

*Caregiving daughters'  
careprovision during cancer  
survivorship:  
Challenges and benefits*

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# Families' Involvement in Cancer Care

- Shift to outpatient care, coupled with less severe cancer therapies, contribute to patients remaining in the community during active treatment
- Families are healthcare advocates, monitoring patient's functioning and health changes, engaging in healthcare decision-making
- Families remain involved in careprovision throughout the disease course, ensuring adherence to cancer management and symptom control routines

# 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 & assistance to older cancer patients**
- **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, & employment**
- **Anxiety & concern daughters experience over their parent’s cancer is compounded by care burden & strain**

# State of Knowledge on Cancer Survivorship and Family 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
- Even less is known about aging family caregivers

# Study Design

- **Sample consists of older adults (60+) receiving treatment for cancer and their adult caregiving daughters**
- **Patients recruited from a comprehensive cancer center in a major metropolitan area**
- **Caregiving daughters nominated by their ill parent**

# Patient Sample Eligibility

- **Been diagnosed with cancer & receiving treatment for not more than two months**
- **Not have a prior history or recurrence of cancer**
- **Have an expected survival time of 18+ months**
- **Be 60 or older**
- **Have a daughter providing illness-related caregiving**

# Daughter Sample Eligibility

- Patient's biological, adoptive or step-daughter
- Had on average over the past month, at least weekly face- to-face contact with parent
- Provide, on average, four+ hours weekly of illness/treatment-related practical, instrumental, or administrative assistance to the patient



# Data Collection

- Interviews conducted by bilingual (English-Spanish) mental health or health care clinicians
- Patient & caregiver interviewed three times
- Baseline within two months of initiating treatment, follow-up six & twelve months later

# Patient Sociodemographics

<b>Age:</b>	<b>65-69</b>	<b>32%</b>
	<b>70-74</b>	<b>23%</b>
	<b>75-90</b>	<b>15%</b>

<b>Gender:</b>	<b>Male</b>	<b>34%</b>
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<b>Marital Status:</b>	<b>Currently married</b>	<b>69%</b>
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<b>Race/ethnicity:</b>	<b>White, Non-Hispanic</b>	<b>89%</b>
	<b>Black, Non-Hispanic</b>	<b>4%</b>
	<b>Hispanic</b>	<b>6%</b>
	<b>Asian</b>	<b>1%</b>

# Disease/Treatment Characteristics

**Months since diagnosis (mean): 4.1 (1.1)**

**Extent of Disease: Local 67%**

**Cancer site: Breast 35%**

**Gastro-intestinal 26%**

**Genito-urinary 22%**

**Respiratory, Head/neck 17%**

**Treatments received: Surgery 96%**

**Chemotherapy 32%**

**Radiation 29%**

# Caregiver Sociodemographics

Age in years (mean): 38.9 (7.4)

