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

B. Mastel-Smith

Melinda Hermanns

The University of Texas at Tyler, mhermanns@uttyler.edu

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“It’s like we’re grasping at anything!”
Mastel-Smith, B., & Hermanns, M.
The University of Texas at Tyler, College of Nursing

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: 10% Latino
Other health care professionals: Knowledge needs

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

Areas for which CGs need education:
- Respite
- Emotional reactions
- Caregiving essentials
- Self-care

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)

Area 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 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

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
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.