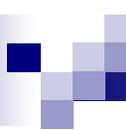


Cancer Survivorship and Adult Daughter Caregivers

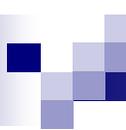
Victoria H. Raveis, Ph.D.
Columbia University
Mailman School of Public Health

Cancer Survivorship: Embracing the Future
October 4-6, 2006 **Bethesda, Maryland**



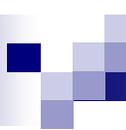
Special Acknowledgements

- This work funded by grants from:
 - National Institute of Mental Health
 - Department of Defense, Breast Cancer Initiative
 - New York State Breast Cancer Research and Education Fund
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 - Daniel Karus, M.S.
 - Sheindy Pretter, Ph.D.
 - Monique Carrero, M.A.
 - Tina Sapienza, L.M.S.W.



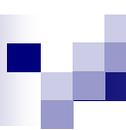
Cancer and Older Adults in U.S.

- Cancer is a major cause of morbidity and mortality in older adults, with its incidence increasing dramatically
- With population aging, the burden of cancer will increase
- 60% of cancer survivors are 65 or older
- 32% are 75 and older



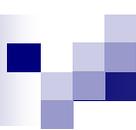
Cancer Care Provision to Older Adults

- Shift to outpatient care, coupled with less severe cancer therapies, contribute to elderly remaining in the community during active treatment
- Cancer diagnosis may not initiate a family's care provision, but expand on existing care tasks
- Age-related physical infirmities and co-morbid conditions complicate treatment approaches, increasing scope and duration of cancer caregiving



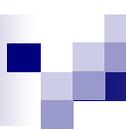
Cancer Patients' Care and Support Needs during Survivorship

- Completion of active treatment does not end a cancer illness event, survivors and family members live with uncertainty over remission, recurrence, disease progression
- Restoration of pre-illness functioning not always possible, especially for the elderly; survivors and family members live with the consequences of cancer and its treatment
- Disease/treatment-related symptoms can be persistent, may emerge months, years post-treatment



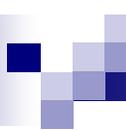
Adult Daughter Caregivers

- Adult daughters are a primary source of support and assistance to older adults diagnosed with cancer
- Caregiving daughters are “women in the middle”
- Adult daughters are likely to be at a stage in the life cycle characterized by multiple role demands from marital obligations, child-rearing, and employment
- Anxiety and concern daughters experience over their parent’s cancer is compounded by the burden and strain of care provision



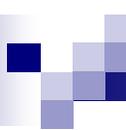
State of Knowledge on Survivorship and Adult Children Caregivers

- Understanding about the impact of the cancer experience on the family is still evolving
- Limited research attention has been focused on cancer survivorship and adult children caregivers
- Research presented will describe the cancer experience and the psychosocial impact of care provision on adult daughter caregivers during the survivorship period



Study 1: Psychosocial Burden of Cancer Caregiving to Aged Parents

- Panel sample of 206 patient-caregiver daughter dyads
 - Older patients (60+) in treatment at urban cancer center
 - Daughter caregivers do not have a history of cancer
 - Patient-caregiver dyad followed for 12 months
- Data collection
 - Female, English/Spanish, clinician interviewers
 - Patient & caregiver daughter each complete three interviews at six month intervals
 - First interview within two months of initial treatment



Study 2: Aging Families & Breast Cancer

- Cross-sectional sample of 72 mother-caregiver daughter dyads
 - Mothers completed treatment at urban cancer center
 - Daughter caregivers do not have a history of cancer
- Data collection
 - Female, English/Spanish, clinician interviewers
 - Patient & caregiver daughter each complete a survey
 - Caregiver daughter also does an in-depth interview

Patient Sociodemographics and Health

| | <u>Study 1</u> | <u>Study 2</u> |
|------------------------------|----------------|----------------|
| Age | 68.0 (5.8) | 64.8 (9.0) |
| Male | 32 | -- |
| White, Non-Hispanic | 89 | 69 |
| Black, Non-Hispanic | 4 | 6 |
| Hispanic | 6 | 24 |
| Other | 1 | 1 |
| # of other health conditions | 1.5 (1.2) | na |

