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A Qualitative Examination of Barriers for Urban and Rural Custodial Grandparents

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Abstract

Focus groups were conducted with 33 community dwelling, urban and rural, custodial grandparents to explore their willingness to comply with a behavioral intervention targeting improving their well-being and financial management. Most participants were African American (91%), female (79%) and middle-aged. Major themes included: 1) inability to access social services; 2) legal assistance; 3) emotional well-being; 4) problems related to the parents of grandchildren; and 5) identification of structured activities for grandchildren. Findings suggest custodial grandparents underutilize services. Future research should address methods to enhance grandparents' utilization of resources facilitated via a peer navigator system along with policy level changes.

Keywords

grandparents; caregivers; rural; African Americans

Epidemiological and clinical studies over the past two decades have provided ample evidence that caregiving is a chronically stressful process which can have potentially negative psychological and physical health outcomes and create financial distress (Bullock, 2004; Bullock, 2005; Minkler & Fuller-Thomson, 1999; Minkler & Roe, 1993; Minkler, Roe, & Price, 1992; Sands & Goldberg-Glen, 2000). An often neglected dimension of caregiving in the United States is the dramatic increase in the number of grandparents serving as primary caregiver to their grandchildren and great-grandchildren. Approximately 4.9 million children are living in grandparent maintained households (U. S. Census Bureau, 2010). This caregiving phenomenon cuts across ethnic and social-class lines; however, the research indicates that custodial grandparents are more likely to be African American, female, poor, and to live in the South (Crowther & Rodriguez, 2003; Simmons & Dye, 2003). There is also a growing group of rural custodial grandparents that have been

underrepresented in the literature (King et al., 2009; Myers, Kropf, & Robinson, 2002; Robinson, Kropf, & Myers, 2000). Although it is well documented that custodial grandparents experience social, economic and legal stressors, the number of grandparents taking on the role of primary caregiver to their grandchildren is rising (Bryson, 2001; Carr, Hayslip, & Gray, 2012; Mills, Gomez-Smith, & DeLeon, 2005), without an increase in resources to address these stressors. Hence, there is an increased focus on coping and well-being within this population.

There has also been an increase in the number of grandparents raising their grandchildren in rural areas (Myers, Kropf, & Robinson, 2002; Robinson Kropf, & Myers, 2000). Despite the reported increase in the number of custodial grandparents in rural areas, the majority of the custodial grandparenting literature has examined grandparents raising their grandchildren in urban settings. Research conducted by Robinson, Kropf, and Myers (2000) suggests that geographic location is a factor that should be considered when examining custodial grandparents. Robinson and colleagues (2000) found that factors such as poverty, limited resources, especially transportation and geographic isolation can have an impact on well-being. Additionally, they found that the combination of very few resources, limited community support, and raising a grandchild with difficult behaviors had the most impact on grandparents' level of functioning. Over time, such stress may result in the emergence of psychological symptoms including depression, anxiety, interpersonal sensitivity, hostility, paranoid ideation, obsessive compulsive behaviors and somatization (Kelley, 1993). Therefore, it is important to understand the complex nature of custodial grandparenting and how it is manifested via urban/rural differences.

The specific factors that facilitate coping and the techniques that would increase underserved caregivers' motivation to participate in caregiving interventions should be tailored to incorporate the cultural values and beliefs of the caregivers' communities. For African American and rural custodial grandparents, an important cultural factor in coping appears to be community-based resources. Despite negative emotional effects caregivers may experience, community-based behavioral interventions address cultural differences that may prevent caregivers from seeking psychological help (Jang, Kim, Hansen, & Chiriboga, 2007; Kinoshita & Gallagher-Thompson, 2004). Middle-aged and older African Americans generally tend to underutilize mental/behavioral health services. Additionally, African Americans are less likely to use community services than Whites (Mui & Burnette, 1994). Diala et al. (2000) found that African Americans' initial attitudes toward seeking mental health services were comparable to, and in some instances more favorable than, those of Whites. However, certain cultural attitudes may reduce African Americans' desire to seek services. Focus group discussions have revealed cultural beliefs regarding the need to resolve family concerns within the family and the expectation that African Americans demonstrate strength. These beliefs were reflected in concern about disclosing information outside a trusted circle of family and friends, and by an association of psychotherapy with weakness and diminished pride. Additionally, the majority of focus group participants noted a perception that African Americans were a disadvantaged group who could and would collectively cope with adversity. Older participants were likely to suggest continued endorsement of these cultural beliefs (Thompson, Bazile, & Akbar, 2004). Such beliefs might inhibit mid-life and older African American caregivers from seeking assistance