Married 70%

Parent 65%

College Graduate 57%

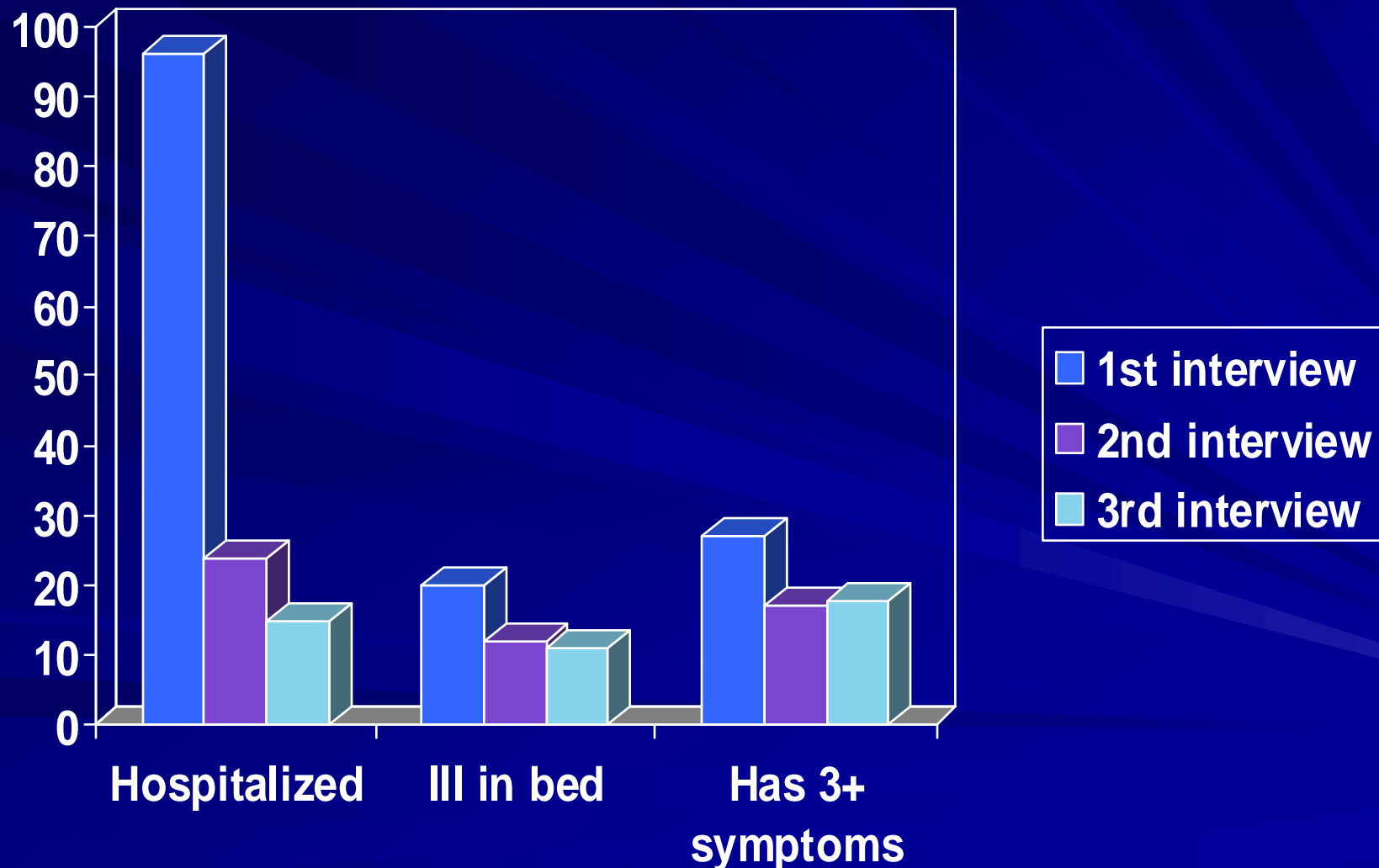
Employed 74%

Household income  $\geq$  \$60,000 60%

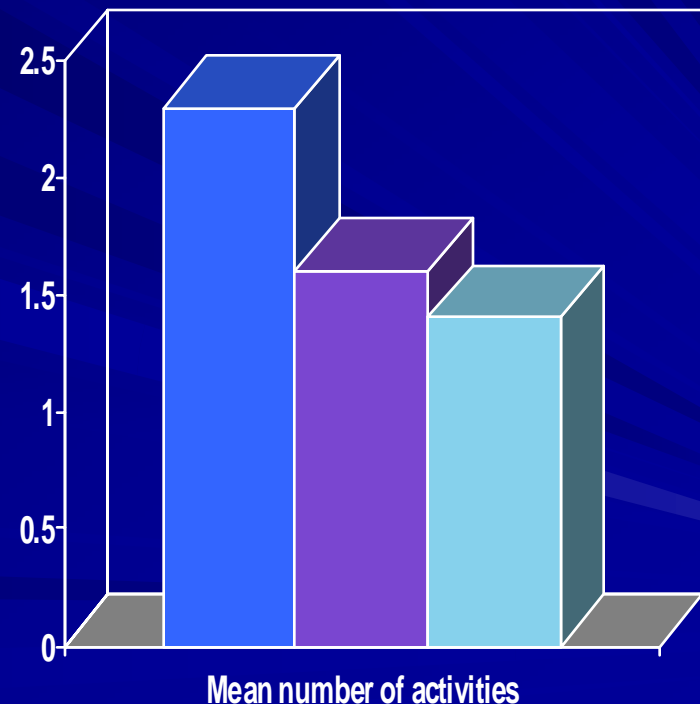
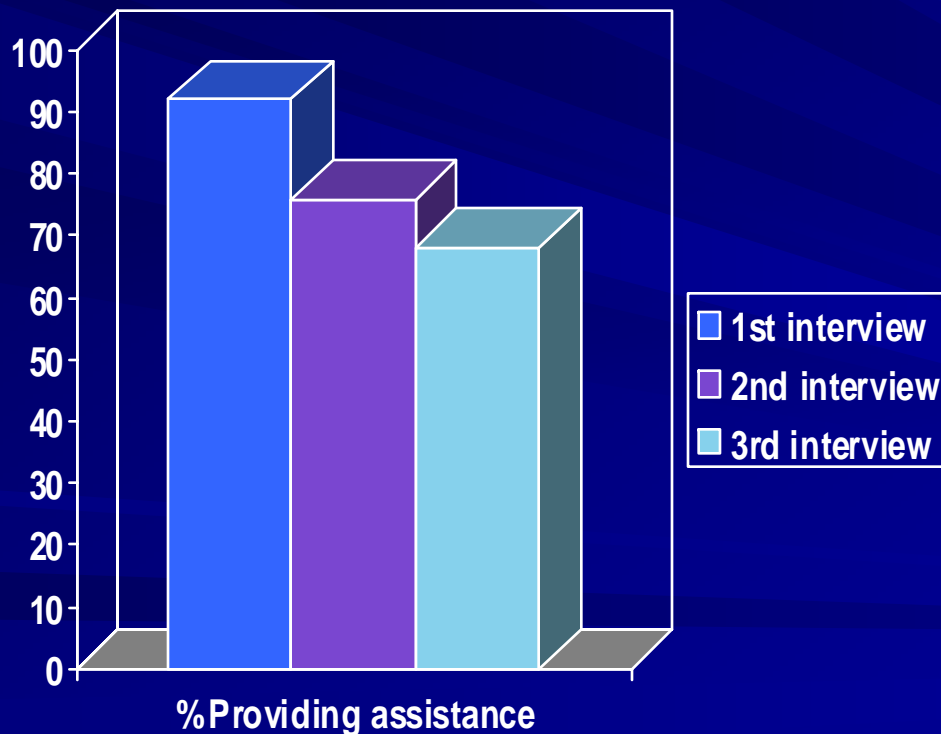
# Caregiving Context