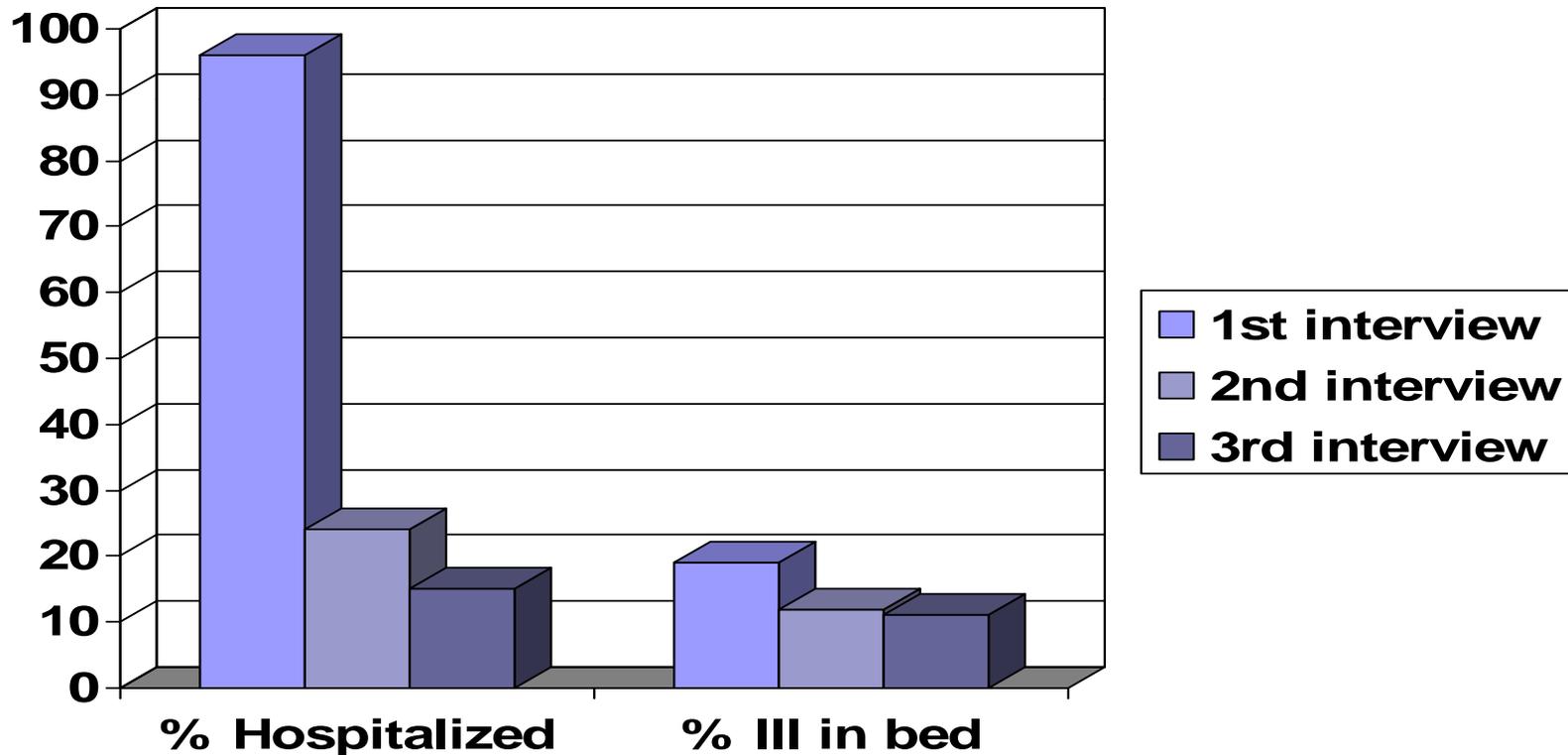
Disease/Treatment Characteristics

| | <u>Study 1</u> | <u>Study 2</u> |
|--|----------------|----------------|
| Extent of Disease: | | |
| Regional/Metastatic | 33% | 32% |
| Local | 67% | 68% |
| Treatments Received: | | |
| Surgery | 96% | 99% |
| Chemotherapy | 32% | 40% |
| Radiation | 27% | 43% |
| Months since diagnosis at (initial) interview | 4.1 (1.1) | 8.2 (2.9) |

Caregiver Sociodemographics

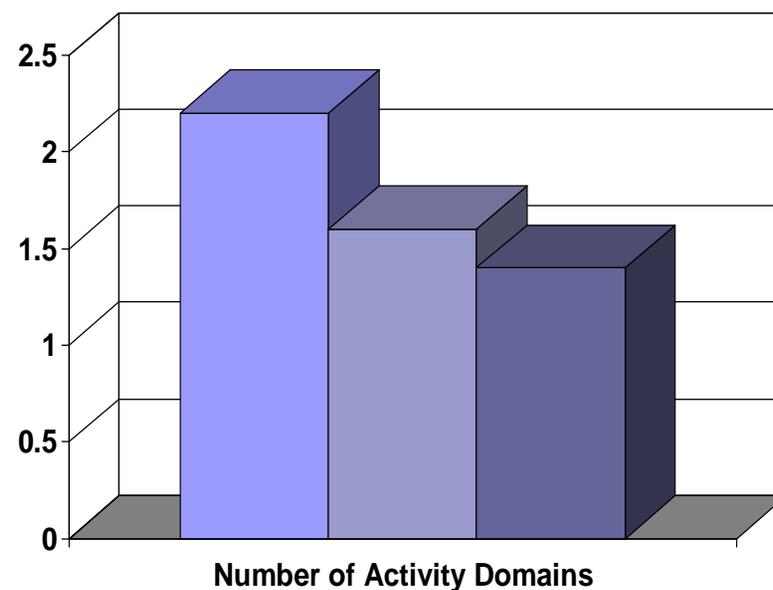
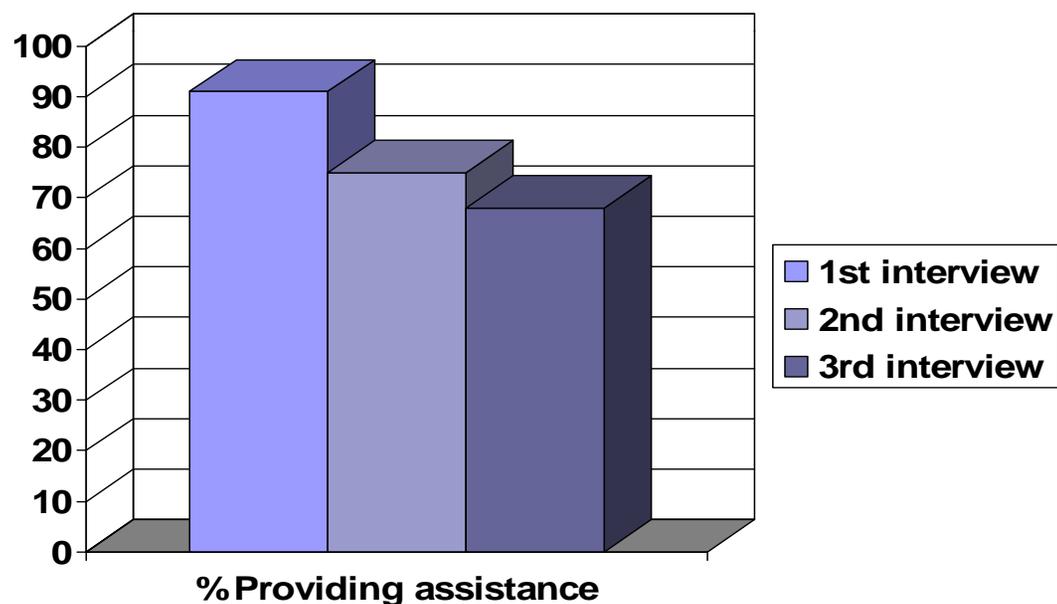
| | <u>Study 1</u> | <u>Study 2</u> |
|------------------|----------------|----------------|
| Age (Mean): | 38.9 (7.1) | 36.9 (9.8) |
| College Graduate | 56% | 68% |
| Employed | 74% | 72% |
| Married | 70% | 54% |
| Parent | 65% | 55% |