outside their family to address personal stress or other difficulties. However, less is known about the specific role of community-based behavioral interventions in coping for both rural and African American custodial grandparents, in other words how do community-based behavioral interventions help or hinder stress and coping for underserved custodial grandparents?

Custodial Grandparents

Before the 1990s, there was a limited amount of research examining custodial grandparenting. Since then, a number of studies have discussed why custodial grandparents assume the responsibility of raising their grandchildren along with the stressors associated with this caregiving role (Pinazo-Hernandis & Tompkins, 2009).

It is well documented that custodial grandparenting is an event with lasting implications for all aspects of the person's life, much like becoming a parent or primary caregiver for an older adult, but with additional characteristics related to the nature, impact, and consequences of the experience. For example, many custodial grandparents have increased psychosocial as well as financial stressors as a result of the caregiving role; in addition to an increase in physical health problems (Bullock, 2004; Bullock, 2005; Fuller-Thomson, Minkler, & Driver, 1997; Mills, Gomez-Smith, & DeLeon, 2005; Wang & Marcotte, 2007).

Because of the significant needs associated with custodial grandparenting, several authors have called for the development of interventions for custodial grandparents that emphasize addressing the multiple needs of the caregivers such as custody concerns, social support, financial stress, emotional well-being and physical well-being (Landry-Meyer, 1999; Minkler, Driver, Roe, & Bedeian, 1993; Neely-Barnes, Graff, & Washington, 2010). Unfortunately, few interventions exist in the area of custodial grandparenting. Those interventions that do exist have demonstrated some improvements for custodial grandparents (Minkler et al., 1993), particularly in the area of social support (Smith, Savage-Stevens, & Fabian, 2002); however, these interventions lack a cohesive theoretical approach to creating and maintaining significant behavior change. Additionally, many of the interventions are support groups that are poorly funded and lack community-based support (Smith et al., 2002). As the number of custodial grandparents increases, concerns about the stress they experience and the social support they receive have been noted. Despite the past decade of research on custodial grandparenting, few interventions have been designed and tested specifically for the unique needs of this underserved population. Developing community-based behavioral interventions are a critical need, for improving grandparents' emotional, physical, and financial well-being, particularly African American and rural custodial grandparents.

We used a caregiving stress and coping model (Pearlin, 1982) to guide our conceptual understanding of the challenges, barriers and resources related to custodial grandparenting. Pearlin's (1982) caregiver stress model is a conceptualization of the stress process in caregiving. In the model, caregiver stress is viewed in terms of the relations among many conditions, and the ways these conditions develop and change over time. The model examines two types of stressors: primary and secondary. Primary stress encompasses the

nature and magnitude of the demands of caregiving. It is the catalyst that initiates the subsequent stress process. Secondary stress is defined as those issues that arise as a result of the caregiving situation. This model emphasizes the importance of adaptational processes, a term referring to the appraisal of caregiving, religiosity/spirituality, and social support as mediators of stress. The model is relevant for custodial grandparenting because it delineates the possible relation between the background and context of custodial grandparenting, the stressors, mediators of stress, and the outcomes or manifestations of stress.

The purpose of this study was to identify the stressors of African American and urban/rural custodial grandparents and their coping strategies as well as identify techniques that would increase their motivation to comply with a behavioral intervention focused on parenting skills, health and emotional well-being and/or financial management.