<b>Daughter provides care to another relative</b>	<b>65%</b>
<b>Parent lives with caregiving daughter</b>	<b>16%</b>
<b>Daughter has a health condition that limits her careprovision</b>	<b>31%</b>

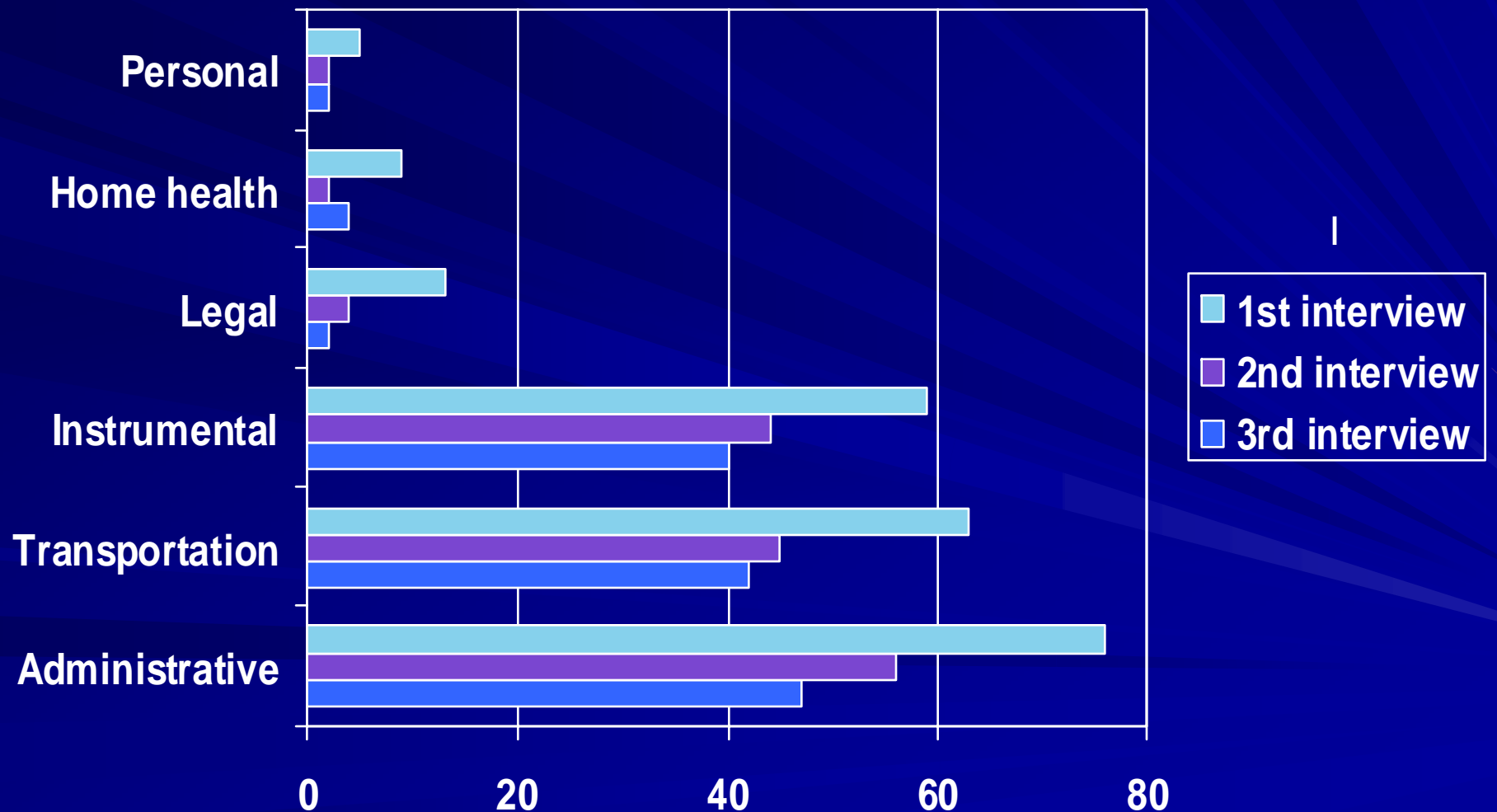
# Patient Health Events at Treatment Initiation and During Survivorship