Patient Health Events: Treatment Initiation, 6 and 12 Month Follow-up



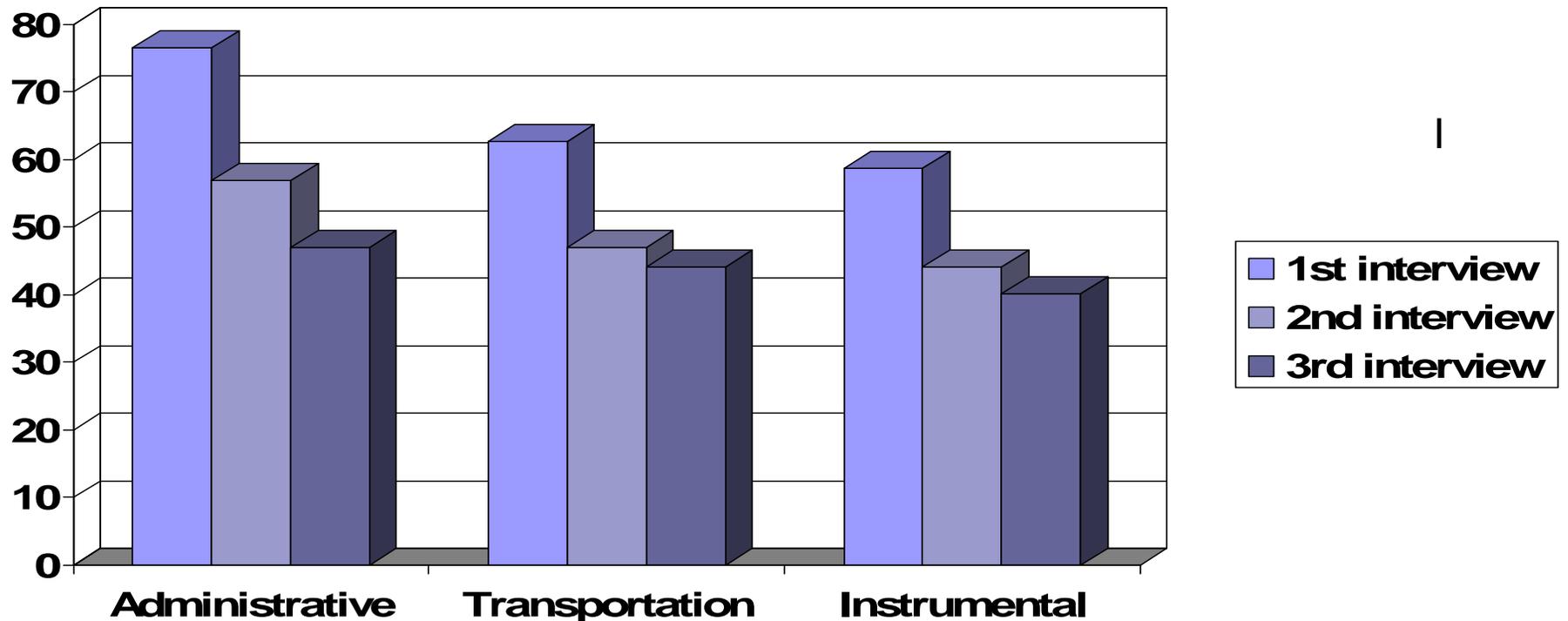
Source: Psychosocial Burden of Cancer Caregiving to Aged Parents

Caregiver Daughters' Care Provision in Daily Living Activities: Treatment Initiation, 6 & 12 Month Follow-up