Methods

Design and Procedure

Grandparent caregivers were invited to participate in the study via flyers posted throughout various senior agencies and community-based organizations in Jefferson County and Perry County, Alabama. Grandparents were recruited utilizing purposive sampling. If interested, the grandparent would call the project assistant and/or give their name and number to a contact person at the recruitment sites. Prospective grandparents were screened by determining the number of grandchildren they were raising and their ages, the reason they were caring for the child, whether formal or informal custody was obtained, residency in one of the participating counties and whether drug or alcohol was being used by the grandparent. The final list of participants was grouped into two groups, a morning session and an afternoon session. Thirty three grandparents participated in four focus groups (see Table 1).

The data was collected via focus groups. Focus groups allow the researcher to explore, in-depth, the context of a phenomenon (Krueger & Casey, 2009). Focus groups are often useful for exploratory studies, situations involving conflict, multilevel complex issues, generation of ideas, and the development of ideas for larger, future projects (Krueger & Casey, 2009).

In this study, four focus groups were conducted in urban and rural Alabama with approximately eight to ten custodial grandparents in each group. The facilitator(s) planned and confirmed the attendance of each grandparent. There were two facilitators. One facilitator was a clinical psychologist. She was responsible for ensuring the smooth running of the focus group, managing the group process and dynamics, introducing relevant issues and ideas for response by the group, and for ensuring that the group's objectives are addressed. The other facilitator had a master's degree in health behavior. The second facilitator was responsible for note taking and monitoring group dynamics. Informed consent was obtained from each participant before beginning the focus group. With the permission of the participants, the discussions were videotaped and later transcribed by staff. During the focus groups, light refreshments were provided and each participant received \$15.00 in appreciation for their time. After completing each session, the grandparents were sent a letter thanking them for their participation. The letter also contained information

about how to access community resources such as support groups for custodial grandparents. This study was approved by the University's Institutional Review Board.

Researchers—The research team consisted of a clinical psychologist with a background in public health, a licensed social worker, a master's level student and a community director. Each researcher had experience working with custodial grandparents and community based research. The focus group questions were created by the clinical psychologist and senior researcher and data collection and coding was conducted by various members of the team.

Focus Groups and Interview Questions

The focus groups were moderated by a licensed psychologist and a research assistant. The purpose of the focus groups was to determine the participant's likelihood to participate in a six week program focused on parenting skills, health and emotional well-being and financial management. The focus groups began with grandparents introducing themselves and indicating the number of grandchildren they were raising. Five questions were used in a funneling sequence beginning with a general topic leading to a more specific topic of interest. The grandparents were asked how long they had been caring for their grandchildren and to describe some of their experiences. The transition question addressed was "Would you agree to participate in a six week group focused on parenting skills and health and emotional well-being?" Thereafter, a key question for the groups was "What would make it difficult for you to participate?" To conclude the discussion, the moderators solicited feedback concerning a suggested name for the future intervention group. See Focus Group Questions (Table 2) for further details. Focus groups were scheduled during a morning or afternoon session and typically lasted for 60 to 90 minutes. Near the end of the interviews, the grandparents were asked what would make it difficult to participate in the program and how they felt about the group name. Each session was videotaped and transcribed by program staff.

Data Analysis

Qualitative content analysis is an interpretative method of analyzing data (Ulin, Robinson, & Tolley, 2005). Data analysis proceeded systematically and continuously throughout the data collection process (Miles & Huberman, 1994). The primary mode of data analysis consisted of the research team using transcript-based procedures for extrapolation of overarching themes. Following each focus group, moderator debriefings occurred with the primary researcher. A third party knowledgeable of qualitative methodology but not involved in the research study provided input on data analysis procedures. The primary investigator and a graduate student reviewed the transcripts for emergent themes. To facilitate coding, members of the research team identified salient themes as the data was transcribed. The focus group sessions were videotaped by the research team to increase accurate documentation of participants' statements and nonverbal expressions. Two moderators conducted each group session, one leading the discussion and one assigned to note-taking. Data collection was completed when data saturation was reached; specifically, when the same topic came up repeatedly across conversations.

Results

Four focus groups were conducted with 33 grandparents (26 grandmothers and 7 grandfathers) from three community agencies. The majority of the participants were African American (91%), and female (79%). The average age of the grandparents was 59 ± 8.4 . Grandparents had an average of two grandchildren. All participants expressed a desire to participate in the proposed six week intervention.