# Assistance Caregiving Daughter Provides with Parent's Daily Living Activities at Treatment Initiation and during Survivorship

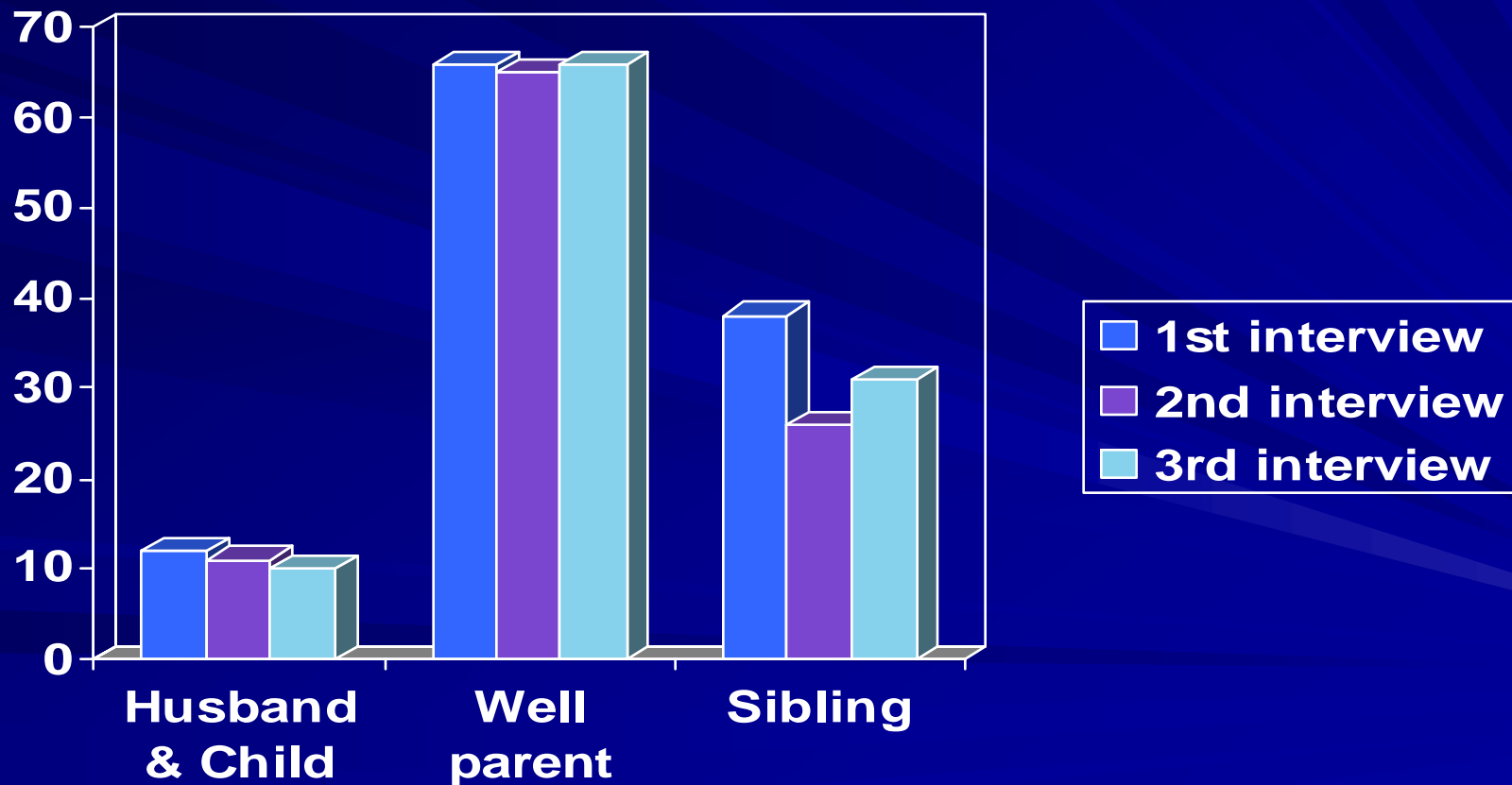


# Assistance Caregiving Daughter Provides at