – 63 yrs	38.5	11.6
Caregiving Duration	1-25 mo	10.52	10.04
Hours Per Day	0.83-24 hr	15.41	9.14

TCU

JPS CCC

Demographic Data cont'd (n = 34)

- 26 (76.5%) born in Mexico
- 22 (64.7%) communicated in Spanish
- 24 (71%) scored at the low acculturation level
- 17 (50%) had < high school education

Results of POMS

- 91% sad
- 88% tense
- 77% nervous
- 70% exhausted
- 70% forgetful
- 67% fatigued
- 62% weary
- 62% anxious

SF-12 Results

- 94% report they are in “*fair or better than fair*” health and their physical health does not limit their activity
- 44% reported emotional problems cause them to be careless and accomplish less

Caregiver Reported Symptoms

- Headaches
- Stomachaches
- Chest pain
- Hypertension
- Stress

“Suffering Apart”

choosing to experience emotions about caregiving internally and not in front of the family member.

Suffering Apart Statements

- “I was always real sad, always at night you know, that’s when I would cry because I didn’t want her to know that I was crying..”
- “I can’t let her see me sad, so I get strength and act strong, even though I might be sad inside..”
- “I suffer apart from everything else...when they go to work I cry, scream, whatever..”

Mirroring Statements

- “When she smiles and says she’s fine, I too am fine. When she is sad and she tells me I feel this way or that way and I hurt her, I feel that pain also.”
- “If she’s depressed then I get depressed”

Reasons for Suffering Apart

“...feel embarrassed....”

- “...end up crying.....”
- “...helps them [patient] get well...”
- “....a smile is like a good therapy...”
- “...she [patient] gets her strength from me..”
- “.....keeps family together....”

Reasons for Suffering Apart continued...

“..because as a mother you have to be the strong one. If the women cries, well, then everything falls apart. The function of the man is different, if the mom gets mad the kids are affected more. So, I feel that I have a huge responsibility, because if I am sad, I feel that the rest of my family will also be sad. But if I am strong they will also be strong as well.”



Assumptions

Caregiver low mood states can be detrimental to their health and the family health.

Mood states can remain invisible to the caregiver and to the care provider.

(Guarnaccia, Rivera, Franco & Neighbors, 1996; Feblo San Miguel, Guarnaccia, Strout, Lewis-Fernandez & Canino, 2006)

Clinical Practice Implications

- Show appreciation for the caregiver role
- Recognize the health needs of family caregivers
- Respect caregiver need to remain strong in front of the patient
- Discuss privately with caregiver her needs
- Provide appropriate support services

Clinical Practice Implications continued

- Create informal networking
- Link caregivers to support Hot Line
- Provide meaningful activities in waiting areas
- Develop cooperative respite services
(Jolicoeur & Madden, 2002)
- Inform about Financial Assistance

Clinical Practice Implications

continued

- Anticipate caregiver skill and learning needs
- Offer educational assistance early
- Assess for changing needs over time
- Allow cg to be strong in front of patient & family

Local Policy Recommendation

- Public hospital needs to provide services to undocumented persons based on a sliding scale.
- Participate in grassroots efforts to bring attention to this issue



The Power of Caregiving

*In appreciation to the
caregivers who shared their
experiences.*

TCU

JPS CCC