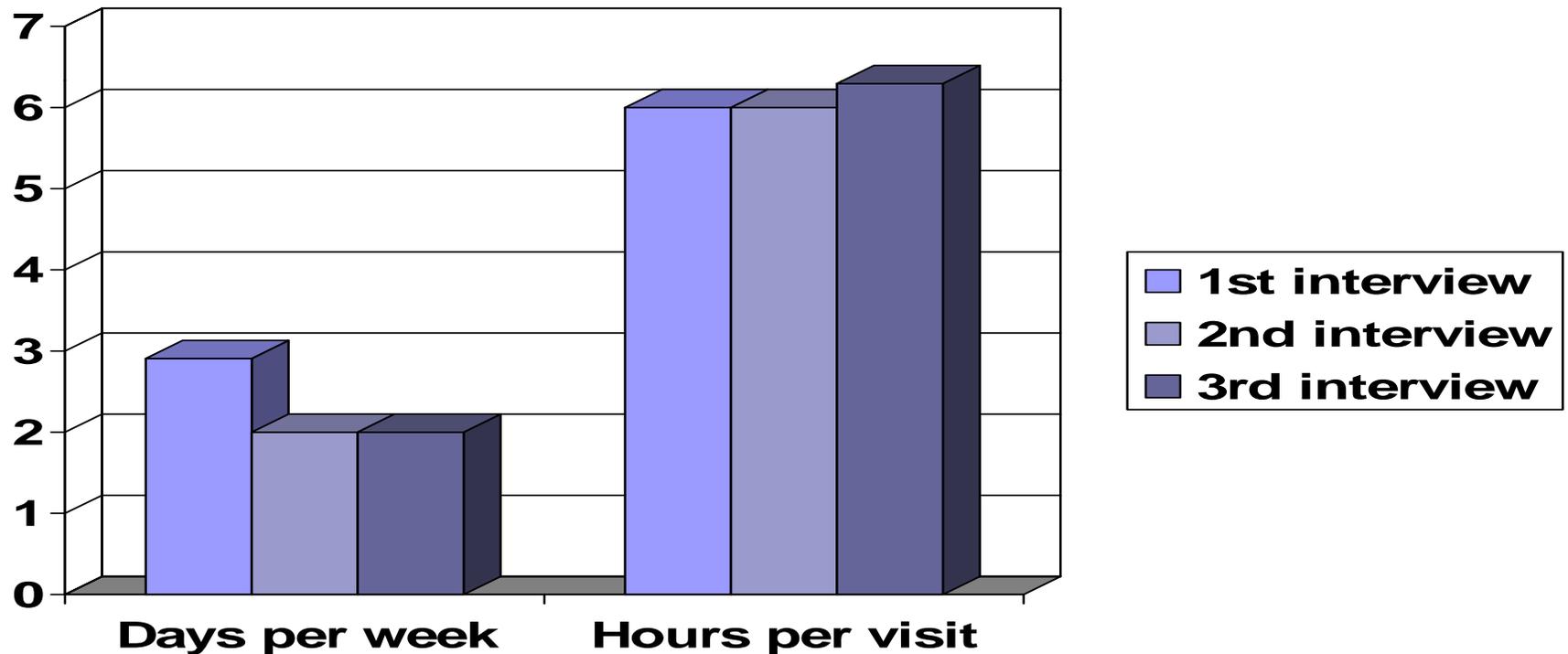
Source: Psychosocial Burden of Cancer Caregiving to Aged Parents

Activity Domains Caregiver Daughter Provides Help: Treatment Initiation, 6 & 12 Month Follow-up

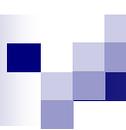


Source: "Psychosocial Burden of Cancer Caregiving to Aged Parents"

Caregiver Daughters' Visits to Ill Parent: Treatment Initiation, 6 & 12 Month Follow-up



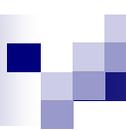
Source: "Psychosocial Burden of Cancer Caregiving to Aged Parents"



Caregiver Burden: Care Provision Can be Difficult and Encompassing

“The first few months it impacted a great deal -- from the amount of time I spent with friends, amount (of) sleep, amount of leisure. I feel like every waking moment was either work or care.”

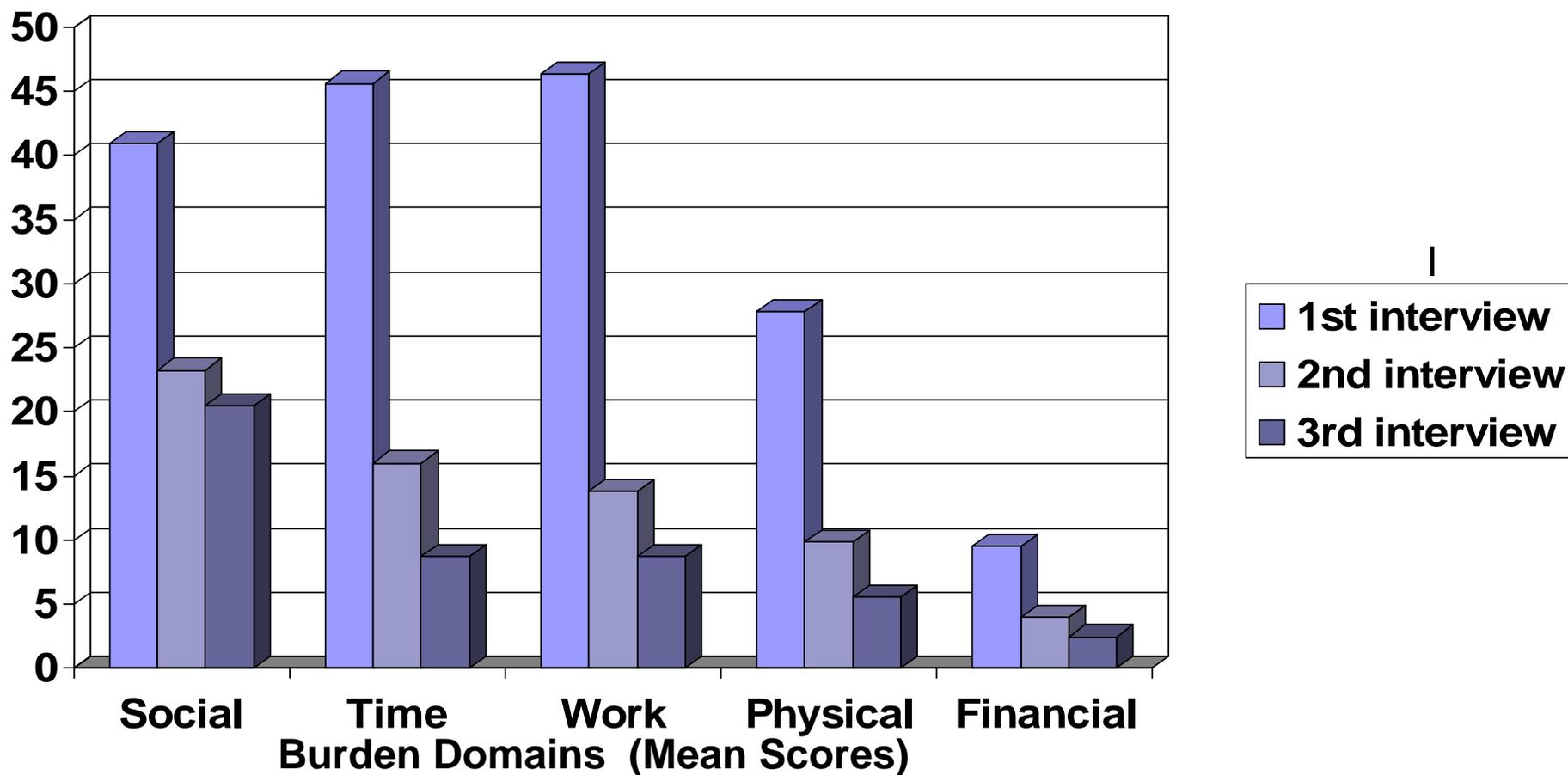
Source: “Aging Families and Breast Cancer”



