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## Introduction

**Background:** 80% of persons with dementia reside in the community and are cared for by family and friends considered informal care partners (ICPs)

- Research on ICPs for people with dementia has focused on spousal care partners and mother-daughter dyads.
- There is a paucity of information on non-spousal ICPs, particularly male non-spousal ICPs.

**Objective:** Evaluate differences in the type and frequency of unmet dementia-related care needs between spousal and non-spousal ICPs by gender and race.

## Methods

**Design:** Secondary data analysis on cross-sectional baseline data

**Participants:** 595 ICPs from two community-based intervention studies: 1) Maximizing Independence at Home randomized control trial (MINDRCT) and 2) Maximizing Independence at Home-Health Care Innovation Award (MIND-HCIA).

**Spousal Status:** Relationship of ICPs to care recipient was coded as:

- Spousal (partner)
- Non-spousal (e.g., child, sister, friends)

**Outcome Measures:** Type and frequency of unmet dementia-related care needs of ICPs were obtained from the Johns Hopkins Dementia Care Needs Assessment (JHDCNA 2.0©) (*Table 2*):

- 6 domain topics included:
  - Dementia Education (understanding stages of dementia)
  - Mental Health Care (undiagnosed psychiatric symptoms)
  - General Health Care (undiagnosed health problems)
  - Informal Support (additional support from family)
  - Daily Living (changes in social and recreational activities)
  - Legal Concerns (POA or advance directive documents)
- 18 total items on care partner needs
- 18 care partner needs are classified as binary variables and considered as “fully met” or “unmet”
- A summary score (range 0-100) provides an average total percentage of unmet dementia-related ICPs needs.

**Analysis:** To assess differences in the total % unmet needs by spousal status, race (African American/Black and White), and gender (female/male), t-tests and ANOVAs were used.

- Frequencies and chi-square tests were used to assess differences in the individual types of unmet needs by spousal status.

## Results

**Table 1**  
*Care Partner Characteristics by Spousal Status*

	Spousal (n=182)			Non-Spousal (n=413)		
	N (%)	M	SD	N (%)	M	SD
Gender						
Female	112 (62)			343 (83)		
Male	70 (38)			70 (17)		
Race						
African American/ Black	50 (27)			270 (65)		
White	132 (73)			143 (35)		
Married	174 (96)			159 (39)		
Employed	32 (18)			201 (50)		
Age (years)	182	74.00	9.15	412	58.03	9.60
Education (years)	181	14.60	3.16	410	14.82	3.10
Hrs. Helping per week	181	43.00	41.4	398	30.75	34.70

**Table 3**  
*Total Percent Unmet Needs by Spousal Status, Gender, and Race*

	N	M	SD
Spousal Male African American/Black	12	34.26	18.17
Spousal Female African American/Black	38	33.63	12.11
Non-Spousal Male African American/Black	39	33.48	13.87
Non-Spousal Female African American/Black	231	33.46	14.92
Non-Spousal Male White	31	31.00	15.23
Spousal Male White	58	30.70	14.60
Spousal Female White	74	29.78	15.10
Non-Spousal Female White	112	28.04	13.75

**Table 2**  
*Total Percent Unmet Dementia-Related Care Needs by Spousal Status*

	Spousal Unmet Needs (n=182)	Non-Spousal Unmet Needs (n=413)	p-value
<b>JHDCNA 2.0© Domains and 18 Items</b>			
<b>Dementia Education</b>			
Dementia Education (H1)	85.71%	89.59%	0.1738
Community Resources (H2)	81.87%	83.05%	0.7253
CP Skills - Behavior (H3)	69.78%	68.52%	0.7602
CP Skills - Communication (H4)	44.20%	42.37%	0.6790
CP Skills - ADLs/IADLs (H5)	17.03%	17.92%	0.7942
CP Skills - Substitute Decision-Maker (H6)	17.58%	22.03%	0.2166
CP Skills - Patient Advocacy (H7)	10.44%	12.83%	0.4095
CP Skills - Care Transitions (H8)	3.85%	6.30%	0.2291
<b>Care Partner Mental Health Care</b>			
Undiagnosed Psychiatric Symptoms (I1)	1.65%	2.18%	0.6686
Untreated Psychiatric Symptoms (I2)	0.55%	1.21%	0.4555
Care Partner Distress (I3)	45.30%	44.42%	0.8415
<b>Care Partner General Health</b>			
Primary Medical Care (J1)	2.75%	3.88%	0.4894
Medical Specialist Care (J2)	8.24%	7.54%	0.7691
<b>Care Partner Informal Support</b>			
Informal Support (K1)	49.45%	39.66%	<b>0.0262</b>
<b>Care Partner Daily Living</b>			
Physically Inactive (L1)	21.98%	21.55%	0.9070
Social Isolation (L2)	20.33%	14.53%	0.0775
Meaningful Activities (L3)	22.65%	14.53%	<b>0.0153</b>
<b>Legal Concerns</b>			
Decision-Making Documents (M1)	58.01%	79.90%	<b>&lt;.0001</b>

- There were 182 spousal and 413 non-spousal ICPs (*Table 1*)
- **Spousal ICPs:**
  - 61.54% Female
  - 72.53% White
  - provided a mean average of **43** hours of help with ADLs/IADLs
- **Non-spousal ICPs:**
  - 83.05% Female
  - 34.62% White
  - provided a mean average of **31** hours of help with ADLs/IADLs
- There were differences in specific unmet needs by spousal status (*Table 2*)
  - non-spousal ICPs had higher unmet needs regarding decision-making;
  - spousal ICPs had higher unmet needs related to informal support and meaningful activities.
- The mean percentage of unmet needs was highest in in male African American/Black spousal ICPs, and lowest among female White spousal ICPs (*Table 3*).

## Conclusions

- Spousal ICPs provide more hours of care than non-spousal ICPs.
- There are differences in the type of unmet needs between spousal and non-spousal ICPs.
- African American/Black ICPs have a higher percent of unmet needs (p <.0006).
- Further research should explore the differences between unmet dementia-related care needs of non-spousal ICPs by race and gender.
- This on-going research will contribute to identifying characteristics and unmet needs of ICPs to determine those who will benefit from specific programs, services, and resources.
- The presence of unmet needs may impact the health of the care recipient, increase ICP stress, and even lead to premature institutionalization of the care recipient.

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