Treatment Initiation and during Survivorship

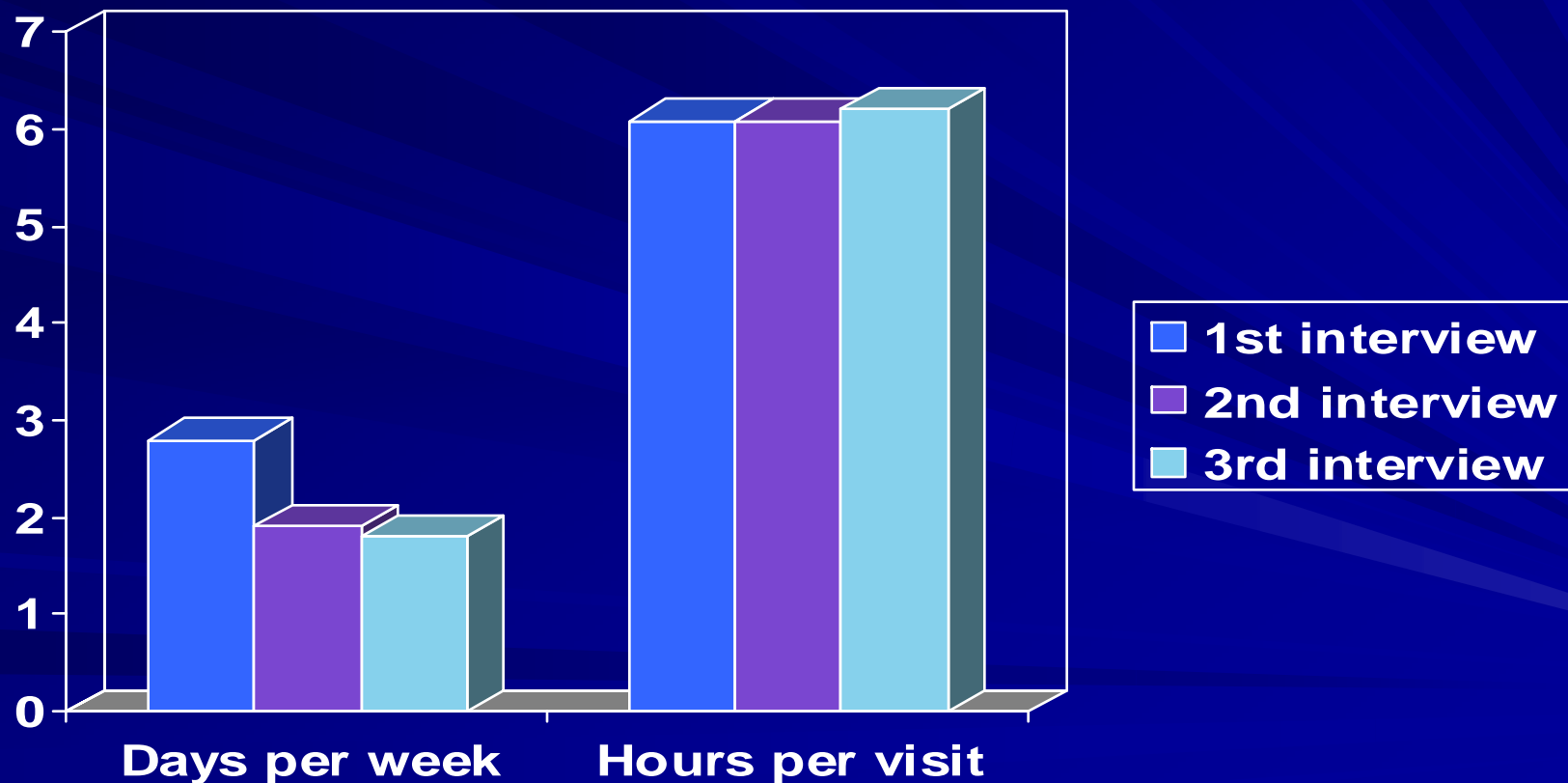




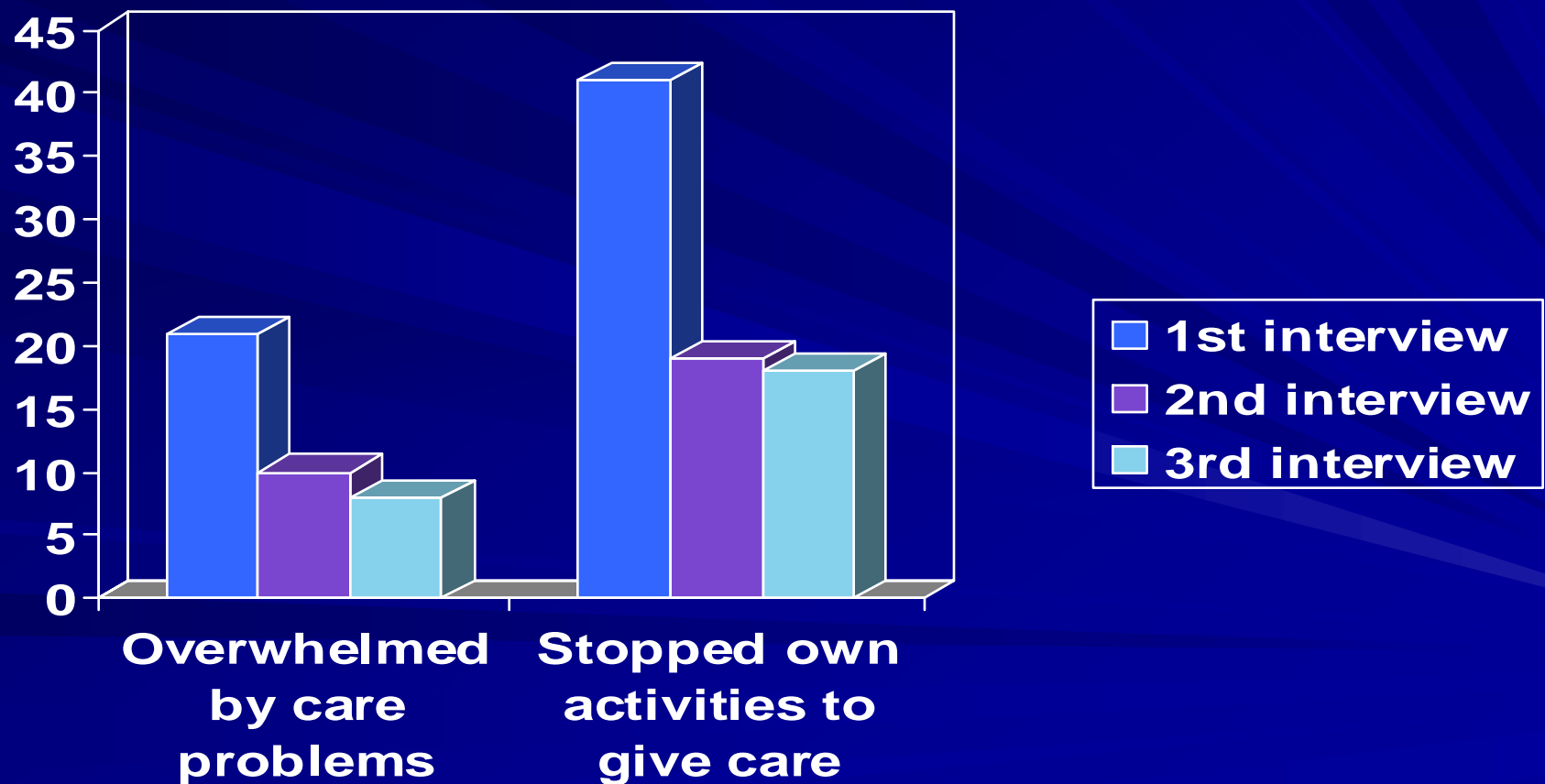
# Other Relatives Who Help Daughter at Treatment Initiation and during Survivorship