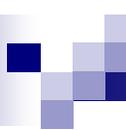
Caregiving Burdens

- Social:** *Impacts time with family members
Impacts time with friends, neighbors*
- Time:** *Reduces time doing regular daily activities
Tasks not done as carefully*
- Work:** *Affects ability to concentrate, do best at work
Comes in late, leave early due to care provision*
- Physical:** *Increases physical strain
Reduces energy for regular daily activities*
- Financial:** *Experiences serious financial problems
Makes changes in financial habits and lifestyle*

Caregiver Burden: Treatment Initiation, 6 & 12 Month Follow-up



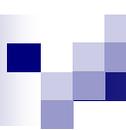
Source: "Psychosocial Burden of Cancer Caregiving to Aged Parents"



Caregiver Burden: Persistent and Long-lasting Changes

“I rarely see my friends anymore. I don’t really go out with them as much...we have to talk about it a week in advance and then it’s still not final until the day we’re going to actually go out, because I don’t know how my mom’s going to feel.”

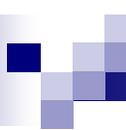
Source: “Aging Families and Breast Cancer”



Caregiving is Meaningful: Personally Fulfilling

“She makes me believe that I’m making a difference in her life, and I’m actually helping her, that she admires me, and that she respects who I am, and as a daughter, especially.”

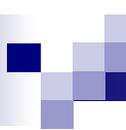
Source: “Aging Families and Breast Cancer”



Caregiving is Meaningful: Forges a Closer Bond

“Although we had a good relationship before, I think that it just gave us that extra connection, because now she really felt she could rely on me.”

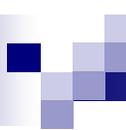
Source: “Aging Families and Breast Cancer”



Caregiving is Meaningful: Provides an Opportunity for Reciprocity

“It feels good to help your mother through a difficult situation, when she’s always been there for you....It’s been nice to be able to help her.”

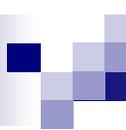
Source: “Aging Families and Breast Cancer”



Caregiving is Meaningful: An Opportunity for Growth

“Now I think I'll be able to deal with another situation. It's very informative because you never take the information because you're not in that situation, but now I think that it's something that has made me very capable.”

Source: “Aging Families and Breast Cancer”



Meaning in Caregiving Role

Positive Attitudes:

Enjoys providing care

Experiences personal growth

Negative Attitudes:

Feels entrapped by care provision

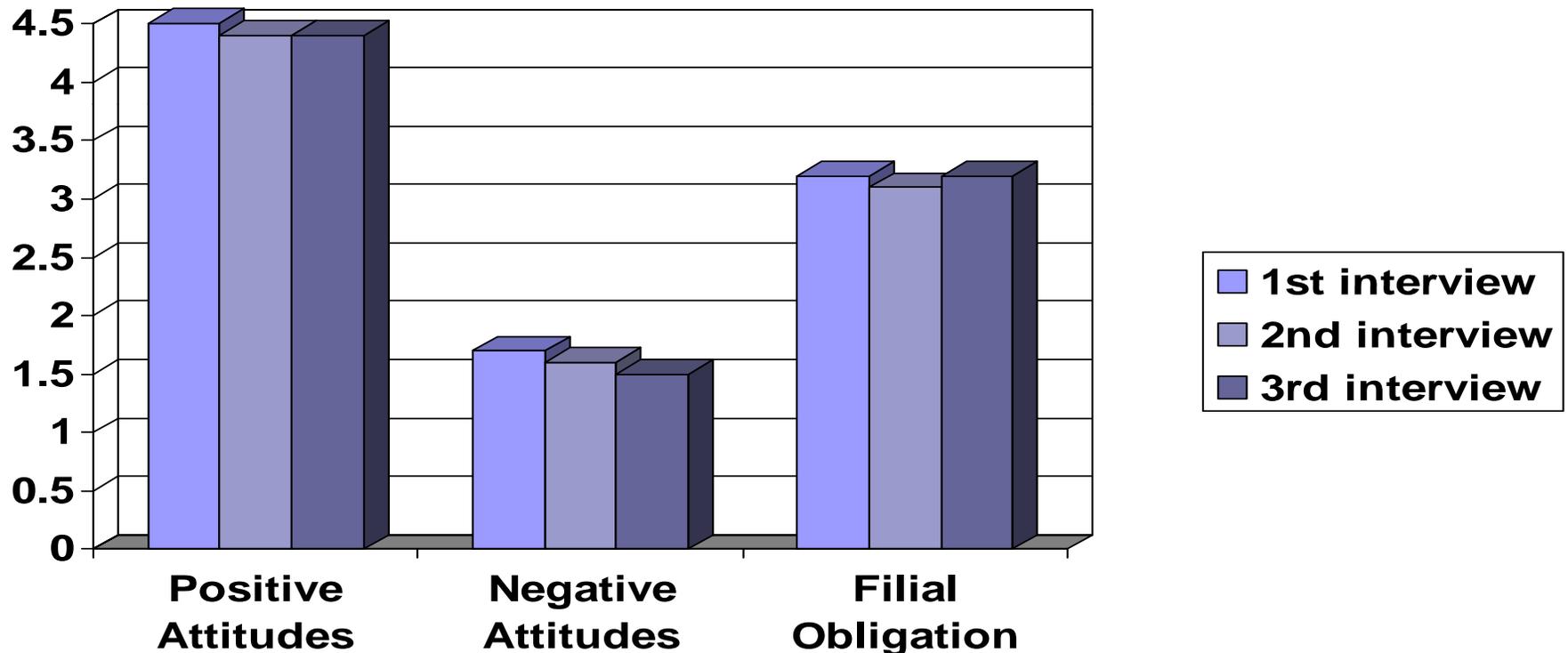
Feels overwhelmed by care provision

Filial Obligation:

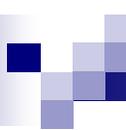
Feels children have a duty to provide assistance

Feels paid help is not a substitute for family care

Meaning in Caregiving Role: Treatment Initiation, 6 & 12 Month Follow-up

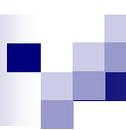


Source: "Psychosocial Burden of Cancer Caregiving to Aged Parents"



Adaptational Challenges Daughter Caregivers Face During Survivorship

- Alterations in interactions between parent-caregiver daughter relationship
- Initiation of life cycle developmental issues related to aging and mortality
- Fears of recurrence and disease progression
- Traumatic experiences



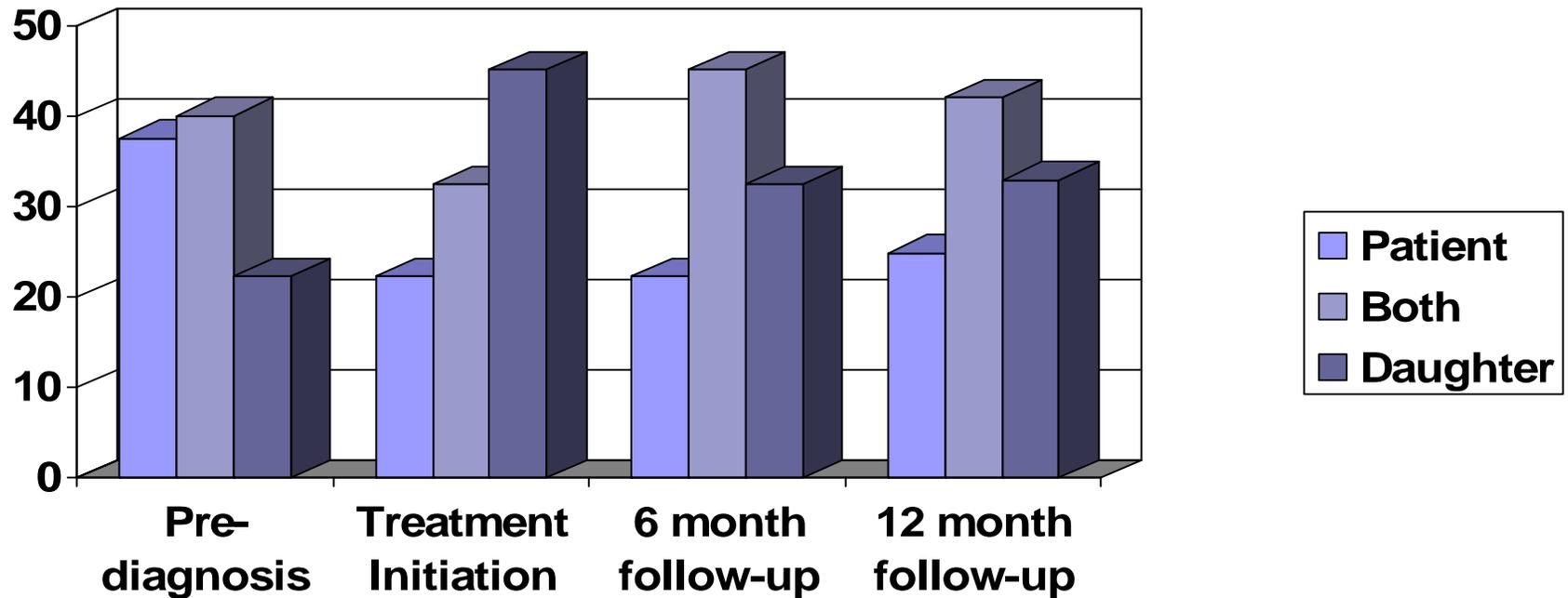
Survivorship Adaptational Challenge: Altered Interactions with Parent

“It was really weird for me, like my mother’s always taking care of me....She was scared. And I don’t know, I felt like I have to be strong for her.... My instincts were to be the kid, but I couldn’t....I feel I have a kid, to a certain extent, sometimes. Like my mother’s my child.”