After reviewing the video tapes and transcripts, fifteen codes were identified and reduced to five major themes based on probing questions during the focus group. All five themes were directly related to factors that posed as barriers to grandparents raising grandchildren. The five themes were: 1) inability to access the social service system; 2) legal assistance; 3) emotional well-being; 4) problems related to the parents of the grandchildren; and 5) structured activity for the grandchildren. Table 3 provides a description of themes as mentioned by the participants.

Inability to Access the Social Service System

Although a variety of services were available to help grandparents take care of grandchildren, few grandparents understood how to access the system. This fact was emphasized by one grandparent stating, "I have difficulty in accessing the services." Another grandparent went on to state, "We need to know the requirements, eligibility, and how you access the system." One grandparent pondered, "Where do we go for help and how do you access agency resources?" Other comments included the burden falls on the grandparent, and, "I don't have no type of insurance to take care of medical needs and I have four grandkids that I am raising." As the grandparents discussed difficulty accessing resources, they went on to share issues related to legal assistance.

Legal Assistance

Grandparents were asked to discuss their interactions with legal assistance services. Grandparents often find themselves in need of legal assistance and resources regarding custody and adoption. They shared similar concerns such as, "I needed help in understanding how to use the law, from the state, up to the federal level, what is the responsibility of the extended family," and "I need assistance in getting temporary custody that will give me rights." Another grandparent went on to comment, "Grandparents cannot get custody from the parents and it is hard to request child support." One grandparent shared some insight into interaction with a lawyer stating, "It helped to have a lawyer acting on the child's behalf." As noted in the comments, grandparents repeatedly stated that all grandparents need legal help.

Emotional Well-being

The mental and physical health of custodial grandparents often declines once they begin caring for their grandchildren. Some participants reported that they rarely have the time to care for themselves while caring for their grandchildren. Despite the topic being the emotional well-being of the grandparents, the grandparents' responses mainly focused on the well-being of their grandchildren. For example, one grandparent stated, "My

grandchildren need therapy,” and another, “My grandchild had a nervous breakdown.” An additional grandparent shared that, “The kids were abandoned by their mother.” On the other hand, the grandparents shared how they tried to support the emotional well-being of their grandchildren as noted in the following comments: “I want to take care of the grandkids so that they can have a healthy and a normal life,” or, “We try to give them the love, care, and emotional support that they need.” The grandparents’ concern for well-being was also reflected in their concern for their children.

Parents of Grandchildren

Many custodial grandparents are very concerned for their children and struggle to cope with feelings of anger, guilt and shame. A grandparent stated, “My daughter needs parenting classes because when she gets angry she just throws the baby on the floor.” Another noted, “It is difficult to manage the parent’s negative influences and making promises that they don’t keep to the children.” Some participants reported that their children were on drugs and had mental illnesses. Comments included, “My son uses marijuana,” and “My daughter has schizophrenia and she think someone is always after her.” Parents of the grandchildren were often a significant source of stress for the grandparents. This added stress makes it important for us to recognize that the grandparents need more emotional and instrumental support. In relation to parenting, one grandparent noted, “Her parents lose patience and use profanity. The physical abuse she went through is just too much.” The concern for both their children and grandchildren receiving assistance was reflected in the response, “I want to figure out a way [so] the kids [can] be helped along with their parents.”

Structured Activity for Grandchildren

Respite for grandparents is often too expensive for custodial grandparents to afford. It is very difficult within a fixed budget to allow much more recreation. One grandparent reflected, “Kids would like to participate in activities and give them something to and we cannot afford it.” Several grandparents expressed a need for structured activity for grandchildren that are being raised by grandparents. The grandparents shared a variety of responses such as “Tutoring would help with their education,” and, “We need groups to help with grandchildren that are being raised by grandchildren.” Grandparents showed support for their grandchildren participating in structured activities stating, “My granddaughter sings with the choir and that keeps her busy and she has a summer job,” and, “I am willing to work together to take care of the children and give them something to do.” All of the grandparents (100%) expressed interest in using these services if they were available. However, many do not know these services are available in their communities, with some services available at a reduced rate.