# Caregiver Daughter's Visits to Ill Parent at Treatment Initiation during Survivorship



# Perceived Caregiving Role Overload at Treatment Initiation and during Survivorship



# Caregiving Burdens

**Social:** *Impacted time with family, friends, neighbors*

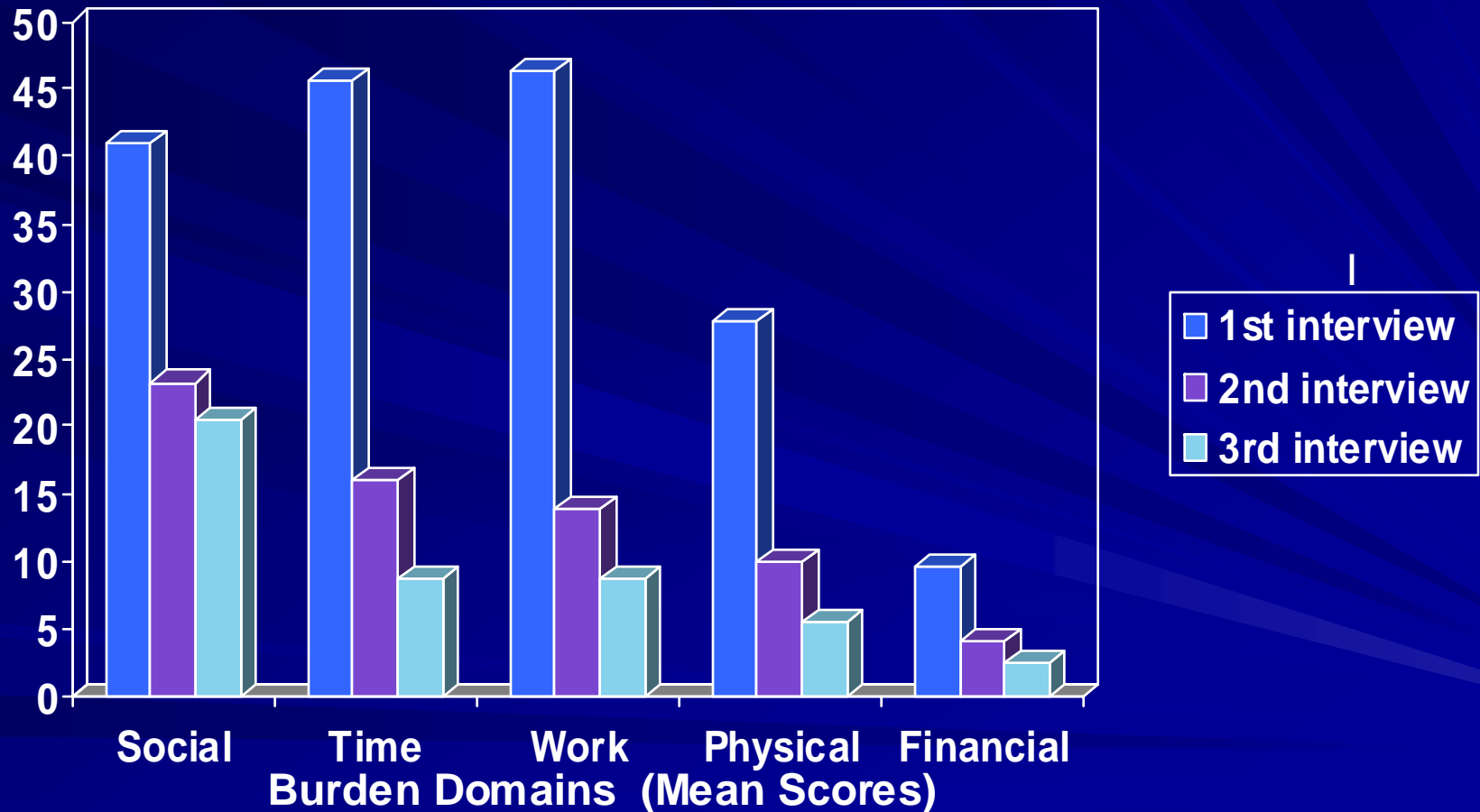
**Time:** *Reduced time doing regular daily activities, not do things as carefully*