Source: “Aging Families and Breast Cancer”

Survivorship Adaptational Challenge: Relationship Changes

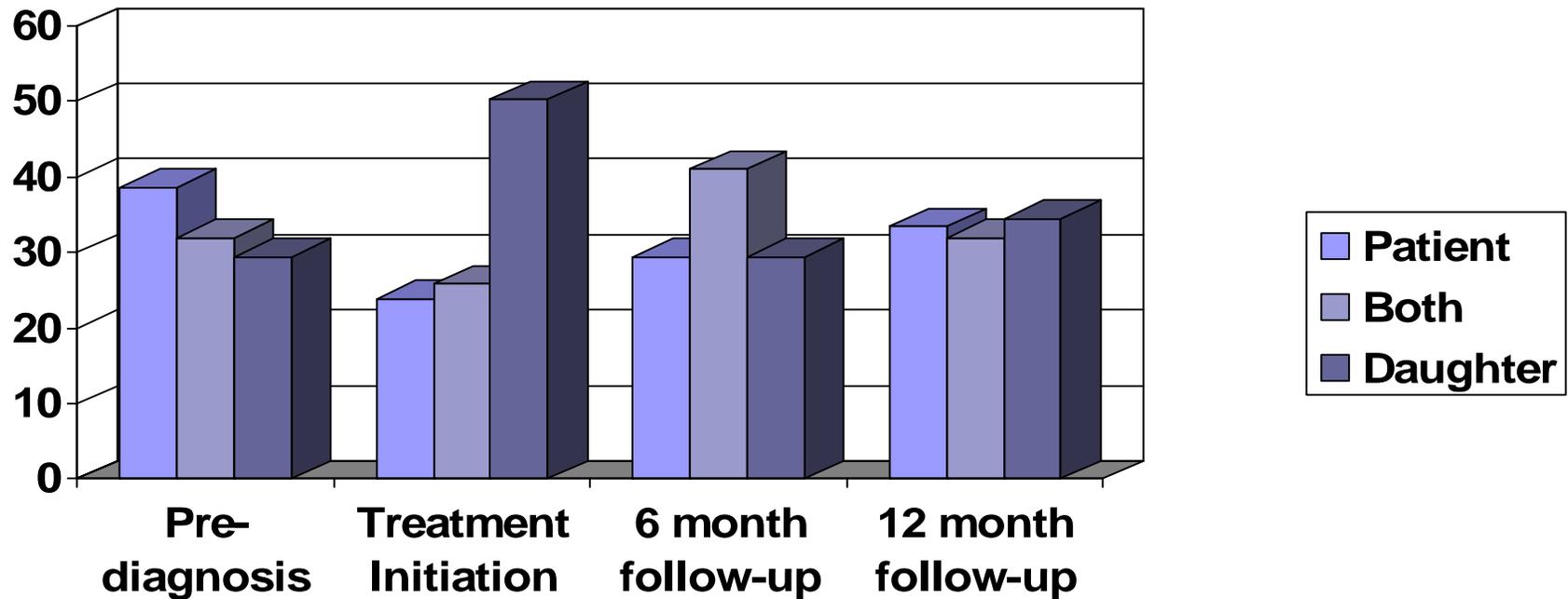
Who takes charge more often?



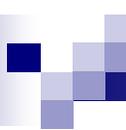
Source: "Psychosocial Burden of Cancer Caregiving to Aged Parents"

Survivorship Adaptational Challenge: Relationship Changes

Who tells the other what to do more often?



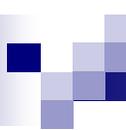
Source: "Psychosocial Burden of Cancer Caregiving to Aged Parents"



Survivorship Adaptational Challenge: Parents Are Vulnerable, Mortal

“Once your parents get sick, it changes, things change...your perception of their immortality, or mortality.”

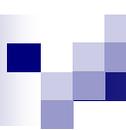
Source: “Aging Families and Breast Cancer”



Survivorship Adaptational Challenge: Cancer Threat is Enduring

“To this day — if someone would tell me she will be a hundred percent fine, which I don’t know if they ever will, I’m going to be scared for her life. I’m going to be scared for her health and I’ll be scared of something happening.”

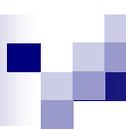
Source: “Aging Families and Breast Cancer”



Survivorship Adaptational Challenge: Trauma of Experience Is Long-lasting

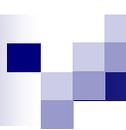
“I’ll never forget having a cell phone for about a week, and trying to call doctors and get information, and to this day, when I hear that ring, I like jump through the ceiling...If I hear that tone, it just hits me – it just brings me back.”

Source: “Aging Families and Breast Cancer”



Additional Adaptational Challenges Daughter Caregivers Face

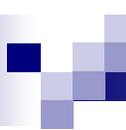
- Adult children learning of their parent's cancer diagnosis may simultaneously be learning of their own heightened risk status as a family history of cancer is indicative of heightened susceptibility to the disease
- Anxiety and concern daughters experience over their personal risk status is compounded by their first-hand exposure through care provision of the cancer experience



Survivorship Adaptational Challenge: Increased Sense of Personal Risk

“It was like a wakening call, just -- you know, I realized that anyone’s at risk, and no matter how young you are, it, just anyone is at risk and it made me realize that I am even at a higher risk, a greater risk than most.”