Discussion

Five themes emerged from the focus groups that were directly related to factors that posed as barriers to grandparents raising grandchildren. The five themes were: 1) inability to access the social service system; 2) legal assistance; 3) emotional well-being; 4) problems related to the parents of the grandchildren; and 5) structured activity for the grandchildren.

Growth in the number of custodial grandparents has contributed to a need for community programs designed to meet the needs of grandparent headed households. Consistent with the literature, most grandparents expressed happiness in knowing their grandchildren were in their care and they felt satisfied in being able to make a difference in their lives. However, several issues arise as barriers in rearing grandchildren, which include governmental assistance, adult children drug abuse, and the high cost of caregiving. In this study, custodial grandparents shared a desire to participate in a six week program aimed at reducing distress among Kincare families. By conducting several focus groups, we were able to capture the realities of custodial grandparenting. Regardless of their age, social, financial, or health status most grandparents have a spirit of survival. Our findings revealed that programming targeting grandparent headed households should be expanded and tailored specific to the caregivers' responsibilities. The majority of grandparents participating in the study experienced higher stress levels and were faced with many financial demands. It is vital that we identify grandparents that are currently raising grandchildren and develop programs that will benefit these families. One of our key findings is to facilitate communication between program providers to better disseminate the appropriate program material to grandparent headed families.

Crucial Areas for Improvement

The findings from this focus group study reveal crucial areas for targeted improvements with grandparents raising grandchildren. These crucial areas include policy development, increasing provision of formal services, effective communication, advocacy, education, and availability of resources. We will discuss these areas in more detail below.

Policy development—Primary attention is needed for policy development to address the lack of services and financial resources. Burton (1992) highlighted grandparents raising grandchildren face unique individual, contextual and familial circumstances which warrant increased formal services to reduce the caregiving strain on the grandparent. Without such services, grandparents facing their golden years must find ways to compensate for parental neglect as well as deficiencies in the social service system.

Formal services—The lack of formal services for grandparents to access produces a greater emotional and physical cost to the grandparent (Burton, 1992) which is very likely to affect the quality of life of the grandchild. The State of Maine has taken the lead in developing a policy white paper to identify priority areas for strategic interventions on behalf of grandparents raising grandchildren (Butler, 2005). To circumvent further detrimental factors for grandparents raising grandchildren, policy makers should consider a more proactive approach and utilize existing research findings to initiate development of identified needed services.

Effective communication—One of our key findings is to facilitate communication between program providers to better disseminate the appropriate program material to grandparent headed families. Effective communication processes in the form of information and referral with follow up procedures is crucial to intervening with these grandparents. Often organizations are unaware that there are grandparent families in their area and

definitely don't know the needs of this type of family constellation. One of our key findings is for professionals working with grandparent families to make sure organizations such as local child and senior services understand the needs of grandparent families and how organizations' services are applicable to this type of family unit. Depending on the background characteristics of the grandparent, many of these individuals may lack the skills needed to efficiently communicate with agency professionals. Therefore, agency professionals should take responsibility for following up on information and referral given to grandparents. Follow up by the agency professional is an opportunity to assess the usefulness of the information and referral as well as provide further assistance if the grandparent encountered any problematic situations. This communication circle reassures the grandparent of community support for addressing their individual needs while at the same time orients the grandparent on how to communicate with other agencies.

Advocacy—Grandparents also need specific instructions on learning to advocate for their needs. Advocacy is “to adopt a stance, advance a cause, and attempt to produce a result in behalf of an interest of a person, group or cause” (Cohen, 2004, p. 9). As self-advocates, grandparents illuminate the realities of what it is like to raise grandchildren beyond their normal season of parenting. Subsequently, who better to exclaim the needs and services of grandparents raising grandchildren than grandparents themselves? Sands and Goldberg-Glen (2000) acknowledged the role of grandparents and professionals in advocating for service development. However, effective advocacy encompasses structured guidance. Clinicians should not assume grandparents possess such advocacy skills. Therefore, clinicians involved with grandparents raising their grandchildren should provide education on how to advocate for needed services in the community.