**Work:** *Affected ability to concentrate, do best, Came in late, left early due to caregiving*

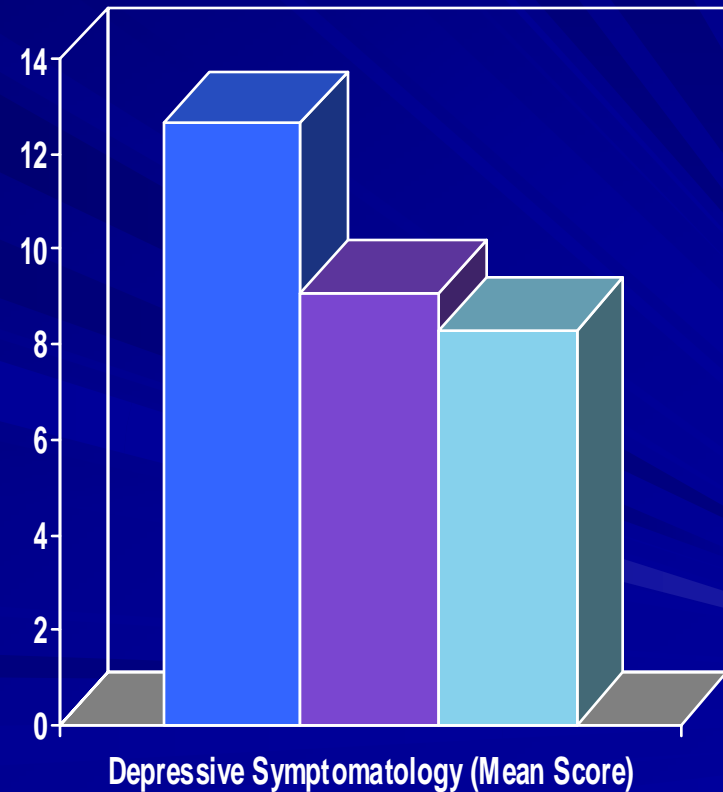
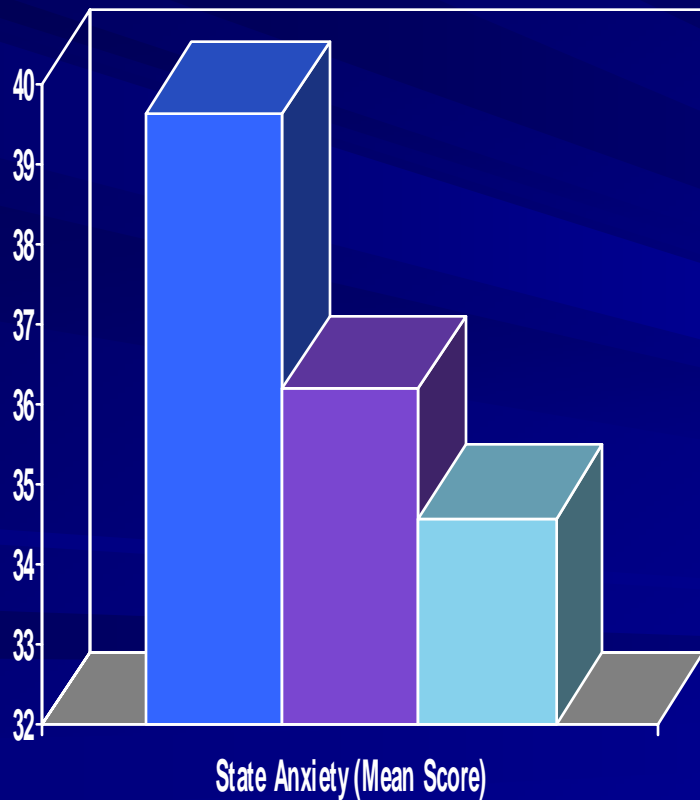
**Physical:** *Increased physical strain, reduced energy for regular daily activities*