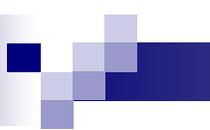
Source: “Aging Families and Breast Cancer”



Survivorship Adaptational Challenge: Intimate Knowledge of Cancer Experience

*“It’s not something I want...and I’m afraid.
Because I’ve seen what my mother’s going
through and getting diagnosed and having
surgery was the easiest part.”*

Source: “Aging Families and Breast Cancer”

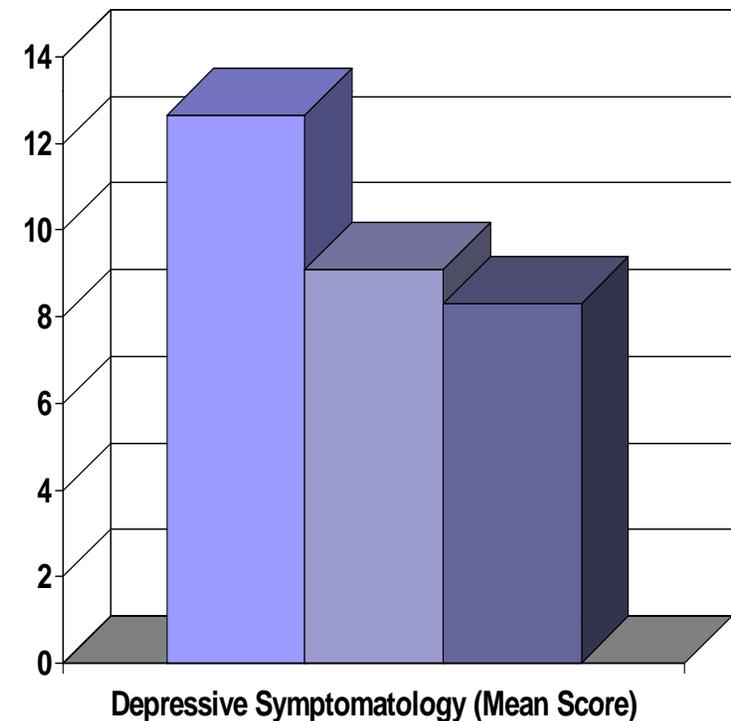
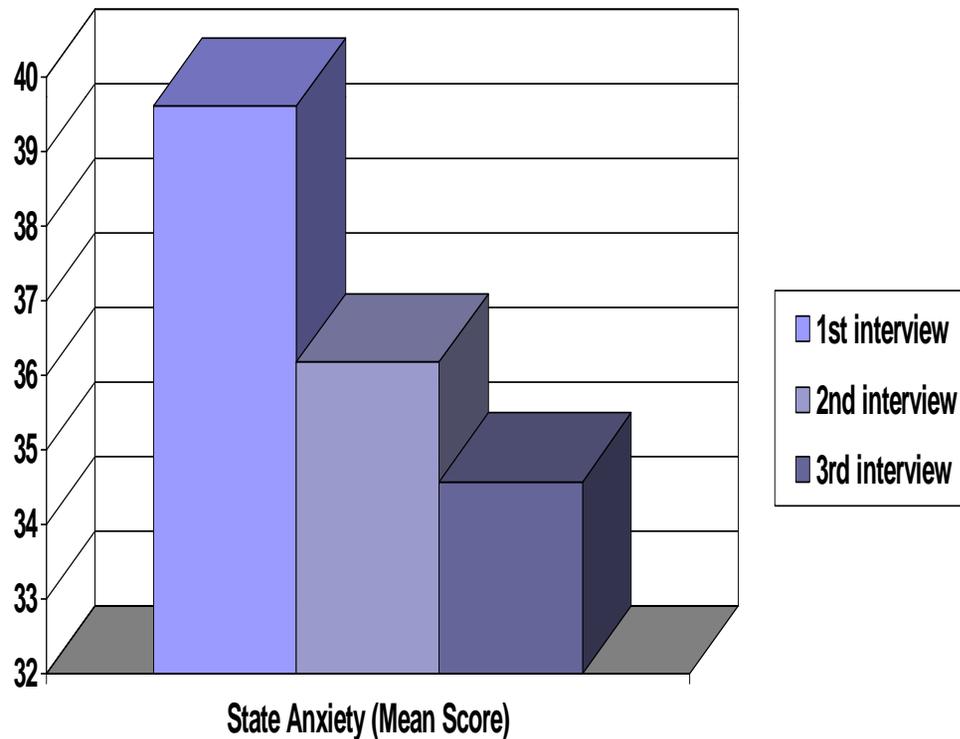


Survivorship Adaptational Challenge: Altered Future

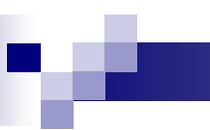
“I was afraid about the anxiety, as much as the prospect of breast cancer — afraid of what the anxiety would be like of getting a mammogram. ...Just living your life knowing that there’s this thing, and you’re at risk for it, and it really could happen.”

Source: “Aging Families and Breast Cancer”

Caregiver Daughters' Psychological Distress: Treatment Initiation, 6 & 12 Month Follow-up

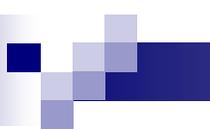


Source: "Psychosocial Burden of Cancer Caregiving to Aged Parents"



Correlates of Caregiver Daughters' Psychological Distress

- Multivariate longitudinal analyses assessed the relative importance of various factors on caregiver daughters' psychological distress
- During treatment initiation, distress was significantly & directly correlated with negative attitudes towards caregiving, greater sense of filial obligation, total caregiver burden; it was inversely correlated with employment
- At the 12 month follow-up, reduction in distress was correlated with younger age, having another role responsibility – spouse, parent, or caregiver to another adult; however, no additional benefit was accrued by having multiple combinations of these roles



Concluding Thoughts and Implications

- As medical advances reduce mortality and increase cancer survival, there is a growing number of individuals whose lives have been impacted by cancer
- Longitudinal data documents that although care provision may continue into survivorship, the intensity of caregiving demands associated with treatment generally abates
- The research also indicates that during survivorship caregiver daughters are confronted with a range of psychosocial issues and concerns meriting attention