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"It's like we're grasping at anything!"

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“It’s like we’re grasping at anything!”

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INTRODUCTION

- >33 million Americans care for an older adult
- 3 organizations recognize caregiver (CG) needs:
 - IOM: Preparation for CG role unknown
 - NINR: Research emphasis aims to improve caregiver & care recipient (CR) quality of life
 - Healthy People 2020 proposed objective: Aims to increase caregiver service use
- Quantitative studies
 - Identified CG education needs
 - Limited participant response to list of options
- CGs obtain information via:
 - Internet
 - Physician
 - Family / friends
 - Other health care professionals
- CGs’ desired learning methods not described

PURPOSE

- To describe:**
- Caregiving tasks
 - How caregivers learn about caregiving
 - Knowledge needs
 - Preferred methods of learning

This study was funded by The Hogstel Gerontological Nursing Research Award

METHODS

- Design**
- Qualitative, descriptive study
- Ethical Considerations**
- IRB approved & written consent obtained
- Settings**
- Non-governmental & health care agencies
 - Urban Gulf Coast & rural Northeast Texas
- Data Collection & Analysis**
- Focus groups (*n*=5):
 - 4 groups (*n*=24): participants had no structured education
 - 1 group (*n*=5) attended structured, disease-specific, 7-week program
 - Interview schedules guided data collection
 - Audio-taped & transcribed verbatim
 - Line by line analysis
 - Codes identified and grouped into categories
 - Trustworthiness achieved through
 - Author-identified biases
 - Summarized key points at end of each group
 - Both researchers coded data

Participants	
21 current & 8 previous caregivers	
76% Caucasian	10% Latino
17% African-American	3% Asian
90% Female	10% Male
Care Recipients	
45% parent	38% spouse
17% other family member	
Mean age 73 years (SD 14)	

RESULTS

- How CG learned about role**
- “There was no training” / “Learn as you go”
 - Care providers (MD, nurse, PT, etc.)
 - Other resources (friend, TV, community agency)
- Areas for which CGs need education:**
- Respite
 - Emotional reactions
 - Caregiving essentials
 - Self-care
- Perceptions of learning methodologies**
- Workshops**
- Demonstrations / return demonstrations
 - Can ask questions face-to-face
 - Social component / learn from others
 - Opportunity for respite
 - May not be able to leave care recipient
 - May not have the energy / time to attend
 - Location must be convenient
- Home visitor**
- Would spend more time
 - Convenient
 - Need not be a health professional
 - Must be reliable / credible
- Internet**
- Can view videos
 - Requires
 - Computer skills / equipment
 - Ability to evaluate information reliability
 - Information must be current

RESULTS

- Why CGs attended education program**
- Support
 - Learn about diagnosis
 - Gain confidence in caregiving skills
 - Emphasized learning was a process
- Benefits of education program**
- “I felt I was gonna make it.”
 - Increased knowledge in many areas
 - May not have immediate need but used later
 - Gained patience
 - Learned how to tell others about diagnosis
 - Formed friendships with other CGs
- Unexpected Findings**
- Expressed satisfaction with role fulfilled
 - Described a closer relationship with CR
 - “It (caregiving) opens your heart”
 - All agreed they would do it again

DISCUSSION / CONCLUSION

Findings support national organizations’ focus on caregiving issues. Caregivers were unprepared for the caregiver role, did not know where to access reliable information, and obtained knowledge anecdotally. Because caregiving situations vary according to care recipient needs, caregivers’ education requirements must be assessed and innovate methods of delivering information that are congruent with different circumstances should be developed and evaluated. Interventions to facilitate formal and informal respite, help caregivers manage their own and the care recipient’s emotional reactions, promote self-care, and empower the caregiver in day-to-day caregiving activities are suggested.