**Financial:** *Experienced serious financial problems, made changes in financial habits*

# Caregiver Burden at Treatment Initiation and during Survivorship



# Caregivers' Psychological Distress at Treatment Initiation and during Survivorship



# Meaning in the Caregiving Experience

## ***Positive Attitudes:***

***Enjoys providing care***

***Experiences personal growth***

## ***Negative Attitudes:***

***Feels entrapped by care provision***

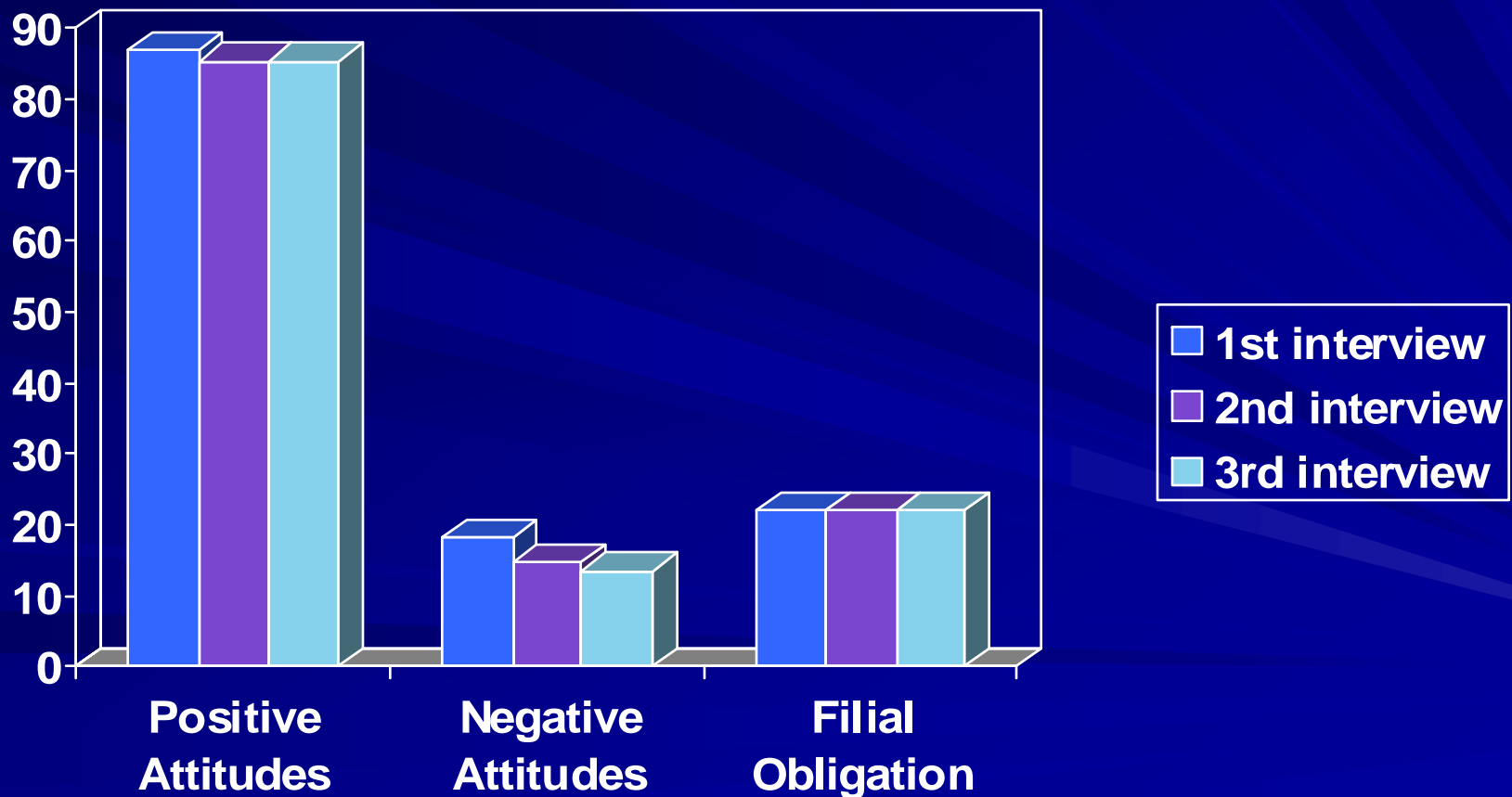
***Feels should not be a caregiver at this time in their life***

## ***Filial Obligation:***

***Feels children have a duty to provide care***

***Feels paid help is not a substitute for family care***

# Meaning in the Caregiving Experience at Treatment Initiation and during Survivorship





# Concluding Thoughts

- **As medical advances reduce mortality and extend cancer survival, there is a growing number of individuals whose lives have been impacted by cancer**
- **Longitudinal data documents that during survivorship:**
  - **Family members remain engaged in care provision**
  - **Intensity of treatment-related care declines**
  - **Burdens & stress associated with care provision also decrease**
  - **Positive meaning derived from care provision persists**