Generations (2004), the publication by the American Society on Aging, which invites experts in the field to write focused articles on a given topic, devoted an entire issue to exploring advocacy issues within the context of the aging population. In the series, Cohen (2004) outlines an overview of advocacy and the pivotal role of advocates in achieving desired outcomes on behalf of individuals while acknowledging potential ethical challenges encountered by advocates. Emphasis is placed upon the successful advocacy achievements of individuals with mental illness and mental retardation in the 1970s to bring about broad sociopolitical change in treatment goals for persons with intellectual disabilities. With the appropriate knowledge base, similar endeavors can be undertaken by grandparents raising grandchildren.

For those clinicians seeking more detailed instructions on advocacy education, the Generations United (2013) website (www.gu.org) offers excellent informational resources as guides. Moreover, providing advocacy instructions to grandparents exposes the grandparents to effective strategies to intervening on behalf of their own needs when the clinician is no longer involved.

Education—Likewise, grandparents need education on available community resources as well as appropriate agencies for specific needs. Well-meaning grandparents many times may visit one agency seeking assistance for all of their needs. Frustration may result for an already overwhelmed grandparent when services or funds are unavailable. In turn, clinicians

may grow weary and impatient with grandparents who frequent a particular agency with limited or no funds. Educating the grandparent on what services are provided by individual community resources would diminish potential negative experiences for the grandparent as well as the clinician. Print material in large print about community agencies might be an effective means of educating grandparents on community resources.

Availability of Resources—Although grandparents in urban and rural communities have similar needs, the availability of formal resources to meet those needs is not always evident. Urban communities with their more dense population offer a wider array of agency services for grandparents to access. Therefore, grandparents are faced with a more visible, diverse packet of services in an urban environment. However, the wide availability of services produces other issues for the grandparent such as appropriate resource identification. The need to identify which resource is more appropriate to meet the current need requires service or agency familiarity on the part of the grandparent. In contrast, rural communities have less dense populations with fewer agencies to provide resources. As a result, grandparents in rural communities may easily exhaust available formal community resources with some needs left unmet. As a result, creative efforts on the part of grandparents or agency professionals are warranted to assist these rural grandparents. Those creative approaches may include informal services such as churches, faith-based community centers, school system related projects and other service oriented community/civic groups.

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Table 1

Sample Characteristics

Grandparents	N = 33
<i>Age (in years)</i>	
Age range	51–67
Mean age (in years)	59
<i>Gender</i>	
Male	7
Female	26
<i>Race</i>	
African American	27 (91%)
White	8 (8%)
Average number of grandchildren cared for	2
Age of grandchildren (range)	2–17
Length of time caregiving	At least one year
Desire to participate in proposed 6-week intervention	100%

Table 2

Focus Group Questions

Type/Question	Purpose	Probes
Opening Question 1. Tell us who you are, how many grandchildren you are raising, and how long you have been caring for them.	This question is designed to get people comfortable talking and warm up to further questioning.	None
Transition Question 2. Would you agree to participate in a six week group focused on parenting skills and health and emotional well-being?	Move discussion to key areas of investigation.	What topics would you like to cover?
Key Question 3. Would you agree to participate in a six week group focused on financial management?	Identify financial challenges and willingness to learn various budgeting methods.	What topics would you like to cover?
Key Question 4. What would make it difficult for you to participate?	Identify participation barriers.	None
Closing Question	Encourage group	None

Table 3

Focus Group Themes

Theme	Description of the theme
(1) Accessing the system	Accessing the system was described as how to determine program eligibility and requirements.
(2) Legal assistance	Legal assistance includes custody, grandparent visitation rights, and insurance coverage
(3) Emotional well-being	Emotional well-being involved grandchild exposure to drugs and physical abuse along with changes in attitudes while growing up.
(4) Parents of grandchildren	Custodial grandparents were concerned with the health of their children and responsibility to take care of children.
(5) Structured activity for grandchildren	Structured activity included providing grouped activities for children being raised by grandparents.