

INDICATORS OF BURDEN IN CONVERSATIONS BETWEEN FAMILY CAREGIVERS

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BACKGROUND

- As baby boomers retire, our population will continue to age.
- Chronic illness is more prevalent with age and requires greater levels of care.
- Family caregivers will be required to provide the majority of care, leading to increased stress and burden.

LITERATURE REVIEW

- The multidimensional caregiver burden inventory measures time dependency, development, physical, social, and emotional burden.¹
- Many attempts to understand the effects of caregiving are through quantitative surveys, such as the Zarit Burden Interview, involving a 0-4 rating system.²
- Quantitative data often lack in-depth and person-centered responses.

METHODS

- Twenty three caregivers participated in small group discussions over the course of four months (N=22)
- Total of 20 audio interview recordings were transcribed into text.
- **Data Analysis:** Two phases of coding:
 - In priori coding
 - Pattern coding

PURPOSE

To examine the representation of indicators of burden in open-ended conversations amongst family caregivers.

RESULTS

DEVELOPMENT

- Career and Finance
"It's affected me financially. It's decimated me. I've got to go to work."
- Family Relationships
"Sometimes I feel like I just need to move down there and live there, but then I'm leaving a lot of responsibilities here, all my kids, my grandkids."
- Retirement and Recreation
"He's going to need help. I'm going to have to provide it... I had different ideas about what I was going to do when I retired."

TIME DEPENDENCY

- Relaxation and Recreation
"There's no time for yourself in that situation like that. I can't go anywhere, we don't go on vacation."
- Job and Family Obligations
"My brother has expressed frustration that he had already spent a lot of time. He's trying to get to work."
- Dependency and Reliance On Tasks
 - Daily Living Tasks (Cooking, Bathing, etc.)
 - Ambulation and Transportation
 - Medications and Doctor's Visits

DISCUSSION

- Caregivers are experiencing barriers to development due to the lack of time.
- The quality of relationship between the caregiver and care recipient play a crucial role.
- Physical hygiene burdens and reliance on daily tasks contribute to struggles with emotional dignity.
- Harm caused by physical violence and safety hazards leads to feelings of guilt.

SOCIAL HEALTH

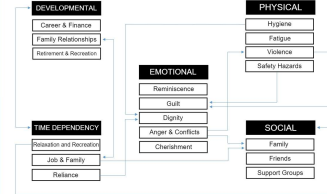
- Family
"We were less able to do things together as a family as time went on."
- Friends
"When we're in social settings he's attached to my hip and my friends kind of steer away a little bit."
- Support Groups
"I go to a support group and it really helps when you visit other people and they have great resources there."

PHYSICAL HEALTH

- Hygiene
"She decided she's going to wash her hands in the toilet right after she had a bowel movement."
- Fatigue
"My health went down, down, and my insomnia got worse."
- Violence
"We can't have her out, she could hurt somebody else or she could hurt herself."
- Safety Hazards
"She lit her microwave on fire five times and melted pots and pans on the stove."

EMOTIONAL HEALTH

- Reminiscence
"It's hard to see your loved one going down so dramatically, when they have been so vibrant and alive."
- Guilt
"Caregivers at a distance have their own set of frustrations, sometimes feelings of helplessness and guilt."
- Dignity
"I want him to be more independent and not rely on me, just for pure dignity. I don't want to treat him like a baby."
- Anger and Conflicts
"The arguing comes up and I get right into the argument, because I want her to see the rational reason why her argument doesn't make any sense."
- Cherishment and Rewards
"I think it's rewarding to know you are giving back to them a little bit."



Indicator	# of Codes
Development	29
○ Career and Finance	13
○ Family Relationships	3
○ Retirement/Recreation	8
Emotional Health	217
○ Reminiscence	20
○ Guilt	30
○ Dignity	8
○ Anger/Conflicts	43
○ Anxiety/Stress	28
○ Cherishment/Rewards	49
Physical Health	70
○ Hygiene	17
○ Fatigue	30
○ Violence	14
○ Safety Hazards	4
Social Health	92
○ Family	24
○ Friends	15
○ Support Groups	11
Time Dependency	97
○ Relaxation/Recreation	19
○ Job and Family Obligations	17
○ Reliance on Tasks	51
○ Daily Living Tasks (eg. Bathing)	16
○ Ambulation/Transportation	11
○ Medications/Doctor's Visits	12

REFERENCES

- Novak M, Guest C. Application of a Multidimensional Caregiver Burden Inventory. *The Gerontologist*. 1989;29(6):798-803. doi:10.1093/geront/29.6.798
- Zarit SH, Reever KE, Back-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*. 1980;20(6): 49-655. doi:10.1093/geront/20.6.449.