"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
• 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

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.

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

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 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

<table>
<thead>
<tr>
<th>Participants</th>
<th>21 current &amp; 8 previous caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>76% Caucasian</td>
<td>10% Latino</td>
</tr>
<tr>
<td>17% African-American</td>
<td>3% Asian</td>
</tr>
<tr>
<td>90% Female</td>
<td>10% Male</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care Recipients</th>
<th>45% parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>38% spouse</td>
<td>17% other family member</td>
</tr>
<tr>
<td>Mean age 73 years (SD 14)</td>
<td></td>
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</tbody>
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